

PASTORAL COMMUNICATION WITH CONFUSED ELDERLY PEOPLE

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I declare that this thesis is all my own work

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ABSTRACT

This research was designed to examine how pastoral communication can be enhanced with confused elderly people. The model under-pinning this research is one which acknowledges the dynamic inter-relationship between theory and practice. It brings theoretical understanding from practical theology, pastoral care and speech and language therapy to bear on the experience of offering pastoral care to the confused elderly individual.

The relating of theory and practice in this way demanded that a variety of methods be used in the gathering and interpretation of data. The triangulation of qualitative and quantitative methods fosters a more complete description and understanding of practice.

The research design was of five inter-related stages. These stages take the form of literature review, structured interviews with speech therapists, structured interviews with people involved with the care of confused elderly people, a postal questionnaire sent to pastors, and in-depth interviews with 11 of the respondents to the questionnaire.

This investigation examines issues which include theological perspectives on dementia, speech and language characteristics of the dementias, the purpose of pastoral care and the spiritual needs of a person with dementia. The evidence is that in addition to the well documented linguistic changes, dementia also results in spiritual changes. The nature of that change is discussed and related to the spirituality of the confused person.

The large amount of information which was elicited by the research, is correlated with pastoral, theological and linguistic perspectives and a model and method for the pastoral care of confused elderly people is developed. Rooted in pastoral experience, and refined by theological reflection, it is maintained that this model and method will be a practical tool for pastors, ordained and lay, useful both for recognising the significant spiritual needs of the confused elderly person, and as a means of offering sensitive pastoral care to the confused individual.

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CHAPTER ONE

PRACTICAL THEOLOGY AND PASTORAL CARE

PRACTICAL THEOLOGY AND PASTORAL CARE

An Introduction to the Theoretical and Conceptual Background of the Research

Introduction

Northcott (1991:24) claims that " the findings of practical theology will take the form of concrete proposals for re-structuring the church's praxis, for individuals and for society". In accordance with this claim the primary aim of this research is a practical one; to empower pastors (a term which is used to refer to all who are involved in pastoral care) to communicate more effectively with confused elderly people.

The impetus for this research comes from experience. The researcher's own experience of working with confused elderly people in the capacities of both speech therapist and minister, and the experience of a number of ministers who conveyed to the researcher that pastoral care of confused elderly people was an area which they found difficult. Some were unsure about its value, questions being raised about whether or not their pastoral intervention made any difference to the confused person, and if, therefore, this area was a real pastoral concern. Others told that they felt insecure, wondering what and how to communicate, and often feeling that the pastoral care which they were offering was inadequate. It was therefore clear from

practical, pastoral experience that such care of confused elderly people presented as an area which needed to be addressed.

Fusing this experiential horizon with that of theory further reinforces the efficacy of research in this area. A basic theoretical, and ultimately theological, question which needs to be addressed is whether or not confused elderly people require pastoral care at all. It could be claimed that if dementia undermines cognitive processing and even personality, it must also destroy the potential for spirituality, and that therefore the confused elderly person does not have spiritual needs or require pastoral care.

An initial review of the literature indicated that the confused elderly person is not just facing physical and psychological crises, but also spiritual crises, which may include, hopelessness, an experience of being abandoned by God, and others, isolation, decrease in self-worth and anger with God. These are detailed and explained in the literature review which follows (particularly in Chapter 2).

It seems therefore that there is a gap, caused at least in part by the communication difficulties which dementia brings, between the pastor who has a mandate for involvement with the confused elderly person, and who is seeking under God to be a channel through which at least some of the needs of the confused elderly person might be met, and the person him or herself who is facing spiritual crises. In the light of the on-going linguistic and pastoral interest in dementia, it appears logical

to examine the potential of language and other means of communication as a means of bridging that gap.

The rationale for undertaking this research is strengthened by other factors. Firstly, although there is a large body of speech and language research describing the language breakdown in dementia, there is relatively little research to date on the application of that knowledge. Indeed there has been a debate as to the efficacy of speech therapists treating people who present with cognitive breakdown.

Secondly, from the perspective of pastoral care, although dementia is an area in which there is a significant level of interest, the spiritual needs of confused elderly people remains an area in which there is continuing potential for further research.

The third rationale arises from an appraisal of demographic estimates of the prevalence of dementia. The Alzheimer's Disease Society (1996) report that there are 650,000 people in the United Kingdom who have some form of dementia, with approximately 60% of that incidence being attributed to Alzheimer's Disease. Given that, on average, people are living longer, and the preponderance of elderly people in many congregations, it is likely that the pastoral care of confused elderly people will be an area which will affect many pastors.

Research Objectives

The primary research objective is examination of the potential for the gap between the pastor and the confused elderly person to be bridged by communication. Ultimately the aim is to produce the outline of a tool, based on linguistic and pastoral research, which could be used by pastors to enhance pastoral communication.

However, whilst unequivocal about the importance of this practical, pastoral aim, it is recognised that this research is undertaken within the discipline of practical theology. Thus the research is related not simply to the practice of ministry, but also to contemporary debates in practical theology concerning the nature of the discipline itself and of the relationship between theology and practice. It is to the nature of this relationship that this discussion now moves.

The Relationship Between Theology and Practice

This is an exceedingly complex area, which subsumes questions of method in ministry, as well as detailed formulations of the theology of pastoral care. Recognising this complexity, the approach taken will be to focus on one specific question. That question is, whether or not it can be claimed that either theology or practice is of primary importance in pastoral care.

In the discussion which follows it is assumed that theology and pastoral practice are related. It is recognised that this is not a universal assumption, and that in some therapeutic models pastoral care is equated with pastoral counselling, and that theology is not integrated with practice to any great degree. This approach will be reviewed later in the literature review (Chapter 4). However, for the purpose of this discussion, focused as it is on one particular area, a relationship of some sort will be assumed.

The Case for the Primacy of Theology

One view of pastoral care is to see it as applied theology, as the proclamation of a learned theology. Thurneysen's (1962) definition makes this understanding clear when he describes pastoral care as "proclamation to the individual of the message proclaimed in general to the congregation on a Sunday."(15)

Schleiermacher's (1966) formative view of theology as a function of the church, with practical theology as the place where theological disciplines meet, led to an understanding of practical theology simply as applied theology. A pyramidal model was the norm, according to which theologians worked with a "trickle-down" understanding of applied theology. The presumption was that the primary or creative work was undertaken in the classical fields of Biblical studies and theology, and that this was then simply applied to the pastoral situation. Pastoral care was the application, not the source of theology. Indeed Lamb (1982) in his book, *Solidarity with Victims*, describes how the most influential theologies of the twentieth century

almost always approached churches from the standpoint of the primacy of theology or theory.

There is, however, a general shift in the available literature away from seeing pastoral theology simply as applied theology. The inadequacies inherent in this formulation, in particular the one-way relationship which it assumes between theology and practice, and the limitations in seeing practical theology only as the study of the Christian ministry, have been recognised. The result is that the issue of the nature of practical theology has become the subject of intense debate, with the emphasis now being on pastoral theology as a critical enquiry which questions the fundamental vocation of the whole church in the world.

Fowler (1995) asserts that the emergence of practical theology as a discipline has challenged this separation of academic, systematic theology from the practices of Christian faith. He describes Biblical texts, Paul's letters for example, and the writings of the Reformation and Counter-Reformation as practical theology, for they were aimed at shaping the practices of the Church so that they reflected faithfulness to Christ. A "practical" approach to theology dictates that Christians are more concerned to imitate their fore-runners' faithfulness and creativity, rather than systemizing and applying their solutions to our age and generation.

If an understanding of practical theology as secondary, or applied, theology devalues its contribution and fails to recognise the influence of experience on theological reflection, the question which must then be examined is whether or not Browning (1991:21) is correct when he claims that "praxis is the basic or prior reality."

The Case for the Primacy of Practice

For Graham (1996) action is not the out working of faith but its pre-requisite. She envisages pastoral theology as being the study of the purposeful practices of the faith community. In Graham's (1996) thinking, theology must be a performative discipline, concerned with those actions or practices of the faith community which lead to transformation in lives and communities. This is the only expression of truth possible in a pluralistic society. What is authentic and true is seen to be orthopraxis, or transforming action, rather than orthodoxy, or right belief. Theology then becomes reflection on the practical wisdom belonging to the gathered faith community, a form of practice rather than a form of abstraction and disengagement. The norms and values of what is done give shape to the faith community, not the reverse. Pastoral theology as a medium in which truth claims are forged and then articulated is a direct reversal of Schleiermacher's (1966) model of practical application of an abstract theology.

Green (1990) takes practice as the starting point for his spiral model of theological reflection on pastoral practice. The claim is made that all theology has a context, for God does not reveal Himself in a vacuum but "always and inevitably by way of an experience" (16). From this starting point of experience he moves to exploration, which includes taking account of prior feelings and prejudices as well as information and insight from related disciplines. His next stage is reflection, which in turn leads to response, and he notes:

"it may even be that a group's response is to continue doing what was done in the first place but this time with more insight and understanding." (17)

In their development of a model to guide theological reflection, Whitehead and Whitehead (1983) also see experience as primary. They contend that theological reflection is the process of bringing the resources of Christian faith to bear on the practical decisions of ministry. Thus, they see effective ministry as being the result of an on-going dynamic of reflection and action, and suggest that there are three sources of information relevant to decision making, namely, Christian tradition, personal experience, and cultural information. The process of theological reflection which they formulate based on this incorporates "attending", or finding information, "asserting", or the inter-relating of relevant information, and decision.

Browning (1983) integrates theory and practice, and also makes practice his starting point. He writes:

"my view is that theory arises out of practice and leads back to practice - theoría is an abstraction from, and a reflection of praxis - praxis is the basic or prior reality. The test of a good theory is largely the adequacy with which it guides practice." (49)

Referring to Tillich's (1963) correlations of questions from existence with answers from revelation, Browning (1991) develops what he terms a "revised correlational method" for doing practical theology. Here he postulates correlation of norms for human action and fulfilment as are revealed in interpretation of Christian witness, and norms for human action implicit in forms of "normal" human experience.

Deeks (1987) suggests that one of the aims of pastoral care is "to encourage people to make sense of their own experience." (80) He goes on to claim that all learning takes place from experience, but in order for that learning to take place the totality of human experience must be taken into account. This includes the irrational elements of our experience, instincts, emotions and intuitions, and spiritual awareness as well as the rationale.

This review highlights the fact that there is a strong movement towards recognising experience as a source of theological reflection. Even this brief review does indicate that it is difficult to isolate either practice or theology as primary in pastoral practice. It may therefore be the truest reflection of the available literature to claim that they are integrally related.

If it is recognised that neither theology nor experience is sufficient to inform practice in isolation, there are implications for the pastoral care of confused elderly people. The implication is that if ministers are to take this aspect of their pastoral responsibility seriously, then they must have positive experiences of it as well as a

theological perspective which informs and motivates them. Whether or not this holds true in practice will be examined in the in-depth interviews (Stage 5 of the research) and in the concluding discussion.

The Case for "Mutually Critical Correlation"

It was Tracy, (1983) who described practice as being based in a process of "mutually critical correlation", whereby:

"interpretations of the situations of present challenges and their contexts are brought into mutually critical correlation with interpretations of the normative sources of Christian traditions and practices." (63)

This emphasis is also reflected in the work of Patton (1990) in the development of inter-active models of pastoral care. Within this approach, questions of primacy recede as the emphasis shifts to what Gadamer (1975) has called the "fusion of horizons". Practical theology, therefore, becomes a means whereby ongoing interpretations of Scripture and Tradition, in correlation with present situations, can fuel processes of change within church practices.

The work of Fowler (1995) stands firmly within this paradigm. Theology and practice being recognised as having the potential to inform and alter one another. "Praxis" is thus defined by Fowler (1995;3) as "a pattern in which action and on-going reflection continually interpenetrate." This definition is helpful for its provision of a succinct description of the dynamic inter-relationship between theology and practice. To speak of either as primary becomes redundant, for no matter what the starting point for reflection, adequacy demands that both be taken into account.

Theology, Practice and a Design for Research

The recognition of the complexities of the relationship between theology and practice has implications for research design. This research must be described as coming from a "praxis-theory-praxis" perspective. The stimulus for it arose from experience - the experience of the researcher as a speech and language therapist and a minister, and also the experience of other ministers relayed anecdotally to the researcher of the difficulties which they experienced in offering pastoral care to confused elderly people.

This research seeks to reflect on this experience bringing theological , pastoral and linguistic perspectives to bear on the experience of dementia. It is recognised that this reflection opens up the possibility of altering either, or both, theological understanding and pastoral practice.

This process is reflected in the structure of the literature review. The starting point becomes a description of the linguistic and spiritual changes which result from dementia. The following chapters bring theoretical perspectives to bear on the experience of dementia from a theological and pastoral standpoint. The research structure which is then developed and described is based firmly on the "continual inter-penetration of theory and practice." (Fowler 1995:3)

Theory and practice are continually inter-related and tested out against one another throughout the research design. This inevitably results in complexity in the

research design and in triangulation of qualitative and quantitative approaches. However, if the aim of enhancing pastoral practice is to be fulfilled, then the constant inter-relating of theory and practice becomes a necessity.

The research design is summarised in Figure 1.1. Figure 1.2 illustrates the correlational dynamics of the research. In Figure 1.3 the research is shown in the form of a spiral model.

Definition of Terms

Before proceeding it is necessary to define some terms which will be used with some frequency throughout the research. The first of these is "pastor". Throughout the research this term is used to denote any person offering pastoral care. For the purposes of this study that includes ministers and priests, it is thus inter-changeable with these terms. It is recognised that "pastor" may have particular denominational associations. However, for the purposes of this research, it is employed as an umbrella term.

This leads to a definition of what is meant by the adjective "pastoral" when applied to communication. When considering this term it is difficult not to stray from definition into discussion. The element which renders communication "pastoral" must be specifically addressed.

FIGURE 1.1

Summary of Research Design

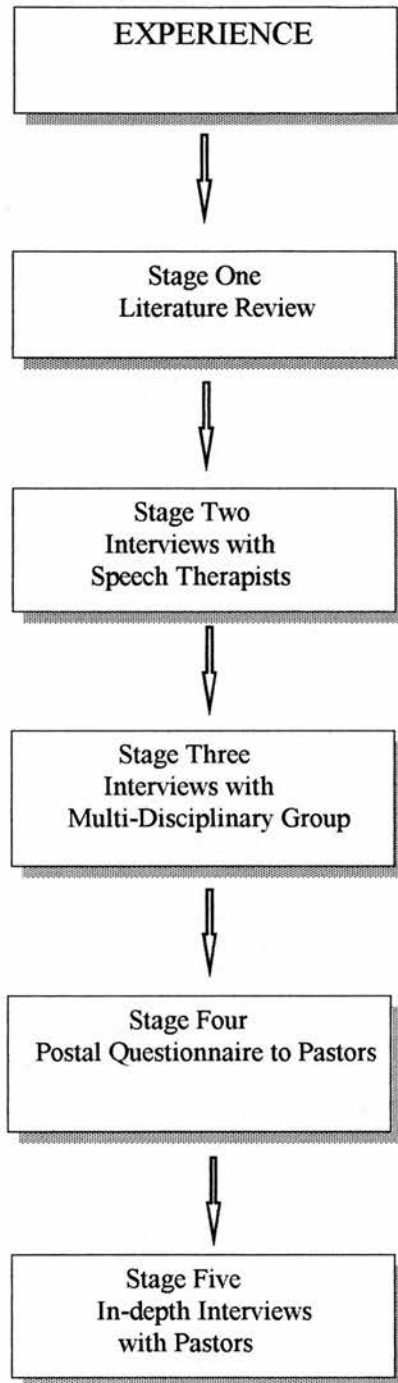
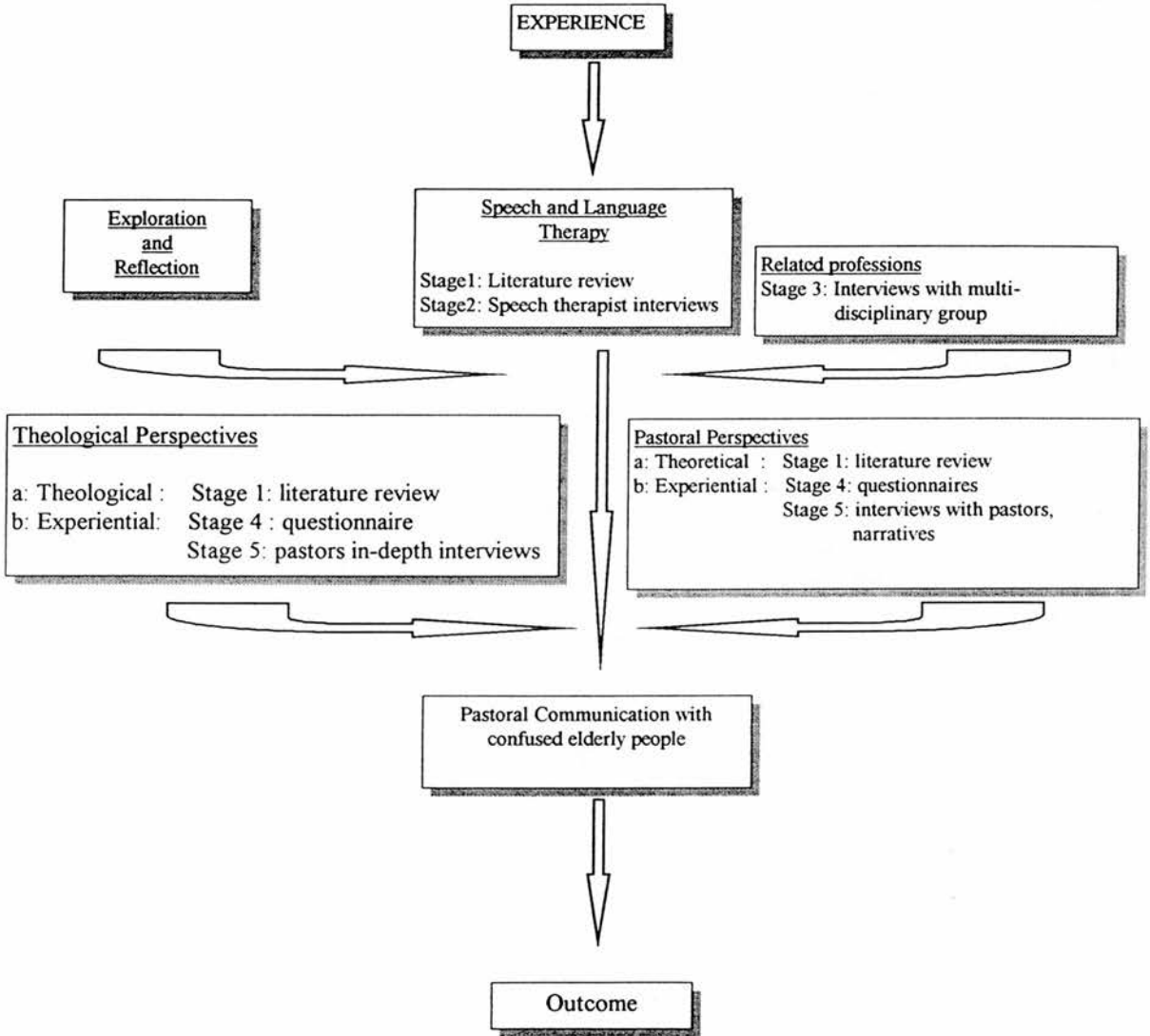


FIGURE 1.2

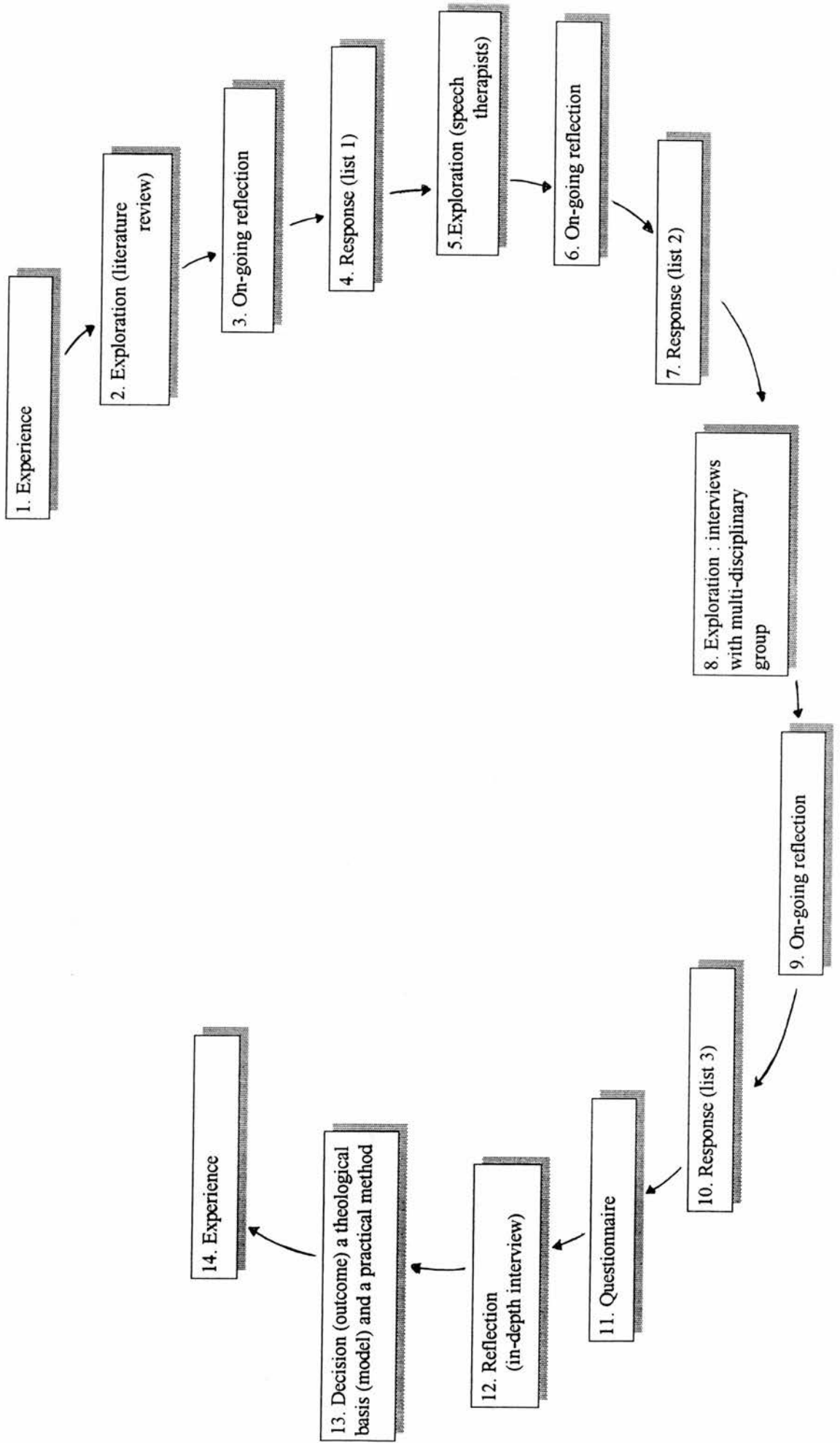
The Correlational Dynamics of the Research.

This figure summarises the different areas which will be related, at different stages throughout the research design, to the pastoral care of elderly confused people.



This figure, although a useful summary, is also a simplification of the process. It must be recognised that each "horizon" in addition to being related to the central issue of "pastoral communication with confused elderly people" is also related to each other. The model guiding the research therefore becomes dynamic in itself.

FIGURE 1.3
 A Spiral Model Illustrating the Research Process.



Patton (1990) makes it clear that the term pastoral is considerably more than an adjective referring to the clergy and that position is upheld in this research. Although clergy were used as the subjects for a questionnaire and interviews, the priesthood of all believers is strongly affirmed. This research does not intend to give the impression that pastoral care is an activity which is limited to clergy. The definition given by Clebsch and Jaekle (1967;4) of pastoral care as being undertaken by "representative Christian persons" may be a more helpful understanding.

For the purposes of this research then, the word pastoral brings with it additional connotations. The primary one concerns motivation. For this study "pastoral" implies that the carer's motivation stems from faith in God, and springing from that faith a desire to love and serve others. The focus of this research is therefore Christian pastoral care.

Another area in which the need for definition is indicated centres on the use of the term "confused elderly people". This phrase is used throughout the research as an umbrella term to denote confusion in elderly people caused by dementia. Definitions of dementia and descriptions of types of dementia are given in Chapter 2 of the thesis.

Having introduced the research and set it in the context of a contemporary debate within practical theology, we now turn to a consideration of the literature. As

has been stated, the starting point for this study is experience, so the initial topic for attention is a review of research on confusion in elderly people.

CHAPTER TWO

THE EXPERIENCE OF DEMENTIA

THE EXPERIENCE OF DEMENTIA

Introduction

"What does it feel like to have Alzheimer's disease?...the devastation of losing self-confidence, parts of the old independent personality, memory, pride as I become a care receiver instead of a care giver, and the ability to control some of my physical functions. The worst personal loss was the spiritual change that suddenly came to me...I am alone in the blackness." (Davis 1989:121)

"Sometimes in weakness and despair I want to give voice to that primal scream starting way down in the hidden recesses of the lungs - down where the ever-present knot in my stomach resides - let it whirl through the vortex that's sucking my life and being into the black hole of never-ending pain, emptiness, and loneliness...No, God, no! Not us! Not this! Not his mind! Not his personhood! ...Death would be better than this - to hold on to the box when the present is used up - hoping the box can bring again the joy of the reality of the gift - but the box is empty! This is what one has to look forward to with Alzheimer's Disease." (Davis 1989: 158-159)

These quotations, the first from Robert Davis, and the second from his wife Betty, provide some insight into the experience of dementia for one confused elderly individual and the person who cared for him. Experiences such as these indicate that dementia has the potential to irrevocably change personality, family dynamics, and relationships with God and others, in addition to communicative abilities.

In an attempt to reach some understanding about the experience of dementia, this chapter will review the literature on the effect of dementia on the individual, the family or carer and, in particular, on communication.

The Effect of Dementia on the Individual

There are some accounts of the experience of dementia, for example those provided by Cohen (1991) and Foley (1992). In order to gain some understanding of the effect of dementia on the individual, a review of the literature concerning the nature of the dementias will be undertaken. Evidence on the specific effects of dementia on spirituality will then be appraised.

1. The Nature of Dementia

Lishman (1978:9) defines dementia as "an acquired global impairment of intellect, memory and personality, but without impairment of consciousness." Bayles (1982) comments that "senile dementia is characterised by chronic progressive deterioration of intellectual function resulting from generalised cerebral atrophy." (265) Short term memory impairment is frequently the presenting symptom, however, as the condition progresses, remote memory is also affected and thought processes become increasingly disorganised.

Dementia is not a homogenous disorder, it is rather an umbrella term used to describe a group of conditions the majority of which are chronic, gradual in onset, of fairly long duration and progressive. Dementia also causes changes in personality, behaviour, and a deterioration in social functioning. It occurs in people of all social, ethnic, religious, economic and religious backgrounds. (St. James O'Connor (1992))

Although demographic information (reported by Benzon 1990) reveals that the incidence of dementia increases with age, dementia can affect people throughout

the life-span. Senile dementia can therefore be used to refer to situations in which people over 65 develop symptoms of dementia. At one stage Alzheimer's disease was characterised as a pre-senile dementia, for example in Miller (1977). However, in more recent studies it has been recognised that pre-senile and senile forms of Alzheimer's Disease are not readily distinguishable by pathological or clinical criteria (Henderson and Finch 1989).

Dementias have also been categorised into degenerative forms and multi-infarct forms. These differ in that the degenerative dementias follow a progressive decline, whereas, in multi-infarct dementia there is a sudden change, caused by a cerebro-vascular incident, followed by a period of stability until the next incident occurs. Lauter (1985) claims that about 50% of dementia is degenerative, 20% is caused by multi-infarct dementia, a further 20% is a mixture of both groups, and the remaining 10% is accounted for by people who present with a combination of diseases, dementia being complicated by the presence of other disorders.

Thompson (1981) gives a comprehensive classification of the causes of dementia. This is reproduced as Table 2.1.

Teri et al (1990) claim that Alzheimer's Disease is the most common cause of dementia accounting for nearly half of the cases examined in several autopsy series. It was first described by Alois Alzheimer in 1907, when he reported the case of a 51 year- old woman who, over the course of 4 years, evidenced progressive

Table 2.1 Thompson's (1981) classification of the causes of the dementia syndrome

1. Intracranial Space-occupying Lesions

Subdural haematoma, brain abscess, tumours primary and metastatic normal pressure hydrocephalus

2. Traumatic

Single severe head injuries, repeated less severe injuries, e.g. brain-damaged boxers

3. Infections

Brain abscess, meningitis, encephalitis, neurosyphilis, subacute sclerosing panencephalitis, progressive multifocal leucoencephalopathy, Creutzfeldt-Jacob disease

4. Vascular Disorders

Multi-infarct dementia, occlusion of the carotid artery, Binswanger's disease, arteriovenous malformations, inflammatory conditions of blood vessels: SLE thromboangitis obliterans

5. Hypoxia and Anoxia

Anaemia, post anaesthesia, carbon monoxide poisoning, cardiac arrest, respiratory insufficiency

6. Metabolic Disorders

Renal failure, hepatic failure, remote effects of carcinomas

7. Toxic States

Intoxication with heavy metals: lead, mercury, manganese, Organic compounds: nitrobenzenes, aniline compounds, bromine hydrocarbons, tri-ortho-cresyl phosphate, carbon disulphide, carbon tetrachloride. Drugs: bromides, barbiturates, phenacetin and a very large number of others, especially in combinations, alcohol

8. Endocrine Disorders

Myxoedema, Cushing's syndrome, hypopituitary syndromes, hypoglycaemia, parathyroid disorders

9. Deficiency Diseases

Pellagra, Wernicke-Korsakoff states, vitamin B deficiency, concentration camp syndrome

10. Miscellaneous

Multiple sclerosis, muscular dystrophy, Whipple's disease, familial calcification of the basal ganglia

11. Degenerative Disorders of the CNS

(a) Principally cortical: Alzheimer's disease, Pick's disease, Schilder's disease

(b) Principally subcortical: Parkinson's disease, Huntington's chorea, Wilson's disease, progressive supranuclear palsy, Friedreich's ataxia

memory loss, personality changes, language disturbances and apraxia. At autopsy Alzheimer discovered neurofibrillary tangles affecting the cortical neurons and senile or neuritic plaques. These remain among the central diagnostic features of the condition. Modern researchers (Davies (1991), Bayles and Kaszniak (1987)) are consistent in the view that the changes found in the brain are a loss or degradation of neurons, an accumulation of neurofibrillary tangles and beta-amyloid proteins found inside and adjacent to blood vessels, and neuritic plaques. However, the cause, or causes, of these changes is unproven, as yet.

There was some controversy concerning the nature of Alzheimer's Disease and its relationship to normal ageing. As recently as 1991 Davies contended that there were two prevailing models of the condition. According to the first, Alzheimer's Disease was understood as a part of the ageing process. Cognitive function began to decline at a certain age and progressed, until, finally, a threshold was passed and the individual was clinically diagnosed as having dementia. This approach is now diminishing in acceptance, in favour of the second model which holds that there is no direct link between ageing and Alzheimer's Disease. It is instead thought of as a separate disease process.

Alzheimer's Disease is a progressive illness. It is usually described as progressing through three stages, mild, moderate and severe, or early, middle and late. Teri et al (1990) investigated whether or not the progression of the condition was influenced by external factors. Their results indicated that the rate of cognitive

decline was variable, patients with various health and behavioural problems declining at a rate of approximately 1.4 times the rate of patients without such problems. Of the factors which appeared to influence the rate of decline, alcohol abuse, additional neurological disorders and agitation were the most significant.

The effect of dementia on the individual is multi-dimensional. Deimling and Bass (1986) report deterioration of cognitive abilities, problems in level of social functioning, and occurrence of disruptive behaviours. In addition to experiencing a decline in mental health Kitwood and Bredin (1992) describe a number of the behavioural changes which may be experienced by the individual with dementia. These include wandering, aggression, sexually inappropriate behaviour, delusions, incontinence and increasing difficulties with eating and bathing.

The progressive nature of dementia means that the experience of the individual may well change over time. Pruchno and Resch (1989) contend that the "forgetfulness" stage may be accompanied by an increase of concern, and evidence of mourning. This, they assert, progresses to more overt manifestations of anxiety, evidenced by agitation, and then to denial. In later stages of dementia they report increasing passivity on the part of the individual.

2. The Effect of Dementia on Spirituality

Moffitt (1996) defines spirituality as " the search for the meaning of life: religion is one way of conducting that search." (19) The direct evidence on the effect

of dementia on spirituality is limited. The indications are, however, that just as dementia brings about cognitive and behavioural changes, it can bring about spiritual changes as well.

Shamey (1993) provides evidence of these spiritual changes based on her experience of offering pastoral care to confused elderly people. While asserting that faith memories can be accessed, she reports that different aspects of spirituality may now be meaningful for people with dementia. Thus, although no longer able to follow sermons, her experience is that familiar hymns and symbols may have profound significance for the confused person.

The assertion that dementia can have spiritual implications for the individual is supported by Weaver (1986). In support of this contention he tells the story of Janet who was 75 and had had Alzheimer's Disease for two years. Janet had been a Christian most of her life, attended church regularly, and was liked and respected as a gentle, concerned friend. When her symptoms of forgetfulness became apparent she struggled to compensate but became increasingly anxious about her condition. Her anxiety about not remembering names and the difficulties which she experienced in following sermons led her to stay away from church. Her sense of isolation was compounded by depression. Her physical symptoms were having a profound effect, not only on her relationship with the church community, but on her relationship with God. She concluded that because of some sin "she was no longer fit for the Lord's

service, and God was placing her aside." (451) Thus, Weaver (1986) contends that for Janet, the physical symptoms of dementia had spiritual implications.

Davis (1989) writes extensively about the spiritual changes which he experienced as a result of Alzheimer's Disease:

"The first spiritual change I noticed was fear, the comforting memories can't be reached. The mind sustaining Bible verses are gone. The sweetness of prayer and the gentle comfort of the Holy Spirit are gone...By sheer stubborn faith I knew that God was there and that Christ was my Saviour. However the feelings I had enjoyed all my life were gone." (121)

Among the other spiritual changes which Davis (1989) notes are loneliness and a change and loss of normal spiritual resources. Complex Biblical passages were no longer understood, and he could no longer participate in normal services of worship. He describes this experience vividly, "Suddenly I stand out in the worship service, silent and continually confused." (129)

The Effect of Dementia on the Family or Carer

Rabins (1985) reports that "the majority of people with dementia in... the British isles...are cared for by family members." (81) It is possible that this has changed since 1985, however, the fact remains that the symptoms of dementia can have significant implications for care-givers. This is universally acknowledged in the literature. (Miller and Montgomery (1990), Miller et al (1991), Young and Kahana (1989)).

Gray and Isaacs (1979) review a number of the problems which may be faced by those who care for people with dementia. These include loss of sleep, faecal and urinary incontinence, dealing with physical dependence and irresponsibility, and unresponsiveness from the confused person. The effect of these behaviours may be compounded by social factors like low income and inadequate housing and by the fact that carers themselves may be elderly. Wilder et al (1983) report that emotional explosiveness, sleeplessness and wandering are among the most difficult problems with which family care-givers report being confronted. Rabins (1985) states that caring for a person with dementia involves dealing with the emotional impact of the condition, as well as the physical symptoms. Thus he claims that carers may be devastated by the emotional and personality changes which they observe in their loved one, and may grapple with the changes in roles and relationships thrust upon them by the illness.

Bergmann et al (1978) report that half of the carers in their study were restricted in their social and leisure activities. It is hardly surprising, therefore, that Sanford (1975) reports that 52% of carers felt anxiety or depression. Rabins (1985), however, sounds a more optimistic note when he claims:

"It is a danger to overdramatize and overestimate these negative feelings, however. Many families report that they have maintained long-term relationships at a meaningful, if changed level." (82)

The relationship between the symptoms of dementia and care-giver stress, has been the subject of intensive investigations (Newens et al (1995) and Kahana et al (1994)). Deimling and Bass (1986) report that cognitive incapacity has less of an

effect on stress as reported by care-givers, than disruptive behaviour and impaired social functioning.

The findings of Pruchno and Resch (1989) indicate a more complex relationship between the behaviour of the person with dementia and the well-being of the care-giver. They suggest that, not only does the behaviour of the person with dementia affect the care-giver, but that there is a relationship between the well-being of the care-giver and the frequency of forgetful and disorientated behaviour, on the part of the confused elderly person.

In response to the recognition of the impact of dementia on families and care-givers, literature stresses the need that families be supported physically and emotionally. (Aronson and Cox Post (1994), and Levin et al (1994)).

The specific focus of this research is on the confused elderly individuals themselves. In the light of the research which has just been reviewed, it is necessary to make clear that this focus is not intended to imply that the needs of carers are not recognised or acknowledged. Rigour in research method demands that this study be clearly focused on one area. However, it is recognised that the confused elderly person cannot be fully understood in isolation. As the findings from Pruchno and Resch (1989) illustrate, the individual and carer are in a complex relationship, affected by each others needs, strengths and weaknesses. The carers, as well as confused elderly people, have profound pastoral needs. Indeed the possibility must be

considered that the appropriate pastoral response to confused elderly people is one which is based on a systems model, and focuses on the carer.

The Effect of Dementia on Communication

McKhann et al (1984) report language impairment to be an important feature of both Alzheimer's Disease and multi-infarct dementia. Murdoch et al (1987) claim that the presence of a language disorder is an important clinical feature of Alzheimer's Disease. Language impairment appears early and progresses steadily, the degree of the communication disorder being correlated closely with the severity of the dementia. Alzheimer himself (1907) described the language impairment in dementia as follows:

"When shown objects she could name them relatively correctly. However her perceptions were extremely disturbed. Immediately after naming the objects she would forget them. ...She used perplexing phrases when speaking or made paraphasic errors ("milk-pourer" instead of "cup")." (109)

The precise cause of the language disorder that accompanies Alzheimer's Disease has been a controversial issue. Kontiola et al (1990) claim that the language disorder associated with Alzheimer's Disease is consistent with its aetiological features. They consider that the degenerative nature of Alzheimer's Disease could explain the deterioration of complex linguistic functions for which it is difficult to compensate.

Bayles and Tomoeda (1983) link the linguistic difficulties with deterioration in the individual's memory, notably semantic and episodic memory. Armstrong et al (1996) claim that the complexity of the aetiological factors underlying dementia, is one of the reasons which has contributed to a degree of uncertainty surrounding the role of speech therapists, with people with dementia. Bayles and Kaszniak (1987) list diagnosis, monitoring, therapy and counselling among the speech therapist's roles in this context. Gravell (1988) suggested that the speech therapist's role would alter as the condition progressed, and de Bourgeois (1991), on the basis of an extensive literature review, suggests that there is some evidence for positive outcomes for treatment.

The current research demands that the literature on the effect of dementia on communication be examined in detail. It is asserted that only on the basis of a firm understanding of language breakdown in dementia, can communication techniques which have the potential to enhance pastoral communication be developed. This task will be the focus of the remainder of this chapter. However, it has been noted that dementia is not a homogeneous disorder. This raises the question of whether or not it is possible to develop a list of communication strategies for dementia as a whole, or whether, instead, specific strategies must be provided for the different forms of the condition. A primary issue which must therefore be addressed is whether or not the language characteristics of various dementias differ from one another.

Language Impairment and Dementia Aetiology

Thompson (1981), as part of his Ph.D. thesis tested the hypothesis that "language pathology differs according to the disease that causes it." His subjects included people who had been diagnosed as having Alzheimer's Disease and multi-infarct dementia, as well as people with Korsakoff psychosis and transcortical aphasia. He compared their language functioning with a "normal" control group and concluded that:

"The pattern of disturbance of language differs between disease groups and controls but there is no real difference between the two dementias... language tasks do not therefore differentiate between the major dementias."
(224)

If there are found to be specific areas of the brain to which there is reduced blood flow, with consequent tissue loss, this will dictate the nature of the language disturbance. People with reduced flow in the temporo-parietal region tend to have deficient receptive speech functions, whereas those with reduced flow in the left frontal region have more difficulty with expressive speech. In Pick's Disease, for example, focal degeneration of the frontal and temporal lobes predominates (Terry and Katzman 1983), but the superior temporal gyrus, (Wernickes area) is usually spared (Hacaen and Albert 1978). It could therefore be claimed that a different pattern of language functioning will result between dementias caused by focal and global deterioration. However, in dementia there is often a combination of focal and generalised deterioration. Wechsler (1977) reports the case of a 67 year-old man whose presenting symptoms were isolated aphasia, impaired repetition and reduced comprehension. Only over the subsequent two years did he develop personality

changes, memory loss, and stereotyped behaviour which is often characteristic of a more generalised dementia. A computerised tomography scan showed generalised cortical atrophy but also a focal lesion on the left sylvian fissure. Subsequent autopsy revealed that this man had Pick's Disease, but his case illustrates how focal and generalised degeneration may be inter-linked in causing the language deterioration in dementia. This inter-penetration of aetiologies could be used to support Thompson's (1981) thesis that it is difficult to isolate a specific pattern of language breakdown in the different dementias.

Murdoch et al claimed in 1987 that the majority of studies on language functioning in dementia to date had qualitatively investigated the language of a heterogeneous group of people with dementia, with a diversity of underlying aetiologies. Consequently, they contend:

"we do not have a thorough understanding of the range, severity, and type of language impairment associated with Alzheimer's Disease."

(123)

Their hypothesis was that there was a distinct pattern of language functioning associated with Alzheimer's Disease and their study was aimed at describing it. Their research design therefore emphasised the diagnosis of Alzheimer's Disease as a criterion in subject selection. Much recent research continues this model whereby the type of dementia has become a criterion for subject selection. (Flicker et al 1987, Grafman et al 1991).

Mildworf and Albert (1978) attempted to investigate if the aetiology of the dementia affected naming ability. They compared the performance of subjects with Huntington's chorea, Parkinson's Disease and normal controls, and found differences in naming ability across the aetilogically distinct groups. However, these findings must be interpreted with care as they did not make it clear that they controlled for dementia severity, which is an essential consideration.

Williams et al (1989) compared the performance of subjects who had Alzheimer's Disease on the Boston Naming Test with two control groups; one of these was elderly normal subjects and the other subjects with other forms of dementia. They did not find significant differences between the two groups who had dementia.

The effects of dementia aetiology and severity on the confrontation naming abilities of people with Alzheimer's, Huntington's, and Parkinson's Diseases were studied by Bayles and Tomoeda (1983). They found that the performance of people with moderate Alzheimer's Disease could be distinguished from that of people who had moderate Huntington's and Parkinson's Diseases.

The patterns of language impairment in Alzheimer's Disease and multi-infarct dementia were compared by Kontiola et al (1990). They found that people with these two conditions appeared to have different patterns of language impairment. They characterised the language impairment in Alzheimer's as being primarily receptive,

evidenced by inability to understand grammatical structures, whereas multi-infarct dementia resulted in difficulties with recognition of words, naming and repetition. These differences were so significant that they suggest that the examination of language functions has potential for the differential diagnosis of dementia. They qualify this, however, by adding that although their study raises suggestions about the aetiological questions, it is up to future studies to prove the actual clinical significance of their results.

Whether or not the language functioning in different dementias can be distinguished from one another is obviously a complex and disputed question. While there do appear to be some differences in language breakdown, it seems that for the purposes of this research, especially for the development of strategies to enhance communication for pastors, the dementias can be treated as a unit. That being said, in the literature review which follows, information on aetiology will be provided if it is given in the original research.

The literature on the effect of dementia on various aspects of communication will now be reviewed in depth.

1. Auditory Comprehension

Kontiola et al (1990) claim that in Alzheimer's Disease the language disorder is primarily receptive in nature while the expressive speech is more fluent and better preserved. (Bayles 1982, Ross et al 1990). They claim that the receptive disorder is

characterised by semantic and syntactic disorders, for example a difficulty in understanding complex sentences.

In their study of eighteen people with Alzheimer's Disease, Murdoch et al (1987) found that auditory comprehension was impaired in all of their subjects. Most of the errors occurred on test items which included syntactically complex commands which would have placed the greatest demands on short term memory. Appell et al (1982) report that simple comprehension is preserved, the subjects with Alzheimer's Disease being able to respond to simple commands and questions. However, more complex sentences involving the use of inference, the understanding of comparatives, or causal relations may present difficulty.

Deficits in auditory comprehension were also found by Thompson (1981). He suggests that this is caused not only by a decrease in auditory memory, but also by an inability to process the spatial, temporal and logico-grammatical concepts that language contains. Schmitt and Moore (1989) found that speaking rate affected the comprehension levels of "normal" listeners who were between 75 and 84 years of age. Their comprehension of passages which were read aloud was significantly worse under 60% time compression than at normal rate. Although it must be recognised that this study was of people who were unaffected by dementia, these two findings taken together may indicate that slowing of speaking rate could enhance the auditory comprehension of people with dementia, due to the fact that this would increase the time available to the confused person to process the incoming information.

These findings indicate that the auditory comprehension of the person with dementia could be enhanced if,

1. short simple sentences are used
2. speaking rate is slightly slowed
3. concrete rather than abstract topics are chosen

2. Comprehension of the Written Word

Halpern et al (1973) pinpointed the relatively poor performance of people with dementia on tasks designed to test their comprehension of the written word. He suggests that the late acquisition of this complex language function may account for its early and marked disintegration. This is consistent with Knotek et al (1990) who claim that remote memory is most durable in Alzheimer's Disease, and that written language is vulnerable due to its late acquisition.

A deficit in comprehension of the written word was also highlighted by Appell et al (1982). They reported that in their investigation of the language functioning of 25 people with Alzheimer's Disease, reading scores were lower than oral language scores.

Thompson (1981) asked the subjects in his study who had Alzheimer's Disease to read high "imageability" words. He found little evidence of surface dyslexia, letter by letter reading, or neglect dyslexia. He reports that there was no real evidence of semantic error reading, or deep dyslexia; however phonological errors

were made. He noticed a functional dissociation of word reading and understanding, a feature also noted by Schwartz et al (1979).

Stevens (1985) suggests that the possible causes of failure to understand the written word may be varied. The less dynamic mode of presentation of the written materials may, she contends, produce a lack of concentration and attention. She believes that these factors, rather than a visual-perceptual deficit, are responsible for difficulties in written comprehension.

3. Pragmatics

Pragmatics is the study of those aspects of communication which centre around appropriate language use for appropriate contexts, activities such as turn-taking and the social use of language.

In 1984 Kathryn Bayles, reporting on a longitudinal study of the effects of dementia on a number of language sub-systems, characterised the pragmatic decline as follows:

- (a) Early stages; some pragmatic impairment may be evidenced. The person may have difficulties with non-literal utterances, humour and sarcasm.
- (b) Middle stages; people with dementia exhibited decreased sensitivity to the conversational maxims that govern normal conversation. At this stage people still know when to talk but they may experience difficulties which inhibit their speech, and also in correcting their errors and understanding non-literal discourse.

(c) Late Stages; Most meaningful communication is absent and language is characterised by muteness, echolalia, jargon or non-sensical utterances.

Murray et al (1984) tested the hypothesis that people with dementia appear to have a greater communicative competence than is actually the case. Their subjects who had dementia scored significantly better on a test of functional communication than a group of subjects who had suffered a stroke. However this pattern was reversed when the same people were tested for their linguistic abilities. Thus their hypothesis that in dementia there is an inverse relationship between communication and language skills was taken as proven.

A relative sparing of social responses in people with Alzheimer's Disease was found by Slauson et al (1987). They used structured conversational interaction to study pragmatic behaviours in severely demented people. Their subjects were comparatively successful at maintaining eye contact, making relevant responses when thanked for their time, and correcting an incorrect statement made by the examiner. They were much less successful at replying to a compliment and making requests for further information.

On the basis of their study of functional communication in subjects with probable Alzheimer's Disease, Fromm and Holland (1989) found that there was a differential deterioration in functional communication categories. For both mildly, and moderately affected subjects the more automatic, over-learned communication acts,

such as social conventions, remain more intact than those which rely heavily on cognitive processing.

The conversational patterns of 11 people with dementia were analysed by Ripich et al (1991) and compared them with a control group of 11 elderly people who exhibited no cognitive impairment. They found that the confused elderly people attempted to compensate for their difficulties in language comprehension and usage, by employing strategies like non-verbal responses and use of shorter turns. Through use of compensatory strategies the people with early and mid-stage Alzheimer's Disease were able to sustain the discourse genre of conversation.

In the early stages of dementia there may be a tendency to develop strategies to conceal deficiencies as the person senses a decline in their mental abilities. On the basis of her 1982 research, Bayles claimed that her subjects who had Alzheimer's Disease tended to repeat the same ideas in order to make what was said seem more substantial.

Obler (1981) points out that in the speech of patients with Alzheimer's Disease there is a lack of questions, commands, second person pronouns, reference to the speaker as an ego, and a loss of terms such as "perhaps" which imply awareness of the truth value of statements. These features reflect the breakdown of language as a tool for communicating with others, for conveying or obtaining information, for directing actions, either of oneself or of others, for generating concepts about the

world and forming propositions about it, and for testing the truth of those propositions and drawing inferences from them.

4. Expressive Speech

Kontiola et al (1990) suggest that expressive speech may be one of the areas in which there is a difference caused by aetiological factors in the dementia. They characterise the language disorder in Alzheimer's Disease as primarily receptive, while the expressive speech is fluent and better preserved. In multi-infarct dementia, however, they contend that the language impairment is mostly expressive, including grammatical over-simplification and restriction of lexical choice.

There are a number of constituent elements to expressive speech. These include syntax (sentence construction), phonology (production of the sounds which make up words), fluency, and naming or word finding ability.

In general the speech of people with Alzheimer's Disease has been described as "verbally fluent but perceptually off course" (Rochford 1971). Appell et al (1982) report that:

"once initiated speech may be verbose and circuitous, running on with a semblance of fluency, yet incomplete and lacking coherence." (75)

(a) Naming

Confrontation naming impairment is one of the most commonly reported and best studied language deficits associated with Alzheimer's Disease (Bayles 1982,

Blackburn and Tyrer 1985, Nebes 1989). As memory begins to fail, difficulty in the elicitation of proper names is frequently the earliest recognisable disturbance of language in dementia. Overman (1979) found that naming impairment is a constant feature in the condition, regardless of specific aetiology, and that naming impairment tends to parallel the degree of dementia.

Researchers in this area report a common pattern of errors in the naming ability of people with Alzheimer's Disease. Thompson's (1981) data for people with moderate and severe dementia serve as a typical example.

Table 2.2 Sample of confrontation naming in Alzheimer's Disease: Thompson (1981)

Target	Nominal Paraphasia	Verbal Paraphasia	Circumlocution
tweezers	pincers nippers	pluckers clippers	to cut eyebrows to clear splinters
torch	lamp lantern	lighter	flash thing
bell	gong		to call with it ring

There is, however, considerable controversy concerning the nature of the naming disorder. Chenery et al (1996) claim that the nature of the controversy is centred on two questions. Is the deficit related to a procedural or structural semantic deficit, and does its nature remain uniform over the course of the condition?

Goodglass (1980) has distinguished three sequential stages in the elicitation of a name. An object to be named must be perceived and perceptually analysed, its lexical semantic representation must be aroused, and its phonological representation and motor articulatory sequence must be activated. Studies of naming in dementia have focused on the first two stages, stimulus recognition and word retrieval.

Some researchers (Lawson and Barker 1968, Rochford 1971) have suggested that the deficits in confrontation naming could be traced to the first stage in this process, and were due to a visuo-perceptual impairment. It was contended that people with dementia misperceived the visual stimuli when they were presented to them and therefore, they misnamed them. Rochford (1971) administered a naming test consisting of eight line drawings of common objects and eight body parts, indicated by the examiner on his own body. Subjects with dementia performed significantly better on the body parts, and analysis of their errors on line drawings showed frequent choice of an item of similar appearance to the stimulus item, suggesting disturbed visual recognition.

This finding is supported by Overman (1979) who found that people with dementia found it easier to name printed letters and numbers than pictures. He concluded that since letters and numbers are both simpler visually and members of more limited sets than pictures, that a visual impairment was responsible for the naming difficulties.

This hypothesis, however, seems to be decreasing in credence. Many studies have failed to support the suggestion that visual perceptual problems may be responsible for the naming disorder exhibited. (Martin and Fedio 1983, Schwartz et al 1979, Bayles 1982). Bayles and Tomoeda (1983) found that when errors in naming occurred they were most likely to be semantically related to the target. They claim that a potential weakness in those studies, which proposed a visuo-perceptual deficit, was that many of the error responses were both semantically and visually related to the stimulus. These authors therefore suggest that the proportion of error responses related only visually to the target was smaller than would be expected, if visual impairment was responsible for the misnaming. In addition, they contend that the ability of subjects with dementia to demonstrate through gesture the recognition of objects which they cannot name, is not consistent with the interpretation of perceptual impairment as the degradation of the incoming signal.

Furthermore the observation that naming errors became increasingly unrelated as the dementia worsens, does not support the perceptual error interpretation. If the

visual signal was degraded the errors would be more random and only semantically related by chance.

The evidence, therefore, seems to indicate a disruption in the second level in the naming process. This impairment could involve either destruction of the lexical (word) store, or alternatively a difficulty in accessing an intact lexical store.

Theories of access dysfunction usually imply variable word finding ability for individual lexical items (Gainotti et al (1980)). Improved naming after phonemic cueing is sometimes taken as evidence of an underlying impairment in lexical access or retrieval. Kirschner et al (1984) found that their subjects with Alzheimer's Disease benefited from phonemic cueing, and Henderson et al (1990) found that such cues improved their subjects' performance 22% of the time. Chenery (1996) suggests the presence of significantly impaired procedural routines in Alzheimer's Disease, with relative sparing of semantic memory.

Some linguists (Luria 1974) believe that language is organised in lexical maps with words that have similar meanings being grouped together. Grafman et al (1991) describe the most common model used to represent semantic memory, which they call the "lexical network" model. According to this model individual items are associatively (e.g. dog-bark) and semantically (e.g. house-dwelling) linked to related items, linked to descriptive features about that item (e.g. canary-yellow) and organised by category (e.g. animal-lion) membership.

It may be that dementia disrupts this lexical-semantic network. Schwartz et al (1979) noted that their subject appeared to accept semantically related words as correct names for pictures. The patient was asked to match a picture to one of five choices, the correct name, one phonological distracter, one semantic distracter, and two unrelated words. Forty-six of fifty-one errors involved the semantic distracter, thus they claimed that their subject was experiencing difficulty in maintaining semantic boundaries. The semantic field of specific words appeared to be abnormally enlarged, for example the subject matched pictures of both dogs and cats to the word "cat".

Martin et al (1985) believe that people with Alzheimer's Disease display either a loss of, or an inability to utilise, those attributes which serve to distinguish semantically related words. This claim is in accordance with the findings of Grober et al (1985) who suggested that the saliency of essential attributes may be reduced in Alzheimer's Disease, so that the more important referent-defining attributes are considered to be no more important than other less essential attributes. According to this model the semantic disorganisation causes the memory deficit, because the disruption in semantic organisation affects the encoding of new information into both the semantic memory and episodic memory.

The lexical semantic abilities of 18 people with Alzheimer's Disease were studied by Smith et al (1989) using confrontation naming tasks. They concluded that the pattern of naming errors suggested that Alzheimer's Disease caused a disruption

in the semantic network. They are, however, unable to pinpoint the cause of that disruption, whether it is disorganisation, or loss of stored information, or dissociation of words from the attributes they represent.

Henderson et al (1990) go further than Grober et al (1985) and suggest that the difficulties experienced by people with Alzheimer's Disease in confrontation naming are due to a loss of semantic information, rather than disorganisation. In their study of 19 people with Alzheimer's Disease they found that naming errors for individual objects were consistent over time.

A combination of aetiological features is suggested by Flicker et al (1987). Their results indicated that the language dysfunction in early Alzheimer's Disease is due to a deficit in semantic memory, in which categorical information remains available, whereas information about specific attributes becomes less accessible. Whatever the deficit underlying the naming disorder in dementia, it should be borne in mind that the deficit will interact with the cognitive factors underlying the condition, thus presenting an exceedingly complex picture.

Thus the word finding deficit is extremely complex. The conceptual element means that there is no easy solution. It may well be that whatever the pastor tries the word may not be forthcoming. However discussion of the nature of the word finding deficit is important for a number of reasons:

1. It illustrates that phonemic and semantic cueing (Chenery 1996) appears to enhance word finding ability whatever the underlying cause. This may be because the cue enables access to an intact store, or, if the semantic store is disrupted, a phonemic cue may promote the selection of the correct lexical item from among several previously indistinguishable members of a semantic category. The effect of phonemic cueing is also compatible with a theory of semantic loss, whereby the cue might compensate for incomplete specifications for some lexical items.
2. Even if the person cannot name an object they may well understand what it is, or at least see its significance. Researchers do seem to imply that even if the lexical-semantic store is extremely disrupted, or even if information is lost, there remains some form of semantic mapping. Despite the additional cognitive deficits, it may well be, therefore, that the individual may retain the ability to understand the nature of an object even when the ability to name that object is lost.
3. Researchers (Lawson and Barker (1968) for example) have found that demonstrating the use of an object by gesture enhances word finding ability.

(b) Syntax

Appell et al (1982) report that although substantive lexical items may be lost in the speech of people with Alzheimer's Disease, the use of syntax may be preserved. Kirschner et al (1984) in their study of eight people with dementia on the Boston Diagnostic Aphasia Examination found that conversational speech in all subjects was fluent, with largely normal scores on melodic line, phrase length, articulatory agility, grammatical form and absence of paraphasia.

The language of a person with advanced presenile dementia was described by Whitaker (1976). He suggested that she seemed to possess a "grammatical filter", capable of functioning independently of cognition. The subject was mute, unresponsive to commands, disorientated for time, place and person, and incapable of self management. She could, however, echo sentences spoken by the examiner if eye contact was established and 50% of the time would correct errors of syntax and phonology without conscious awareness. At no time, however did she correct semantic errors.

Schwartz et al (1979) examined a person with dementia on a bi-monthly basis for 30 months. During this time they observed progressive anomia and naming difficulty; however speech was rapid and well articulated. Their subject retained ability to perform correct grammatical operations like modifying word endings, or tenses, or adding plural endings.

A description of language in dementia in early, late and middle stages is provided by Bayles (1982). In advanced stages she maintains that word order was largely correct, despite the fact that the content of the utterances was meaningless.

The cognitive decline in Alzheimer's Disease means that syntax is not left unaffected. Thompson (1981) reports that people with Alzheimer's Disease demonstrate difficulty in holding words in memory long enough to construct sentences with them. Constantinidis et al (1978) found that sentences were often left

unfinished, phrases may be left hanging and there was a breakdown in grammatical agreement.

(c) Phonology

The phonological system of the person with Alzheimer's Disease appears to be relatively spared, although not error free. Gustafson et al (1978) reported the percentage of phonological errors to be between 10 and 30%. According to Constantinidus et al (1978) vowels are better retained than consonants and phonemic repetitions may occur in the midst of relatively well constructed sentences.

Murdoch et al (1987) suggest that the relative sparing of syntax and phonology is due to the fact that the phonological aspect of language is related to the automatic, non-volitional component of language, which is presumed to occur within the central language system itself. On the other hand, it is suggested that the semantic component of language is linked to volitional language and cognition, and that processing of the meaning of words takes place somewhere external to the central language areas.

A further feature of the expressive speech of a person with Alzheimer's Disease is perserveration. This has been observed to have three forms (Bayles 1982), compulsive repetition, impairment of switching whereby a response elicited correctly for one stimulus is repeated inappropriately for a later stimulus, and ideational perseveration where phrases and themes appear repeatedly in spontaneous speech.

Obler (1981) claims that the inability to inhibit prominent or accessible responses should be seen as highly characteristic of the language of individuals with dementia.

Irigaray (1973) understands the tendency to perseverate as being an inability to redirect and change attention from one task to the next. She sees traces of perseveration in other tasks, echolalia for example.

5. Reading

In general, five types of dyslexia are described in the literature. These are:-

- (a) deep dyslexia which refers to errors of semantic name reading ("bot" for girl), derivational errors ("art" for "artist"), visual errors ("shape" for "sharp"), visual semantic errors ("fragment" for "fracture"), visual and then semantic errors ("sympathy" for "orchestra") and function word errors ("off" for "of")
- (b) phonological dyslexia, which is the misreading of letters
- (c) surface dyslexia, where similar letters produce confusion of sounds, for example "pog" is read in place of "dog"
- (d) spelling the letters rather than reading the word
- (e) neglect dyslexia, for example reading "through" for "thorough"

In his study Thompson (1981) reports that there was little evidence of dyslexia, and that his subjects who had Alzheimer's Disease were able to read aloud. However, he is in agreement with Schwartz et al (1979), who suggested that there may be a functional dissociation of word reading and understanding. Thus, initiating



the use of written material as an aid towards facilitating comprehension and enhancing communication is contra-indicated.

6. Nonverbal Communication

"We hear a particular set of words, but how we interpret and understand them will depend on more than words. The tone of voice, the accent, accompanying gestures or facial expression will all influence our understanding...The actual words would be regarded as verbal communication. All the other features would come into the category of nonverbal communication." (Ellis and McClintock 1990:35)

Kitwood (1993a) contends that confused elderly people may retain an ability to communicate nonverbally and to interpret nonverbal communication:

"dementia sufferers sometimes seem to have a heightened awareness of body language, and often their main meanings may be conveyed non-verbally."(64)

Rau (1993) supports this view. She comments:

"the capacity to understand non-verbal messages, such as touch, tone of voice, and gesture, may remain intact when verbal comprehension and expression is no longer working well." (5)

These theoretical assertions are supported by evidence based on experience.

Goldsmith (1996) provides the following quotation from the proprietor of a residential home:

"I find that non-verbal communication is often preferred by people with dementia even when they can communicate verbally...the most important form of communication is tactile. When speaking we touch residents, kiss them goodnight, hello and good-bye - our residents respond in kind - through this their mood, wants and needs can be interpreted." (112)

The literature thus indicates strongly that confused elderly people use nonverbal communication. This assertion is supported by a review of the guidelines given by Rau (1993). She suggests touching the arm of the confused elderly person to ensure that the speaker has her or his attention. She advocates establishing and maintaining good eye contact, using a calm tone of voice, becoming a good observer so that one is aware of nonverbal communication from the confused elderly person and being aware of what one's own body language is communicating. All of these suggestions rely on aspects of non-verbal communication and are indicative of a belief that the processes underlying the interpretation and use of non-verbal communication may be relatively spared in dementia.

An emerging field within the study of dementia is based on the theory that much of the behaviour of the confused elderly person, which may, in the past, have been classified or dismissed as anti-social or difficult, is actually an effort to communicate. The work of Naomi Feil (1992) and the "Validation Technique" which she developed is central in this area. She proposes that behaviour of disorientated old people can best be understood as the behaviour of people in conflict, who are trying to resolve a task of old age which might have been avoided had earlier stages in life been better managed.

Her theory is based on the work of Erikson and she adds a further stage to his Life-stages model, which she calls "resolution versus vegetation". Based on her experience she dismisses reality-orientation as an approach, as she contends that it

pushes people with dementia into further isolation and instead "validates" their behaviour. In practical terms this means that she no longer expects or asks the people with dementia to conform to her standards of behaviour and instead acknowledges the truth of their feelings. This she accomplishes by:

"empathy, touch, eye-contact, mirroring body movements, matching voice and rhythms, picking up cues about feelings and putting them into words, accepting without judging, and genuine total listening." (1985;92).

Feil's (1992) experience is that this approach enables people to resolve life tasks, make peace with their past, express bottled up feelings and that often the people with dementia return to present reality and begin relating to others in present time.

This model signalled a seed change in the interpretation of the behaviour of people with dementia. Behaviour was no longer simply something to be managed, it was to be interpreted as an act, or at least an effort, to communicate. Goldsmith (1996) reports the comments of a development nurse in dementia services who wrote:

"I spend a large amount of time discussing with ward staff who have asked to have teaching on management of aggression...The hardest part to put across is that we should stop trying to manage...and start really looking at that behaviour more closely. Not just looking , but really "seeing" and making the connections tangible." (132)

The literature on the effect of dementia on various aspects of communication, namely auditory comprehension, understanding the written word, pragmatics, verbal expression, reading aloud and nonverbal communication, has now been reviewed.

The longitudinal over-view provided by Ferguson (in Shamey 1993) is a helpful summary.

Table 2.3 Ferguson's (1992) longitudinal overview of the effects of dementia on communication

Effects of Dementia on Communication:			
	EARLY STAGES	MIDDLE STAGES	LATE STAGES
CONTENT Ideas	May drift from topic Difficulty understanding new Information Vague Difficult producing series of relevant sentences	Frequently repeats ideas and forgets topic Talks about past events and with fewer ideas	Unable to produce sequence of related ideas Content irrelevant and bizarre Marked repetition of words and phrases
WORDS	Vocabulary shrinking Trouble finding right word	Word finding problems Difficulty naming objects	Poor vocabulary May use jargon Marked naming difficulties
GRAMMAR	Generally correct	Sentences broken up Longer complex sentences not understood	Lack of understanding of many grammatical forms Sentences fragmented
USE	Long-winded but knows when to talk Apathetic - fail to initiate conversation when it would be appropriate Difficulty following humour, sarcasm, non-literal statements May try to correct errors Gestures begin to reduce	KNows when to talk Recognises questions May fail to greet Poor social skills Rarely corrects errors	Generally unaware of surroundings and context Insensitive to others Little relevant language Some mute and some echolalia

(Cited by Shamey 1993)

Implications of the Research on the Effect of Dementia on Communication

(a) Verification of Findings

Review of the literature has verified Murdoch et al's (1987) view that "demented patients do not show an equal degree of impairment across the different types of linguistic knowledge." (124) The significance of this finding for this study is clarified when it is juxtaposed with Thompson's (1981) claim that:

"knowing the patterns of the breakdown of language in dementia may allow professionals and the carers to modify verbal input to patients to improve their comprehension and ability to function." (241)

If this can be extended to the pastoral situation it may imply that being aware of, and using those aspects of language which are less impaired, could help the pastor to enhance his or her communication with confused elderly people.

(b) Manipulation of the Environment

It is recognised that strategies for the management of aphasia are inappropriate to the management of dementia. Unlike rehabilitation following a stroke, the basic failure of memory and learning may hinder language therapy in dementia. However, manipulation of the communicative environment is one area which research suggests has the potential to enhance communicative behaviour. Thus, for example, Miller (1977), in his review of management areas for the demented, proposes ergonomics to adapt the environment to the patient's deficits.

Ford et al (1987) studied the effect of light on people with dementia. They found that lowering the light level during meal times had a marked effect, leading to a

decrease in noise and in disturbed behaviour and an increased level of food consumption.

Knopman and Sawyer-Demarts (1990) suggest a number of environmental changes including reduction in extraneous stimulation, use of calm, quiet colours, wall coverings that were of solid colours and the avoidance of television, which they conclude is a source of delusional and hallucinatory experiences.

Dunlop (1994) in his study of architectural design for elderly, disorientated people, supports these findings. He writes:

" the hypothesis... supports the premise that the physical environment can influence the behaviour of people who have cognitive impairment." (3)

Environment is not only physical. As has been reported, Pruchno and Resch (1989) studied the relationship between the well-being of the care-giver and the forgetful, asocial and disorientated behaviours of the person with Alzheimer's Disease. Their results from 262 interviews indicated that asocial and disorientated behaviours have a linear relationship with levels of burden, specific mental health problems associated with care-giving, and the extent to which care-givers sacrificed aspects of their social life. Thus the environment created by the care-giver's behaviour affected the behaviour of the confused elderly person.

The evidence from the literature thus indicates communication in dementia is affected by environmental factors.

(c) Language and Cognition

A decline in intellectual powers is central to the concept of dementia, and Miller (1977) points out that a straightforward examination of the IQ levels of individuals with dementia confirms that intellectual deterioration does exist. It has already been pointed out that the underlying cognitive deficit which is present in dementia will affect not only the presenting language disorder, but also any attempt to intervene.

Irigaray (1973) in her review of the language of dementia points out that basic neurological and cognitive mechanisms, such as memory and attention, play a role in normal language performance. Miller (1977) claims that this recognition, combined with the intellectual decline evidenced in dementia, led some writers to claim that the nature of intellectual performance in dementia is qualitatively different from that of normal subjects of the same age.

Inter-acting with the general intellectual deterioration is the memory disturbance which may be the presenting symptom of dementia. As was the case with intellectual deterioration, the issue is not whether or not the disturbance is present but what its essential nature is.

Miller's (1977) conclusions on the nature of the memory impairment are based on Broadbent's model of normal memory. This divides memory into a temporary short-term store of limited capacity and a more permanent long-term store. Miller

develops a two factor explanation of the memory disorder in dementia. He concludes that there is both an impaired capacity of the short-term store and an additional difficulty in establishing new material in the long-term store. It is interesting that Miller's hypothesis about long-term memory ties in with theories of a disruption in the lexical semantic store in which it is difficult to encode incoming information, due to loss or disruption of labels.

On a practical note Miller (1977) found that slowing the rate of presentation enhanced the ability of "normal" elderly people to recall a list of items. This is due to the fact that slower presentation meant that words built up less quickly in short-term storage, thereby giving the earliest words a better chance of being transferred to long-term storage. This, however, was not the case with people who had dementia.

The interplay between language, cognition and memory renders the language disorder in dementia an extremely complex area, and means that cognitive deficits must be taken into account in any attempt to enhance communication.

In this chapter the literature on aspects of the experience of dementia has been reviewed, its effect on the individual, on the family, and in particular on communication. In the chapters which follow, first theological and then pastoral perspectives on dementia will be introduced, as part of the process of relating these experiential and theoretical insights.

CHAPTER THREE
THEOLOGICAL PERSPECTIVES

THEOLOGICAL PERSPECTIVES

Bringing a theological horizon to bear on the experience of dementia

Introduction

Keck (1996) terms Alzheimer's Disease the "theological disease" and contends that it raises more acute theological issues than most other illnesses. The occurrence of dementia may well raise profound questions for those involved in pastoral care. These may concern sin and sickness, the nature of the person, or the relationship of reason and memory to faith. These questions in themselves are indicators of a dynamic inter-relationship between theology and practice. In this chapter the literature will be reviewed on a number of theological issues or perspectives which impinge on the experience of dementia. The issues on which the literature will be reviewed are: a theology of ageing, eschatological perspectives, personhood, sin and sickness, the nature of the individual, suffering, and a theology of hope.

A Theology of Ageing

Moffitt (1995) writes of the following case presentation being given to a class of graduate nurses:

"The patient is a white female. She neither speaks nor comprehends the spoken word. Sometimes she babbles incoherently for hours on end. She is disorientated about person, place and time. I have worked with her for six months but she still does not recognise me. She shows a complete disregard for physical appearance and makes no effort to assist in her own care. She is toothless so her food must be pureed. Her sleep pattern is erratic. Often she wakes in the middle of the night. Most of the time she is friendly and quite

happy. Several times a day, however, she becomes quite agitated without apparent cause and screams loudly until someone comes to comfort her." (16)

After the presentation the nurses were asked how they would feel taking care of such a patient. Moffitt (1995) reports that the words "frustrated", "hopeless", "depressed" and "annoyed" predominated. A picture of the patient was then passed round. It was a six-month-old baby!

This example illustrates that societal perspectives on ageing are often negative. Campbell (1971), surveyed nurses' attitudes to geriatric patients, and claims that there was evidence of a lack of desire to work with ageing patients. Indeed Kastenbaum (1977), contends that an old-age stereotype has become so wide-spread and deep-rooted that it may even be shared by old people themselves. He asked some people in their 70's and 80's what it would mean if they described themselves as old. One responded "it would be like saying I'm not much of a person any more". (7) Responses such as these support Pruyser's (1975) claim that "culture is a powerful determinant of attitudes toward aging and, hence, of feelings about selfhood." (104)

A review of the literature reveals that it would be inaccurate to speak of one biblical view of ageing. Rather there is evidence of a number of perspectives. Maves and Cedarleaf (1949) report that the biblical writers viewed ageing as a phase of life which affected individuals on three levels, personal, familial and societal. The familial dimension of ageing was that in which individuals faced responsibility for the protection and support of the ageing members of their families. On a societal level

each person was seen as a part of the whole, the individual's life inter-twined with the community at large. So Dulin (1981) writes:

" to be an aged member of the family meant to be protected by the family, to have a purpose in strengthening the family and to be assured of a dignified life in old age." (78)

When respect and care for the elderly waned this was seen as an indicator of a more general degradation of society. Treetops (1992) reports that the people's attitude to the aged was understood by both Isaiah and the Deuteronomist as a measuring gauge of the nation's life as a whole. They both agreed that respect for the elderly was the precept upon which society thrived. For both, a society which abused the elderly was doomed to destruction because it was diseased from within. A notable aspect of this mindset, Treetops (1992) continues, is that care for the elderly members of the family or community is not dependant upon any contribution which the elderly person may make, nor is the carer seeking any personal gain.

There is also a biblical perspective on ageing which stresses sadness at the approach of age. The psalmist recognises the despair which can be associated with old age. "Those who see me on the street flee from me. I am forgotten by them as though I were dead." (Psalm 31:11-12 NIV)

Dulin (1981) contends that in Israelite thought "length of days" indicates a desire to over-come the consequences of ageing and postpone death, in a context where ageing was understood as a process of gradual separation from society and God, a separation which was completed at death. Nouwen et al (1974) pick up this theme and suggest that for many people old age is characterised by segregation,

desolation and loss of self. Segregation comes about because elderly people are rejected by a society which views "having" as more important than "being". Thus, they claim that elderly people who are no longer as influential, "productive " or powerful as they once were, are side-lined by a society which no longer sees them as useful or desirable. Simone de Beauvoir (1972) describes this as a loss of personal dignity.

A considerable amount of attention in recent years has been concentrated on the development of a theology of ageing. Thus, for example, Pruyser (1975) contends that a peak-slope view of life is misleading. Instead, ageing should be recognised as bringing gains as well as losses. He concludes that "the life course is neither upward nor downward, but a forward movement full of new discoveries." (102)

Katz (1975) contends that the Jewish approach to old age is constructive. Old age is seen as the Sabbath of life, and he proposes that it be seen as the high point of the human career. Browning (1975) is realistic about the experience of ageing. Based on a theological understanding which stresses salvation and hope he concludes that while older people may need relaxation and may work through a process of disengagement (Cumming and Henry (1961)) "they also want to express care for the cycle of the generations and the future of the world." (165)

While reflection on a theology of ageing is a vital development in theology and pastoral care, a review of the literature reveals that there are limits to the degree

to which these theological insights can be applied to dementia. A theology of ageing rightly stresses that old age is a time of losses and gains. However the experience of dementia is predominantly one of loss. Many of the gains of ageing, like wisdom, maturity, and the potential to feed insights back into society, cannot be applied to dementia. Thus the insights developed by theologians in response to the experience of "normal" ageing (for example Capps 1985), while helpful in themselves, do not take into account many of the questions raised by dementia.

An Eschatological Perspective

Tracy (1975) proposes that by employing an eschatological perspective human beings can come to respect ageing as "the concrete expression of our common human experience of ourselves as temporal beings." (119) His approach is in broad accordance with Tillich's (1963) method of correlation and he suggests that the Christian doctrine of eschatology bears intrinsic disclosive power for illuminating human beings' temporality and history. These are important dimensions of our common human experience of ageing.

Tracy's (1975) argument is that time should properly be understood, not as a series of moments, but as a process. If this process model is accepted it then follows that there may be past, present and future meanings in any present moment; thus, for example, when a person refers to a particular meaningful moment in their life, they do not simply mean a particular present moment in a series of moments. The meaningfulness of that present moment may derive from the past, through memory of

past experience, from the present enjoyment and from future anticipation. Therefore, the meaningfulness of any given moment may be comprised of all three modalities of human time.

His contention is that what is true for the moment is true for life in general, and thus it is that ageing becomes accepted and respected as part of the whole life experience. This view stands in stark contrast to any who see ageing as a cruel twist of fate at the end of life. Ageing (and this line of reasoning would appear to apply to dementia too, although Tracy does not mention it) is thus seen as a concrete expression of our temporality and also as a reminder of human beings' union with nature.

Ageing, therefore, is regarded as lawful; part of the way God created the universe to run. It is thus freed from any hint of punishment or curse. As Tracy (1975) summarises:

"If we learn that respect, then we may also learn to respect again - even to revere - but not to romanticize - the diverse modes of authentic temporality and aging that each of us individually and, by analogy, our society and our culture may experience." (132)

This type of approach is consistent with Hiltner (1958 b). He contends that joy and fulfilment can only be experienced in old age when individuals have faced losses in their own life. There are also definite parallels between Tracy (1975) and Erikson (1980). In Erikson's (1980) thinking there is a correlation between the low status of old people in contemporary western culture and a lack of direction and

sense of meaning in adolescents. He contends that unless the young have come to terms with old age they will have difficulty developing a sense of purposeful sequence in the different phases of their lifetime.

Personhood

Goldsmith (1996) raises the issue of personhood with regard to dementia, he writes:

"We are left with the unresolved question as to whether there is still a 'person' remaining as the illness advances, or does the very notion of dementia destroy what makes someone a person?" (20).

In this section of the literature review, opinions on the nature of personhood will be reviewed. In the Discussion, (Chapter 8), this review in conjunction with information gathered from the questionnaire (Stage 4), and the in-depth interviews (Stage 5), will form the basis of a discussion on the following areas:

1. Can 'personhood' be described in terms of criteria or is it immutable?
2. Can a status of 'personhood' be lost or gained?
3. Theologically is 'personhood' related to worth in God's sight? This question is raised by the medical model whereby in situations like euthanasia and abortion 'rights' are attached only to persons. If this model is applied theologically the question of the relationship between personhood and worth is necessarily raised. Pastorally this relates to the integration of the pastor's experience of the deterioration of the person with dementia, with an objective, theoretical, theological affirmation of their value, and God's love for them.

Underlying all of these questions is the controversy with regard to the nature of personhood. It is on that controversy that this section will focus. A review of the literature highlights a division between those who understand personhood to be defined in terms of criteria and those who define it simply as membership of "Homo Sapiens".

1. Criteria of Personhood

Fletcher (1975) outlines ten criteria, which he describes as "indicators of humanhood". Among these is minimal intelligence. He contends:

Any individual of the species homo sapiens who falls below the I.Q 40 mark in a standard Stanford-Binet test...is questionably a person; below the 20 mark, not a person."(1)

Fletcher's criteria also include self-awareness, self-control, a degree of control over one's existence, and a sense of time.

An extreme position is taken by Tooley (cited by Fletcher 1975) who contends that the real pre-condition to personhood - he terms it having a serious right to life - is self-awareness. A requirement not evidenced by foetuses and even infants.

Based on a social view of personhood, McFadyen (1990:153) constructs the following definition, "a person is an integrated, centred and autonomous subject of communication." He understands the capacity for relationships to be integral to personhood, "our personal identity", he claims, "is the way we relate to others." (152) Personal identity is therefore diachronic, open to others and open to change. Within this paradigm there is a connection between the quality of relations and the quality of

personhood, and it raises questions about the 'vertical' relationship with God, which is also shaped, at least partly, by communication. Can it be devalued if the capacity for communication and relationships is no longer apparent?

Kitwood (1993 b & c) stresses the importance of relationships with regard to maintaining the personhood of the individual with dementia. There is obviously an underlying implication in their remarks that dementia diminishes personhood. He claims:

"The dementia sufferer needs the Other for personhood to be maintained...the Other is needed, not to work with growth, but to offset degeneration and fragmentation; and the further the dementing process advances the greater is the need for that 'person work' - the self that is shattered in dementia will not naturally coalesce; the Other is needed to hold the fragments together. As subjectivity breaks apart, so intersubjectivity must take over if personhood is to be maintained." (Kitwood 1993 b285)

Definitions of personhood which rely on criteria, are based on the implicit belief that personhood is a status which can be gained or lost, and demeaned, that is, that one individual can be "less" of a person than another. This is made clear by Fontana and Smith (1989) who use the phrase "unbecoming a self" to describe the effect of dementia on an individual. Their claim is that in the early stages of the disease people continue to interact with others as if they were sentient beings, whilst what is actually happening is that they are losing the rational part of their self and relying on deeply embedded forms of sociability to carry them through social situations. The self of the person with dementia slowly begins to deteriorate as the disease progressively attacks the mind, leading not only to bodily deterioration but a

complete loss of mental functioning. Until, where there was once a unique individual there is emptiness. Jacques (1992) makes a similar claim when he says:

"At the final stages the patient may be assumed to have no real subjective awareness, no sense of self at all, and to be, in this sense mentally dead." (172)

Sabat and Harre (1992), on the basis of empirical evidence derived from the structure of discourse, and the behaviour of 3 patients who had Alzheimer's Disease contend that the self of personal identity persists far into the severe stages of the disease. However, it is their belief that that the self of multiple personae which are projected into the public arena, and which require the co-operation of others to come into being, can be lost. Similarly Cohen and Eisdorfer (1986) delineating six phases of the change experienced by people with dementia describe the last stage as "separation from self".

Thus, coming from a criteria governed model of personhood, these researchers claim that dementia diminishes the personhood of the individual. A major difficulty inherent in this approach is how to differentiate between the different stages of dementia. How does one define when the personhood has diminished, when the self has "unbecome"?

2. Membership of the Species "Homo Sapiens"

In contrast with those models which seek for criteria as evidence for personhood, are those who equate personhood with life. For the purposes of this discussion it should be noted that these two models are diametrically opposed to one another on the issue of whether personhood can cease before physical death. Thus

May, (cited by Fletcher (1975)), argues that membership of the species, "Homo Sapiens" is of supreme moral significance. Individuals being human by virtue of what they are, not by what they achieve or do. Watts (cited by Bird 1989) reaches a similar conclusion from a different starting point. He sees a strong link between personhood and spirituality, stemming from a study of the Greek word *pneuma*. He claims that while the person is still breathing the spirit is present and the personhood of the individual maintained. Ramsey (1967) makes the following claim:

"The value of a human life is ultimately grounded in the value God is placing on it...thus every human being is a unique, unrepeatable opportunity to praise God. His life is entirely an ordination, a loan, a stewardship." (72)

Bird (1989) claims that the sanctity of life is deeply embedded in the Judeo-Christian ethic and can be traced from the Creation narratives, through the Ten Commandments, to the Sermon on the Mount. Human beings are regarded as being a part of the created order. Thus Genesis 2:7 reads:

"And the Lord God formed man from the dust of the ground, and breathed into his nostrils the breath of life, and man became a human being."
(NIV)

Therefore, Weaver (1986) contends that on a Biblical basis, life must be seen as being synonymous with personhood, he writes, "as long as the breath is in us, we may live in responsibility and love with God." (446) He bases this claim on the interpretation of the Hebrew word *nephesh*. The Hebrew text of Genesis 2:7 states that when God breathed the breath of life into the dust of the ground the human being became *nephesh*. This word is given various translations, in the King James version it is soul, but it can also be interpreted as the person's throat, neck, desire, and the vital

processes which maintain life. Therefore Weaver (1986) contends that it is impossible within Hebrew thinking, to separate soul from body, and that there is a holistic view of personhood pervading the Old Testament, in contrast to the dualism which has been claimed to underlie some New testament writing. This is strengthened by his claim that *nephesh* can also refer to the continuing relationship of our body to God.

Pailin (1992) develops what he terms a "theology of human being" from his experience of knowing Alex, a severely handicapped child. He contends that "the worth of persons lies in the love of others for them, and absolutely in the all-embracing love of God for each individual." (123) He goes on to make the case that persons are loved by God, as the persons they are now. Pailin (1992) obviously sees the attitudes of other people and God to the person as being significant, and does appear to equate life with personhood in that it is his contention that God does not cease to love His people.

An essential feature of Barth's (1961) understanding of life was that it is a loan from God, to be treated with respect, because God has given life a particular distinction as evidenced by the incarnation. Bromiley (1979) summarises the Barthian view as being that an understanding of life rests on seven necessary premises:

"(1) in addressing us, God acknowledges our life, (2) he acknowledges it in its unity, distinction and order, (3) He acknowledges it as this specific life (4) He acknowledges it in its independence and spontaneity, (5) He acknowledges it as a constant if mutable life in which we are always ourselves as subjects, (6) He acknowledges it in its determination for freedom before himself, (7) He acknowledges it in its determination for freedom in fellowship." (165)

Those who believe that personhood can only be equated with life, and is not therefore a status which can be achieved or lost, claim that one of the clearest affirmations of the sanctity of human life derives from the knowledge that man, as male and female has been created in the image of God. The author of Genesis writes, "So God created man in His own image, in the image of God He created him."

(Genesis 1:27 NIV).

Theologians and Biblical scholars have long argued about what exactly is meant by being made in God's image. Their discussions will now be reviewed. It is necessary to examine whether or not scholars believe that the image of God can be lost while life persists, for this has implications for the equation of life with personhood.

Simmons (1983) claims that the theologians Schaeffer and Koop equate the image of God with animation or biological form. Thus personhood cannot cease before death, and even those who are comatose or diagnosed as being brain dead have not lost the image of God. The image of God is therefore understood as an objective possession which cannot be lost. This is the equivalent of the genetic argument in the abortion debate, whereby personhood is identified with the individual's genetic code. The foetus's genetic code being different from the mother's thereby implies that the foetus cannot be identified with or simply seen as part of the mother. In addition the genetic code is present from conception, implying that the child's personhood was present from that time.

The view of the "anthropomorphites" is that man is made physically in the image of God. Calvin (1559) reflects this view when he writes in the Institutes "even in man's body some sparks of God's image glow."

Those who support an identification of "image of God" with physical appearance, point to places in the Old Testament where God appears to manifest Himself to people in human form; for example, in the prophetic visions as in Amos 9:1, "I saw the Lord", and to other anthropomorphisms and anthropisms. The implication is, therefore, that when the Hebrews thought of God they thought of him in some sort of human shape or form.

Arising out of this context, theologians and Old Testament scholars have claimed that there may well be a physical likeness implied by the term "image of God". Von Rad, (1962), for example, rejects interpretations which limit God's image to man's spiritual nature. He relates the concept of image to dignity, personality and decision making ability, and includes the possibility of bodily likeness, when he comments, "the marvel of man's bodily appearance is not at all to be exempted from the realm of God's image". Von Rad (1962) claims that the recurrence of the same Hebrew word for image in Daniel 3, when Nebuchadnezzar made an image of gold, implies that the Hebrew author's original idea was that man's outward form was a copy of God's. He therefore concludes that scholars should be wary of splitting the physical from the spiritual as the whole person is made in God's image.

An alternative approach is taken by those who contend that to be in the image of God implies a representative function. Just as in the Book of Daniel, Chapter 3, Nebuchadnezzar's image was placed to represent him, so scholars (Dyrness 1979) claim that man is set in the midst of God's creation as His statue. Tied in closely with the concept of representation is that of dominion. Man's representative function being carried out as he exercises authority over creation on God's behalf.

Of particular pertinence to the issue of dementia is the claim that the essential feature of being made in the image of God is humankind's capacity for self-conscious reason. This concept was prominent among theologians up to the time of Aquinas, due, at least in part, to the observations that the capacity to reason is a distinguishing feature between humans and the rest of the created world, and that the ability to exercise dominion requires reason as a pre-requisite. Petzsch (1984) claims that Barth, like Brunner, saw the likeness of God in man in terms of relationship, but, he contends, the degree to which that relationship depends upon rationality in man, in Barth's thinking, is not clear.

Simmons (1983) summarises the main features of the biblical portrait of personhood as follows. Firstly, biology and animation are integral to personhood, the person is regarded as animated flesh (Genesis 2;7). Secondly, people bear the image of God and this distinguishes them from the rest of creation. (Genesis 1 26-28). The third feature of personhood is choice making, based on moral reasoning (Genesis 3;22). Thus Simmons claims:

"being created in the image of God...means to be fashioned with a "life" that has powers like those of God Himself...The person is one who is (1) alive, (2) related to others, (3) reflective, (4) able to make moral decisions (5) spiritual." (127)

The classical source for ethical and theological accounts of the nature of the person is the definition of Boethius, "the individual substance of rational nature." (cited by Chadwick 1981) This view stresses individuality and rationality, and was developed by Kierkegaard (1847) who wrote, "Had I to carve an inscription on my grave, I would ask for none other than 'the individual'."

Davidson (1904) suggests that this emphasis may have developed due to the tendency of each age to interpret the "image of God" in terms of its own highest ideals. If conscious reason is the seminal concept in being in the image of God, then it could be claimed that people with severe forms of dementia have lost that image.

Following the Reformation, the theory that image denotes the moral character of God was developed. Bonhoeffer (1959:269) contends that, "Created man is destined to bear the image of uncreated God." Within this paradigm the entrance of sin into the world is seen as spoiling that image, but the image of God in mankind, although lost in the Fall, is restorable through the initiative of God and in relationship with Him. (See Romans 8:29 (NIV) "For those whom God foreknew He also predestined to be conformed to the likeness of His Son"). Thus Bonhoeffer (1959) asserts that when a person follows Jesus he bears the image of the incarnate, crucified and Risen Lord. The implication for this research is that, within this paradigm, if the

image of God is restored by God Himself, nothing, even by extension the devastation of dementia, can take that image away.

Sin and Sickness

Robert Davis (1989) writing of how Alzheimer's Disease began to affect his relationship with God comments:

"This was unfair and unthinkable. I could only cry out bitterly to the Lord, "Why, God why? How can you leave me at a time like this? Is there some unpardonable sin that I have unconsciously committed?" (53)

The question of a link between sin and sickness, particularly of sickness being a direct punishment for personal sin is one which has dominated pastoral care. Grant (1990) goes so far as to claim:

"The nature of pastoral care in the Hebrew and Christian communities since before the time of Job has been shaped by the way the relationship between these realities has been understood." (1176)

Grant (1990) continues that much of the book of Job is concerned with the question, "Is suffering always caused by sin?". He maintains that scholars see this questioning arising out of the context of God's relationship with the nation of Israel. In Exodus and carried through into the prophets, God is seen as sending suffering as punishment when the nation rebels. The underlying belief in a direct, causal link between sin and sickness continues into the Gospels. This is evidenced by the disciples' question to Jesus when they encountered the "man blind from birth". "Who sinned?" they ask "This man or his father that he was born blind?" (John 9:2). Indeed, Grant (1990) claims that it could well be argued that a belief in the link

between sin and sickness underlies modern societal attitudes to psychiatric illness and even cancer at times.

The nature of the link between sin and sickness has been explained primarily in three ways. Firstly, that there is indeed a direct causal link. Grant (1990) classifies this view as "Classical theism". God is understood as being personal and omnipotent, sickness and suffering are therefore God's choice, His will. Within this view therefore salvation and healing are sequentially related. If healing does not result then the illness is interpreted as an opportunity for revelation. This standpoint is opposed by those whom Grant (1990) classifies as "Dualists".

Dualists take into account the possibility that sickness is a direct consequence of the Fall. This is the position set forth by Athanasius in *De Incarnatione*. Thus, not all sickness is due to personal sin. Having entered the world as a result of mans' rebellion, sickness now operates according to physical laws. Thus dualists propose one realm of existence where physical laws always rule, and another where God's judgement and strength operate. According to this view God is not responsible for sickness, and He is relied upon for strength in the face of suffering.

A third approach as "holistic" (Clinebell 1984). According to this position every area of life, spiritual, physical and psychological inter-relate. Modern medicine is adding credence to this view as links between life-style and health are being uncovered. Clinebell (1984) advocates that the pastor working within this approach

seeks to help the individual discover where causal links exist, and, where necessary, to repent of damaging characteristics and habits. Healing and salvation are closely related, for any action that enhances one area of life enhances all.

The relationship between sickness as a natural part of creation, and sickness as the result of personal sin is developed by Becker (1978) in the context of ageing. In his article *Judgement and Grace in the Aging Process* he proposes that the law of God should be understood in a double sense, as order and command. Order implies the lawfulness of creation. In this context it also implies the lawfulness of ageing. Thus ageing is freed from overtones of punishment, curse or sin, and recognised instead to be part of the lawfulness of nature. He writes:

"We understand aging as a part of creation, a natural process, a gift or blessing, though not always a welcomed or enjoyable gift." (186)

The other aspect to God's law, claims Becker (1978) is command. This implies human beings' response to the gracious but lawful act of God in creation. In the pastoral situation he maintains that individuals may need to be enabled to assess what aspects, if any, of the situation are their responsibility.

It is recognised that the link between sin and sickness may be a real concern for the confused elderly individual and their family. However, while aetiological factors remain unproven, the proposal of a direct link between dementia and the individual's particular and personal sin seems to have little to support it. Such a

position blames the individual and re-inforces the isolation which he or she may well be experiencing.

Body, Soul and Spirit?

The individual who has dementia, along with their families and pastors, may well come to the point of grappling with theological questions concerning the nature of humanity. This is an area which has provided meat for discussion between and among theologians, philosophers and Biblical scholars for centuries, it is therefore important to be selective in the issues raised. With regard to dementia therefore it seems that two primary questions are raised:

1. How does the immortal element in people relate to the body?
2. How does the immortal element relate to the mind?

Within the context of this discussion the terms "soul" and "spirit" will be treated as synonymous. This approach is taken for two reasons:

(a) It is felt that the Biblical evidence, although fiercely disputed, does seem to favour their identification. (see for example the close parallels between Paul's use of "spirit" and Peter's use of "soul"). Vine (1940) supports this contention when he writes:

"The language of Hebrews 4:12 suggests the extreme difficulty of distinguishing between the soul and the spirit, alike in their nature and their activities. Generally speaking the spirit is the higher, the soul the lower element. The spirit may be recognised as the life principle bestowed on man by God, the soul as the resulting life constituted in the individual." (54)

(b) The distinction is not material to this discussion. What is vital is that there is an immortal element to humankind. It is recognised that this is not a universally agreed proposition. Behaviourists would contend that man is made up of his actions and

responses and that physical death ends life. However the majority of Christian theologians assert that there is an immortal element in humankind. There is a controversy over whether or not humankind is immortal by nature, or if immortality is conferred when an individual comes into relationship with Christ.

Wright (1988) outlines three approaches to the origin of the soul. Platonism, whereby the soul is thought to enjoy some higher existence prior to entering human bodies; transducianism which argues that the soul, like our bodies, is derived from our parents and creationism which asserts that God creates the soul out of nothing for each human being.

1. A Holistic Understanding

It is recognised that the question of "What happens to the spirit as the body deteriorates?" is only relevant within a dualist paradigm. Within a Monist model, which characterises Hebrew thinking, there was no separate identity of soul and body. Therefore the physical death of the body marked the end of personal identity and the falling out of relationship with God. This picture is reflected in the Old Testament in the Psalms of individual lament. As the body in its entirety deteriorated, the individual was understood to become increasingly separated and isolated from the community, until that isolation was completed by death. (Weaver 1986).

2. Dualism

(a) The Relationship between Body and Soul

The nature of the relationship between body and soul is a controversial issue. Plato emphasises the soul, which he postulates lives on after death while the body is shed like a garment, a position often described as Platonic dualism. As has been outlined, Monism refuses to make any distinction between soul and body as separate entities. The soul is either seen in its consciousness as the whole person, or alternatively, the body is seen as the whole person and the soul merely as an expression of the body's behaviour.

Guthrie (1981) claims that the New Testament writers in general distinguish between a "bodily" and a "spiritual" aspect in people. For example Paul describes the spirit of God as witnessing to man's spirit, to that part of man which is capable of responding to Divine influences (Romans 8;16); and in James 2;26 there is a distinction made between spirit and body where the author maintains that both are necessary for life.

Within Pauline theology the body (*soma*) and the flesh (*sarx*) are distinguished. *Sarx* is used to denote mankind in its weakness and creaturely nature (Galatians 1:16); it is seen as standing over and against God, and is used by Paul as the contrast to spirit. On the other hand the body (*soma*) is mortal but is capable of being renewed and given life by the spirit. Robinson (1952) highlights the distinction between *sarx* and *soma*:

"While *sarx* stands for man, in the solidarity of creation, in his distance from God, *soma* stands for man, in the solidarity of creation, as made for God." (31)

The body (*soma*) is not meant for immortality (1 Corinthians 6:13), rather its real purpose is to be the Temple of the Holy Spirit (1 Corinthians 6:19).

While there is a clear distinction between *sarx* and *soma*, Guthrie (1981) claims that both are contrasted to spirit. With regard to spirit-*pneuma* Guthrie (1981) contends that:

"It is difficult to conceive of *pneuma* as something added to man's existing state. It is more reasonable to consider that a man's natural spirit, which in his unregenerate state is inactive, is revived at conversion by the Spirit of God." (166)

Ludemann (1872) notes the complete absence in Paul's epistles of the Hellenistic concept of the soul's pre-existence before the existence of the body.

Philosophical arguments may also have some light to offer. Socrates thought of his real self as something distinct from his body. Descartes (cited by Davies 1982) sums up the independence of the soul from the deterioration of the body when he writes:

"My essence consists solely in the fact that I am a thinking thing...I possess a distinct idea of body, inasmuch as it is only an extended and unthinking thing, it is certain that this (that is the soul by which I am what I am), is entirely and absolutely distinct from my body and can exist without it." (120)

Within a dualist model these arguments, in combination with the previously discussed theology of ageing, which emphasises the wisdom, growth and maturity

which older people can develop despite increasing physical deterioration, support the contention that spirit need not deteriorate as the body ages.

(b) The Relationship between Mind and Spirit

The evidence which is available suggests that dementia does bring about spiritual changes. These are described in detail elsewhere (Chapter 2), but typically they include feelings of isolation from others and from God and paranoia. Davis (1989) describes himself as a "strong, self-willed disciplined man," who thought that nothing could ever shake his mind. He writes:

"For years I have claimed Isaiah 26; 3-4 as a promise for those who trust God "You will keep him in perfect peace whose mind is steadfast"---yet the devastation wrought by this disease brought me to despair. Gradually because of not hearing, not remembering or not comprehending fear swept over me as I lost more control of my circumstances." (102)

Davis (1989) illustrates that, in his experience, spirit and mind cannot be viewed independently.

It has been claimed that the Holy Spirit can be identified with the spirit of Christians. Guthrie (1981) rejects this view, claiming that there is a clear distinction between man's spirit and the Holy Spirit. He contends that at conversion the human being's natural spirit is given new life by the Spirit of God. Guthrie (1981) writes:

"For the believer, *pneuma* seems to mean the whole man committed to God. It is man moved and motivated by God. It is man in fellowship with God." (166)

God's spirit thus is understood as working in and through the individual's personality.

Stoessel (1963) writes that mind (*nous*) is seen as a universal aspect of humanity, not good or bad in itself, its moral standing being dependent on what dominates it. *Nous*, thus, is the thinking or willing aspect of the person. Romans 12:2 implies that a renewing of the mind follows conversion. So Black (1973) can claim that:

"True dedication of the spirit is to engage powers of the mind, in the quest for perfection, or rather for the perfect will of God for us." (151)

The theme of the unity of the individual can be discerned within Pauline theology. Insights from Guthrie (1981) and Black (1973) have made it clear that for Paul wholeness is attained when all aspects of the person are in harmony. That being said, distinctions are made between different aspects of the individual. In 1 Corinthians 14:14 for example, the mind is contrasted with the spirit, emphasising, claims Guthrie (1981), that emotional experience must be linked with understanding.

It may therefore, be possible to claim that there is potential for independent functioning. If the functioning of the human spirit is dependent on the Spirit of God then cognitive deterioration need not undermine what is spiritual. If the spirit is indissoluble, a conclusion which may be drawn is that the spiritual changes in dementia represent not a change in the "spirit" but an accessing problem. Thus even in dementia the Holy Spirit can communicate with the human spirit.

Suffering

The existence of dementia may raise the theological problem of suffering. Simply stated, "How could a loving and good God allow people to suffer this disease?"

Traditionally, suffering has been classified as one form of natural or metaphysical evil (Ahern 1971). This he defines as evil which exists in the universe, and is part of the natural world. It is contrasted with moral evil, which is morally culpable behaviour.

According to classical theism (as summarised by Owen (1971) for example), God is omnipotent, omniscient and perfect. Davies (1982) summarised this by saying God is "all powerful, all knowing and all loving" (16). Statement of this belief however leads to the problem of how can the existence of God and the existence of evil be reconciled. Augustine has traditionally been said to have formulated the dilemma thus "Either God cannot abolish evil or He will not. If He cannot then He is not all powerful; if He will not then He is not all good."

Ward (1990) maintains that there are four main theories used to account for the co-existence of evil and God. The first is that evil does not really exist. Aquinas is associated with an alternative response and that is to view evil as the privation of good. The third possibility which Ward (1990) reviews is that evil is caused by forces which are opposed by God, perhaps a fallen cosmic being. The difficulty inherent

with this view is whether or not the existence of such forces is compatible with the existence of an omnipotent God.

The fourth possibility outlined by Ward (1990) is that "evil is a necessary part of a very good whole" (86). A number of philosophers and theologians have developed theodicies based on this model.

Hick (1977) argues that the existence of evil is necessary for mankind's development. He suggests that God does not coerce people into following Him. Man is prone to sin, but is able to develop and mature because he is given the opportunity to face evil.

An approach characteristic of some conservative theologians (Dobson (1993), for example) stresses the absolute sovereignty of God and sees no inconsistency in the co-existence of God and evil. Suffering occurs because God wills that it should, not for its own sake, but for some reason which may not be understood. This approach encourages the person who suffers to accept suffering for the good of his or her own character, and in the hope that their attitude might challenge others.

Swinburne (1979) suggests that natural evil gives people the opportunity to grow in knowledge and understanding. He contends that if people are to understand that there are consequences to evil actions then laws of nature must operate regularly,

and that there will, inevitably, be what he terms "victims of the system". This, he contends, is sad, but necessary, if humankind is to learn about good and evil. Thus the existence of some evil is a consequence of the great good which God wills.

A criticism aimed at these theories is that if they are followed to their natural conclusion they imply that God allows terrible things to happen to individuals for the greater good of mankind. In the face of awful suffering, therefore, the question that must be asked, is, "Is it worth it?"; and major questions are raised about the "good" nature of God. To illustrate, Davies (1982) cites a speech from the Brothers Karamazov:

"And if the sufferings of children go to swell the sum of sufferings which was necessary to pay for truth, then I protest that the truth is not worth such a price." (Dostoevsky cited by Davies 1982:20)

A Theology of Hope

Travis (1988) claims that:

" 'Hope' has two main senses in theology. It can define either the object of hope, namely Christ and all that his final coming implies, or the attitude of hoping." (321)

Barth (1949) maintains that hope has both a present and a future nature. This is made clear in the following statement:

"Easter is indeed the great pledge of our hope, but simultaneously this future is already present in the Easter message." (122)

On one level the affirmation of Christian hope would appear to have profound application to the experience of dementia. Travis (1988) maintains that one aspect of

hope is that the Christian can look forward to life beyond death. He explains that in raising Jesus from the dead God has overcome the power of sin and death and those who believe in Christ share in His victory over death. In Ephesians 1, Paul pictured this victory as a coming together of all things in creation, a placing in order under the Lordship of Jesus. Through Christ's work thus the image of God in mankind can be renewed. The "hope of glory" is that death cannot end the believer's relationship with Jesus, but that, like Him, they will be raised from the dead with the personal identities which their bodies give them, but freed from the body's infirmities.

While affirming the centrality of hope, Pailin (1992) has hesitations about a theological understanding which stresses loss of personal limitations after death. On the basis of a consistent affirmation of the value which God places on a person as they are now, he contends:

"While, therefore, it may seem comforting to those who love a handicapped person to believe that after death that person will enjoy a state of being which is not limited, such a belief is mistaken if and in so far as it implies that the handicapped person does not have worth to God as the particular person whom we know here and now. It is the person, not some potential person who may come to exist in the future, who has worth." (165)

Suffering and hope are explicitly linked by Weaver (1986), who states that hope for the future evokes patience in present suffering. However, he contends that Christ's life shows that hope is only made possible through suffering. Therefore, if human beings appropriate the hope made possible by Christ, then they must expect to follow Christ's path toward this end - the way through the suffering and death of this present life. He claims that the suffering of individuals in this life identifies them with

the suffering of Jesus, whose sacrifice even separated Him from the presence of God. To support his argument he turns to Revelation, Chapter 5, which suggests that the present suffering of the saints brought about through the powers of darkness, and the prayers and laments which express that suffering, further the plan of Christ's redemption and will, at the end of time, lead to the unleashing of Divine judgement and full revelation of God's renewed creation. He concludes that an individual's long suffering with Alzheimer's Disease foretells an intimate identification with the victorious suffering Lord at life's end.

Weaver (1986) makes an additional point concerning the present reality of the Resurrection, which, if accepted, could be a source of hope to the individual in the early stages of dementia, who may be concerned about the effect of the Disease on their relationship with God. He contends that Christ's resurrection not only has the power to transform life after death but the present as well. Hebrews 6:5, speaks of how we have already tasted the power of the age that is to come and in Colossians 2:9&10, we are told that through Christ the very fullness of God, which resides in Him, already overflows to us. Therefore Weaver (1986) claims that the renewing and upholding power of God is active now. This power upholds human identity and keeps people in the life of Christ, even in the midst of mental deterioration, when their experience may seem very distant from God.

There are aspects of hope therefore, which can be applied to the experience of dementia, which may have great significance for carers and for individuals in the early

stages of the condition. That being said, there are aspects of a doctrine of hope which are problematic when brought into relationship with dementia. These aspects are: its active nature, and the relationship between hope and memory. These will now be examined.

1. The Active Nature of Hope

Beardslee (1972) writes that a number of the Gospel stories about Jesus project a particular vision of the relationship between the present and the future. Jesus' teaching implied that the Kingdom of God would come at some time in the future. However, Jesus, in His life, and through his teaching and miracles, was a sign that the Kingdom was coming now. Therefore Beardslee (1972) claims that while looking forward to the coming Kingdom, Christians are expected to participate in the task of bringing the Kingdom in. He postulates an active hope, based on the motif of participation and reward.

The active nature of hope is also stressed by Travis (1988). Building on Moltmann's (1967) theology of hope, he maintains that Christians should commit themselves both to the proclamation of the gospel, and to the socio-political struggle for liberation.

Browning (1975) contends that this aspect of hope is an important one for a theology of ageing. He explains:

" New Testament apocalypticism gives ideological reinforcement to our efforts to make generativity and care victorious over stagnation and self-absorbtion." (162)

The active nature of hope is one aspect which may be problematic for the person with dementia who has been forced into passivity by the Disease. However Browning (1975) goes on to make a point which may have significance for them, whilst they are still in the early stages, before cognitive decline makes it difficult for them to grasp new ideas:

" efforts to care for and renew that world are not totally dependent upon my own individual efforts. Therefore, when our own vitality declines and the range of our contributions becomes narrowed, we can still have the sense that our efforts will have some objective meaning in the life of God and that activity toward the renewal of the world will go on beyond the cessation of our own labours." (162-163)

2. Hope and Memory

Becker (1978) exemplifies the explicit link which many theologians make between hope and memory. He states:

"remembering is of the same piece as the "anamnesis", the recollection of God's past mercies, in the Eucharistic prayer. It is a kind of "basking" in the warmth of these meaningful, healing, grace-laden relationships of the past which lend hope and possibility to the future. (188)

In the Old Testament, Becker (1978) claims that remembering the deeds of God became almost a matter of ritual for the children of Israel. (Exodus 20:2). So, he contends:

"the past is a prologue to the future; and if the past contains experiences of God's grace, it becomes impetus for courageous, trusting walk into the future." (189)

Seeing memory as such a vital component in hope is obviously problematic for the person with dementia. Is hope possible when a person can no longer

remember? Hope may always be an objective reality, but when memory has deteriorated does the point come when it ceases to be a subjective reality?

Two insights emerge from a review of the literature which speak to this problem. The first comes from Elliott (1995) and concerns the role of the Church as "a storehouse of memories" (218). His thesis is that the Church contains, within its tradition, memory resources which can act as a counter-balance to the destructive memories of communities. Perhaps the Church could be understood as holding "a storehouse of memories" for the person with dementia, which could be accessed through worship, symbols and knowledge of life-story.

The second insight arises from the work of Pailin (1986). His understanding of eternal life is that people are held in the memory of God. Thus, even when individuals can no longer remember for themselves, there is profound truth in the realisation that God continues to remember them.

Summary

This chapter began with Keck's (1996) description of Alzheimer's as "the theological disease". It is contended that a holistic pastoral response to the experience of dementia demands that theological perspectives be appraised, and integrated with emerging pastoral and experiential perspectives. That process was initiated in this chapter with a review of the literature on a theology of ageing, an eschatological perspective, sin and sickness, personhood, the nature of the individual, suffering and

hope. In the following chapter the process continues with a review of literature on pastoral perspectives which relate to dementia.

CHAPTER FOUR
PASTORAL PERSPECTIVES

PASTORAL PERSPECTIVES

Bringing a pastoral horizon to bear on the experience of dementia

Introduction

One aspect of the experience with which this study began was that of pastors asking questions about pastoral care of confused elderly people. "What is its value?" "Why spend my time with these people when I have a host of other tasks which demand my attention?" "Do confused elderly people require pastoral care?" One minister demanded, "Prove to me that my pastoral care makes a difference to the confused elderly person, and then I'll do whatever you tell me in terms of communication."

It was questions and demands like these which drove this research and provided at least a degree of its motivation. They are illustrative of a theological and experiential grappling with the aims of pastoral care. To borrow Foskett and Lyall's (1988) terminology these questions may reflect a gap between a 'learned' and an 'owned' understanding of the nature of pastoral care.

In this chapter the task of bringing pastoral perspectives to bear on the experience of dementia will be begun. The approach taken is a systematic review of motives for offering pastoral care. This review provides the background for the detailed correlation of these motives with pastoral care of confused elderly people which will be developed in the discussion (Chapter 9).

"Unspoken Values" : A Search for Motives

"At the heart of every pastoral encounter are unspoken values about the conduct of that relationship, and the aims and objectives to which pastoral care is directed."

(Graham 1993:211)

From its very beginning the study of pastoral care has had an examination of motives as one aspect of its remit. This is reflected in Clebsch and Jaekle's (1967) classic definition of pastoral care as:

"The ministry of the cure of souls or pastoral care consists of helping acts done by representative Christian persons directed towards the healing, sustaining, guiding, and reconciling of troubled persons whose troubles arise in the context of ultimate meanings and concerns." (4)

The search for motives is complicated by the fact that it is taking place in a context marked by confusion about the nature of pastoral care. The existence and nature of this confusion is marked by Graham's (1996) observation when she claims in the context of an historical overview of practical theology that:

"It was no longer possible to claim that any consensus existed about the nature of pastoral care, how it should be executed, by whom, within what sort of church, its proper sphere, its relation to mission and social action, and the truth claims upon which it rested." (77)

The search for motives may have been a characteristic of pastoral care, however, it may well be a search that, on one level, is doomed to failure from the beginning. On one hand, it takes place within a context characterised by debate about the nature of the discipline. On the other it must be recognised that no review of motives can ever be complete. Motivation for pastoral care will be as varied as the individuals who undertake it. That being said, it is necessary that the task be

attempted if the experiences and questions which prompted the research are to be taken seriously. A review of the literature highlights a number of primary motives, or formative concepts. These are, proclamation, service, revelation, sustenance, change, and companionship. It is to a review of these that attention now turns.

1. Proclamation

"Pastoral care is proclamation to the individual of the message proclaimed in general to the congregation on a Sunday."
(Thurneysen 1962:15)

A proclamatory motive for pastoral care was, and perhaps remains, a dominant feature of a perspective described as reformed and protestant. Those, like Thurneysen, who emphasise proclamation as the basal motive for pastoral care, understand pastoral care as relying primarily and crucially on the Word of God. The exposition of scripture, through preaching and teaching, thus becomes the guiding norm of pastoral practice. Graham (1996) summarises this approach in the following way:

"pastoral care is effectively *kerygma*, or proclamation, by word or deed; the pastor can listen in a pastoral relationship, but only insofar as such listening clarifies and informs the subsequent and necessary act of exhortation." (74)

This motivation for pastoral care has a strong biblical basis in the Old Testament prophets and in some Pauline teaching. The goal of the Church becomes the heralding of the message. Thus Dulles (1988) claims that faith and proclamation are emphasised over inter-personal relations. Focusing as it does on the centrality of authoritative preaching, this approach can be recognised as being greatly influenced

by Barth's (1961) thinking. Authentic pastoral care is seen as arising from the church community in which the pastor has an authoritative function as interpreter of the Word of God.

In his book, *The Church*, in which he examines some aspects of Barthian theology, Kung (1968) makes a point which has immediate implications for understanding the motivation for pastoral care. He contends that the Church is not the Kingdom of God nor does it work to extend that Kingdom on earth:

"It is the reign of God which the church hopes for, bears witness to, proclaims. It is not the bringer or the bearer of the reign of God which is to come and is at the same time already present, but its voice, its announcer, its herald. God alone can bring this reign; the Church is devoted entirely to its service." (96)

The sovereignty of God is primary. The response of people is not to work for betterment of society, or enrichment of relationships; it is to proclaim the word. Bonhoeffer (1965) exemplifies this position when he writes:

"The intention of the preacher is not to improve the world, but to summon it to belief in Jesus Christ and to bear witness to the reconciliation which has been accomplished through Him and His dominion." (350)

Within Thurneysen's (1962) thinking the total content of the kerygma was forgiveness:

"Like the proclamation of the church generally, pastoral conversation has as its only content the communication of the forgiveness of sins in Jesus Christ...man in his totality is addressed as a sinner under grace." (147)

This emphasis has, however, been broadened by Burck (1978) who makes a plea for the recognition of what he understands as the breadth of content in the kerygma:

"Thurneysen's emphasis on forgiveness erred theologically in that it ignored the breadth of human meaning and of human responsiveness to life in the dimensions of creation and redemption, e.g.. joy, peace, love, hope, kindness and a responsible communication of the gospel." (221)

The response to proclamation of the kerygma, however broad its content, is faith, which is understood as being the necessary pre-requisite for the receipt of salvation. There is thus a significant level of reliance on an intellectual understanding and an ability to remember, and appropriate, facts concerning matters of faith and belief.

Despite the recognition of "the breadth of human meaning", Campbell (1986) highlights the fact that appropriation of a strictly proclamatory motive for pastoral care may lead to difficulties in dealing with diversity:

"Our age is far from unique in having divergent theological opinions, as even a cursory study of church history will show, but there is now an increasing tendency to *welcome* pluralism (his italics) and imprecision in doctrine rather than to deplore it." (4)

A comment which has been made about this approach is that it allows for very little interaction between theology and practice, indeed it would not see that inter-action as necessary. Psychological approaches were recognised, indeed Thurneysen was knowledgeable about Freudian psychoanalysis, but they were regarded as being auxiliary sciences. Thus psychology and psychotherapy were thought of as contributing to a humanistic view of what it is to be a person, but not to a theological understanding. They were therefore isolated from pastoral care. Thus Foskett and Lyall (1988) can legitimately describe this approach as "applied

theology". A difficulty which may arise is that if this approach, in which theology is seen as unchanging and unchangeable, is adopted, the pastor is necessarily limited in his response to challenging situations in which his or her given theology does not fit comfortably with pastoral experience.

A further criticism is aimed at this model by Dulles (1988). He contends that a strictly proclamatory approach focuses too exclusively on witness to the neglect of action. Thus McBrien (1970) states that the Church is understood as "a community of proclamation rather than of socio-political diakonia." (58)

2. Service

Service has traditionally been seen as a motive for pastoral care. It can be traced through the Old Testament - in the "suffering servant" passages of Isaiah 42 and 61 for example - and into the New Testament. When James' and John's mother asks that her sons be given special treatment in the Kingdom, Jesus tells his disciples that:

"the Son of Man did not come to be served but to serve, and to give his life as a ransom for many."

(Matthew 20:28 New International Version)

On this Biblical basis Cushing (1966) can set out the image of Jesus the Servant:

"Jesus came not only to proclaim the coming of the Kingdom, he also came to give himself for its realisation. He came to serve, to heal, to reconcile, to bind up wounds. Jesus, we may say, is in an exceptional way the Good Samaritan. He is the one who comes alongside of us in our need and in our sorrow, he extends himself for our sake. He truly dies that we might live and he ministers to us that we might be healed." (6)

The 1960's were a pivotal period in theological thinking, characterised by a reaction to neo-orthodox theology. Theologians like Robinson (1965) argued that the world had to be put on the theological agenda:

"The house of God is not the Church but the world. The Church is the servant, and the first characteristic of a servant is that he lives in some-one else's house, not his own." (92)

This thinking had obvious implications for practical theology and pastoral care. Service was stressed as a central reason for the Church's existence. So Cox (1965) writes in *The Secular City*:

"The church's task in the secular city is to be the *diakonos* (his italics) of the city, the servant who bends himself to struggle for its wholeness and health." (134)

Bonhoeffer (1967) illustrating a shift from his earlier position within a proclamatory model supports service as motivation for pastoral care and indeed the Church's mission in general:

"The Church is the Church only when it exists for others. To make a start, it should give away all its property to those in need. The clergy must live solely on the free-will offerings of their congregations, or possibly engage in some secular calling. The Church must share in the secular problems of ordinary human life, not dominating, but helping and serving." (203-204)

Dulles, (1988) building on this concept terms service a "secular-dialogic model". He explains:

"secular, because the Church takes the world as a properly theological locus, and seeks to discern the signs of the times; dialogic, because it seeks to operate on the frontier between the contemporary world and the Christian tradition (including the Bible), rather than simply apply the latter as a measure of the former." (92)

The focus of pastoral care is thus understood as being society in general. Pastoral care is not offered in the hope that a faith response will be evoked, as was the case in the Proclamatory model. Rather, pastoral care is offered in order that people might be supported, encouraged and given material help.

The contention that service is a valid motive for pastoral care has received criticism from feminist theologians in particular. Thus Berry (1993) claims that:

"Served and servant ... are images which derive from a framework of hierarchical power, - a context in which some are superior to others, of power over, even if that power is being used benevolently." (172).

Borrowdale (1989) in her appraisal of attitudes to women argues that the concept of service has been used as a tool to exploit women, with the result that the servant's own needs are subsumed and passively induced in those who are served. She claims that when those who have no power are called to serve it not only reinforces their oppression, it gives it legitimacy. Sadly, therefore, what could be a powerful image has to be treated with some degree of caution. However, it would be wrong to ignore this image entirely, for if it is understood in the context of Jesus' life and example, it speaks of unassuming self giving by one who has authority, position and power. (see Phillipians 2:6-11).

3. Revelation

"Pastoral care may be understood as the expression of fundamental values of the Christian community and that their enactment in human terms is the means by which Christians disclose the purposes and actions of God in human affairs." (Graham 1993:169)

When revelation or disclosure is a primary motive, pastoral care becomes the out-working of the values of the Kingdom, which is a revelatory act. Fowler (1995) describes this enactment of the values of the Kingdom as being an effort of the people of God to be responsive to God's call to partnership. The basic tenets of the Christian faith evidenced in the life of Jesus, such as unconditional love, a belief in the worth of each individual, and empowerment of those perceived as powerless are "enacted" and in a sense given life and potency as pastoral care is undertaken. This point is borne out by Graham (1993) who writes:

"Christian pastoral practice has the potential to reveal a God who is startlingly present in human encounters. In their relationships and actions of care Christians believe they can effect some of the creative and redemptive work of God and that such care will also express something of the Divine reality."
(220)

The motive of disclosure for pastoral care can be linked with an approach to pastoral care which emphasises incarnation as a central metaphor. Gerkin (1990) states that the term "incarnational pastoral care" can encompass a number of meanings, such as:

"the intentional effort of the pastor symbolically to embody in the pastoral relationship to persons a relationship analogous to the incarnation of God in the human Jesus." (573)

Gerkin (1990) claims that Luther developed the concept of incarnation and pastoral care and proposed that Christians should be "little Christs to our neighbours". Thus Christians are encouraged to embody the love of God to others.

Gerkin himself (1979), had earlier broadened the focus of incarnational pastoral care from being limited to the characteristics of the pastoral relationship towards a recognition of the incarnate presence of God in all of human life. This he developed into the concept of "prophetic pastoral practice" (Gerkin 1991), whereby the pastor, in relationship with God and exercising wise judgement can illustrate values of the Kingdom of God to, and in, the world. It is within this context that a ministry of presence can be proposed as a potent form of pastoral care, and indeed pastoral communication.

Pastoral care is therefore one aspect of an obedient and joyful response to God undertaken with no hidden agendas, evangelistic or any other type. One feature of this model is that pastoral care, motivated by a desire to reveal aspects of the Kingdom of God, becomes 'Christian' by necessity and is set free from a perceived need to talk about God. Taylor (1983) makes this clear when he writes,

"pastoral care is Christian not because it always reaches distinctive conclusions, but because it has distinctive points of reference." (35)

There is a further aspect to revelation. God is not simply revealed in the actions of the carer, but also in the person and situation of the one to whom care is being offered. Moltmann (1974) expresses this powerfully when he comments:

"The incarnate God is present and can be experienced in the humanity of every [person] and in full human corporeality...there is nothing that can exclude [them] from the situation of God between the grief of the Father, the love of the Son and the drive of the Spirit." (276-277)

As the motivation of revelation is developed it becomes apparent that just as aspects of the Kingdom of God are revealed in the carer, they are also there to be seen in the suffering of those who are rendered powerless and marginalised. God reveals His nature to us in the humanity, suffering and death of Jesus as well as in the power of the Resurrection. Graham (1993) reinforces this concept and links incarnation and suffering when she writes:

"The notion of the suffering God suggests that pastorally God is disclosed as much in the person and situation of the cared for as the carer." (221)

The fact that God entered and continues to enter into human affairs is thus recognised and concepts of mutuality and incarnate love are integral to this model.

A metaphor which could well be understood as being encompassed by revelation as a motive for pastoral care, and which gathers together a number of the themes which have been introduced, (mutuality, and suffering for example), is that of 'the wounded healer'. This image was first expounded by Nouwen (1972) and developed by Campbell (1986) in response to the question of how care can be offered in such a way as to avoid patronising the one being cared for. His thesis is that the pastoral relationship is not dependent on acquisition of a body of knowledge or particular skills, but is based on the individuals' personalities and shared humanity. Wounds and hurts are part of that humanity, and part of the carer's task therefore becomes the empowerment of those with whom he works to confront the brokenness within themselves. Thus healing is facilitated when there is a willingness to share vulnerability and aspects of the Kingdom of God are revealed through mutuality and relationship. This reflects Jesus' own example very powerfully. Campbell (1986)

claims, it was through Jesus' own wounds - His suffering on the Cross, that God chose to reconcile the world to Himself.

4. Sustenance

Pastoral care may find its motivation in a desire to sustain, or maintain individuals as part of the church, both particular congregations and the Church universal. It will be recalled that "sustaining" appeared in Clebsch and Jaekle's (1967) definition of pastoral care; it can thus be recognised as an historical emphasis in pastoral practice.

Placing an emphasis on sustenance as motivation for pastoral care may be understood as being particularly related to one model of the Church, namely that described by Dulles (1987) as "institution or society". Within this model the Church is seen as a single, concrete society, which is rule governed, with members and a controlling group. Of particular significance is the issue of membership. Vatican I asserts that "it is an article of faith that outside the church no-one can be saved". Within this model, therefore, individuals are regarded as being members if they profess approved doctrines, partake of the sacraments and subject themselves to duly appointed pastors. Dulles (1988) applies the metaphor of "the boat of Peter which carries the faithful to the farther shore of heaven" (41) to this model of the Church and Church membership. If the Church is seen as a ship then when within it the individual is safe, guaranteed salvation and security. Outside the confines of the ship however all are inevitably lost. If this approach to the Church is appropriated, it

becomes obvious that the maintenance of the individual within the life of the Church, through participation in the sacraments and suchlike, becomes an integral motivation for pastoral care, in order to ensure that the individual is not lost. Dulles (1988) states that all which is required of an individual if they are to remain safe and secure within the Church, is obedience and a reliance on the ministrations of those in authority.

What is perhaps a broader understanding of sustenance, or maintenance, as a motive for pastoral care is also possible. The individual is supported in their faith, not out of fear that God will cast them aside if they fail to adhere to particular rules or standards, but in the belief that the person's life may be enriched through being helped to gain access to the resources of their faith.

The issue of pastoral care as duty can be related to this model, but not exclusively so. Duty as a motive in pastoral care can be applied to both clergy and lay people, but within this model it has particular relevance to those who are ordained. The pastor has the responsibility and duty of pastoral care laid upon him or her at ordination. The model of Church as institution with its hierarchical structure stresses this duty, and the authority of clergy. Dulles (1988) claims that:

"In the institutionalist ecclesiology the powers and functions of the Church are generally divided into three: teaching, sanctifying and governing...in each case the Church as institution is on the giving end." (37)

Being hierarchical, rule-governed and open to the criticism of inducing passivity in its members (Dulles 1988), this model of the church must also stress the

duty of clergy to maintain the people in the faith. However, duty is not limited to one model, nor should it be portrayed as a negative motivation. Duty is one aspect of a mature recognition of the responsibilities inherent in a meaningful response to the love of God in Jesus. With regard to ordained pastors there is the explicit duty to keep promises made at ordination.

A metaphor of the shepherd informs and relates to sustenance as a motive for pastoral care. If the metaphor of servant has been criticised in modern times the same can surely be said for the image of shepherd. This metaphor, stressed by Hiltner (1958 a), although useful in highlighting God's intimate involvement with, and care for, humanity has been criticised as being paternalistic, patronising and authoritarian.

Berry (1993) makes this point clear when she writes:

"seeing ourselves as sheep is hardly likely to help human beings affirm their strength of character, sensitivity and responsibility or will to act, and to characterise some as shepherds of others seems condescending if not insulting to those who are described as flock." (173)

Campbell (1986) however, makes a strong case for the restoration of the image of shepherd as applied to pastoral care. He admits to many of the criticisms which have been applied to this picture but asserts that the image is redeemable if the quality of courage is reinstated. He claims that the Biblical picture of a shepherd was one which took courage for granted, and that it would have been obvious to Jesus' listeners that the Middle Eastern shepherd needed courage if he was to protect his flock. So, Campbell (1986) maintains, it takes courage and other shepherd-like qualities like tenderness, skill and self sacrifice to enter into costly, risky pastoral

care. Furthermore, it is proposed that Jesus uses the care and concern of the shepherd as a paradigm for God's love for the individual. When viewed in this way, instead of engendering superiority, the image highlights the costly nature of pastoral care and underlines the carer's inability to undertake the task when isolated from the grace of God.

5. Change

Historically pastoral care was understood as being largely task oriented. This is reflected in Baxter's (1655) list of seven pastoral functions: conversion of the unconverted, advice to enquirers, building up of the already converted, oversight of families in the congregation, visiting the sick, reproof of the impenitent and exercise of discipline. Each one of these tasks concentrates on change.

A task-oriented approach continued to dominate during the period when pastoral counselling was seen as being the central paradigm for pastoral care. Thus Hiltner (1949), a formative figure in this movement can write:

"Broadly speaking the special aim of pastoral counselling may be stated as the attempt by a pastor to help people help themselves through the process of gaining understanding of their inner conflicts." (19)

Within pastoral counselling, therefore, the emphasis was largely on problem solving. Graham (1996) reflects this when she describes Hiltner's approach to practical theology as "task oriented empiricism" (73). Approaches which focus on pastoral counselling have been described by Foskett and Lyall (1988) as "applied

psychology", and criticised for their failure to integrate theological and psychological insights.

However, the appropriation of change as a motive for pastoral care is not limited to those approaches which focus on problem solving. An impetus for change is also apparent in the writings of some who specifically reject such an emphasis. Lambourne (1971) made his hesitations about pastoral counselling clear when he wrote:

"My thesis is that the pastoral counselling called for in this country during the next twenty years cannot be built around a practice and conceptual framework derived from professional problem solving and prevention of breakdown." (26)

While being unequivocal in his rejection of a problem-solving paradigm, change remains an underlying motive. This is reflected in the definition which follows:

"Pastoral care is that activity, undertaken especially by representative Christian persons, directed towards the elimination and relief of sin and sorrow and the presentation of all people perfect in Christ to God."

(Pattison 1988:13)

Lambourne and those who followed him may have rejected pastoral counselling which under the influence of various psychotherapies stressed problem solving. However their writing, as illustrated by Pattison's statement above, indicates that they retained change as a motivational factor in pastoral care. It is true that the nature of the change which was hoped for altered. The goal of pastoral care was now conceptualised in terms of mutual enrichment, rather than the paternalistic giving of wise counsel, but change is retained as a motive. To cite Pattison (1988), "...pastoral care is part of changing the world, as well as simply being in it." (18)

A model of pastoral care which is unashamedly motivated by a desire to see change is that which has developed from liberation theology. The struggle of oppressed people in Latin America was the context out of which liberation theology grew. Gutierrez (1983), a Peruvian priest, reflects this when he claims that "...the theology of liberation is rooted in revolutionary militancy." (205) Pattison (1994) outlines that one source of liberation theology was 'base communities' of lay people who met to worship, study the Bible and take action to help each other. As these groups met in the context of their own political situations, the theology of Vatican 2 and Marxist theory, there developed the impetus for Christians to seek justice for the poor throughout Latin America. This had significant implications for practical theology. Rosa (1990) contends that the pastoral care movement in Central and South America pursues social transformation as the appropriate response to human need. Returning to the issue of change, McGovern (1989) claims that the role of theology is determined by its ability to transform the world.

As these insights were developed, two fundamental truths which have direct relevance to this study emerged. Firstly, it became clear that practical theology and pastoral care must be seen in a political context, to cite Wilson (1985) "pastoral care is situational and neglects its context at its peril." (14) Secondly, an exclusive focus on the individual in pastoral care is erroneous. Pattison (1990) brings these points together when he writes:

"If the purpose of pastoral care is the alleviation of suffering and the facilitation of growth for all people there must be a consideration of the wider factors which impinge on that goal." (209)

A review of the literature therefore, has found change to be a pervasive and primary motivation in many different models of pastoral care.

6. Companionship

The wide scale rejection of models of pastoral care which were understood as being paternalistic and focused on the acquisition of skills and professional competence, led to a search for images which stressed mutuality, and common humanity. One motivation for undertaking such care thus became a desire to accompany others on the journey of life. So Campbell (1986) develops the metaphor of companionship on the journey of faith as applied to pastoral care.

This emphasis confronts head-on the issue of power in the pastoral relationship. An essential equality is stressed. Thus Cassidy (1988), writing about pastoral care for people who are dying, while not denying the resources of sacrament and experiential and counselling skills, contends that in some cases there will be a sense of shared powerlessness. She gives a picture of patient and carer stripped of their resources, present to each other, naked and empty handed, as two human beings. Admitting that there is difficulty and pain in coming to terms with that impotence she writes:

"All that they ask is that we do not desert them; that we stand our ground at the foot of the cross. At this stage of the journey, of being there, of simply being; it is in many ways the hardest part." (64)

The issue of power in the pastoral relationship remains unresolved. It is too simplistic to state that when approaching pastoral care with the primary motive of companionship, that power ceases to be an issue in the pastoral relationship. The fact remains that the pastor may well be perceived as having power, whether it be because of a particular position within the Church, or because she or he has access to a particular body of knowledge. The issue therefore is not whether that power exists in the pastoral relationship, but how that power is used.

In response to these facts, Berry (1993), writing from a feminist perspective, introduces the concept of "power-in-relation". This is set in contrast to what are termed as traditional models which emphasise power over others. This paradigm emphasises the truths that people can care for one another through the "power of relatedness, and of partnership and of mutuality." (174) Implementation of this type of model, Berry contends, enhances the feeling of self-worth in the one who is being cared for, as they are encouraged to feel that they are valuable and have a real contribution to make.

The motive of companionship while not explicitly mentioned, can be seen to be related to a number of more recent developments in practical theology and pastoral care. Among these is the emergence of a narrative theology of pastoral counselling. It is perhaps not without significance that Charles Gerkin (1991), who was instrumental in the development of a narrative or hermeneutic approach drew on 'journey imagery', when he proposed the image of "interpretative guide" for the

pastor working within the contemporary situation. There is an understanding of mutuality and shared concerns inherent in the later development of his hypothesis that each individual's life-story is of relevance to the pastoral relationship. He writes:

"The pastoral counselor is not only a listener to stories; he or she is also a bearer of stories and a story. The pastoral counselor does not come empty handed to the task of understanding the other's story and offering a new interpretation. The pastoral counselor brings his or her own interpretation of life experience with its own use of both commonly held symbols, images, and themes from the cultural milieu of the counselor, and the private nuanced meanings that have been shaped by the pastoral counselor's own life experience and its private interpretation." (1994:27)

An acknowledgement of mutuality, an understanding of being on a journey together, thus appears to be implicit in Gerkin's (1994) emphasis on the impact of each "living human document" (a phrase which he borrows from Anton Boisen) on the counselling relationship.

One further point warrants consideration. It appears that a motivation of companionship has the potential to empower those involved in the pastoral relationship to struggle profoundly and meaningfully with the chaotic. Only when the pastor abandons the notion that he or she must always have an answer, will he or she be freed to grapple with what is profound, and heart-rending.

This theme is expanded by Aldcroft (1993), who raises the issue of chaos in connection with childbirth, but it can equally be applied to the pastoral care of people with dementia. In examining the need for, and the form of a liturgy for childbirth, she suggests that there is an often neglected need for the expression of anger. She notes a

tendency to drive out darkness, fear, and chaos in religious contexts because goodness was equated with order, discipline and control. Aldcroft (1993) goes on to suggest that only by inviting chaos back into our lives will the immensity of God be realised. She claims:

"At the heart of Christian belief I sense an awareness that chaos is not to be shut out and ignored; that, on the contrary it may be the specific task of the Christian to explore, confront, become conscious of and even befriend chaos."
(185)

The image of "befriending the chaos" is an extremely powerful one. It opens the pastor up to the possibility that what appears to be chaotic might instead be meaningful. Naomi Feil (1992) claims that much of the behaviour associated with dementia which has traditionally been interpreted as meaningless, such as wandering and repetition, for example, is instead an attempt by the individual to communicate or to complete unresolved life tasks:

"A woman whose whole existence was her motherhood caresses her hand. She longs to be useful. She sees, in her minds eye, with her vivid (eidetic) image, her baby. Her retina is damaged, but her image is clear. She begins to talk to her hand - her baby. Her sensory cells do not inform her that her hand is in front of her. She restores her motherhood - her dignity - by re-creating her baby through using a body part. She has wisdom to create in old-old age."
(76)

St James O'Connor (1992) writes of how changing his attitude to the behaviour of people with Alzheimer's Disease fundamentally changed the pastoral care which he was able to offer. He decided to view their behaviour as indicative of wisdom rather than melancholy, and in so doing was enabled to see meaning in what he had previously thought was chaotic and meaningless behaviour.

This section on companionship as a motive for pastoral care has been a lengthy one. However it has been necessary to review the literature not only on companionship as an underlying motive, but also on its implications. These are, power in the pastoral relationship, how companionship is reflected in narrative theology, and companionship and the confrontation of chaos.

To summarise so far, in this chapter a pastoral perspective to the experience of dementia is introduced. The questions which pastors were asking about pastoral care of confused elderly people appeared to be indicative of uncertainties about motives for pastoral care. In response to this, the literature on a number of motives for pastoral care was reviewed. These motives are proclamation, service, revelation, maintenance, change and companionship. The way in which these factors work to influence pastoral practice will be investigated in the questionnaires (Stage 4) and the in-depth interviews (Stage 5), and brought into the discussion in Chapter 9.

In this review reference has already been made to some central modes of pastoral communication, for example, a ministry of presence. This chapter will be completed by an examination of the literature on a number of other practical forms which pastoral care of confused elderly people may take. The focus will be specifically on methods of pastoral communication to which reference has not previously been made.

Pastoral Communication with Confused Elderly People

In Chapter 2 the claim was made that dementia can be used as an umbrella term. A similar claim can be made of communication. Reflecting this, Rau (1993) provides the following definition:

"Communication is a broad term that includes all of the ways in which people send and receive messages. Speaking, listening, reading, writing and gesturing or pantomime are all forms of communication. Drawing, sign language, facial expression, and body postures are other forms of communication between and among people." (2)

With such a broad remit a systematic approach is required. The literature will therefore be reviewed on some salient forms of communication with confused elderly people. These are worship, with particular reference to liturgy and ritual, touch, and music.

(1). Liturgy and Ritual as Pastoral Communication:

"I can come in and the person can tell me the same story several times over, and yet as soon as I begin the Eucharist she's there, following intently, giving the right responses."

Ramshaw (1987;81)

"I marvelled to see how even quite withdrawn persons were visibly moved at the time of communion...and again at the sign of peace, when hands were grasped and smiles and greetings exchanged."

Clayton (1991;177)

Clark (1993) places worship firmly within the realm of communication when he writes "worship...always has something of the character of an ongoing

conversation between God and people". Ramshaw (1987) places worship firmly within the remit of pastoral care when she writes:

"the paradigmatic act of pastoral care is the act of presiding at the worship of the gathered community." (13).

Worship, and the liturgical form which it may take, thus becomes a central form of pastoral communication.

Moreover, the literature indicates that this central form of pastoral communication is meaningful for confused elderly people. The quotations with which this section began support this claim. A review of the literature reveals a number of potential reasons for the power of liturgy to communicate. These are its symbolic nature, familiarity, structure, and its potential for participation.

(a) Symbolic Nature

Ramshaw (1987) makes the claim that all ritual communicates meaning and that formal rituals carry the core meanings of the social group performing them. She suggests that in situations where language is inadequate symbols, like a cross, express the deepest meanings that humans know. Copsy (1994) contends that symbols are a means of communicating deep meaning, yet they do not seem to rely on language, memory or intact intellectual processes. Therein may lie much of their communicative potential for people with dementia.

Renner (1979) points out that it was Erikson who pointed to the ontogenic beginnings of a number of elements found in adult ritualisation. Within Erikson's paradigm Renner (1979) explicitly links ritual and symbolism:

"Within the trust relationship [between mother and child] we are getting the dramatization, the enactment of the attitude of care; and this, if we can understand it rightly, is a symbolizing of the sacramental care of Him who is Life giver. We sense the total embrace of God is being emulated in this act...the essence of this mother - child [relationship] is - or ought to be - reflected in the rituals we undertake in the care of especially dependent and distressed people in crisis." (164-165)

The possibility is therefore raised that the ritual nature of liturgy symbolises aspects of a mother's care for the person with dementia. This may endow the ritual with meaning, and give a sense of security even in the chaos caused by the condition.

Shamey (1993) contends that symbols have the potential to trigger deeply held faith memories, which she believes are retained even in severe stages of dementia. The experience recalled by St. James O'Connor (1992) supports this view. He writes that in his pastoral care of confused elderly people he decided to use traditional religious symbols, like wearing a clerical collar and traditional prayers. He also brought a stuffed lamb on to the hospital ward one day and showed it to an elderly woman with Alzheimer's Disease. He gives an account of the conversation which followed:

"I said to her "Do you know the story of the lost sheep?" Sally took the lamb and hugged it close to her chest.

"Yes," she replied, "I was lost in the church.. I didn't know where to go and my Father came in and found me."

"You were scared- like the lost sheep," I replied.

"Yes, I was. I sure was lost," Sally said.

"Your father was a good shepherd and he took good care of you. You trusted him."

"He found me a number of times".(11)

In this encounter he claims that the religious symbol of the lamb accessed or brought back this memory for Sally.

There is an additional aspect to the power of symbols to evoke memories. Brown and Ellor (cited by Shamey 1993) claim that when a memory is evoked the feelings associated with that memory also return and moreover they remain. Thus, for example, they claim that if an individual takes part in a Communion service and the symbols of bread and wine remind her of the love of God, that feeling of being loved and nurtured will remain even if she forgets that there was a Communion service.

(b) Familiarity

The literature reviewed in Chapter 2 made it clear that the language breakdown in dementia is characterised by a relative sparing of social convention abilities, and that it is the more automatic, over-learned communication acts which have a higher probability of remaining intact. Thus, for example, Stevens (1985) found that most subjects in her study responded appropriately to questions which required a conventional response, "How are you?", for example. However those same people had significant difficulties with requests for information.

Doughty (1984) suggests that liturgical responses may well be among the most conventional, over-learned acts of communication in their repertoire, and therein lies their strength for the person with Alzheimer's Disease. Even the most severely affected individual may respond appropriately to "The Lord be with you",

and they may well join in with the Lord's Prayer and the Twenty-third Psalm. Inclusion of these familiar "landmarks" provide not only a sense of security but also a feeling of competence.

Clayton (1991) claims that, "...familiar scripture, music, prayers and symbols retain their power to touch...people through the feeling functions of the right brain." (178) Carder (1984) on the basis of his work with mentally handicapped people suggests the use of familiar litanies and responses. These findings indicate that the rituals of blessing, and confession and absolution have power to evoke faith memories for even some severely confused people.

Clark's (1993) findings support this claim. He proposes that in situations where at some level the confused elderly person feels that there is a link between sin and sickness, worship can provide opportunities to receive a blessing which can aid them in coping with what is perceived as a curse-laden life situation. The fact that blessing in worship is a ritualistic act, often accompanied with stereotypical gestures and familiar words, means that that blessing can be appropriated by the confused elderly person.

Prayer has received attention in the literature as a form of pastoral care. (Dalrymple 1990) A review of the literature highlights the fact that prayer has potential as a useful form of pastoral communication with confused elderly people, as illustrated by Clayton (1991) for example. The familiarity of liturgical prayer may be a

factor in this. However, both in the context of public worship and one-to-one pastoral interaction prayer can be characterised as a ritualistic act, often accompanied by stereotypical gestures and posture, all of which are factors which foster communication with confused elderly people. St. James O'Connor's (1992) experience illustrates this point:

"I held a communion service for some Roman catholic patients. As I celebrated the liturgy, all of the patients responded to the traditional prayers. They knew them, remembered them and spoke them. These prayers has special meaning." (12)

Thus it is recognised that prayer may have potential in pastoral communication. A communicative potential which is heightened by its physical, and symbolic nature, and deepened by its spiritual significance.

Based on the principle of familiarity, Shamey (1993) and Clayton (1991) propose that "older" versions of the Bible should be used for the scripture readings in the service. Clark (1993) disagrees with this approach. He uses the New International Version, or the New Revised Standard version, he explains this as follows:

"My decision was that it was more important for the message to be heard in clear English prose, rather than the more familiar but archaic language of the King James version." (178)

Clark (1993) generalises the principle of familiarity to the choice of themes for worship. He suggests that helpful emphases for worship are, the promise of everlasting life, forgiveness, Jesus' love for the sick, and the availability of God's love and grace for all people. These themes are in accordance with Boisen's (1948) seven criteria, by which worship materials may be judged for their appropriateness to a

psychiatric setting. These are, that they should provide for expression of the consciousness of one's faults and needs; the love and forgiveness of God; an attitude of faith and dependence upon God; personal courage and action; a future hope; special problems common among people in institutionalised settings and special occasions, like holidays and festivals.

(c) Structure

Clark (1993) contends that for confused elderly people in residential or nursing homes, having a regularly followed order of worship, held at the same time on the same day provides a predictability that can lend structure to their lives. He claims that such a schedule reinforces the sense of living in a reliable environment, and can help reality orientation. The structure, or order, of worship thus emerges in the literature as a significant factor in its meaningfulness for confused elderly people.

Doughty (1984) provides an order of service which includes six short passages of scripture with brief comments, three hymns and a time of prayer, all built round a meaningful theme. Clayton (1991) proposes sharing the sign of peace and the Lord's prayer, and Carder (1984) included litanies and responses in his services with mentally handicapped people. The order of service which Clark (1993) suggests begins with words of welcome and a declaration of intent. These centre on reality orientation and may take the form of the minister introducing himself by name and role, and then a statement like "This is a Christian worship service. Today we will be singing, praying, reading the Bible, and taking Communion together." (1993;179)

This was followed with an extempore prayer of invocation, and the singing of a familiar hymn (if possible played on an electronic organ, which reminded the participants of their church organs). A prayer of confession said in unison, which includes an assurance of forgiveness is then suggested, followed by a responsive reading, the second hymn and the New Testament lesson. The homily then followed. This was often illustrated with objects or pictures. Participants were invited to offer their comments in response to the homily, which led into Prayers of Intercession and the Lord's Prayer. Holy Communion and the Benediction completed the service. It is not without significance that the "Order of Service for the elderly suffering memory loss and confusion" developed by Shamey (1993) is strikingly similar to that of Clark (1993).

The major issue on which the two approaches differ, is that of the homily or sermon. Shamey (1993) does not include one in her suggested order of service, nor does Doughty (1984). They contend that a sermon is largely interpretative or instructional, relying on the logical functions of the brain which may be beyond many confused elderly people.

(d) Potential for Participation

A general principle emerging from the literature review seems to be that the potential for meaningful pastoral communication is enhanced when confused elderly people are encouraged to participate in worship in ways that are appropriate to them. Clayton (1991) contends that participation enhances the individual's self-esteem and

the sense of community among those who are present. The forms that participation takes vary. Carlson and Seicol (1990) encourage people to help in practical tasks like giving out hymn books and setting out chairs and they also encourage feedback, following the homily. Shackelford et al (1979), in the context of worship in a psychiatric unit, encourage "disciplined, yet spontaneous participation in worship." (134) They invite the participants to sing, pray and discuss together. Clark (1993) applies their suggestions to worship with people with dementia and claims that "this attitude [of disciplined spontaneity] welcomes and honours each person's efforts to relate themselves to the worship event, even if their efforts could create potential distractions." (397)

It would be wrong to move on from the issue of participation without examining the issue of whether or not people with cognitive disabilities, as is undoubtedly the case with people with severe forms of dementia, should be allowed to partake of the Eucharist.

Arguments against their participation focus on the premise that people with cognitive disabilities cannot fully understand the nature of the Eucharist and its significance. Paul's advice in 1 Corinthians 11:28 that "A man ought to examine himself before he eats of the bread and drinks of the cup." (NIV) and his subsequent warning, "For anyone who eats and drinks without recognising the body of the Lord eats and drinks judgement on himself" (1 Corinthians 11:30 NIV), may be interpreted as supportive of this view.

In addition Shackelford et al (1979) discourage the use of the Eucharist because there exists a wide variation in meaning and in a therapeutic milieu a common theological understanding cannot be presumed. Carder (1984) provides pre-requisites which he sees as necessary for participation in the Eucharist. These are, evidence that the person has some idea of what the Sacrament is, and that they show a desire to receive it.

There is a large body of opinion in favour of the participation of confused elderly people in the Eucharist. Arguments are made on a number of different levels, the first is theological. The Augustinian position is described by Peters (1987). Augustine argued that Communion was a pre-rational experience. He saw the human condition as being one of total helplessness, and maintained that God acts in and through Communion in the community called the church to help the helpless. God chose basic foods in order that His love might be expressed in ways that ordinary, helpless people can perceive.

Peters (1987) contends that sharing in the Lord's Supper is a strong expression of the community of the church; the exclusion of some people from that Table is also a strong expression, not only to them and to the church but to the world at large. Sapp (1988) claims that participation at the Lord's Table illustrates that all people are valuable and loved by God, and that in Christ distinctions of class, status and ability are erased. He continues,

"a sound body or mind, therefore, is not required for acceptance by God. The heart of Christian theology, in fact, is the affirmation that the only perfect sacrifice - the most pleasing and acceptable body ever offered to God - was

the crucified body of Jesus of Nazareth - a beaten, humiliated body...to be judged less worthy and less acceptable because of the deterioration of body or mind runs contrary to the fundamental message of the Christian faith." (99)

The second thrust to the argument for participation is experiential. Shamey (1993) recounts her experience powerfully,

"I take the Holy Communion to people with very, very severe dementia, people that no one else thought possible to receive except the people who work with them. The staff pleaded for someone to take them the sacrament. These people have not taken one independent action for months, but when I hold Christ's body before them, out come their hands and they say "Amen"." (15)

The literature thus provides many and varied reasons to support the finding that liturgy is a potent form of pastoral communication for confused elderly people. These reasons include those which have been reviewed, its symbolic nature, its familiarity, its structured nature and its potential for participation.

(2) Touch as Pastoral Communication

In Chapter 2 it was reported that research indicates that nonverbal communication appears to be relatively spared in dementia. The findings reported by Rau (1993), Kitwood (1993a) and Goldsmith (1996) support this contention. Touch is a primary form of nonverbal communication, which has explicit links with pastoral care (Graham 1990). The research on touch as a form of pastoral communication with confused elderly people therefore warrants consideration. In the context of a discussion of the role of touch in pastoral care, Graham (1990) gives this definition:

"touching is physical contact between persons, usually for the purpose of communicating positive attitudes, values, and intentions toward the person touched." (1279)

This definition clearly puts touch within the category of communication. Ellis and McClintock (1990) reinforce this view when they claim that "touch does play an important part in human communication and relationships." (47) Indeed they go further and claim:

"Touch...can often be more expressive than language. In moments of extreme emotion - when words literally fail us - we often resort to using touch." (47)

Estabrooks (1987) describes touch as "an integral part of comfort" (33), and Koontz (1979) calls touch "a sense through which one person shares themselves with one another." (5)

This emphasis on touch as a central and primal means of communication may derive some of its support from child development studies. Thus, for example, Bowlby (1952) demonstrated that in infancy touch between the child and its mother was a vital factor in the development of trust and the child's own capacity to love.

Moltmann-Wendell (1994) reports that in the healing stories of the New Testament there are different types of touching. There is *kratein* which is used to denote grasping. So Jesus is reported (Mark 5:41) as grasping the hand of Jairus' daughter and snatching her back from death. Then there is *epitithenai* which is used on occasions where there is an official, more ritualistic, laying on of hands. In these cases power is understood as moving from the stronger to the weaker party, as when, for example, Jesus heals the blind man as retold in Mark 8:23 ff. Another term for touch is *haptain*. This occurs in several passages, and is used when Jesus touches

lepers (Mark 1:41) and children (Mark 10:3). However, it is also used when some people touch Jesus, (Luke 6:19) and in the case of the woman who bathed Jesus' feet in perfume (Luke 7:38). Moltmann-Wendell thus claims that this is a more democratic type of skin contact, not used in any hierarchical or ritualistic sense but for loving, affirming contact. An affirmation which Jesus is described as giving and receiving.

With this developmental and New Testament background it is hardly surprising that as Graham (1990) claims:

"Pastoral care draws heavily upon touching and physical support in ministering to persons suffering from major material and interpersonal losses, acute anxiety and depression, and serious illness. By these...means pastoral care transcends an exclusive reliance upon the written and spoken Word in making present and furthering a sense of hope and of God's providence."
(1279)

The importance of touch in the care of confused elderly people in particular is also affirmed by a review of the literature. In their study of interpersonal communication between nurses and elderly patients, Oliver and Redfern (1991), found that nurses' interactions with patients tended to be infrequent and brief and that touch was often limited to situations in which treatment was being given. They recommend that nurses working with elderly patients are trained to use touch appropriately.

Goldsmith (1996) also stresses the importance of touch as a result of his investigation of communication with confused elderly people. He reports the

following comments made by two people involved in caring for people with dementia:

"Touch becomes very important - reassurance by stroking or holding hands can be more effective than verbal communication."

"Touch is very important and validating...often people with dementia have reduced networks and changing relationships and therefore do not have the same positive experience of touching that we may be accustomed to. I am always very struck by the notion that some people may only be touched when they are having something done to them - this cannot be said to be a validating experience." (113)

The literature indicates that some cautionary comments be made about touch. The first is the need to recognise the fact that touch is culturally conditioned. Thus Ellis and McClintock (1990) point out that Northern Europeans are less likely to use touch than people from Southern Europe or the United States of America. Secondly, Graham (1990) reports that a therapeutic use of touch is disputed. Touch is not always used in a nurturing and healthful way. Touch can be used to abuse and control others, it is not always associated with comfort. Graham (1990) claims that it has been linked to the formation of inappropriate dependencies or sexual expectations. Thirdly Moltmann-Wendell (1994) draws attention to potential gender differences with regard to touch. For women, touch may be associated with nurture, for men it may have sexual connotations.

With the exception of these caveats the literature is supportive of touch as a means of meaningful pastoral communication with confused elderly people.

(3) Music as pastoral communication

Goldsmith (1996) cites the following contribution from an occupational therapist which illustrates the potential of music in the care of confused elderly people,

"I have one client in her early sixties and with a very advanced condition. She has no speech and is very restless, usually pacing the corridors for much of the day, and it can be very difficult to get her to sit down and rest or eat a meal etc. Initially I felt at a loss when trying to think of an activity which she could join in with...She was then tried in a music group where clients were given a choice of music and the opportunity to sit and listen. the change in her behaviour was marked...From her expression, she appeared very calm and relaxed and content, and at times tapped her foot or fingers to the music."
(116)

This quotation supports the assertion that music has the power to alter behaviour in confused elderly people. Tyson (1989), who is a nurse in a unit for people with dementia, makes the following comment:

"The best, and possibly the only, recreational therapy which has helped our patients is music...Music is so evocative and often to hear a particular melody brings to mind images and feelings that perhaps have been dormant for years. Sometimes it is the very poignancy of these memories that can trigger a reaction from someone with Alzheimer's Disease." (19)

The finding that people with dementia may respond to music is supported further by studies of worship in which confused elderly people are participating. Clark (1993) reports that he selects familiar hymns for worship so as to encourage as many people as possible to participate. Clayton (1991) claims that :

"familiar scripture, music, prayers, and symbols retain their power to touch many ...people through the feeling functions of the right brain. This approach matched that of many Alzheimer's caregivers who used music, aroma, touch, and other emotionally powerful ways of "reaching" patients long after all memory had failed." (178)

The indications are therefore that music may have potential as a means of pastoral communication.

In summary, a review of the literature reveals that worship, particularly in its liturgical and ritualistic aspects, touch, and music all have potential as means of pastoral communication. They will thus be incorporated into the research design and the experience of their helpfulness in communication explored further.

In these four chapters of literature review the practical and conceptual background to the research has been introduced. The experience of dementia was described, and theological and pastoral horizons or perspectives placed in juxtaposition with that experience. The aims and structure of the research were influenced by this experiential and theoretical background, and given shape and structure by insights from research methodologies.

CHAPTER FIVE

THE METHOD

THE METHOD

Introduction

It has been noted that "a research problem can arise in two ways; it can come to you or you can look for it" (Reid and Boore 1987:14). This research arose in both. The seeds from which this study grew were anecdotal evidence and personal experience. People involved in the pastoral care of confused elderly people reported that they were finding this area difficult. This was reflected in the writer's personal involvement in hospital chaplaincy. Underpinning this and contributing another perspective to this evidence was the researcher's qualification in speech and language therapy and knowledge that communication with confused elderly people is a rapidly developing area. It thus seemed that there may be potential for these perspectives to be conjoined. An underlying hypothesis was that if insights from speech and language therapy, theology, and pastoral care were related with one another, it might become possible to develop a method which would be instrumental in helping pastors to communicate more effectively with confused elderly people.

Research Design

This study was thus designed to examine how pastoral communication could be enhanced with confused elderly people. It was decided that the basic research design would be that of inter-related stages which would feed in to one another. This decision was taken for two reasons:

1. The Inter-action between Theory and Practice

As has been explained in Chapter 1, the model guiding this research is one which acknowledges the dynamic inter-relationship between theory and practice. This research is based, to cite Gadamer (1975), on the "fusion of a number of horizons" or the inter-facing of different perspectives, be they theological, pastoral or linguistic. Thus the research design took into account the need for the continual inter-penetration of theory and practice, and the integration of insights from both. Theory and experience were continually inter-related and tested against one another throughout the research design. While it is acknowledged that this paradigm results in a degree of complexity in research design and in the triangulation of qualitative and quantitative approaches, if the aim of enhancing pastoral practice is to be achieved, this approach is required. A clearly defined structure, therefore, becomes necessary if a complex picture is to be clearly seen.

2. Location and Population

This research was undertaken in two locations, Belfast and Edinburgh. This allowed for generalisation. It was desirable that the findings developed through this research would have a wide application and would not just be applicable to one geographical area. Due to the unique opportunity presented to the researcher of studying in one location and living in another, it was decided to take advantage of this situation and collect data in two places, using the insights and understanding from those in both areas. It was felt that the two locations had sufficient cultural and denominational similarities, and differences, to warrant such an approach. It is

recognised however, that this approach does introduce an additional variable. In recognition of this, population as a variable was tightly controlled. Only one location was used for each stage, so division of the research into discrete stages facilitated the use of different locations and made examination of population possible as a factor in the outcome. An over-view of the research design is provided in Figure (5.1). Each of the stages will be described individually, following a discussion of the research method.

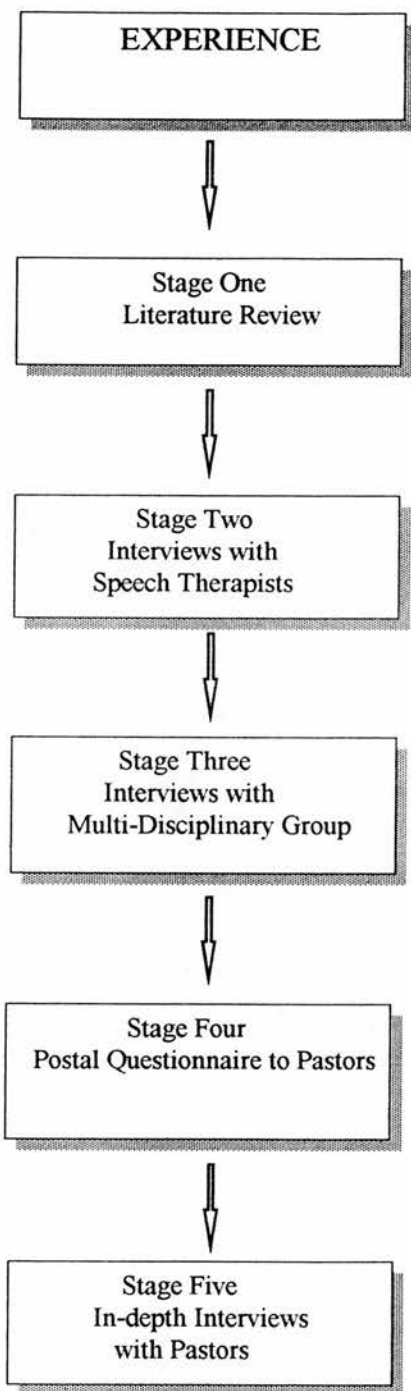
The Triangulation of Research Methods

A variety of methods were used in the gathering and interpreting of data. (see Figure 5.1) A theoretical defence of this approach, in terms of the desire to reflect practice in different disciplines, and also relate theoretical insights to practice, has been given. However, it is recognised that such an approach opens the research up to criticisms of methodological inadequacy. It is that criticism which will be addressed at this point.

Flew (1979) defines methodology as "the aims of organisation of a discipline and a study of its methods." Clarke (1995) and Rolfe (1995) in their reviews of the strengths and weaknesses of the main methodological positions, make it clear that there is debate concerning different models of research, and whether or not different approaches can be combined. The different methods will be briefly reviewed.

FIGURE 5.1

Summary of Research Design



This diagram was introduced in Chapter 1 (Figure 1.1). It is included here to facilitate understanding of the Research method.

Positivism is defined (Bryman 1988) as the position where all knowledge is contained within the boundaries of science. Following in the tradition of Comte (1853), the claim is that science is the objective, systematic study of phenomena which allows the development of general laws, which are logically linked together as theory. Positivism therefore relates to the quantitative approach, which takes the position that reality can be objectively observed through the senses, or with some instrument. Quantitative methods are therefore useful in providing knowledge that connects events and technical know-how (Shotter 1985). However, significant criticisms have been levelled at the positivist position with regard to the evaluation of practice. Stevenson (1995) contends that they do not provide the practitioner with the right kind of knowledge in order to enhance practice, and claims therefore, that quantitative means may have reached their limit in the explanation of complex systems of which humans are a part.

Clarke (1995) suggested that qualitative research is really a creative activity, which is primarily concerned with practice and the accessing of the complex processes by which practices have arisen. Thus, while a qualitative approach has advantages in terms of the flexibility to describe complex situations, it could be argued that its emphasis on gaining knowledge from practice is problematic, because, to quote Stevenson (1995), "tacit knowledge acquired through professional socialisation is...difficult to articulate." (103)

In recognition of the complexities of research methods, and in an effort to increase the information obtained from participants, and to provide a more holistic view of the world, researchers have increasingly used multiple research methods in the same study - a process known as "triangulation". (Fielding and Fielding 1986). This is not to be identified with the methodological pluralism and "anarchistic epistemology" advocated by Rolfe (1995), in which the normal rules and methods of the research process are put aside until the end of the research process. Rather, it could be understood to be representative of a positivist position, which assumes that a single reality or truth can be found, and that data gathered by quantitative and qualitative means can be combined to form a complete picture. Burns and Grove (1993) define triangulation as "the combined use of two or more theories, methods, data sources, investigators or analysis methods in the study of the same phenomenon", and Knafl and Breitmayer (1991) propose that the twin goals of triangulation are (a) confirmation of findings and (b) completeness of data. Triangulation was the approach chosen for this research. It seemed that the combination of methodologies allowed for a more adequate description and understanding of practice, as well as improvement in its depth, quality and accuracy .

This approach was not selected without consideration of the criticisms which have been levelled at triangulation. Clarke (1995) has suggested that:

"too often the application of multiple methodologies creates a diffused picture, with precision sacrificed and material inadequately examined because it is not subjected to sustained, accurate analysis." (587-588)

Guba (1985) argues strongly that quantitative and qualitative approaches cannot be combined. However some of these criticisms can be undermined by clear documentation and the incorporation of reflexivity into the research process.

Reflexivity as defined by Sapsford and Abbot (1992) implies a

"showing at each stage of the report that you have a reasonable grasp of what went on, how you were seen and construed by the informants, and the extent to which your own preconceptions, theoretical frame or professional status may have interacted with the data and your interpretation of it." (57)

Stevenson (1995), therefore, recommends a reflexive methodology in which the researcher continually reflects on the choice of method. He also recognises that the individual is a part of the research process and that each brings knowledge about the researched phenomenon into existence.

In summary, therefore, research methods have been briefly reviewed, their individual strengths and weaknesses and the debate which continues concerning their use has been acknowledged. In light of the aim of this research, not only to describe experience, but also to fuse horizons and bring different backgrounds and expertise to bear on the reality of offering pastoral care to confused elderly people, the design of choice is triangulation, involving a combination of qualitative and quantitative methods. The criticisms which have been levelled at triangulation are acknowledged, but it is hoped that these can be overcome through features of the research design. In particular the structuring of the design into discrete stages in which either qualitative or quantitative methods are employed, reflexivity and the standard careful recording of data.

The stages, which constituted the research design will now be described individually. This was a five stage project, as illustrated in Figure 5.1. The first was a literature review, the second focused on eliciting concepts and practical ways in which speech and language therapists communicate with confused elderly people. The third stage brought in a different group to further clarify and refine the concepts. In Stage 4, a postal survey was constructed to see if the clarified concepts matched with the experience of pastors. The fifth stage took the form of in-depth interviews to elucidate the information from Stage 4.

Stage 1: Literature Review

Stage 1 could be described as preparation and concept clarification. It consisted of exploration of the topic, and took the form of an in-depth literature review.

A review of the relevant literature is a vital stage in any research design. In accordance with this claim, a focused, in-depth review was undertaken. The structure of the literature review reflected the theoretical understanding underpinning the research. It therefore began with an examination of the experience of dementia. The areas receiving particular attention were the effect of dementia on speech and language functioning, and findings on the possibility of enhancing the communicative potential of a person with this condition, in addition to the effect of dementia on spirituality. On the basis of this review List 1 was constructed. (see Appendix 1, p.394)

This list has forty-four items and is divided into six sections;

1. preparation
2. the context of communication
3. enhancing comprehension (i.e. increasing the likelihood of being understood by the confused person)
4. encouraging the confused person to express himself
5. understanding what the confused person says
6. public worship.

Items on the list were in note form, so that the speech and language therapists, who would be asked for feedback on the list in Stage 2, would not be hindered from responding as freely as possible. Words and phrases which might be described as professional jargon were retained, as this was felt to be the familiar terminology for the population which was using the list.

Stage 2: Interviews with Speech and Language Therapists

Stage 2 (a) Design

In this stage exploration and concept clarification was further refined. Having constructed List 1 based on the theoretical findings which arose from the literature review (Stage 1), experiential feedback was elicited from speech and language therapists. This approach was undertaken so that the validity of communication principles could be ascertained, not only in theory, but also in practice. In this Stage we are thus provided the first example of the dynamic inter-relating of theoretical and

practical, or experiential, insights. The method chosen to test the validity of the theoretical communication principles was structured interviewing based on the pre-prepared and pre-circulated written list.

It is acknowledged that alternative methods of data collection exist, observation and questionnaires for example, and that each method has distinct advantages and disadvantages (see Reid and Boore 1987). It was decided that face to face interviews would be the preferred method for this stage because:

1. Interviews allow for freedom. One of the aims of this stage was to provide as wide a response as possible to the prepared list and to allow respondents to add to that list if they wished. Such wide ranging feedback is best collected by interview.

2. Interviews permit flexibility. Henerson et al (1987) point out that this is achieved in a number of ways. Interviewers can clarify questions, and, of particular relevance in this study, the interviewer can ask subsidiary questions and seek concrete examples. Furthermore, interviews allow for an estimation of the strength of an attitude, or in this case the usefulness of an approach. This was thought to be particularly useful at this stage when the validity of theoretical principles is being tested in practice. In an interview, the respondent may subtly indicate doubts as to the usefulness of a procedure, whereas in a questionnaire they may not have the opportunity to do so.

Stage 2 (b) Participants

The subjects used for this stage were six speech and language therapists. They were contacted by telephone, and indicated a willingness to participate fully in the research. All had on-going professional contact with confused elderly people. The validity of this approach is maintained, because the aim of this stage was not to investigate the subjects attitudes or to test them, but to elicit feedback based on their experience and expertise. It was vital, therefore, that they would be willing to co-operate fully. This approach is in accordance with Northcott's (1991) assertion that:

"...good qualitative research involves a degree of reciprocity such that the subjects of the research are drawn into the researchers findings , observations and conclusions are shared and therefore tested as to their truth appropriateness or otherwise." (30)

Stage 2 (c) Location

This stage of the project was carried out in Belfast. This decision was made on the assumption that speech and language techniques and approaches, being based on a common body of knowledge, are not significantly affected by geographical location. This is reflected by the fact that one professional body oversees training and registration in the United Kingdom. All of the interviews took place in the therapists' offices. As Oppenheim (1992) points out, being on home territory has the advantage of being quiet and free from distraction, and provides a relaxed context in which the interview could take place.

Stage 2 (d) Data Collection Procedure

Prior to the interviews being carried out the subjects were circulated with the prepared list. This took place approximately one week in advance of the interview. The list was posted to each participant with a written explanation as to the aims and objectives of the research. This was done in an effort to undermine any ambiguity as to the nature of the research and to further focus the interviews, so that the fullest and most relevant data could be collected.

The interviews were carried out face to face and were structured. The pre-circulated list provided the interviews' structure as the therapists were invited to work each item with the researcher. Positive and negative responses to the items were noted, as were anecdotes and explanations. Each interview took approximately forty-five minutes.

Stage 2 (e) Outcome

List 1 was extensively revised on the basis of these interviews, a copy of the revised list entitled List 2 is provided in Appendix 1 (p.397).

It is interesting to note that while the form of the list was altered, the content did not change radically. The stylistic changes which were made were a reflection of the fact that the revised list was aimed at a different audience. Jargon words and phrases were removed, items were elaborated upon, and examples given. Thus the aim of eliciting practical and experiential feedback can be seen to have been achieved.

It is significant that all of the speech therapists expressed the opinion not only that pastors have a vital role to play in the care of confused elderly people, but also that the acquisition of some skills could enhance their ability to communicate effectively. All of them, having read the list, commented on the issue of motivation for the pastor, asking questions like, "what would give pastors the motivation to implement these suggestions?" When that question was asked of the speech therapists directly, the answer that emerged concerned the issue of change, in particular, whether or not pastors feel that their intervention makes any difference to the confused elderly person. It seems to be a reasonable assumption that if pastors' experience leads them to be unsure about the value of their own intervention, then their motivation may be undermined. Motivated effort to intervene is undoubtedly required if pastoral communication is to be enhanced.

A further point, which two of the therapists raised, concerned the potential difficulty with which pastors are faced due to the subject matter with which they are dealing. Confused elderly people can deal more readily with concrete subjects. Often, however, matters of faith and belief are far from concrete. The therapists, therefore, emphasised the need for pastors to earth their discussions, perhaps by using concrete examples and referring frequently to the person's own life history.

Completion of Stage 2 had thus resulted in a list of communication principles which, as evinced by extensive literature review and in-depth interview, has a sound base both in theory and practice.

Stage 3: Interviews with the Multi-Disciplinary Group

The aim of Stage 3 was to elicit information and expertise from related professionals. This could be described as further concept clarification and concept refinement. The care of confused elderly people has many dimensions. The responsibility for their care may be shared by family, healthcare professionals, social workers, and, when applicable, staff of a residential or nursing home. The hypothesis was that people who had on-going contact with confused elderly people, might have developed insights through their experience, which would be helpful in enhancing communication with confused elderly people.

As has been pointed out, the research deliberately leans towards eliciting as much practical experience as possible from people who have expertise in the field of communication with confused elderly people. Communication can take place in many different ways, and it is recognised that those in close contact with confused elderly people may well have developed excellent communication skills, as a result of their experience. List 2 had been constructed on the basis of literature review and interviews with speech therapists. However, it was felt useful to broaden the base of the expertise being sought, and interview people from other backgrounds who were in contact with this client group.

An additional factor governing this decision was that the final list was not aimed at speech and language therapists, but at pastors. The interviewing of related professionals was done in an effort to ensure that the list was relevant to, and

understood by people who did not have in-depth training on the effect of dementia on speech and language functioning. In addition, it was hoped that the additional interviewees would have helpful insights, which could be incorporated into further stages and into the questionnaire design.

Stage 3 (a) Study Design

In-depth interviewing was the chosen method. This decision was made because interviews:

1. facilitate flexibility. An aim of this stage was to have a wide ranging interview and to elicit examples which might be useful at a later point.
2. allow for in-depth exploration of a topic.

In addition, as Oppenheim (1992) points out, interviews are useful in eliciting high response rates and in explaining the rationale for the research, and thus motivating the subject to respond. Furthermore, the number of subjects was small, so the recorded disadvantages of interviews, like their time consuming nature and the cost of travel, were negligible.

Stage 3 (b) Study Participants

The respondents for this stage were a multi-disciplinary group of seven people, with one being substituted following an unsatisfactory interview. These were;

1. a nurse
2. a doctor

3. a physiotherapist, working in a geriatric hospital
4. a social worker, whose primary responsibility is for the elderly
5. a care worker from a residential home
6. a person who cares full time for an elderly family member who is confused
7. an elderly person, in full possession of his or her mental faculties, who is living in a residential home

These categories were selected as they represented a range of disciplines, and others with interest in care of the elderly. People in all of these categories would have daily experience of communicating with confused elderly people.

Obviously the primary criterion for selection was membership of one of these categories. In addition, the person had to have a real interest in the research so that they could offer the fullest possible feedback.

All of the subjects were either known personally to the researcher, or were recommended by people known to her. The background to the research was explained to all of the participants, and all of those approached agreed to participate. It is recognised that this could raise the issue of respondent bias. However, the necessity of obtaining a high level of co-operation with the respondents was felt to outweigh the danger of the respondents giving what they felt the researcher wanted

to hear. Indeed later analysis proved that there was a frank exchange of ideas in the interviews.

There were 5 females and 2 males. This is reflective both of females longer life-expectancy, (the carer and the resident in a residential home were both female), and the fact of large numbers of women working within the Health Service (i.e. the nurse, physiotherapist, and care worker, were female).

Stage 3 (c) Location

All of the respondents in this stage were living or working in the Greater Belfast area.

Stage 3 (d) Interview Schedule

List 2 (Appendix 1, p.397) had six sections, which were fairly diverse in nature. Thus, for example, the preparation section included some items which focused on background knowledge of the disease and expectations as to how it affects the person; whereas the section entitled, Helping the Confused Person to Understand, was composed primarily of factual statements. Unlike List 1, each item was explained and illustrated if necessary. This resulted in the major weakness of this list as a research instrument, namely, its length. It has nine pages and fifty-four items. The only alternative would have been to omit some of the items. It was felt, however, that it would be of significance to obtain feedback on all of the items.

Stage 3 (e) Data Collection Procedure

Seven interviews were undertaken. These were arranged by telephone, at which time the researcher also explained the background to the research. The interviews took place in the interviewee's place of work or residence. In all cases this provided a quiet, comfortable environment which was relatively free from distractions.

List 2 formed the basis of, and provided the structure for, the interviews. It was sent to the respondents approximately one week in advance of the interview, to enable preparation to take place.

The interviews took an average of one and a quarter hours, and notes were made of the proceedings during, and immediately after they had taken place. These notes were analysed, and the results were fed directly into the construction of the Stage 4 questionnaire.

Every effort was made during this stage to minimise interviewer bias. All of the interviews were carried out by one person, and although they were by nature free flowing and wide ranging, every effort was made to elicit some response to all of the items.

The main difficulty which was encountered was maintaining the respondent's motivation, due to the length of the research instrument. This was especially true in Section 3 which was long and consisted of a list of factual items. At times, it was necessary to ask additional direct questions about this section as the respondents tended to rush through it, omitting items. A further factor which may have influenced respondents' response to this section, was that it was the one most directly based on techniques from speech and language therapy. Some of the subjects responded to a number of the items with phrases like "I had never thought of that but it sounds like a good idea." Thus, although they were giving positive feedback, it was not based on their practical experience.

One of the respondents appeared to find the interview difficult. It appeared from her responses that she had not read the list in advance of the interview. Furthermore her responses were limited to agreeing to all of the items, but she did not offer any additional information. It is difficult to ascertain why this occurred. It may have been that she felt threatened by the interview, as she is working for the church organisation with which the researcher is associated. The aim of this stage was not to test the respondent's level of knowledge or expertise, but to elicit feedback so that the list and the questionnaire would be as full as possible. Due to this fact, it was decided to select another respondent from the same group and conduct another interview.

Stage 3 (f) Outcomes

Stage 3 yielded much useful information. On the basis of these interviews, List 2 was altered. In particular, it was structured more clearly. The fact that the content was not altered significantly is an indication that, by and large, the opinions of the multi-disciplinary group were in accordance with those expressed by the speech and language therapists, who were interviewed in the previous stage. The revised list is available in Appendix 1, labelled List 3 (p.406). The items in this list fed directly into the questionnaire design .

Stage 4: Questionnaire

In this stage, the information gained from the speech and language therapists (Stage 2) and the multi-disciplinary group (Stage 3) was united with, and applied to the pastoral situation. The aim was to elicit information from those involved in pastoral care, about their experience of pastoral communication with confused elderly people.

Stage 4 (a) Design

A postal questionnaire was the method of choice for this stage. The decision to use this method was made in the knowledge that there are advantages and disadvantages associated with such an approach. Writers about research methods clearly outline both, with the proviso that each researcher needs to consider the merits and demerits, in the light of his or her own study. (Denzin 1989)

Oppenheim (1992) outlines the advantages and disadvantages of a postal questionnaire. He proposes that the main advantages are

"low cost of data collection, low cost of processing, avoidance of interviewer bias and ability to reach respondents who live at widely dispersed addresses." (102)

The point of primary relevance to this study, is that of being able to contact people across a wide geographical area. This, in addition to the aim of eliciting responses from a large number of people, made postal questionnaires the method of choice.

That being said, the disadvantages of this method of data collection were not ignored. Reid and Boore (1987) agree with Oppenheim (1992) that the main difficulty encountered with postal questionnaires is that of a low response rate. Along with low response rate, and associated with it, is the issue of bias. That is, it is felt that the people who do respond, when there is a low response rate, do so because they are interested in the topic, and therefore the information which is obtained is not representative of the sample as a whole. Moser and Kalton (1971) for example, point out that a high non-response rate can render data unrepresentative of the sample population, through the likelihood of the non-respondents differing significantly from the respondents. In recognition of these dangers it was decided to employ as many strategies as possible to improve the response rate. These were:

1. inclusion of a stamped addressed envelope
2. inclusion of a covering letter from one of the supervisors

commending the researcher and the project (Appendix 2, p.429)

3. giving a definite date by which replies should be received
4. addressing the envelope personally to the respondent
5. giving assurance of confidentiality
6. sending a reminder letter after the initial expiry date, which included a copy of the questionnaire in case the original had been mislaid as well as a further stamped addressed envelope. (Appendix 2, p.430)

In addition, one of the major factors in questionnaire design was recognised as ease of response. Therefore, the questionnaire was clearly laid out and had a high proportion of closed questions. All these things were done to encourage a good response rate, in order that representative and wide-ranging feedback be attained.

Stage 4 (b) Variable List

The content, or scope, of the interviews was determined directly by the data collected in the in-depth interviews of Stages 2 and 3. A purely subjective analysis of Stage 2 and 3 interviews would leave the researcher open to the danger of biasing the questionnaire to her own particular interests and theories. Although postal questionnaires minimise the danger of interviewer bias, Oppenheim's (1992) caveat is recognised that absence of an interviewer does not mean no interviewer bias. He suggests that respondents may interact with the questionnaire, and may project a person or organisation behind the questionnaires and thus bias their responses. In order to minimise the possibility of bias, it was decided to carry out an objective content analysis of the interviews. The structure of List 2 lent itself to this type of

analysis. Each item on the list was numbered and the response of each subject to each item was coded, and a Lickert Scale was drawn up. Rating of "1" was given when the subject highlighted the item spontaneously in the course of the interview. A response was rated "2" when the subject agreed with an item when directly asked about it; "3" indicated ambivalence; "4" was given when the subject disagreed when asked directly; and "5" when they spontaneously disagreed. The responses of all of the subjects to all of the items on List 2 were rated.

This rating scheme was of great significance to the research because it gave rise to the variable list, which would guide the content of the questionnaire. It was therefore decided to double-check the rating system, using a blind trial with a second assessor. This person was familiar with the research and the rating system and they independently rated the questionnaires. There was found to be an 88% level of compliance between the two ratings, and this was taken to be an acceptable level of accuracy and consistency.

As has been stated, the overall aim of this research is to provide those offering pastoral care to confused elderly people with strategies and skills which will enhance communication. For this reason, the items which were rated at the extremes of the scale were of particular interest. Those which the subjects had rated as being very important were included in the questionnaire, in order to investigate if ministers had also found them to be effective. Those which elicited only neutral responses were omitted as being probably ineffective.

There were however exceptions to this principle and they were in Section Three of List 2. (Appendix 1, p.397) These variables referred to the data which came from speech and language therapists. In general, the responses to these items had to be coded as "neutral". It is likely that the reason for this occurrence was that these variables referred to specifics of speech and language. The subject group in Stage 3 (multi-disciplinary group) had not received specific training in this area and were therefore, as would be expected, unaware of the potential of these items to enhance communication. This theory was borne out by the fact that speech and language therapists rated these items as being "very important". Therefore, despite the fact of their neutral rating in the interviews from Stage 3 (multi-disciplinary group), these variables were included.

The content analysis gave rise to a list of variables which were categorised into the following groups;

1. Technicalities of pastoral communication; for example eye contact, use of gestures
2. Communication in public worship

An additional variable list was drawn up which was concerned with pastor's attitudes to the pastoral care of confused elderly people. This section was included as a result of literature review and interviews, (Stages 1, 2 and 3), where it was proposed that the effort which a pastor makes to communicate with an confused

elderly person will be affected by the individual's attitude to the person, and their perception of the effectiveness of their pastoral intervention.

A further area which impinges on pastoral communication with confused elderly people are the personality, interests and experience of the pastor. It was therefore felt necessary to include another set of variables. Thus questions were included which related to demographic information, and to the pastor's experience with this population, presently and in the past. Specifically, had they experience in another profession prior to entering the ministry which brought them into contact with confused elderly people, and if they had experience of dementia among their own friends or family. All of these variables could have an effect on the pastor's communication. These, then, are the groups of variables which were included in the questionnaire, a copy of which is included in Appendix 2 (p.415).

Stage 4 (c) Questionnaire Structure

It was important that the questionnaire be clearly laid out, with concise unambiguous instructions. As has been said, a major criterion in the questionnaire design was the facilitation of a high response rate, in order that a wide range of opinion might be elicited. Thus closed questions were chosen as the main response format. Employing closed questions also enabled the researcher to obtain information on a large number of variables.

That being said, the questionnaire did include some open-ended items to permit some ventilation of feelings, to cover unanticipated outcomes and to obtain some unprompted responses. Therefore, although this questionnaire could be described as "mixed" with regard to response format, the balance was on the side of closed questions. This can be validated when the overall research design is borne in mind. The next stage was follow-up formal, in-depth interviews; thus it was hoped that the responses from the closed questions could be given depth at that stage.

A further advantage of closed questions was that they facilitate ordinal analysis. Thus frequencies, and percentage rates could be calculated. In addition, collection of data in this form facilitates non-parametric tests, which can be used to demonstrate the statistical significance of variables.

Oppenheim (1992) points out that the build-up of question sequences within the structure of the questionnaire is of great importance. He contends that having committed themselves to responding, people are expecting questions which are directly related to the topic, rather than personal data. For that reason, the section on personal data was placed last in the structure. Care was also taken in introducing that section so that respondents would not feel threatened, but rather be willing to contribute such data.

Sections Two and Three of the questionnaire were concerned with pastoral communication with confused elderly people, and with public worship. It was hoped that by the time the respondents reached section Four - the one which concerns attitudes and the effectiveness of pastoral care - a section which could be seen as threatening, they would feel at ease and able to respond openly and honestly.

Having determined the order of sections, attention was then paid to the order of questions within each section. In Section One, funnel and filter questions were used in order to ascertain the pastor's past and present level of involvement with confused elderly people, both professionally and personally.

Sections Two, Three and Four required the respondents to rate their responses according to a given, Lickert Scale. Particular care was taken in the ordering and wording of these items, so that responses would be scattered throughout the scale; rather than a pattern emerging which could lead the respondents to believe that the "right" answers come from a particular end of the scale.

A coding system was devised which would allow the results to be analysed by computer, using "The Statistical Package for Social Services". In addition, a personal coding system was developed. This denoted the respondent's denomination and full identity.

Stage 4 (d) Questionnaire Validity

De Vaus (1986) claims that " a valid measure is one which measures what it is intended to measure." (47) At this stage the questionnaire was tested for face and content validity. In the first instance, subjects who were pastors, but not connected with the study population, were selected at random to examine the clarity of the language used. No major changes were deemed necessary.

Content validity, which de Vaus (1986;48) defines as "the extent to which the indicators measure the different aspects of the concept", was tested by two ministers and two speech therapists, who had current experience working with confused elderly people.

Stage 4 (e) Population

The target population for this stage of the study were all clergy in the Edinburgh area. In order to obtain as full and unbiased a survey as possible, it was decided to send a questionnaire to all Episcopalian, Church of Scotland, Roman Catholic and Methodist clergy in the city. This came to a total of 156 subjects.

It was hoped that contacting all of the clergy would diminish the risk of obtaining a biased sample, and would enable the researcher to obtain feedback based on a wide variety of opinion and interest. However this approach inevitably resulted in the denominational groups being of different sizes as illustrated in Table 5.1.

Table 5.1 Stage 4: Numbers of clergy by denomination in the Edinburgh area.

(n=156):

Denomination	Number	Percentage
Church of Scotland	84	53.8
Episcopalian	47	30.1
Methodist	4	2.6
Roman Catholic	21	13.5
Total	156	100

Stage 4 (f) Recruitment

The names and addresses of the clergy were obtained from the relevant church lists and publications. The questionnaire was sent with a stamped addressed envelope, and a covering letter from one of the research supervisors. This letter explained the aims of the research and commended the researcher. (see Appendix 2,p.429)

The subjects were asked to respond within three weeks. If no reply had been received at the end of this period a reminder letter was sent, (see Appendix 2, p.430) with a copy of the questionnaire and another stamped addressed envelope.

Stage 4 (g) Response Rate

141 replies were eventually received. This corresponds to an over-all response rate of 90.3% (n=156). However, this figure includes 17 letters accompanied by blank questionnaires explaining why the respondent could not complete the questionnaire. The main reason was illness. Due to the fact that the subjects were not personally known to the researcher, and the decision to send questionnaires to all ministers of the selected denominations, some had, inevitably, been sent to those who were retired and/or in ill health. It was therefore understandable that they did not complete the questionnaire. It emerged that this applied, in particular, to the Roman Catholic priests and explains their apparently lower response rate in terms of actual questionnaires completed. It is, however, interesting to note that most of those who could not fill in the questionnaire replied by letter, expressed their interest in the area of study. The second most frequent reason given for reply but non-completion was that the respondent was on sabbatical. Thus 124 completed questionnaires were received. The response rates for completed questionnaires for each denomination is shown in Table 5.2.

Table 5.2 Stage 4: Response rate for questionnaires by denomination

Denomination	no. sent	no. received	% response rate
Church of Scotland	84	71	85
Episcopalian	47	38	81
Methodist	4	3	75
Roman Catholic	21	12	57
Total	156	124	79.5

Stage 4 (h) Analysis

The responses were first coded according to the system which had been developed during the questionnaire design. This was a clearly formulated coding system, with little potential for error with regard to the closed questions. It was recognised that potential for error did exist with regard to the coding of open and "other" responses. Error could have developed through assignment of a response to the wrong category, or through inconsistency, due to the large number of questionnaires being coded. In response to this recognition it was decided that two people would code the responses independently. It was felt that this resulted in consistently accurate coding.

The questionnaires were then analysed using the S.P.S.S. computer programme.

1. Each variable was examined separately, and frequency tables were produced illustrating how many respondents fell into each response category. Percentage, and if appropriate, mean scores were also produced.

2. Pairs of variables were then selected and examined in order to explore the relationship and strength of association between them.

The results of this analysis are detailed in Chapter 6. These results provided the content for Stage 5 interviews.

Stage 5: Interviews with Pastors

Stage 5 (a) Introduction

In this stage, the outcomes from the questionnaire were further applied to the pastoral situation through in-depth interviews with a sample of the respondents.

The model underlying the research, which is illustrated in particular by the research design, is that of relating principle to practice. As has been outlined, this is done in the hope that this research will result in a tool which is useful for the minister in the pastoral situation. According to this paradigm, practical theology informs, and through on-going theological reflection, modifies pastoral practice. However the relationship is more complex than this, because reflection on pastoral practice may require modification of the theological approach, in order for consistency to be achieved. In this context, and through this process, a theology which is 'owned', rather than simply learned, can be developed.

In accordance with this approach the research design demands that theoretical findings are continually fed back, applied and re-applied to the pastoral situation. Stage 5 (Pastors' Interviews) is part of that process. At this point, the generalised statistical findings were fed back to the respondents with three primary goals,

1. to investigate their validity in particular pastoral situations,
2. to explore the issues raised in more depth,
3. to obtain anecdotal evidence to substantiate the findings.

Stage 5 (b) Data Collection Procedure

The method chosen to fulfil these research goals was that of formal, semi-structured, in-depth interviewing.

A list of questions was drawn up based on the questionnaires, in which findings, and what motivated those findings, was explored. These questions were then ordered and a standardised introduction formulated, in which the background to the research was re-iterated.

Stage 5 (c) Participants in Study

Eleven subjects were selected according to two different sets of criteria. The over-riding criterion for all subject selection at this point was willingness to participate. The final question on the questionnaire asked if respondents would be willing to be interviewed at a later stage; only those who responded positively were submitted for potential selection.

In responding to the questionnaires some subjects had shown special interest in the pastoral care of confused elderly people, arising from professional contact through specialised clubs for the elderly which met on church premises, or through personal family experience of dementia. As has been repeatedly stated, the main aim of the research was not an assessment of pastoral competence, but the gleaning of pastoral expertise and experience. With that in mind, it seemed wrong to ignore this obvious expertise, so it was decided to construct one group for this stage from those who had shown special interest. Five people were thus selected from this "sub group" of interested pastors. They were representative of all the denominations except Roman Catholic, and of both genders. This group consisted of one Methodist minister (male), three Church of Scotland ministers (two female and one male), one Episcopalian minister (female). It is recognised that the construction of this group is not reflective of the group as a whole. However their expression of interest in dementia, or their evidence of particular relevant experience, was the main criterion of inclusion.

The second group of six people were chosen at random. The only additional condition being that they would counteract the imbalances of gender and denomination in group 1. This group therefore consisted of two Roman Catholic priests, two Episcopalian priests (male) and two Church of Scotland ministers (male).

These subjects were contacted by telephone and all agreed to participate in a "follow-up" interview. All but two of the interviews took place in the subject's own home, the others being in a church hall. Permission was asked to tape all of the interviews, and in every case this permission was granted.

Stage 5 (d) Analysis

Each interview was transcribed and analysed manually. Responses to the questions were compared and contrasted, and the major themes which emerged were highlighted.

With regard to analysis, it should be noted that the interviewer's technique improved as the interviews progressed, as she became more adept at highlighting and exploring the complexities of issues raised. As a result, more information can be obtained from the later interviews.

The results of the interview analysis are presented in Chapter 7.

CHAPTER SIX

RESULTS

RESULTS

Analysis of the Results from the Questionnaire (Stage 4)

Introduction

This descriptive, exploratory study was designed to examine how pastoral communication could be enhanced with confused elderly people. The aim is to develop strategies which have a sound theoretical base, in addition to a real practical application.

The relating of theory and practice in this way demanded triangulation of research methods, both qualitative and quantitative approaches being utilised. The initial stages of the research took the form of a literature review (Stage 1) and structured interviews (Stages 2 and 3), and through these primarily qualitative methods, a list of communication principles was devised and refined.

It was then felt necessary to test the practical application of these communication principles with pastors, who had direct experience of pastoral care of elderly people who are confused. The method of choice was quantitative, a postal questionnaire. This decision was taken on the grounds of the number of pastors being contacted and the suitability of the material for a questionnaire format. The target population for the questionnaire were ministers and priests in the Edinburgh area. In order to obtain as full and as unbiased a survey as possible, it was decided to send a

questionnaire to all Episcopalian (n=47), Church of Scotland (n=84), Roman Catholic (n=21), and Methodist (n=4) clergy in the city. A total of 124 questionnaires were returned. This corresponds to a response rate of 79.5% (n=156). The aim of this section is to describe the results which arose from the questionnaire.

Data generated from the questionnaires was subjected to descriptive analysis. The primary motive underlying the questionnaire was not a search for causal relationships, it was to explore and indeed tap into pastors' experience and expertise, in order that their insights might be compared with the findings from literature review (Stage 1), and interviews with speech therapists (Stage 2) and the multi-disciplinary group (Stage 3). Thus the statistical analysis described in this chapter is descriptive rather than analytical.

A copy of the questionnaire is provided in Appendix II, (p.415) along with the results from every question in Appendix III, (p.431). Throughout this chapter the results presented are cross-referenced to this section in Appendix III. The appropriate page number is given and the figures in square brackets refer to the number of the variable in the results appendix, (pages 431 - 472).

The structure of this chapter mirrors, by and large, the structure of the questionnaire itself. Thus, following a review of demographic data, the results are presented in the following major sections:

1. Areas of responsibility:- Section One of the questionnaire, the variables examined include the amount of time the pastor spends with confused elderly people and the places where the pastor meets with them.
2. Pastoral Communication with confused elderly people:- Section Two of the questionnaire, this section examined specific principles of communication.
3. Public Worship :- Section Three of the questionnaire
4. Pastoral Care of confused elderly people:- Section Four of the questionnaire

The first task, however, is to review the demographic information pertaining to the respondents.

Demographic Information

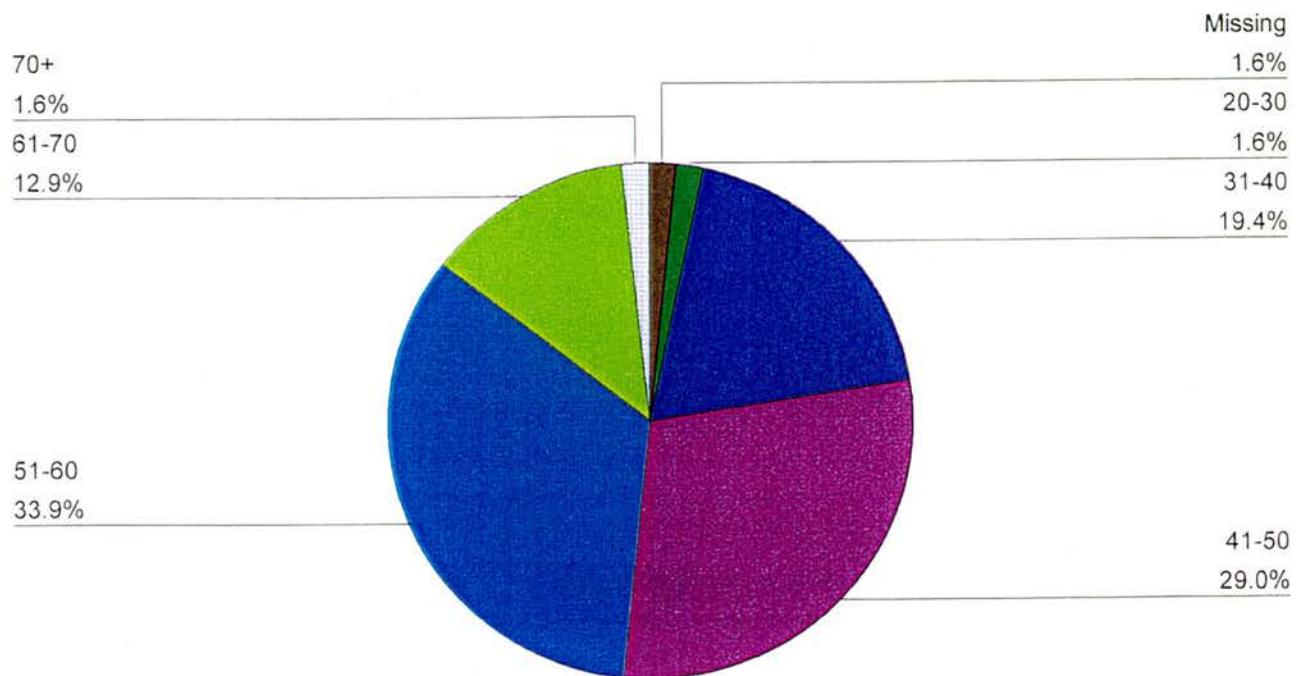
1. Age of respondents [5:1] p.470

The age distribution of the respondents is illustrated in Figure 6.1. The largest proportion of respondents (frequency 42, 33.9%, n=124) were in the age range 51-60.

2. Years since Ordination [5:2] p.470

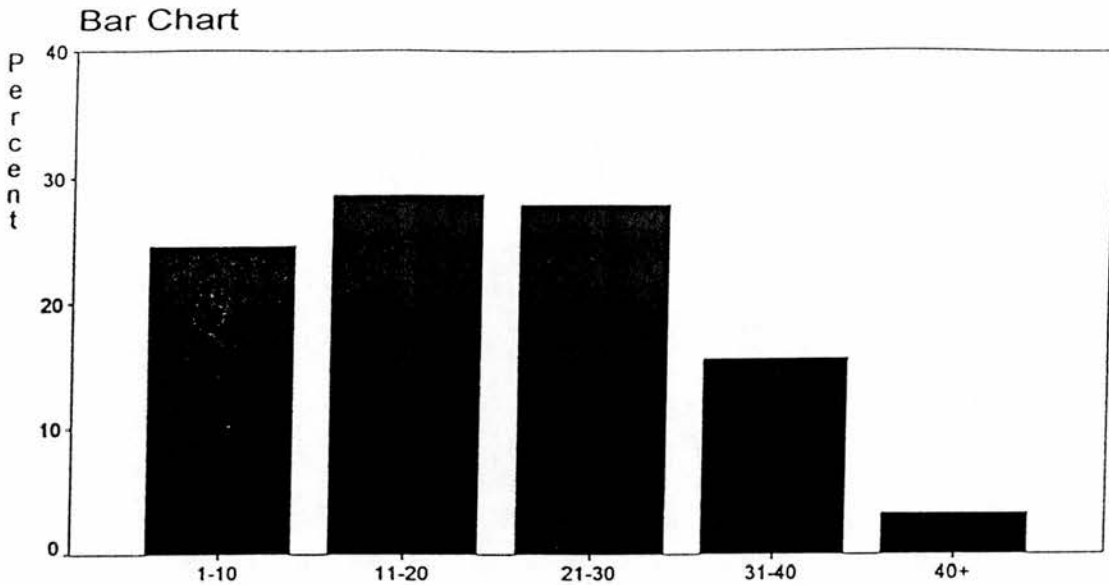
This variable was included as a means of monitoring the probable level of the pastor's experience. Pastors can enter the ministry at any stage in life, therefore chronological age in itself is not necessarily a reflection of pastoral experience. Results are shown in Figure 6.2. This bar chart illustrates a fairly even spread across

Figure 6.1 : The age distribution of the respondents. (n=124) [5.1]



the ranges 1-10 years, 11-20 years and 21-30 years, with the largest percentage being 11-20 years at 28.2% (n=124).

Figure 6.2: Number of years since the respondents were ordained. [5:2] p.470



3. Occupation Prior to Entering the Ministry [5:3] p.471

Respondents were asked "Have you had another occupation other than ministry?" It was felt necessary to ascertain if the respondents had had experience relevant to pastoral communication with confused elderly people, prior to entering the ministry.

Of those who responded 44 (35.5%) reported that they had had no other occupation. Of the remaining 80 (64.5%), 66 (53.3%) were deemed to have had occupations which did not have direct relevance to care of elderly people who are confused. The remaining 11 (8.8%) had pursued occupations which are likely to have had a formative effect on their attitudes and approach. There were 3 (2.4%) missing values with regard to this question.

The occupations which were deemed to be relevant to this field were social worker, nurse, carer for the mentally handicapped and counsellor. Table 6.1 provides the complete list of occupations along with the number of respondents who had pursued each career.

Areas of Responsibility

An underlying premise of this research is that pastoral care of confused elderly people is a task in which clergy are involved. In order to test the veracity of this assumption questions were constructed with a view to ascertaining how much time pastors actually spend with confused elderly people. Questions were also asked concerning the contexts in which that pastoral interaction takes place.

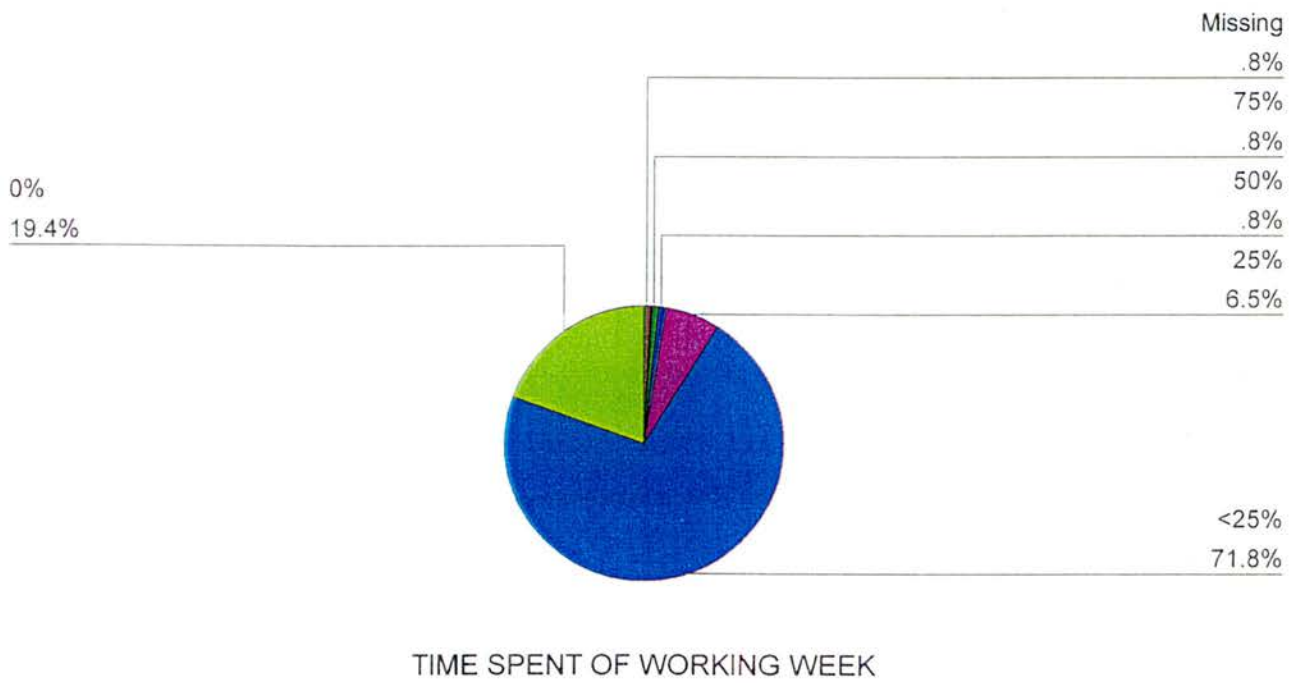
1. Time Spent with Confused Elderly People [1:1] p.432

The respondents were asked to estimate the percentage of their working week which they spent with people who were elderly and confused. Figure 6.3 illustrates the range of responses and shows that the majority (71.8%, n=124) assessed

Table 6.1: Respondents previous occupations [5:3] p.471.

Previous Occupation Frequency n=124		Previous Occupation Frequency n=124	
	(%)		(%)
None	44 (35.5)	Police	2 (1.6)
Teacher	10 (8.1)	Nurse	2 (1.6)
Administrator	8 (6.5)	Journalist	2 (1.6)
Social worker	6 (4.8)	Carer for mentally handicapped people	2 (1.6)
Banker	5 (4.0)	Farmer	2 (1.6)
Sales	5 (4.0)	Chemist	1 (0.8)
Armed forces	5 (4.0)	Artist	1 (0.8)
Engineer	4 (3.2)	Counsellor	1 (0.8)
Solicitor	3 (2.4)	Decorator	1 (0.8)
University lecturer	3 (2.4)	Driver	1 (0.8)
Missing	3 (2.4)	Research scientist	1 (0.8)
Civil servant	2 (1.6)	Factory worker	1 (0.8)
Surveyor	2 (1.6)	Librarian	1 (0.8)
Probation officer	2 (1.6)	Publisher	1 (0.8)
Accountant	2 (1.6)	Educational researcher	1 (0.8)

Figure 6.3 : The amount of time pastors estimate that they spend with confused elderly people in a "typical working week" (n=124) [1.1]



themselves as spending more than 0%, but less than 25%, of their week with confused elderly people.

It is interesting to note that 99 of the respondents (79.8%), rated themselves as spending some time every week with people with dementia. It can therefore be asserted that the pastors involved in this study, do have a significant level of contact with confused elderly people during a typical working week.

2. The Context of Pastoral Care

The pastors were asked where they met with confused elderly people, either in the context of their current responsibilities, [1:2] p.432, or in the past, if they recorded themselves as not meeting with confused elderly people at the moment [1:4(a)] p.438. These questions were included in order that a picture of the pastoral care being offered might be gained, and also so that the communication principles being developed might be tailored to the context in which pastoral care is taking place. The number and percentages of pastors who replied that they met with confused elderly people in different contexts is shown in Table 6.2.

A wide range of activities was mentioned by pastors in response to the request to name "other church activities where you meet people who are confused" [1:2 (g)] p.432. This may reflect a level of pastoral concern for confused elderly people, on behalf of the minister and the congregation as a whole. The activities mentioned were social gatherings, clubs for the elderly, women's organisations, youth

activities, day-care centres, church meetings and groups specifically for people with dementia which meet on church premises.

3. Public Worship

The respondents were asked whether they led services of worship at which confused elderly people were present [1:3 (a)] p.436. In response, 92 of the respondents (74.2% n=124) replied that this was one aspect of their current responsibilities. A filter question was directed at those who replied that they had no current contact with confused elderly people. They (n=25) were asked if they had ever had regular contact with confused elderly people at church services [1:4(g)] p.440. Of these 10 replied in the affirmative. Therefore it can be claimed that 102 of the respondents (82.3% n=124) have now, or have had in the past, experience of public worship with confused elderly people.

Of the pastors who currently lead worship (n=92) at which confused elderly people were present, 37 (40.2%) replied that people with dementia were part of their Sunday congregation. The most frequent context in which the pastors in this survey lead worship at which confused elderly people are present is Nursing and Residential Homes, 74 (80.4%) reporting their participation in services of this type. [1:3 (b)] p.436.

Table 6.2: Places where pastors meet with confused elderly people: (n=124)

[1:2] p.443, and [1:4] p.438.

Place	Respondents
Residential/ Nursing Home	107 (86.3%)
Person's own home	95 (76.6%)
Hospital	94 (75.8%)
Church services	73 (58.9%)
Carer's home	46 (37.1%)
Hospice	22 (17.7%)
Other church activities	56 (45.2%)

Pastoral Communication with Confused Elderly People

Within this section respondents were asked, in their experience, what strategies had enhanced pastoral communication with confused elderly people. The form of response was a Lickert Scale whereby they rated their reply on a scale from 1 (strongly agree) to 5 (strongly disagree).

1. Background Information

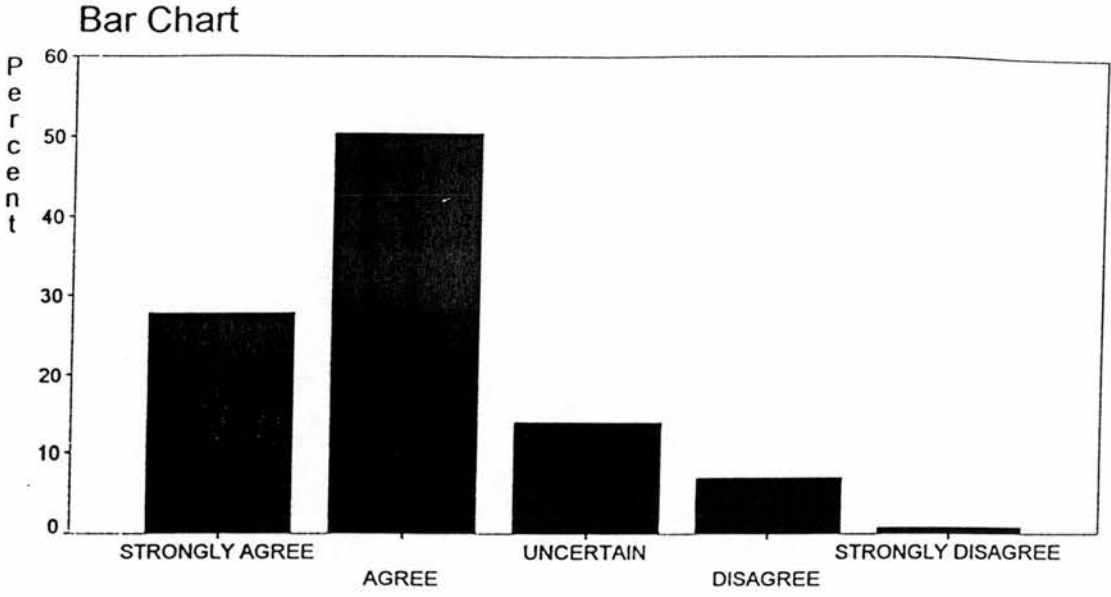
A group of questions was asked which explored the relevance to communication of information which the pastor might have about the confused person.

When asked if they found it easier to communicate with confused elderly people if they are sure about their degree of confusion [2:2] p.442 , 67 (54%) agreed, or strongly agreed, that this was helpful. From a speech and language perspective this is less than might be expected as ascertaining the level of confusion would be a high priority. However, this finding may reflect pastors' experience that being sure about level of communication does not impinge on the communication strategies which they employ, or it may be indicative of a lack of awareness about the progressive nature of the condition. It might also indicate an inhibition about asking exactly what is wrong with someone, unlike the health professional who expects automatically to have such information.

A slightly different perspective on knowledge about the dementia was examined by asking pastors to rate the statement , " In my experience I have found it easier to communicate with confused elderly people if I know what behaviour to expect from a confused elderly person" [2:11] p.447. As Figure 6.4 below illustrates there was a high level of agreement with this statement.

Hearing is an issue which impinges directly on communication. The results did reflect the pastors' understanding of the importance of having knowledge about the confused person's level of hearing acuity. 99 (79.8%) agreed, or strongly agreed, that communication was enhanced if they knew about the person's hearing level [2:3] p.443.

Figure 6.4: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I know what behaviour to expect from a confused elderly person" [2:11] p.447



So far attention has focused on the pastor's knowledge about the confused elderly person. According to principles of reality orientation, as outlined by Kitwood and Bredin (1991) for example, communication will be enhanced if efforts are made to orientate the confused elderly person in time, place and person. In order to explore pastors' experiences of reality orientation, they were asked if they had found communication to be enhanced if they identified themselves clearly to the person with

dementia [2:5] p.444. The result was over-whelmingly positive, 97 of the respondents, 78.2%, rating this as helpful, or very helpful.

2. Life-Story

The importance of knowledge about the individual's life-story in communication with confused people is a developing area in recent research (Goldsmith 1996). So questions were asked which explored whether or not, in pastor's experience, knowledge about the confused person's history [2:6] p.444, and family, [2:12] p.447, facilitated meaningful communication.

The results are summarised in the Figures below (Figures 6.5 and 6.6). They highlight the fact that, in these pastors' experience, knowledge of the confused person's life-story enhanced meaningful pastoral communication.

Figure 6.5: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I know something about their lives." [2:6] p.444

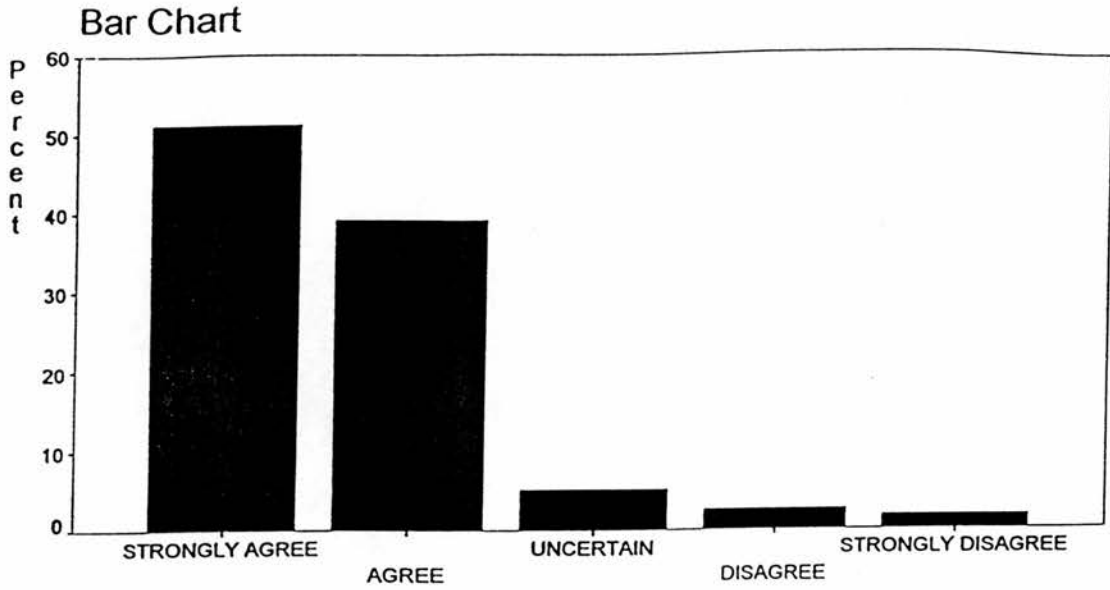
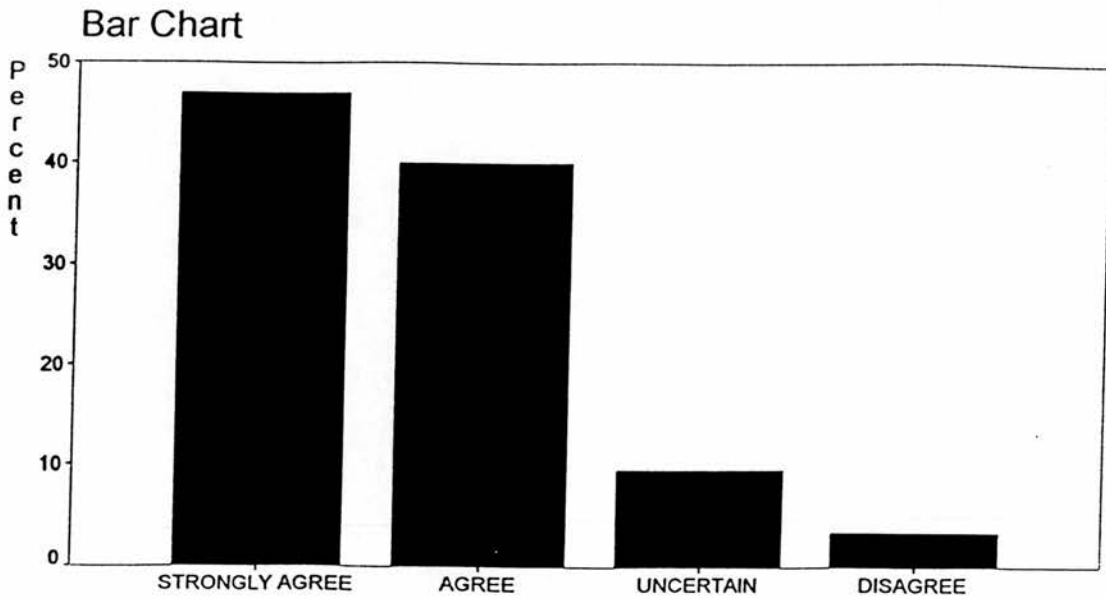


Figure 6.6: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I know the names of close family members". [2:12] p.447



Taking the time to learn or remember the individual's life-story may facilitate communication, but in addition it is a powerful theological signal that the life of this person, despite his or her level of confusion, is of importance to the pastor and by extension to God. Long-term memory is relatively spared in dementia. (Appell et al 1982). In theory therefore, being able to access that memory through knowing family names, and being willing to talk about the past could open up opportunities for communication. The indications from this research are that this theoretical contention holds true in pastoral practice. Asked if they had found it easier to communicate with confused elderly people if they talked about the past, [2:18] p.450, 99 (79.9%) responded positively. This is consistent with the stress placed by many practitioners on the value of reminiscence with confused elderly people. (Cohen and Eisdorfer 1986). That the importance of knowledge about life-story is understood by pastors is further reflected by the high level of correlation between the variables concerning talking about the past, [2:18] p.450, and knowing family names, [2:12] p.447. These two variables relate with a likelihood ratio of 0.009, which indicates a high level of correlation.

As well as the pastor knowing about the person, there was a strong recognition that communication is a "two-way" process and that the pastor had a role as a listener as well as a talker. When asked if they agreed that communication was facilitated if they listened to the confused person's stories, [2:23] p.452, 108 (87.1%) agreed, or strongly agreed, and this was reinforced by the finding that 92 (74.2%) disagreed, or strongly disagreed, that the confused person should be corrected when they ramble, [2:8] p.445.

This finding is of relevance to Feil's (1992) Validation technique. Feil (1992) adds an additional stage to Erikson's (1980) life-cycle theory and suggests that "old-old" people must complete a stage which she terms "resolution or vegetation". Within this model, she interprets much of the behaviour of confused elderly people as an effort to complete life tasks which were left incomplete at an earlier stage. She contends therefore that it is important to listen to the "ramblings" and interpret them. It is Feil's (1992) experience that apparently confused behaviour may well be meaningful. These results indicate that pastors, in their practice, perhaps unknowingly and for different motives - whether it be an effort to communicate God's love or out of a sense of duty - may well be implementing aspects of her approach.

3. Nonverbal Communication

A number of questions addressed this aspect of communication. The general findings indicate that pastors have found that nonverbal factors are important in interaction with confused elderly people.

The pastor's ability to communicate will be facilitated by sitting facing the confused elderly individual, [2:21] p.451. Of the respondents, 104 (83.9%) agreed or strongly agreed that this was the case. Other factors which impinge on nonverbal communication are eye-contact, [2:1] p.442, touch, [2:4] p.443, and gesture, [2:9] p.446. Questions were asked on each of these areas. Results are illustrated in Figures 6.7, 6.8, and 6.9.

Figure 6.7: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I maintain eye-contact". [2:1] p.442

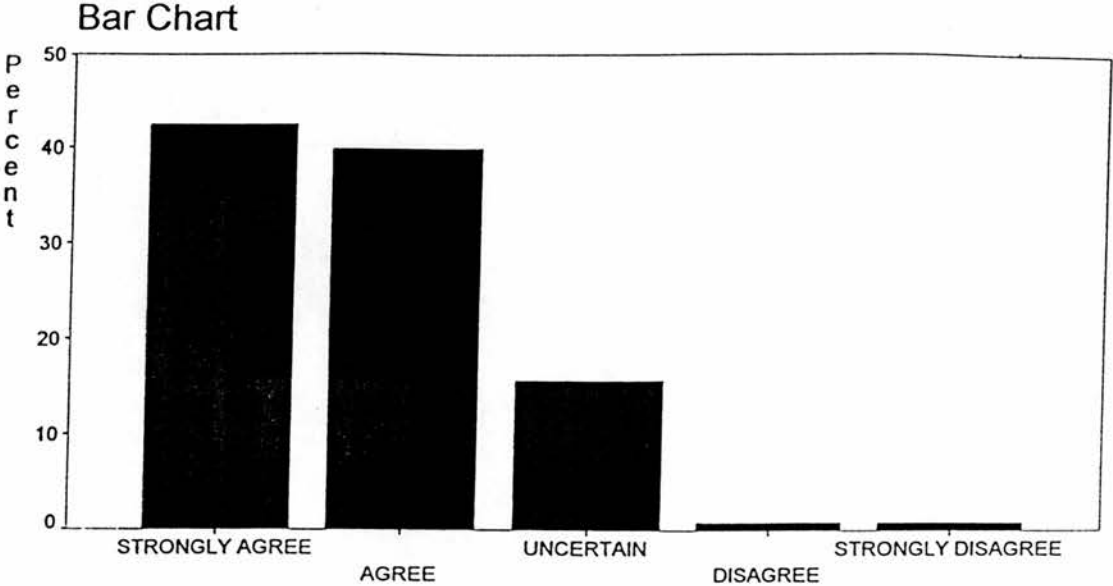


Figure 6.8: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I hold their hand." [2:4] p.443

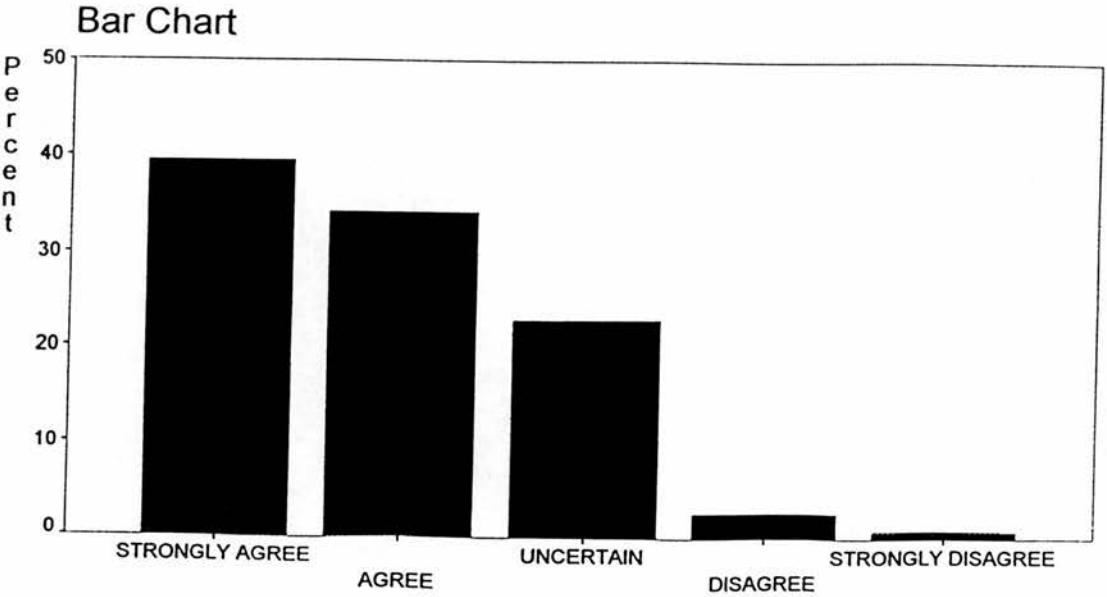
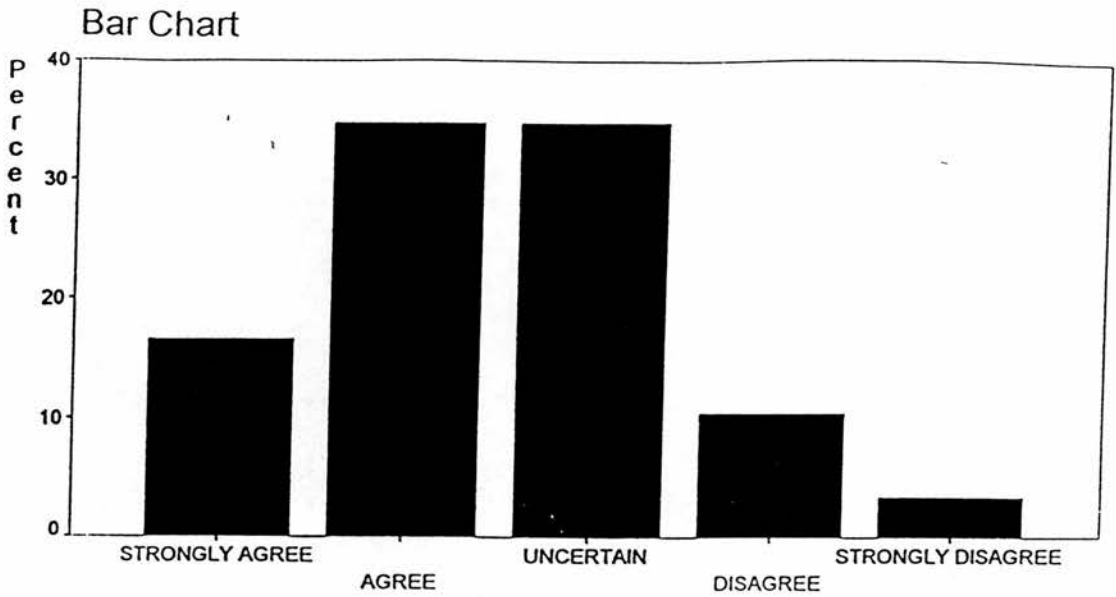


Figure 6.9: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I use familiar gestures." [2:8] p.445



These Figures make it clear that pastors' experiences were positive, particularly in the areas of eye-contact, [2:1] p.442, and touch, through holding hands [2:4] p.443. Thus these results reflect an understanding of the importance of non verbal communication. However, a significant feature of all of these profiles of responses is that they reflect a high level of uncertainty. In particular, with regard to "using familiar gestures", 45.2% (n=124) registered uncertainty or disagreement [2:9] p.446.

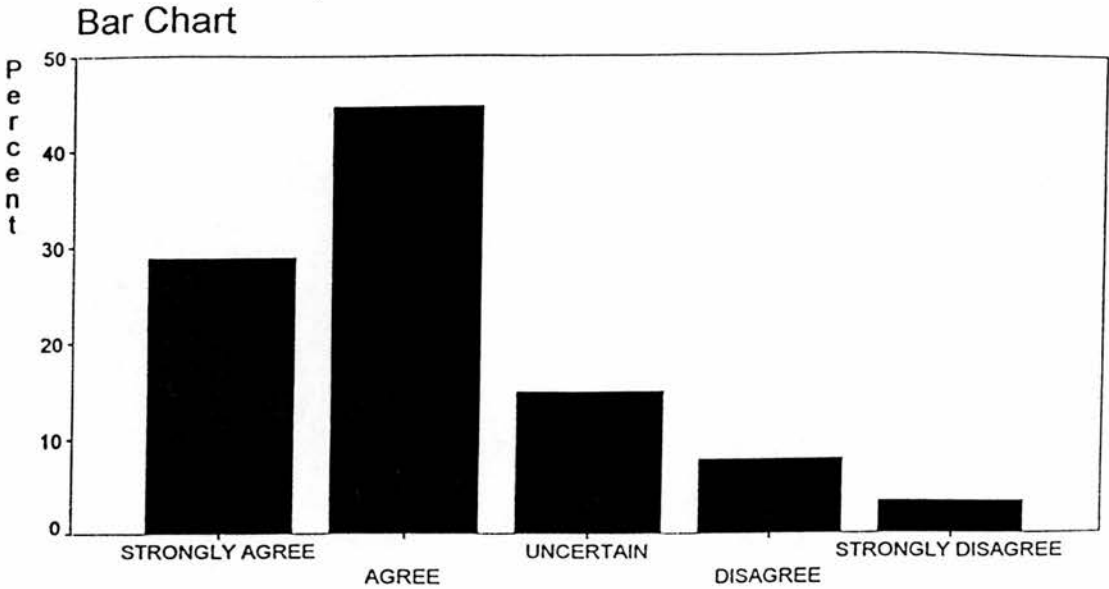
This high level of uncertainty could be a result of a number of factors. Pastors may have registered uncertainty as a result of the way in which the question was worded, if, for example, the question was unclear, or did not contain enough detail. An alternative explanation is that uncertainty is a reflection of the fact that

pastors are implementing good practice, but are unsure about it. If pastors have not received practical training in pastoral communication with confused elderly people, they might never have been given guidance and feedback on this area of their pastoral practice. Therefore, although they may well have developed good practice based on their experience, they may not be confident in that practice.

Further possible explanations for the findings of high levels of uncertainty include the likelihood that pastors were genuinely uncertain as to the value of communication techniques, due to the difficulties in interpreting feedback from confused elderly people. Alternatively, it is possible that these ministers have never thought of some of the procedures that they were being asked about and were therefore uncertain as to their use because they had never tried them. This is not surprising because these ideas arose from the expertise of speech and language therapists, a body of information to which pastors may not have had access previously.

The question of wearing a clerical collar, [2:17] p.449, can also be included under the heading of nonverbal communication, although it is also an aspect of reality orientation. The results with regard to this variable are presented as Figure 6.10. This illustrates that there was a spread of opinion, the practice of wearing a clerical collar being affected by many factors. However 84 of the respondents, (67.7%) did feel that wearing a collar enhanced communication.

Figure 6.10: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I wear a clerical collar" [2:17] p.449.



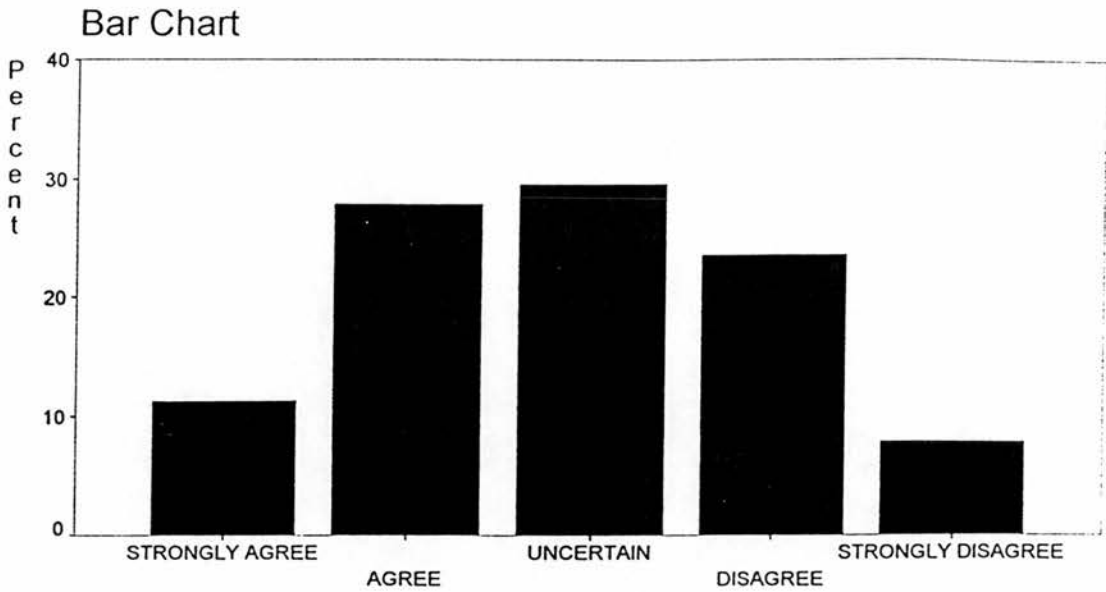
4. Expressive Speech

In Section Two of the questionnaire, in addition to statements which focused on background knowledge, life-story, and nonverbal communication, statements were included in which aspects of expressive speech were explored.

There is evidence in the research (Schmitt and Moore 1989), which suggests that speaking slowly may give the confused person longer to process the incoming message, thus facilitating comprehension. This claim is made with the caveat that speech is not slowed to an abnormal level. Pastors' experiences, as reflected in the questionnaire, would seem to echo this claim as 84 of respondents (67.7%) agreed, or strongly agreed, that speaking slowly made communication easier [2:7] p.445.

Respondents were then asked whether or not they found it helpful to ask the confused person questions, [2:10] p.446. As illustrated below, pastors' reflections on this topic are almost exactly evenly divided.

Figure 6.11: Percentage response rates to the statement: "In my experience I have found it easier to communicate with confused elderly people if I ask them questions." [2:10] p.446.



The clear division of opinion on whether or not pastoral communication is enhanced if the confused elderly person is asked questions, may reflect a difficulty in

generalising approaches from one person to another, and even with the same person on different occasions. Although questions can be useful in orienting the person they can also be stressful for the person with dementia.

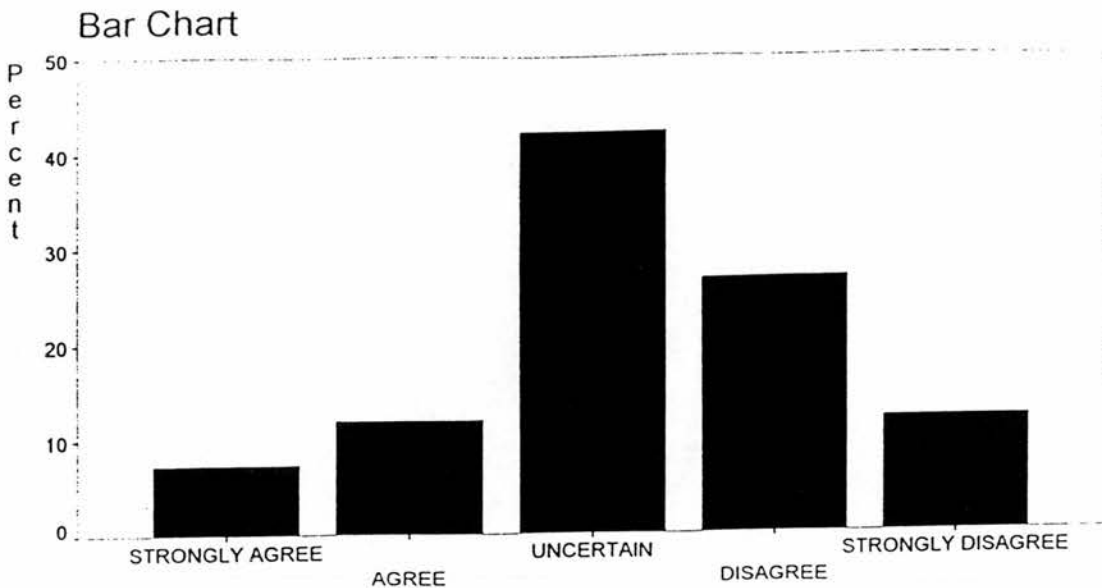
Pastoral practice was seen to reflect theoretical principles (Flicker et al 1987) in the findings that 69 pastors (55.6%) disagreed, or strongly disagreed, with the statement that repetition was not helpful, [2:14] p.448, and 93 (75%) agreed, or strongly agreed, that the use of short simple sentences facilitated meaningful communication [2:15] p.448.

Asked if maintaining a calm and even tone of voice, made communication easier with confused elderly people, [2:22] p.452, 97 of the respondents (78%) agreed, or strongly agreed, that it did. As was reported in the literature review, (Shamey 1993), it has been asserted that people with dementia remain sensitive to the tone of voice used by a speaker, especially if it contains criticism or reprimand. When a question was asked about whether or not speaking loudly [2:19] p.450 made communication easier, there was a spread of opinion, 41.9% (n=124) registering some level of disagreement, 19.3% (n=124) agreeing, or strongly agreeing, and 30.6% (n=124) responding that they were uncertain.

Pastors' experience of the helpfulness of a ministry of presence, as described by Fackre (1990) was also explored. Asked if "sitting quietly at times" [2:13] p.448 made communication with confused elderly people easier, 82 (66.2%) agreed, or strongly agreed, that it did.

An alternative mode of communication is the written word. Pastors were asked if they had found that communication with confused elderly people had been made easier through writing down key words [2:16] p.449. The results from this question are presented in Figure 6.12. This figure is included because it illustrates that again there was a high level of uncertainty recorded (37.1% n=124). The balance of opinion was that writing did not enhance communication. This is reflected in the fact that 42 of the respondents (33.8%) disagreed, or strongly disagreed, that it made communication easier, while only 21 (17%) had found writing to be helpful in enhancing communication. In general, the research findings indicate that writing does not enhance communication with people with dementia, especially in the later stages. (Thompson 1981). This is the result of a number of factors, these include possible visual-perceptual deficits, as well as difficulties in memory and cognition.

Figure 6:12: Percentage response to the statement: "In my experience I have found it easier to communicate with confused elderly people if I write down key words" [2:16] p.449.



In summary, of this section, therefore, analysis of the pastors' responses to questions on their experience of specific aspects of pastoral communication with confused elderly people support many of the findings from speech and language research. There is thus a degree of consistency between the two disciplines. It may well be, therefore, that either through instinct, or as a result of their experience, pastors are implementing good practice.

The research indicates, however, that pastors may not be aware of their good practice. This possibility is supported by the high levels of uncertainty recorded in response to a number of items in this section of the questionnaire, and by the desire evidenced by a number of the respondents for additional training in this area. In Section Five of the questionnaire [5:4] p.472, respondents were given an opportunity to make comments on any issue related to pastoral care of confused elderly people. Of those who responded to this section (n=46), 10 (21.7%) mentioned training, and in particular that they would value additional input in this area.

The finding of good practice in itself may warrant further investigation in the in-depth interviews (Stage 5). It is possible that the indication of good pastoral practice could have arisen due to the method of questioning, i.e. pastors were presented with the ideas and did not have to generate them for themselves. It may, therefore, have been possible, that when presented with a concept they responded on the basis of "that sounds like a good idea", rather than on the basis of their experience of the implementation of that idea.

Public Worship

The section on "Public Worship" in the questionnaire (Section Three) aimed at exploring the pastors' experience in this area and asked what elements or constituents they had found helpful and meaningful.

Involvement in worship emerged, in this study, as a significant aspect of pastoral care of confused elderly people. Of the respondents 83.2% (n=124) stated that they had experience of worship with confused elderly people, either now or in the past [1:3 (a)] p.436 and [1:4 (g)] p.440. This indicates, not only that worship with this population may be an area of interest for pastors, but, in addition, that pastors may have a wealth of knowledge about worship with people with dementia. Knowledge which this research may be able to tap into and encapsulate.

Pastors were given a Lickert scale ranging from 1: very helpful, to 5: very unhelpful, and were asked to rate variables according to their experience of that variable's helpfulness in public worship with confused elderly people. The response to these variables will now be examined systematically.

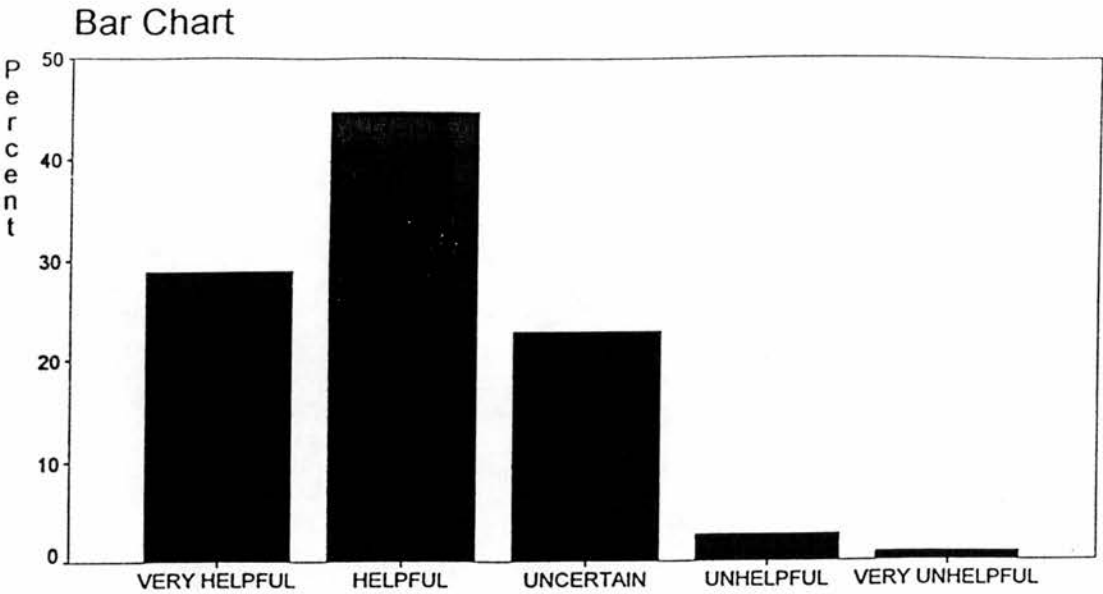
1. Standard Liturgy [3:9] p.456, and Order of Worship [3:8] p.456

Writing about leading worship in a Methodist Home for the Aged at which there was a high proportion of people with dementia, Goodall (1996) claims:

"We came to realise that what appears to be needed is consistency and repetition, which then becomes a familiar framework for this special time together." (1)

The importance of consistency and structure with regard to public worship with confused elderly people was explored when the pastors were asked if they found using the same order of worship helpful in public worship with confused elderly people [3:8]. The results are illustrated in Figure 6.13. This shows that 67.7% of the respondents (n=124) rated consistent order as helpful or very helpful.

Figure 6.13: The respondents' rating of the variable "using the same order" as a helpful component of worship with confused elderly people [3:8] p.456.



The results on the issue of use of a standard liturgy [3:10] p.457, are more ambiguous. They reflected a high level of uncertainty among the respondents, 46 (37.1%) responding in this way. This may be a reflection of denominational differences as pastors who come from a tradition in which standard liturgy does not

have a high profile, may not have had experience of its usefulness or otherwise. That being said, 58 (45.8%) did rate use of a standard liturgy as helpful or very helpful.

Although there are denominational differences in the use of formalised liturgy, a set order in worship is a feature of all the denominations investigated. Members of particular denominations may, therefore, be very familiar with a particular order of worship, even if they are in a denomination which does not use standardised liturgy routinely. These responses indicate that this familiarity with the order of worship is a helpful element for confused elderly people.

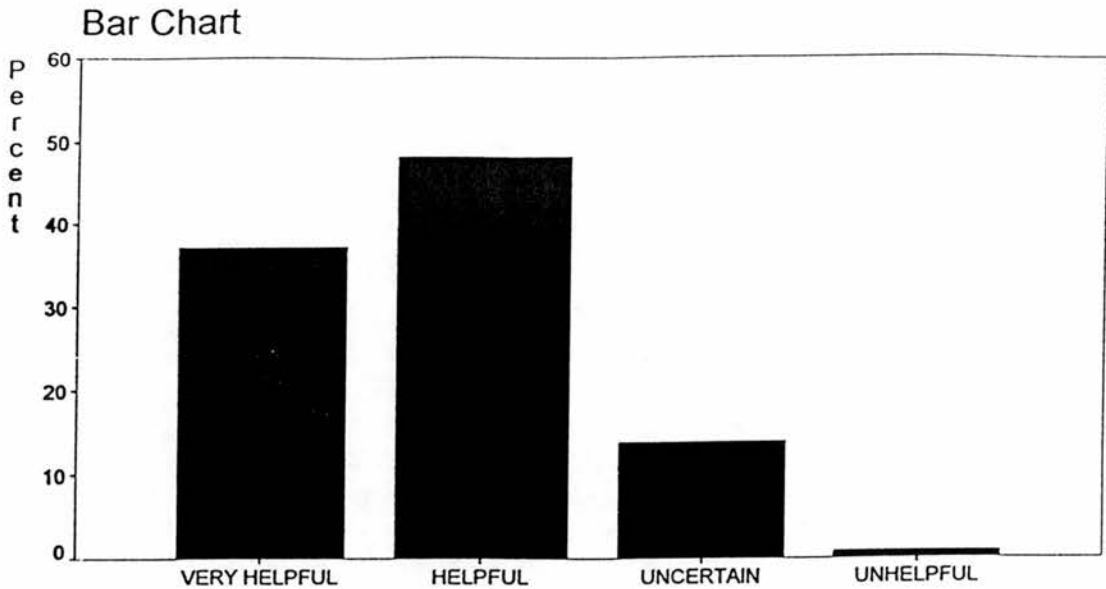
The pastors' experience of the helpfulness of a standardised order of worship raises the possibility that it may be useful for those who share in worship on a rota basis, in residential and nursing homes, to adopt a standard order where possible.

2. Sacraments [3:11] p.457, and [3:12] p.458

In all of the denominations surveyed Holy Communion is recognised, and is a situation in which there is a high level of familiarity, repetition, and routine. The over-whelming opinion in the literature was that it is a powerful means of pastoral care and communication (Peters 1987). This experience was ratified by the respondents in this study, [3:11] p.457, 99 of them (79.9%) rating Holy Communion as a helpful, or very helpful, element of public worship with confused elderly people. (Figure 6.14). It is worth noting that only 1 respondent (0.8%) had a negative view, seeing Holy Communion as unhelpful with this group. This very positive view may be

indicative of an underlying theological opinion which does not exclude people with dementia from participation in this sacrament. This is an issue which was examined in the literature review (Chapter 4) and which will be investigated further in the in-depth interviews (Stage 5).

Figure 6.14: The respondents' rating of the variable "Holy Communion" as a helpful element in worship with confused elderly people [3:11] p.457.



The helpfulness of other sacraments was also investigated [3:12] p458. Here again denominational differences are a factor in the interpretation of the results. This variable is most applicable to the Roman Catholic respondents. That this was indeed the case was reflected both in the high level of "uncertain" responses, 52 pastors (41.9%) responding in this way, and in the low level of negatives replies, only 9 people (7.3%) rating "other sacraments" as unhelpful or very unhelpful. However, 34 pastors (27.4%) did rate them as helpful or very helpful. This is a topic which

warrants detailed exploration with the Roman Catholic interviewees in the next stage of the research.

3. The Lord's Prayer [3:5] p.454

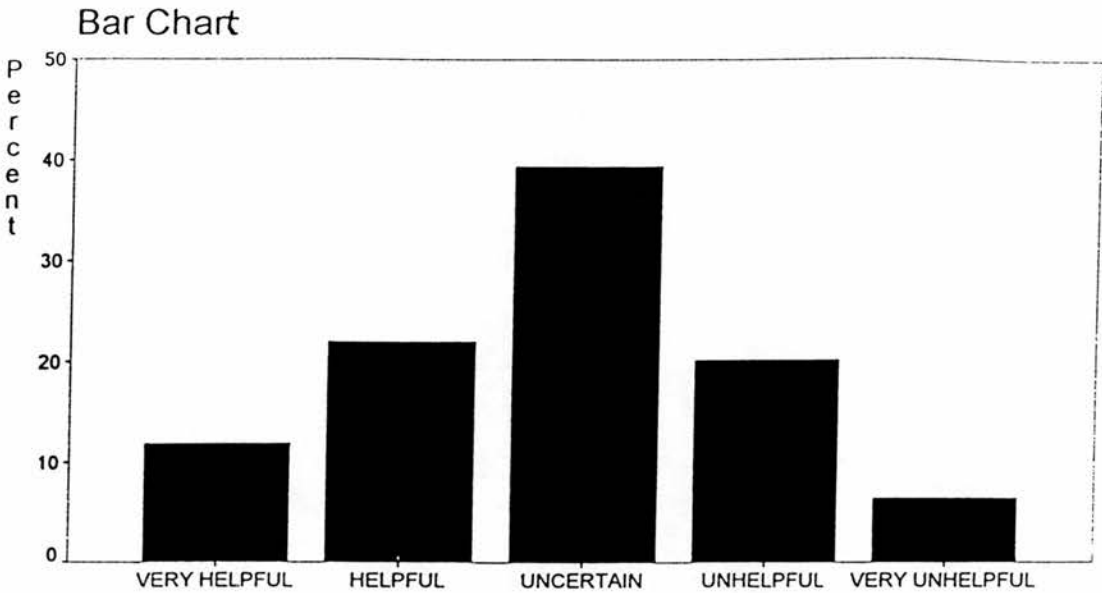
Responses to the helpfulness of the Lord's Prayer are included at this point as it too, could be regarded as a liturgical aspect of worship. As such it is familiar, perhaps even over-learned, thus, the literature (Bayles 1984) would suggest that it should be a helpful element in worship. Experiential evidence presented in the literature supports this assumption (Clayton 1991). In this study none of the pastors had experienced inclusion of the Lord's Prayer to be an unhelpful element in worship with confused elderly people. On the contrary 112 (90.3%) rated it as helpful, or very helpful. There is therefore a high level of consistency on this issue between the findings presented in the literature and the findings emerging from this study.

4. Sharing the Peace [3:7] p.455

This variable is noteworthy in that it resulted in an almost equal spread of opinion across the categories. This is illustrated in Figure 6.15. There is a slight balance towards its being a helpful element but it is far from being conclusive. This is interesting in that in the literature on worship, in particular Peters (1987), it is seen as a very helpful and meaningful aspect of worship with this group. This inconsistency may, in part, be explained by denominational differences. In Peter's (1987) study, the sharing the peace was a familiar element of worship for the confused elderly participants. Being familiar, and accompanied by stereotypical gestures of

hand-shaking it was meaningful in that context. In some denominations however, the sharing of the peace may not be a familiar feature, it may therefore be a source of anxiety, rather than comfort for confused elderly people.

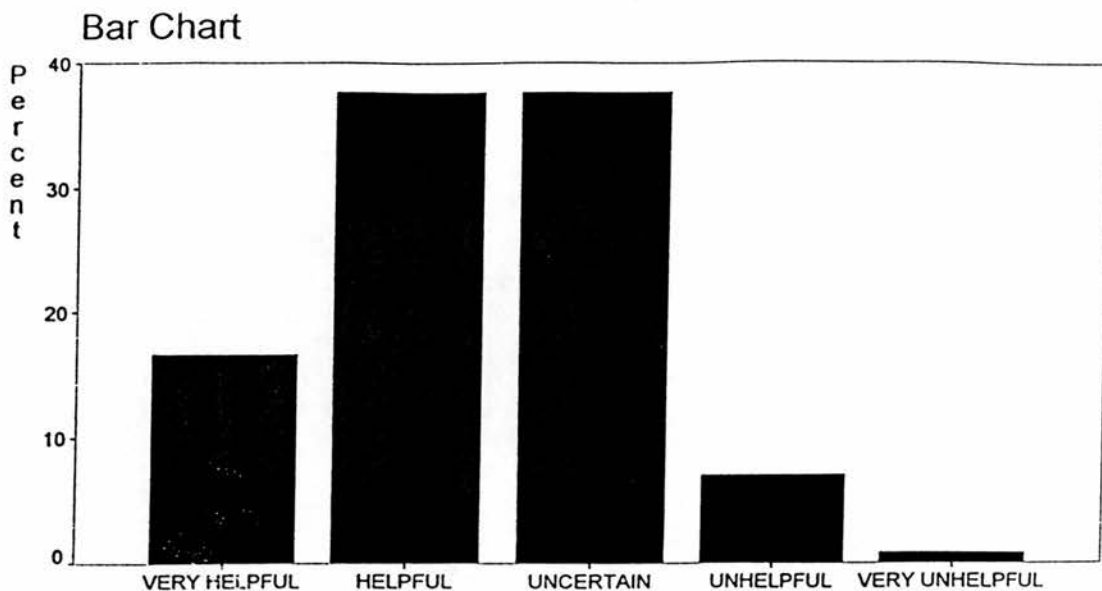
Figure 6.15: The respondents' rating of the variable "Sharing the peace" as a helpful component of worship with confused elderly people. [3:7] p.455



5. Use of One Version of the Bible [3:10] p.457

A further aspect of familiarity and consistency was explored when pastors were asked whether or not they found it helpful to use one version of the Bible [3:10] p.457. Of those who responded 62 (50%) reflected that they had found this helpful. This finding is illustrated in Figure 6.16.

Figure 6.16: The respondents' rating of the variable "Using one version of the Bible consistently" as a helpful element of worship with confused elderly people. [3:10] p.457



With hindsight, it would have been interesting to ask for the pastors' opinions on the helpfulness of particular versions of the Bible. To examine, for example, if they had found the Authorised Version with its familiarity to be more helpful than the clearer modern language of the more recent versions. This variable will be isolated, where it occurs in the in-depth interviews (Stage 5).

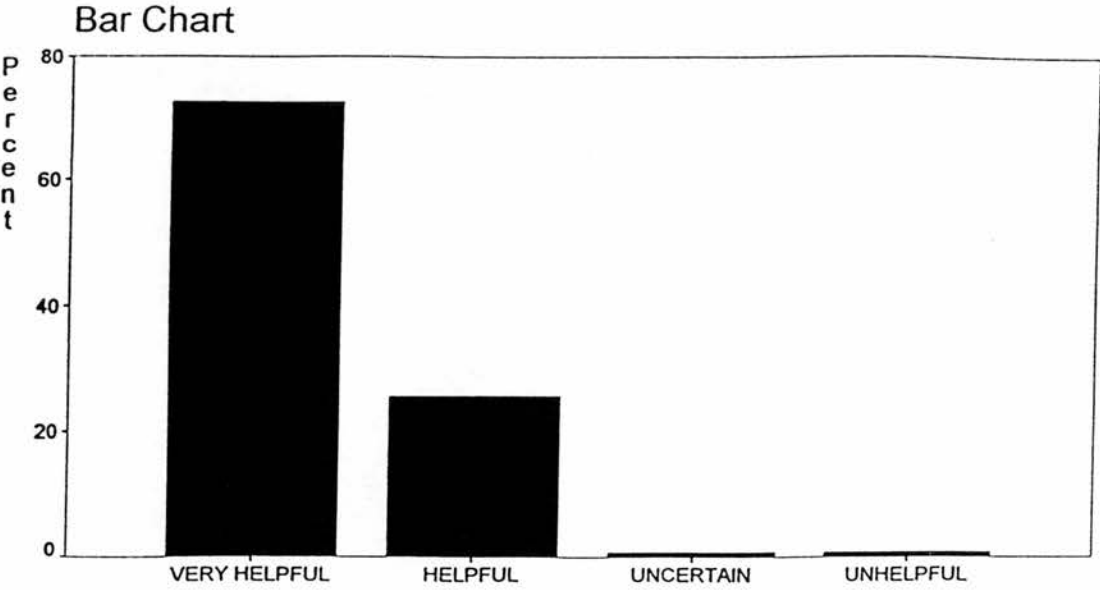
The other feature of the response to this variable, which the Figure (6.16) makes obvious is the high level of uncertainty, 43 respondents (34.7%) registering this response. A number of reasons could be postulated to explain this finding. Among them is the possibility that pastors had not seen the choice of Bible version as

a significant feature of pastoral communication with this group, and therefore felt unable to comment, because they had not isolated it in their own minds.

6. Familiar Hymns and Bible Readings [3:1] and [3:2] p.453

The positive response to the inclusion of familiar hymns in public worship, [3:1] p.453, with confused elderly people was overwhelming, 83 (66.9%) rating them as very helpful and 29 (23.4%) regarding them as helpful. This corresponds with the findings in the literature review both with regard to music as pastoral communication (Chapter 4) and specifically, with research findings on hymns in worship. (Shamey 1993, Clark 1993, Goodall 1996). The response to this variable is illustrated in Figure 6.17.

Figure 6.17: The respondents' rating of the variable "singing familiar hymns" as a helpful element of public worship with confused elderly people. [3:1] p.453

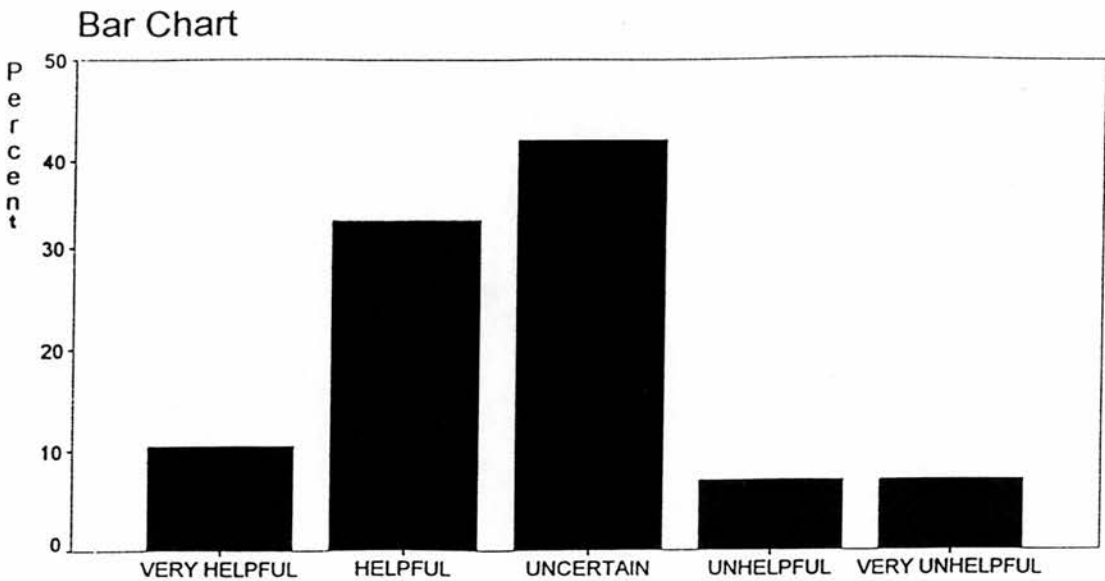


The emerging hypothesis that familiarity enhances the helpfulness of elements of public worship with this group is supported by the response to the variable "familiar Bible readings" [3:2] p.453. These were also rated positively, 99 pastors (79.8 %) assessing them as helpful, or very helpful, in their experience.

7. Extempore Prayer [3:4] p.454

There was a broad spread of opinion with regard to the helpfulness of extempore prayer in worship with confused elderly people. This is evidenced by Figure 6.18. A rating of helpful, or very helpful, was recorded by 40 (29.9%) of the respondents. Of the remainder, 43 (34.7%) were uncertain as to its helpfulness, and 29 (23.3%) rated extempore prayer as an unhelpful, or very unhelpful, element of public worship with this group.

Figure 6.18: The respondents' rating of the variable "Extempore prayer" as a helpful element of worship with confused elderly people. [3:4] p.454



A number of the reasons cited as possible explanations in other situations may also apply in this case. Extempore prayer is, by definition, unstructured. It may contain stereotypical phrases, and be accompanied by stereotypical posture, but it does not have the familiarity of the Lord's prayer, or other liturgical prayer. Furthermore, extempore prayer may well rely, for its structure and form, on the ability to follow an argument or line of reasoning - skills which may no longer be available to the confused elderly person. Thus the lack of support for this extempore prayer is not surprising, given its nature.

8. Sermon or Homily [3:3] p.454

Traditionally, the sermon or homily has had a central place in services of worship, both theologically and practically. Given this fact, it is interesting to find that 48 of the respondents (38.7%) rated a sermon or homily as an unhelpful, or very unhelpful, element of worship with confused elderly people, [3:3] p.454. This may reflect an openness on behalf of pastors to the realisation that all traditional approaches may not be applicable to this population and a willingness to experiment, even to the extent of omitting what is traditionally a central element of worship.

The response to this variable again reflects that pastors may, instinctively, be picking up on the needs, the strengths and the weaknesses of the person with dementia. Being highly verbal, often long and containing a complex progression of ideas, many researchers (Shamey 1993), would claim that a sermon is difficult for the confused elderly person to follow and understand.

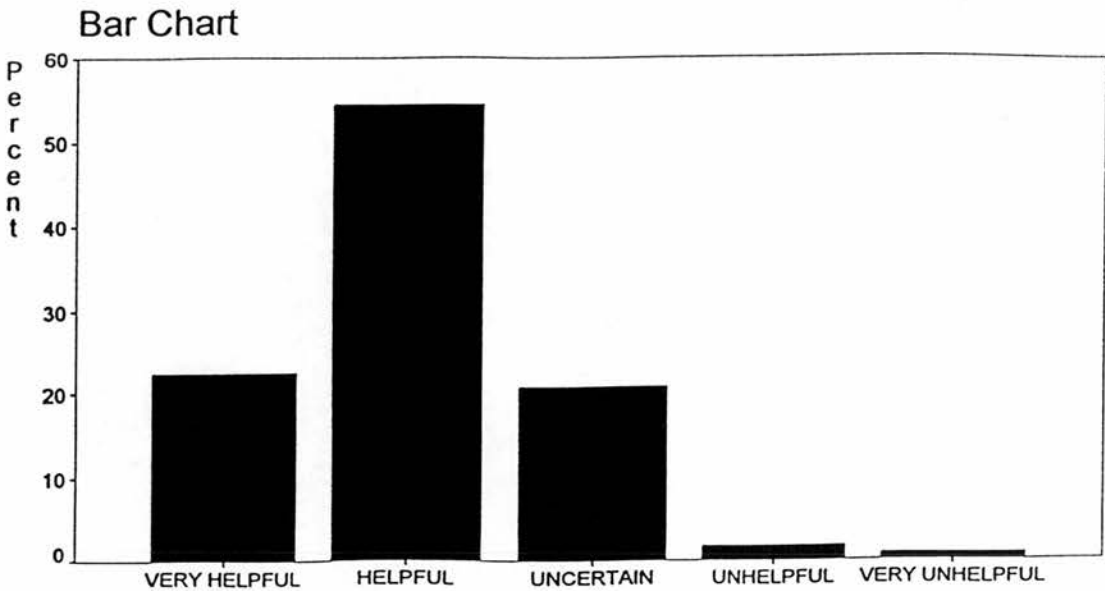
9. Times of Silence [3:6] p.455

The balance of opinion on the helpfulness of times of silence in public worship with confused elderly people [3:6] p.455, was evenly split. Uncertainty as to the value of silence was reported by 48 respondents (38.7%), 30 pastors (24.2%) had experienced it to be helpful, or very helpful, and 35 (28.2%) felt that it was unhelpful, or very unhelpful.

10. Symbols , Visual Aids and Drama [3:15], [3:14] p.459 and [3:13] p.458

Despite the spread of denominations, which could reflect differences in attitudes to and the use of symbols in worship, this variable evoked a positive response, 86 respondents (69.4%) rating the use of symbols in public worship as helpful, or very helpful. This finding is presented in Figure 6.19.

Figure 6.19: Respondents' rating of the variable "symbols" as a helpful component in public worship with confused elderly people [3:15] p.459.



Visual aids [3:14] p.459 share the common ground with symbols, of being concrete. Their significant difference is that, in some cases, they do not have the familiarity which some symbols have. This may contribute to the pastors rating them as less helpful than symbols in public worship. When asked to rate the helpfulness of visual aids in public worship with confused elderly people, 63 respondents (50.8%) registered agreement, or strong agreement.

Drama in worship, [3:13] p.458, was not so highly rated. This may be partly due to the fact that it may not be a widely accepted element of worship in any context. Thus pastors may not have experimented with it in public worship with confused elderly people. That this is indeed the case may be reflected in the finding that 47.6% of the sample (n=124) were uncertain as to the helpfulness of drama as an element of public worship with confused elderly people. Of the remainder, 19 pastors (15.3%) rated drama as helpful, or very helpful and 29 (23.4%), as unhelpful, or very unhelpful.

11. Additional Comments made by the Respondents [3:16] p.460.

As well as rating the variables in this section, the respondents were asked to respond to an open question. They were given the opportunity to list other elements of public worship which they had found to be helpful with this population.

A large number and wide range of additional comments were made, 30 comments being recorded. This may reflect the respondents' level of interest in this

area. The most frequent comment concerned the participation of young people and children in worship with confused elderly people (n=6). In particular, 2 of the respondents mentioned that they had encouraged young people from their congregations to attend these services and that this had been helpful, not only for the confused elderly people, but for the young people as well. An additional comment was made by 2 respondents who had found participation of others in general to be helpful in worship in this context.

The importance of music was mentioned by 5 respondents. Others (n=2) had found it helpful to encourage participation from the elderly people, 1 had found reminiscence to be helpful, another respondent emphasised laughter, another the wearing of a clerical collar.

A number of comments (n=7) emphasised the use of different senses; 2 of the respondents proposed utilising the confused person's sense of smell, and others suggested making use of sight, through memory aids (n=2), pictures (n=1) and videos (n=1). Touch was suggested by 1 pastor. The significance of rosary beads, which combine use of the senses with symbolism and familiarity was mentioned by 1 respondent.

The value inherent in being part of a "normal" congregation was noted by 1 participant, 1 recommended hand clapping, another mentioned simple worship, and another the importance of a good atmosphere at worship.

Summarising this section, therefore, it appears that in the respondents' experience, familiarity is an important factor in enhancing the meaningfulness of public worship with confused elderly people. Familiarity applied both to the elements of worship, hymns for example, and the symbolic aspects of worship, like Holy Communion.

So far, two other significant features of the results have become apparent. These are a high level of uncertainty registered in response to a number of the variables, and a high level of agreement with the research findings as presented in the literature review (Chapters 1-4).

It appears almost paradoxical that these two features should exist side by side. This unusual juxtapositioning could reflect insecurity and lack of confidence in their practice, in general, on the part of the respondents. It could, on the other hand, be indicative of the fact that pastors are secure in many areas of their pastoral practice and expertise, and in the context of that confidence are ready to admit uncertainty in this particular area. If this were indeed the case it would strongly support the need for further training in pastoral communication with confused elderly people, both in colleges and in service.

Pastoral Care of Confused Elderly People

In this section (Section Four) of the questionnaire, statements were made concerning issues surrounding the provision of pastoral care to confused elderly people. The respondents were asked to rate statements on Lickert scales ranged from strongly agree (1) to strongly disagree (5).

Through examination of the responses to these statements it was hoped that insight might be gained into the pastors' general experience of offering pastoral care to confused elderly people. Here again, the theme of the inter-relationship between theology and practice recurs, for as patterns of pastoral care emerge, there may be indications of understandings of practical theology which could be explored in the in-depth interviews with pastors (Stage 5).

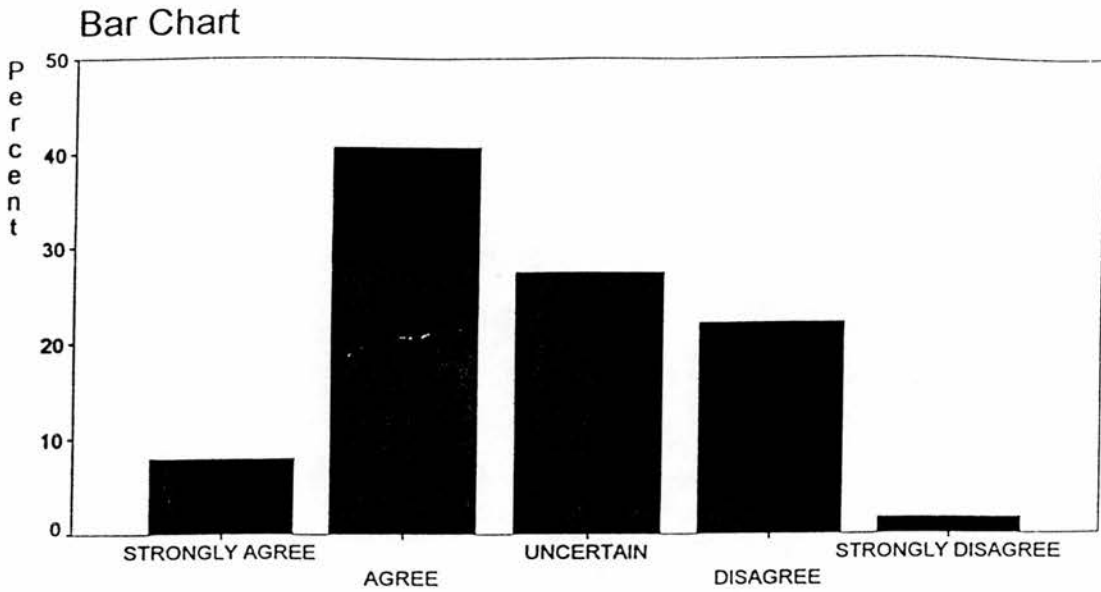
The results from this section will be presented under the headings of:

1. the pastors' experience of the pastoral care of confused elderly people
2. the content of the pastoral encounter

1. The Pastors' Experience of the Pastoral Care of Confused Elderly People

When asked to rate the statement "Pastoral care of confused elderly people is a priority for me", [4:1] p.461, 55 of the respondents (44.4%) agreed, or strongly agreed, 31 (25%) reported themselves to be uncertain, and 27 (21.8%) registered disagreement, or strong disagreement. This result is presented in Figure 6.20.

Figure 6.20: The pastors' response to the variable: " Pastoral care of confused elderly people is a priority for me" [4:1]p.461.



Prioritisation of pastoral tasks is an issue that is raised, both in the in-depth interviews, (Stage 5, described in Chapter 7) and in the Discussion (Chapter 9). Many factors can impinge on whether or not a particular group is regarded as a priority by a pastor. These include the demographic features of his or her congregation or parish, the pressures put upon the pastor be they real or imagined, by his or her congregation and by central Church authorities, as well as the pastor's own theology of ministry. In the light of this diversity of influencing factors it is hardly surprising that a range of opinions was elicited by this variable.

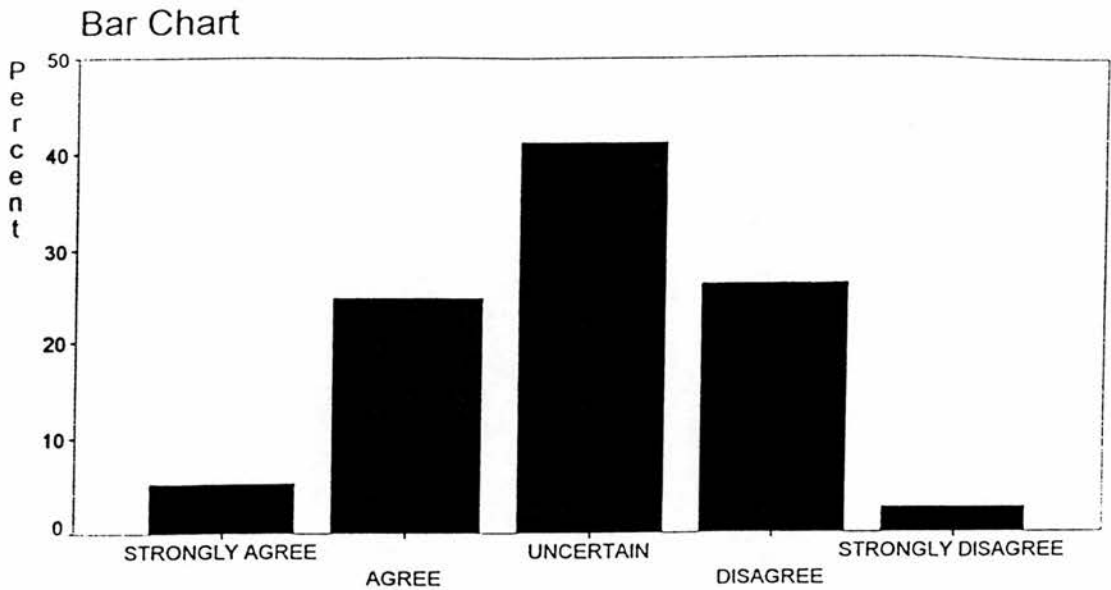
When asked to respond to the statement, "At times I put off visiting confused elderly people", [4:13] p.467, 41 pastors (33%) agreed, or strongly agreed, while 53 (42.7%) registered disagreement, or strong disagreement. Responses to the variable

"I generally delegate the pastoral care of confused elderly people to others", [4:12] p.466, showed a higher level of conformity. Of those who responded to this statement, 100 (80.6%) disagreed, or strongly disagreed. There must however, be a degree of caution in interpreting this result as support for the contention that pastors are not ignoring this group. Disagreement with delegation may reflect the fact that the pastor has no one to delegate to, rather than an active desire to personally undertake this aspect of his or her work. All that being said, these results should be interpreted in the light of the finding presented earlier that 79.8% (n=124) of the respondents estimate that they spend some time every week with confused elderly people [1:1] p.432. This indicates that, whether or not it is rated as a priority, pastoral care of confused elderly people is a task on which pastors are spending time.

Pastoral care of confused elderly people cannot be claimed to be a universal priority for these pastors, and yet it is still being undertaken. This finding puts an exploration of motives for pastoral care into context. Statements were included which sought to explore this topic. The potential motives included were enjoyment, duty and change.

The response to the variable, "I enjoy visiting confused elderly people" [4:11] p.466, is shown in Figure 6.21. This illustrates that opinion almost exactly split on this issue. Uncertainty was reported by 47 of the respondents (37.9%), of the remainder 34 (27.4%) responded that they agreed, or strongly agreed, and 33 (26.6%) disagreed, or strongly disagreed.

Figure 6.21: The pastors' response to the variable: "I enjoy visiting confused elderly people". [4:11] p.466.

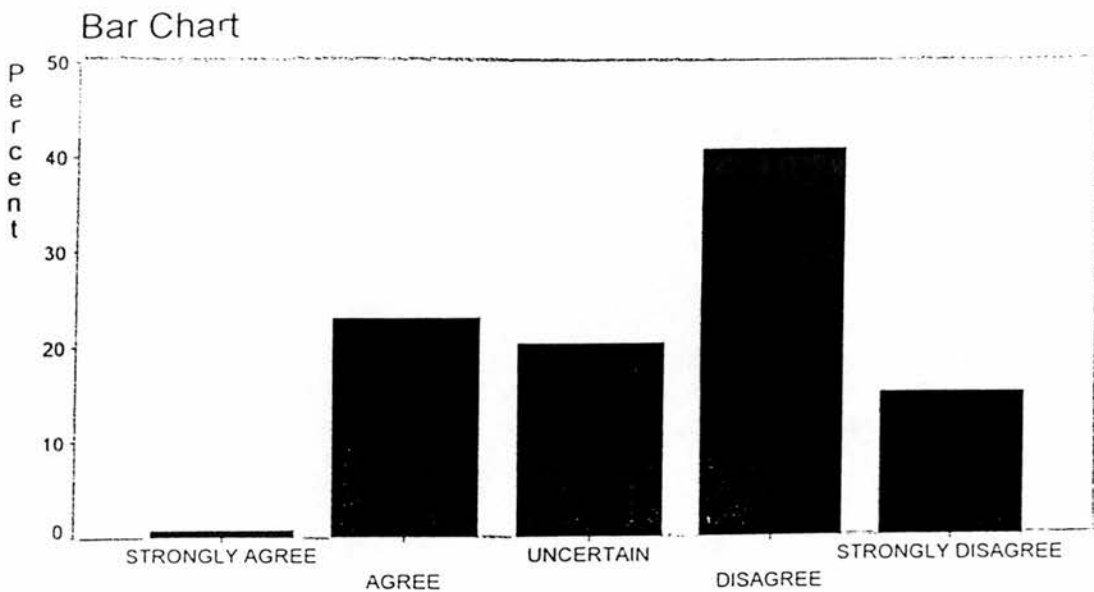


There was thus ambivalence surrounding the issue of enjoyment with regard to motivation for pastoral care. It can hardly be without significance that, again, with regard to the variable of enjoyment, there is a high level of uncertainty. This variable is slightly different in character to many of the others already examined. It does not rely on expertise, therefore the suggestions that uncertainty reflected a degree of insecurity in pastoral practice do not apply in this case. It is possible that pastors have not thought about enjoyment with regard to pastoral practice. This, however, seems an unlikely possibility, due to the amount of time which pastors devote to this activity. Perhaps some pastors are reluctant to register enjoyment in connection with the tragedy and devastation of dementia.

The next issue to be examined was whether or not duty was the primary motivator. The results, while indicating that duty is a motivational factor for some,

are not conclusive. When asked to rate their level of agreement or disagreement with the statement, " I visit confused elderly people out of a sense of duty", [4:9] p.465, 27 (21.8%) of the respondents agreed, or strongly agreed; however 46 (37.1%) disagreed and 17 (13.7%) registered strong disagreement. This result is presented in Figure 6.22.

Figure 6.22: The pastors' response to the variable: "I visit confused elderly people out of a sense of duty" [4:9] p.465.



In order to explore the topic of motivation further, it was decided to investigate if, and how, these two variables related to one another. Was the pastors' primary motivation for pastoral care of this group neither enjoyment, nor duty, but some other factor? Or were these results reflecting the presence of two different groups, one of which found motivation in enjoying the visits, and the other in duty.

A crosstabulation of the results was undertaken. The resulting table is reproduced below as Table 6.3. The results support the hypothesis of the presence of two groups. These two variables appear to exclude each other, pastors either enjoyed this aspect of their work or undertook it out of a sense of duty, rarely both.

Table 6.3: Crosstabulation between the variables, "I visit confused elderly people out of a sense of duty", and "I enjoy visiting confused elderly people" [4:9], and [4:11].

Page 1 of 1

Count	SENSDUTY					Row Total
	STRONGLY AGREE 1	AGREE 2	UNCERTAIN 3	DISAGREE 4	STRONGLY DISAGREE 5	
ENJOYVIS						
1 STRONGLY AGREE			1	1	4	6 5.4
2 AGREE		3	2	13	9	27 24.1
3 UNCERTAIN		6	16	22	2	46 41.1
4 DISAGREE	1	15	4	9	1	30 26.8
5 STRONGLY DISAGREE		2			1	3 2.7
Column Total	1	26	23	45	17	112
	.9	23.2	20.5	40.2	15.2	100.0
----- Chi-Square -----		----- Value -----		----- DF -----	----- Significance -----	
Pearson		55.04482		16	.00000	
Likelihood Ratio		52.33653		16	.00001	

The third potential motivating factor for pastoral care with confused elderly people, which was included, was change. In order to explore this, respondents were

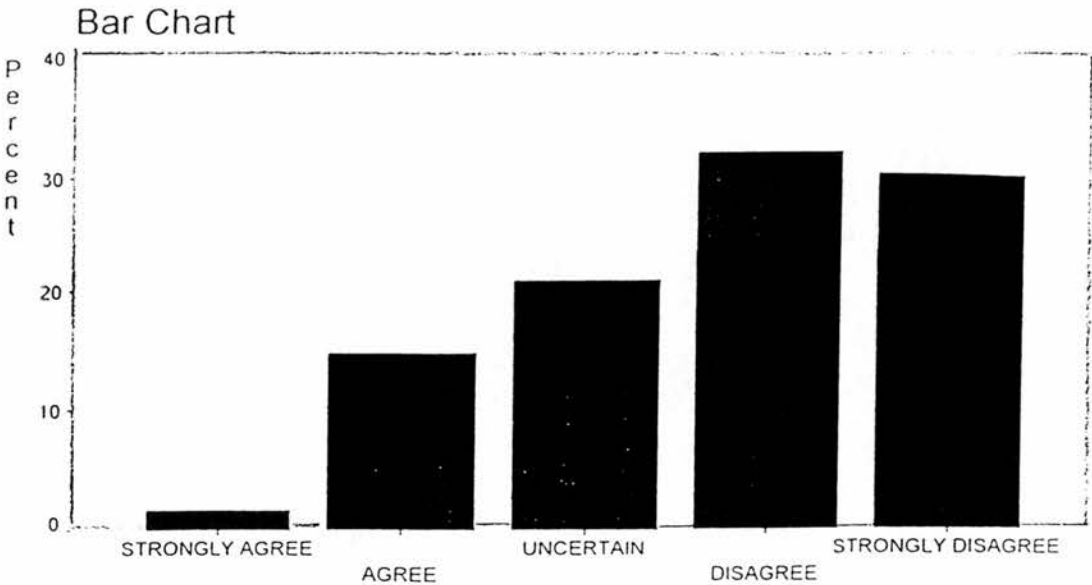
asked to rate their level of agreement with the statement, "I often feel that pastoral visits make no difference to confused elderly people" [4:10] p.465. Disagreement, or strong disagreement was reported by 66 of the respondents (53.2%). Thus it can be claimed that approximately half of the pastors in the sample believe that their pastoral care of confused elderly people, brings about change. In the literature review (Chapter 4), when the literature on motivating factors for pastoral care was reviewed, it emerged that change is a feature of a number of paradigms. It may well be, therefore, that if pastors have seen evidence of change that this may be motivating them.

2. The Content of the Pastoral Encounter

The first aspect of content of the pastoral encounter to be reported is verbal communication, 70 of the respondents (56.4%) reported that they found it difficult to know what to say to the confused elderly person. [4:2] p.461. Combined with this result was the finding that 59 (47.8%) disagreed, or strongly disagreed, with the statement, " I find it easy to make confused elderly people understand me" [4:15] p.468. In addition 51 (41.12%) of the respondents registered some level of agreement with the statement, " I find it difficult to assess the level of people's confusion" [4:17] p.469. These three results indicate that pastors have experienced the difficulties inherent in communicating with confused elderly people, difficulties which encompass both expressive and receptive aspects of communication.

Despite these difficulties, the results indicate that in these pastors' experience, there is spiritual or religious potential in the pastoral encounter. This claim is made on the following grounds, 73.4% (n=124) of the pastors disagreed, or strongly disagreed, with the statement: "It is difficult to have any meaningful religious element in a visit with confused elderly people" [4:5] p.463. Also 58% (n=124) of the respondents disagreed, or strongly disagreed, with the statement: "I find it difficult to be sure that confused elderly people can be assured of the love of God", [4:14] p.467. The response to this variable is illustrated in Figure 6.23.

Figure 6.23: Showing pastors' response to the variable: " I find it difficult to be sure that confused elderly people can be assured of the love of God" [4:14] p.467.



The pastors' experience of the communication difficulties which results from dementia, combined with the assertion that confused elderly people can be assured of

the love of God, begs the questions, "How do pastors know or assess that meaningful pastoral communication has taken place?", "How do they know that the individual with dementia is, or is not assured of the love of God?". This issue will be explored in the in-depth interviews (Stage 5).

A further indication of the pastors' experience that confused elderly people do have spiritual needs is gained from an examination of responses to the statement, "I am surprised when confused elderly people express anger with God" [4:6] p.463. In response to this variable 104 (83.8%) of the respondents registered disagreement, or strong disagreement, in response to this variable.

In Stage 3 of this research, during structured interviews with the multi-disciplinary group of people who had on-going contact with confused elderly people, some interviewees reported that their perception was that pastors were embarrassed at times by the reaction of people with dementia. This perception is not supported by the pastors' response to the statement " At times I am embarrassed by what confused elderly people say or do" [4:3] p.462. No-one registered strong agreement with this statement and 73.3% (n=124) of the sample disagreed, or strongly disagreed.

The results from this section indicate that pastors' experience is that one-to-one visiting with confused elderly people, despite the inherent communication difficulties, is a means through which God may choose to work. One implication

which may be drawn from this finding is that pastors would appreciate skills which might help them to cope with the explicit communication difficulties.

The last area which was briefly appraised in this section was the issue of the carers of confused elderly people. It has been asserted elsewhere in this study that, while recognising the devastating effect of dementia on the carers, and their real pastoral needs, the focus of this research is deliberately on the individual who is confused. However, statements were placed in this section which related to the family. This was necessary to assess whether or not pastors felt that systems pastoral care (as developed by E.M. Pattison 1972), was the most appropriate response to the pastoral needs of the confused elderly person. According to this model, the pastor involves him or herself in the social system, by, for example, focusing his or her energy and attention on the carer, hoping that by so doing the welfare of the individual with dementia would be indirectly improved.

The pastors were asked to rate the statement " I find that the most effective way of caring for confused elderly people is to support the carer(s)", [4:7] p.464, 60.4 % (n=124) of respondents agreed, or strongly agreed, with this assertion. There are therefore strong indications that a systems approach is the pastoral response of a number of these pastors.

Additional Comments

Having completed the questionnaire, the respondents were given the opportunity to make comments about the pastoral care of confused elderly people, [5:4] p.472. It has already been pointed out that of the 46 comments which were made at this point, the largest proportion, 10 (21.7%), concerned training.

The needs of carers were mentioned by 6 of the respondents in this section (13%, n=46); and 1 person, in particular, told of his experience of a relative being embarrassed by the behaviour of the confused elderly person, and becoming increasingly isolated as a result. In addition 3 pastors noted that they, themselves, had personal experience of the impact of dementia in that members of their families were affected by the condition.

Comments related to the pastoral care of confused elderly people were made by 13 of the respondents. Of these, 3 mentioned their positive experience of the work of lay visitors. Positive experiences of worship were noted by 3 pastors, 2 of whom wrote of small groups worshipping in Residential Homes, and 1 of Holy Communion in the elderly person's own home. That confused elderly people can be reassured and reminded of the love of God, was asserted by 1 respondent. With regard to practical hints on enhancing communication, 2 respondents wrote of experiences in which the person with dementia had been enabled to recognise the pastors by feeling or touching their clerical collar. Another noted the potential of music, as a means of

communication, and 1 pastor wrote that she found that chocolate broke down barriers!

Aspects related to the underlying nature of pastoral care with confused elderly people were raised by 9 of the respondents. Of these, 4 wrote that pastoral care of confused elderly people was deeply rewarding for them, and 3 responded that, in their understanding, the nature of the pastoral task with people with dementia was to "be beside them" - this is perhaps an indication of companionship as a motive for pastoral care (see Chapter 4). There were other indications that pastoral practice was prompting reflection, 2 respondents wrote that their experience with confused elderly people had led them to reflect on the nature of the pastoral relationship.

Euthanasia was mentioned by 1 respondent, who wrote that his experience with confused elderly people had raised the issue in his mind. Political dimensions were noted by 3 pastors, 1 advocating the provision of more respite care, and 2 telling of their experience of lack of provision for confused elderly people, with regard to Nursing and Residential Home care.

In this chapter, the results arising from the questionnaire (Stage 4) have been described. Two of the predominant features of those results are, their level of agreement with the research findings as described in the literature review, and the

level of uncertainty registered in response to a number of the variables. Possible reasons for these findings were noted in the text.

The findings from the questionnaire will be fed directly into the in-depth interviews (Stage 5), in which there will be an opportunity to explore the reasons underlying the research findings to date.

CHAPTER SEVEN
INTERVIEW ANALYSIS

INTERVIEW ANALYSIS

Introduction

One of the guiding principles of this research is that theoretical concepts are related closely to practice. This principle arose from the recognition of the dynamic relationship between theory and practice. It was further hoped that the implementation of this approach to research would foster the development of a method of pastoral communication which not only had a sound basis in theory, but was useful in practice. In accordance with this model, the research design demanded that theoretical findings were continually fed back, and correlated with practice.

Stage 4 of the research involved sending a questionnaire to all of the Roman Catholic (n=21), Church of Scotland (n=84), Episcopalian (n=47), and Methodist (n=4) clergy in Edinburgh. An interview schedule was constructed based on the statistical analysis of this data. The interview was designed to elicit additional, explanatory, in-depth and anecdotal information which the questionnaire, by its nature, could not produce. The interview also allowed feedback and reflection from pastors on the results which had already emerged.

Eleven interviews were carried out, each of which was taped and manually transcribed and analysed. The transcriptions are an accurate reflection of the interviews which took place. As such, they portray the spoken rather than the written

word. The pastors who participated in these in-depth interviews were promised that their identities would not be revealed. In accordance with this promise the letters used to refer to the interviewees are not the initials of their real names. In this chapter the aim is to describe the major themes which arose in those interviews.

When the method underlying this research was described it was recounted that two groups of pastors were chosen for in-depth interviews. Members of the first group (n=5) were selected because they had shown particular interest in pastoral communication with confused elderly people. The second group (n=6) were selected more randomly. When the interviews were analysed there were no discernible differences between the groups; group membership, therefore, will not be included as a factor in this interview analysis.

Theological Perspectives

The experience of the devastating changes which dementia can bring to the individual on every level, may raise significant theological questions for pastors and carers, and indeed for the individual themselves in the early stages of the condition. The literature on a number of these theological issues has been reviewed (Chapter 3). In the in-depth interviews, many of the pastors were asked about the theological issues which pastoral care of confused elderly people raises for them. Predominant among the theological areas raised were personhood, the nature of the individual and

suffering. The pastors' experiential evidence on these issues is presented in this section.

1. Personhood

The response to questions on personhood, along with the frequency with which participants referred to this topic spontaneously, indicated that this was a major issue in the pastors' thinking and understanding. Two pastors mentioned that the topic of personhood had been raised for them when relatives mentioned the intellectual and personality changes evident in their loved one. K.L. commented:

"There is a real theological issue about when death happens. People are always saying "That's not my mother", they have some perception that death has happened and yet" (KL:30) "I have fairly orthodox views about death and resurrection and so I find it hard when they want me to affirm that this person has in any sense, entered into glory." (KL:31)

Q.R. spoke of similar experiences:

"suffering is caused to the people who know them and who feel that they have lost them" (QR:70),(QR:71) "and that they are left with what appears to be the physical shell but the person they knew is no longer there." (QR:74)

In his approach to pastoral care M.N. said that he was helped by having a different view of the personhood of the individual with dementia:

"I do feel quite strongly that when I go to visit folk who are severely confused that to a large extent, it isn't the person, because the person is just slowly draining away and the body is still ticking. Now that is maybe a wrong picture, but it's a helpful picture for me as I am ministering." (MN:16)

This quotation illustrates the difficulty with which many of the pastors appeared to be grappling. That is, the holding together of the intellectual, theological assertion of the objective value and retained personhood of the individual with dementia alongside the pastoral experience, coming to them directly and through the comments of carers, of a life radically changed by the condition.

The importance which U.V. placed on the retained personhood of the person with dementia was evident in many of her comments about her grandmother who had become confused. For example, she told of a situation in one nursing home where her Granny was told that she had to wear a hospital gown because of her incontinence:

"she doesn't want to be told that she has to wear something, like a hospital gown, just because its convenient. They say "Well, we've got to look after her" and I thought the whole thing is, do we look after her as an animal or as a person. I hate it when people say something like "You know she's been awfully confused today", it's as if the person is not a person and that is so difficult." (UV:94)

In the interviews, there was a strong and consistent affirmation of the worth of the confused elderly individual. This is illustrated by the following quotation from K.L.:

"I would want to set it in the context of a conviction that I have here ...about the place of confused people being absolutely certain in terms of the Gospel and of the death and resurrection of Jesus and of belonging in the body of Christ; in no sense do we belong to God in terms of our abilities or our capacities." (KL:34)

M.N. makes a similar point and links his belief in God's view of the worth of the person with pastoral care:

"I always find it difficult in those kind of situations [trying to communicate with a very confused elderly person] because there is this thing

of, "how much are people actually taking in?" but God loves people of whatever shape or form and it is His work and if He wants to get through, He'll get through and you have to trust in that." (MN:6)

On the same topic, C.D. made the following comments:

"I feel that it is so important to treat people as people, and I've been so surprised, many a time, by some old folk who are really out of touch and yet you hear about what they did, and you realise all these people are individuals with a long history and story of their own, and I try to respect them on that basis." (CD:3)

No matter what one's view of the personhood of the individual, there was unanimous agreement that the person is always valuable in the sight of God and that nothing can remove them from His love. Q.R.'s comments make this clear:

"In the eyes of society this person may be a cabbage, but in God's eyes they are not. They are still somebody who has value because our value doesn't depend on our own ability." (QR:78)

Even if it is argued that dementia results in a diminishment of personhood, these pastors consistently asserted that it does not result in a diminishment of the person's worth in the sight of God, nor should the person's dignity be undermined. I.J. comments:

"I don't think I can say, "So you have cancer, so I'm not talking to you" - I think they have a human dignity which has to be observed." (IJ:6)

At a later point he followed his assertion up with an example which illustrates the way in which, through sensitive pastoral care and the sacraments, the dignity of a person with dementia was maintained. Speaking of Confession he said:

"For someone who is confused and has got this niggle at the back of their mind, again I think too in terms of older people who would be very aware of the Catholic Doctrine of dying in mortal sin condemning them to hell, it could be very, very difficult. So, if I have got someone like that, I think

I would have to take that very seriously. I would say "That is OK." and I would hear their Confession, and I mean it may be a total jumble sort of thing, but I need to try and let them have the experience of removing this thing, the experience of Confession." (IJ:21)

Valuing the person appears to be a pre-requisite to taking them seriously, a theme which also recurred in the interviews. C.D. said:

"I found in one to one conversations that if I could try to suspend the whole business of time and space, and listen to them and talk myself into what they're coming at, and in that way, I found we got into a conversation which became very interesting, although it wasn't directly related to here and now." (CD:2) "It's this whole business of taking them, of taking what they are saying seriously and not imposing upon them what appears to be sensible now. I mean if they think they are back in 1928 with their mother, obviously that doesn't relate to now, but if you go back with them to there, there's a whole lot of things which all fit into place." (CD:22)

Thus for C.D., valuing the individual because they are of value to God, and taking the person seriously, opened up the possibility of meaningful interaction. U.V. picked up the same theme when speaking of her grandmother. She told of how her grandmother was unwilling to undress while the television was on in her room, because she believed that the people on television would be watching her. U.V.'s response was so take her grandmother's concern seriously:

"Well, I said, "Well Gran, I'm younger than you, he'll be watching me" and fine, you just address the problems as they come along. If you say "Don't be silly" then that can get aggressive." (UV:40)

In summary, the theological issue of personhood with regard to confused elderly people was raised for the pastors, by the experience of offering pastoral care. There were some differences in theological conclusions, but the over-riding theological and pastoral response was affirmation of the person's worth and value in

the sight of God. This affirmation led a willingness to take the person seriously and to treat their utterances as meaningful which, in turn, opened up the possibility of meaningful pastoral communication.

2. The Nature of the Individual

What happens to the "soul" of the person who has dementia? When body and mind have deteriorated is there something of the soul which remains? U.V. raised this question spontaneously in the course of her interview, and then went on to give her own answer:

"I've had a few discussions about it with colleagues - is the soul awake to anything" (UV:87) "and that brings in spirituality. There are certain things, and not necessarily things which are "churchy" which cause emotions and to me, emotions come from the soul." (UV:88)

M.N.'s belief is that the presence of dementia does not rule out a relationship with God. He commented, when talking of an elderly lady, "She was obviously very confused, but it was a genuine sort of repentance and openness to God" (MN:8). So too, U.V. in stating " My Granny is so simplistic in her faith " (UV:29), makes it clear that she was in no doubt that her Granny, who was confused, continued to have faith in God. O.P. gave the following example from her experience:

"I think that they are aware of what's going on in a strange way. I said earlier that at this place [a Residential Home], [there was] a lovely woman now dead who was a missionary for twenty-seven years I think and was an Elder in our congregation. She became confused and I remember the minister of a neighbouring church 'phoning me up and saying would I take a service, and I said "yes, you've got one of ours there now." He said "that lady, I couldn't get out of her what she'd done or where she'd come from, but I was aware of the fact that here was a woman who could pray." You know for all that her mind was deteriorating and disintegrating right up to the day she died there was a woman in communion with God. It was an awe-inspiring thing

because I sometimes think, if my mind and body goes, how much of my soul is there to have a relationship with God?" (OP:39)

C.D. also spoke of seeing evidence of an on-going relationship with God:

"I have had several situations when I've realised that they (confused elderly people) have a relationship with God and there's no doubt about it, that that makes a great difference, and I think you sense there's something happening because there's a reciprocal response" (CD:12)

K.L. was the only pastor who spoke of a complete loss of spirituality:

"Just last week I was visiting an older man from the congregation, who was, in the best sense, very spiritual but that seemed to be all dead" (KL:26) "I do find it quite hard to have any view of God at all, at work in the situation of the decaying life of a confused elderly person" (KL:32)

It can thus be claimed that, in these interviews, there is strong, but not unanimous, experiential evidence of some form of on-going spirituality even in severe forms of dementia. Neither experience, either of the death of the spirit, or of the continuing life of the spirit, can be discounted. The contrasting experience is perhaps one of the many paradoxes with which dementia presents us.

A number of the ministers made comments which indicated their understanding that at the root of dementia is an accessing problem, that the "spirit" or "soul" remains intact but is rendered inaccessible by the condition. E.F. referred to "something about being trapped inside the body", she said:

"We don't know what happens, we haven't experienced that. I would say her eyes weren't happy, I felt that she was struggling within the limitations of what was going on. I don't think I've ever seen such horror in someone's eyes before, ...something about being trapped inside the body - but I don't believe that the Spirit of God would abandon in any way." (EF:33)

C.D. described dementia as disconnection:

"I believe that with people who are confused or disoriented or disconnected in some way, that if you can get into the key, I think there are keys, and if you can get that key you can begin to follow through." (CD:21)

A question was asked by U.V.:

"I was just very confused about things and I started to think, how much do people with dementia understand and how much of it is a failure to communicate?" (UV:57)

O.P. put it this way:

"I wondered if people who are demented can't also hear something locked into this bit of them that's in prison. Maybe they can hear things like that, maybe they also retain pictures of the glistening crocuses or the dancing daffodils, the sun on the water." (OP:61)

Thus for O.P. some aspect of self is believed to be maintained, and that self makes it possible for pictures and perhaps even emotions to be retained. These ministers appear to believe, albeit intuitively, that the soul of the person is inaccessible. If this is true then communication may be one key to access.

Based on their experience a number of the pastors strongly affirmed an on-going "spiritual" aspect to the confused elderly person. A claim of this sort is impossible to prove objectively. However, it is interesting that at least two comments emphasised an inner knowledge on the part of the pastor with regard to this spirituality - the minister talking to O.P. said "I was aware" (OP:39) C.D. put it "I think you sense". (CD:12) The implication from these speakers was that this was more than simple intuition, perhaps the work of the Holy Spirit.

3.Suffering

One third of the interviewees mentioned the issue of suffering in conjunction with confused elderly people. K.L.'s comments are helpful as an introduction:

"This will sound extremely naive, but there are theological issues about the relationship of God to suffering and that has two aspects, the aspect of the suffering of family and what I perceive, but do not know to be the suffering of the confused person." (KL:30)

There are questions too from M.N. who links the suffering of the confused elderly person with the suffering of Jesus:

"I think about the people whom I have known who have become confused, whom I have known previously when they weren't confused and who were as sharp as nails, very bright and very intelligent. I mean I would hate that to happen to me, but I see people who are suffering and I think that because God has suffered that He is, in some way, in that suffering. You know the folk that I deal with are generally Godly, Christian folk who are suffering and its a great problem, "Why do Christians suffer?" and I suppose its being there and being able to say to the person and to the family, and trying to make sense of a situation which it is difficult to make sense of. You know, the suffering servant, Jesus being in there and taking it all on board. ...I do struggle with it, I struggle with it a lot, especially when its people whom I have known, you know, great people." (MN:13)

For some of the interviewees the issue of suffering was not raised because their perception was that confused elderly people were "happy" in their confusion. U.V. recognises that different people are affected by dementia in different ways and comments:

"Someone can be scared by dementia, someone can be quite undisturbed, and quite happy, singing all the time." (UV:80)

At another point in the interview she reinforced this by saying:

"others seem quite comfortable, as if they are quite happy, they're not being unduly hurt by the situation." (UV:3)

C.D. also recognised a distinction between those who were apparently undisturbed by their confusion and those who were obviously suffering . He commented:

"Looking on is possibly more distressing than what the person, herself, is feeling. They may be confused, but they are not "distressed confused", well fine keep them happy with people to look after them and care for them." (CD:29)

4. Summary

The attempt to isolate theological issues is a difficult task. In interviews concerning pastoral care, there is inevitably a theological perspective to much of the interaction. That being said, the primary theological issues raised in the interviews were personhood, the nature of the individual, and suffering.

Pastoral Perspectives

In this section, the evidence which arose from the interviews on motives for pastoral care will be presented. Following this, two issues which relate to the pastors' experience of pastoral care will be appraised. Firstly, the experience of God being at work in the pastoral encounter, and secondly, the pastors' prioritisation of the care of confused elderly people as a pastoral task.

1. Motives for Pastoral Care

In Chapter 4 the literature on motives for pastoral care was reviewed. When the results from the questionnaire (Stage 4) were presented in Chapter 6, motivation for pastoral care was also examined as a theme, and enjoyment, duty and change

were examined. The in-depth interviews provided more scope for the exploration of this central theme. As was the case in the literature review, the information which arose in the in-depth interviews on motivation for pastoral care will be presented under the headings, proclamation, service, revelation, sustenance, change, and companionship.

(a) Proclamation

Proclamation as a model of pastoral care was not a significant theme in the interviews. It was not ignored however:

"It's basically a mission to share my faith with whoever. I find folk like that (confused elderly people) quite interesting - its quite a challenge."
(CD:17)

S.T. believed that the prayer which he offered in a pastoral visit with a confused elderly person had a proclamatory nature:

"I suppose that the prayers that I might share follow a pattern, there are certain phrases which I use repeatedly and that might be a reminder that they are not forgotten by God. But that is more at the level of proclamation." (ST:27)

(b) Service

Service and an Incarnational understanding of pastoral care were frequently linked as motives. M.N. explains:

"My feeling is that Jesus seemed to spend a lot of time with people who would have been regarded as hopeless cases, people who other folk would have shied away from. I suppose in our society we do shut folk away with Alzheimer's, it's like death, when someone is dying we don't know what to say or what to do in that situation. Jesus would have always got alongside folk and ministered to them and generally brought healing to that situation." (MN:12)

U.V.'s comments are in a similar vein:

"Jesus got alongside people. He wasn't issuing prayers all the time, it was a working conversation in life, it was being there as love, in flesh, and to me that's what the ministry is all about - the acceptance of someone and loving them and doing what would be best for them." (UV:78) "No hidden agendas, just accepting them. Every situation is different, you know every person with dementia is different, just as every person is different." (UV:79)

In the statements which follow there are indications that service and proclamation inter-act as motivation:

"I have no doubt that it [pastoral visiting of confused elderly people] is a good use of their time ...just the value of the face on the other side of the door ought to be enough" (GH:15) "pastoral care from the ecclesiastical sense is for the care of souls. The pastoral side to me is trying to meet the needs within the resources which are available to me ...the main thing is that you feel you're able to respond with the love of God and your own Christian philosophy." (GH:15),(GH:16)

Part of E.F.'s motivation for service arises out of an understanding that people with dementia are precious to God:

"I think it's part of my faith that anyone who is unable to help themselves is so precious. ...I think it's up to society to look after them and to bring out the best in them and I think tremendous things can be done for them." (EF:34)

Thus E.F., as well as recognising the on-going value of confused people to God, also recognised an on-going potential, which, for her, fed into their dignity and personhood. These comments make this clear:

"I suppose it's this "image of God" thing which I find important. I find God's likeness in people ...I'm drawn to the brokenness which seems to be in all people and that's in essence, to me, the heart of God in people - their brokenness and their powerlessness and a weakness which so often, well we ignore at our peril ...They are doing something for me." (EF:14)

(c) Revelation

An understanding of pastoral care as revealing aspects of God's character, in particular His love, was inherent in a number of the interviews. For Q.R. a ministry of presence expressed a powerful theological message:

"You are saying that you are with them in what is a very difficult and demanding situation, and while the person is still able to understand who you are, when you come, you are making a statement that they still matter."
(QR:81)

In the questionnaires (Stage 4), 58 per cent (n=124) of the respondents disagreed, or strongly disagreed, with the statement "I find it difficult to be sure that confused elderly people can be assured of the love of God." [4:14]. Consistent with this finding, reminding confused elderly people of their importance to God, and that they are in His care, was mentioned by a number of the interviewees as being an impetus for pastoral care. K.L. brought this together with the issue of change in his response to the question "Why bother with people who are confused?"

"I need no persuading that the elderly, the house-bound, the intellectually limited whose contact with the world is brief are every bit as precious and as valuable to God as people who are the chief office bearers in the congregation. I cannot ever see the pastoral task of the minister with confused people as one of healing or solving or bringing light or even talking things through. I don't find myself able to speak on that sort of level at all with confused people. What I think I'm there to do is for a moment to help them to feel they're not alone, for a moment I hope to help them to feel part of a congregation, and because God is better at this than I am, helping them to be reminded that they belong to God and that nothing, even their lack of understanding, can remove them from God's care." (KL:10)

Thus although change, or as he described it "healing, solving, bringing light" is an aim of pastoral care in other situations, he dismisses it as a motive in the care of

confused elderly people. In its place he substitutes models of presence, and representation, both of God, and the continuing love and care of the congregation.

Pivotal in this understanding is the recognition of the on-going value of the confused person.

In her stressing of the importance of "dignity" U.V. also links the concepts of the value of the person and a ministry of presence:

"I like them to have their dignity, and that is spiritual as well. You see, sometimes you feel that, as a minister, you can't do very much on the spiritual line, but to me, spirituality is just being with someone." (UV:77)

M.N. having spoken at an earlier point of the way in which his understanding of ministry was linked with Jesus' incarnation, in that he sees ministry as following the example laid down by Jesus, spoke of his experience of a ministry of presence:

"There have been times when it has been a case of "being there" rather than "speaking" because you can't have a conversation with some folk and yet it has been quite clear that they didn't want you to go. You know if it is a lady, I would take her hand and give her a peck on the cheek and she just wouldn't let my hand go - she obviously wanted me to stay." (MN:19)

Revelation as a motive for pastoral care and a ministry of presence were linked in the literature review (Chapter 4). The quotations which have been given illustrate that they were also linked in the minds of some of the pastors. Presence was seen as one way of revealing God's love for the confused elderly individual. Many other aspects of revelation and disclosure as a motive for pastoral care were evident in the interviews, and are inherent in other sections of this chapter. These included the

practical concern illustrated by some congregation's active efforts to remember the person with dementia.

(d) Sustenance

That the person with dementia be sustained or maintained within the life of the church and the congregation emerged in the interviews as a significant motive for pastoral care. Two central methods of maintenance were developed, maintenance through the sacraments, and through being remembered by the congregation.

(i) Sustained by the Sacraments

In the case of the Roman Catholic priests a sacramental understanding of pastoral care was formative, to the extent that I.J. claimed:

"The basic function of my visit would be Communion, I mean I would always take Holy Communion with me on my visits, both to old folk's homes and hospitals. I would never be without it." (IJ:7)

Within this sacramental model A.B. highlighted the importance of the priest's role:

"My main reason for visiting them is that some priests leave it entirely to the lay folk. Now the older generation like to see a priest and he's always most welcome." (AB:14)

(ii) Sustained by being Remembered

Through visits, either their own or those of lay people, some pastors believed that a link between the confused elderly person and the local church was maintained.

Thus Q.R. said; "I want them to know that God loves them, that they are part of the

church." (QR:81) The same theme is picked up by S.T. who spoke of a group for confused elderly people which meets on church premises, as well as individual pastoral visitation:

"the group where I visit is at the moderate to severe end, my visit reinforces the fact that they are meeting on church premises and secondly that the church is glad that they are there. The individual visits to members of the congregation who are sufferers, in each case it is maintaining a long link which they have with the church." (ST:25)

When asked to explain the message which the church was trying to communicate with confused elderly people, O.P. replied "I think generally it's a sense of care, that the church still cares." (OP:11) She went on to speak of the highly developed way in which she, and members of the pastoral visiting team, seek to communicate that care and maintain links with the on-going life of the congregation:

"Starting off from January there will be daffodils at Easter, then there are flower services in June, and I actually send a picture postcard to every single one of my old folk when I'm on holiday." (OP:13) "With ones who have dementia I don't really say much, I just say "Having a lovely time, hope you are keeping well, love [OP]", and I put a little sticky label of who I am on the card so that the nurse or next-of-kin knows, and the next thing will be harvest and then Christmas presents, in fact last night our Youth group - thirteen of them wrapped one hundred and twenty Christmas presents that I had bought. In fact they will be delivered by the elders and I have signed all the Christmas cards so they have more than just the visit which can be forgotten very quickly. So they have the card which they can hold in their hand or the soap and face flannel. One of the nurses will say, "good, where did you get this from?" "The overall thing is care. As well as that the visiting team visit once a month," (OP:14),(OP:15),(OP:16),(OP:17),(OP:19) "and they take the monthly magazine even though they can't read it, but the idea is that if a sister or daughter or granddaughter comes in ,she will say "Oh the church has given you a magazine" to try and get them to feel that we haven't forgotten them and we still care about them." (OP:21)

The usefulness of leaving a card as a practical reminder of a pastoral visit, as well as its value in reality orientation for the confused person, was mentioned by S.T.:

"leaving behind a card so that somebody else might say "Oh has [ST] called?" and that is a reinforcement, a member of the family or home help or whoever it might be may say " Who was this?; Did they call yesterday? ; and what were you doing when they called?" (ST:26)

Underlying this emphasis on maintaining links with the church was an implicit understanding of the Church's representative function. The Church's demonstration of their love and concern for the individual was a practical way in which God's on-going love and concern could be shown. As S.T. states when speaking of visiting, "that may be a reminder that they are not forgotten by God." (ST:27)

Duty, as a motivation for pastoral care was linked with maintenance in the literature review (Chapter 4), and explored as a motive in the aftermath of the questionnaire (Chapter 6). In the interviews duty did emerge as underpinning understandings and approaches to pastoral care of confused elderly people. This is made clear in a comment made by K.L.:

"I don't think it (pastoral care of confused elderly people) is ever a waste of time - maybe I'm just too insensitive, but it never occurs to me not to do it. I'm absolutely certain that it's right to do it, I feel it's my duty and I wouldn't consider striking that person off the list. That it should be done for God and for the church I feel is quite essential. Whether or not it's always a great thing for the visited person is another matter altogether." (KL:8)

This understanding of duty places an objective significance upon the pastoral task. The questions of whether or not it is a good use of time, and whether or not the visit makes any difference to the confused person, therefore, become secondary. He

feels he has to undertake this task anyway, because it is his duty. I.J. evidenced a similar understanding when he said:

"As a priest I wouldn't say that I can just sideline them or side-track them, I think they still need pastoral care." (IJ:1)

Other pastors also mentioned the impetus that comes from duty. S.T. for example: "I visit because of the need - it is because my work is to visit, is to be alongside those in need" (ST:23) and O.P.: "I just sat with her, that's one of the things I have to do." (OP:59)

It thus appears that duty is an important motivator, in particular when subjective motivation is missing. This is interesting, as it is in accordance with the finding which arose from analysis of the questionnaires, where it was found that duty and enjoyment were inversely related. That is, if a pastor rated themselves as enjoying pastoral care of confused elderly people, the tendency was for them to rate duty poorly, as a motivating factor. Analysis of the interviews reinforces this finding, as pastors mentioned duty as important in situations where there was no other motivation.

(e) Change

The question was asked in the interviews if the pastors believed that their visits with confused elderly people "made a difference to them". This question was also given impetus by the results from the questionnaires and a comment which had been made to the researcher during piloting, when a minister had said "You prove to

me that my visits make a difference and I will do whatever you ask me to do, in terms of communication techniques". This comment obviously arises from a particular understanding of pastoral care in which change is a central concern. The validity of this view, in addition to potential alternatives, has been examined in the literature review (Chapter 4). However, since "making a difference" appears to be one aspect of some pastors' perception of the validity and purpose of pastoral care, it therefore seemed useful to gather evidence in the interviews whereby the question could be evaluated.

Opinions on this topic were mixed. Alongside affirmations of the value and importance of visiting confused elderly people, a number of the interviewees also expressed doubts as to whether or not their intervention was helpful to the confused person. I.J. 's experiences were based on chaplaincy in a large Edinburgh hospital, and on pastoral visits in residential and nursing homes. He said:

"I suspect the Alzheimer patient in the hospital has such a short attention span that my visit really, would not have any great effect (IJ:1) ...sometimes I would opt out, because for the poor soul who is getting confused this means little or nothing." (IJ:6)

M.N. commented:

"I mean, if you have been there for twenty minutes or half an hour in total silence you can't help feeling "What's the benefit of me staying, especially when you have a lot of other places to go?" (MN:19)

This comment raises the issue of priorities to which in-depth attention will be paid at a later point. Suffice it to say that the pastoral care of confused elderly people will always be vying for attention and time against many other valid pastoral

concerns, and M.N.'s comment makes it clear that this increases the pressure to see pastoral care of this population as valid, and worth the time investment.

K.L. also voiced doubts about the difference which visits make:

"I wish I could say that I had all sorts of clever insights, but most often I go away thinking I haven't really made any sort of breakthrough" (KL:3) "I don't think you can possibly say that every visit rings a bell for people - every visit doesn't - I think I'm more confident about reading the Bible and saying a blessing than I am about saying "It was good to see George yesterday". I think I'm more confident that that might have some significance. I think I'm more confident that being close to someone and holding their hand and giving them a wee kiss and a smile, is more significant than what I say. That isn't to do with empirical evidence or because I have seen results, it's just intuition, hunches and what I believe about God and what I believe about people." (KL:24),(KL:25)

Yet, there were others whose experience led them to say that their visits had made a difference. A.B., from a Roman Catholic tradition, spoke about the significance of the sacraments:

" I do find that the sacrament can definitely calm them - even as soon as a Priest comes I do think that it calms them." (AB:16)

Q.R., a Presbyterian minister speaking of a woman in his parish who was confused and believed that her possessions were being stolen said:

"I think the very fact that, at that stage, she understood who the minister was, and where I was coming from, made her feel that I was someone she felt able to trust, she felt able to talk about her fears and I think that made a difference to her." (QR:64),(QR:65),(QR:66)

O.P. when asked what she thought were the factors which made ministers feel that they had made a difference told this story:

"Well I remember once in a hospital I saw this woman who didn't recognise me and who was doing quite a lot of rocking backwards and forwards and I had a busy time check list of people to see and things to do, you know the usual pressure, and I thought this is a useless visit. And the woman herself got up in a restless way and went off to do something else and I spoke to the charge nurse and said "I think its a waste of time there" and she said "why don't you just hold her hand and time yourself for ten minutes", she said "we no longer have the time to do that, and we used to, and if she doesn't want it then you will know it , but in our experience she will respond to that". When she came back I put out my hand and she took my hand and I spoke quite softly about things that had been going on in church, like we had a coffee morning on Saturday and lots of people came, there was a lovely baking stall . Oh, we had such a nice service on Sunday because we lit the Advent Candle, there was a parade of the Boys Brigade. I just talked, stroking her hand and it did soothe her, and I literally timed it for ten minutes and the last five minutes was just silence. What she said didn't make sense to me, just unconnected words, but the charge nurse left me out and said "She'll be different tonight because you have given her time."" (OP:55)

The willingness to spend time, despite a busy schedule, combined with the use of touch, to make a difference in the life of the confused person. However M.N., in talking of her theology of pastoral care, raises the question of whether or not making a discernible difference, is a valid criterion for evaluating pastoral care:

"I suppose my belief is that my job is to do that (show Jesus' love); not necessarily to have them restored to full memory or clarity of mind, but a matter of sharing Jesus' love, because that is what He would have done. As to what is actually happening, I don't know, but in a lot of a minister's job you don't know what the effect is and often you don't see the fruit and you hope that by being there and speaking that a positive , lasting effect is taken from it." (MN:12)

The literature review (Chapter 4) makes it clear that change is a central motive for pastoral care. This observation does highlight the fact that this is not the only approach, nor perhaps the most helpful one, when applied to confused elderly people where change may not always be an observable outcome.

(f) Companionship

None of the interviewees mentioned companionship explicitly as a motive for pastoral care. In the literature review the motive of companionship was linked with mutuality and a recognition of common humanity. Inherent in the stress on acceptance are some of the emphases of this approach.

C.D. referred to the importance of accepting the person with dementia "as they are" when he spoke of "letting them talk to you, rather than going with a prescribed agenda." (CD:24) His remark was indicative of a willingness to listen to what the confused elderly person wanted to say, and an openness to letting them steer the interaction.

U.V. broadened acceptance to include not just verbal communication but also behaviour. Referring to her grandmother she said:

"Acceptance is very important, just to accept. You know we've had things with my granny, she used a waste-paper bin instead of going to the toilet in the Nursing Home and we just had a laugh about it." (UV:11)

Within that family, it therefore seems that acceptance of the granny's behaviour combined with a sense of humour, enabled them to work through a potentially difficult and awkward situation. Two of the pastors spoke of the way in which an attitude of acceptance helped them to plan and lead worship. O.P. told of one of her experiences of leading worship in a Residential Home. She began by talking of how she encourages residents to choose hymns as part of worship, and how they frequently choose well-known hymns:

"If that is what is religious for them then we pick up on it, and I think one time it was Christmas and they didn't have any Christmas things because they wanted all these ones like , " Oh love that wilt not let me go" and "Abide with me" and then I said very firmly "It's Christmas and would Mr M choose one", he was one of my elders and they were all happy for him to choose and he chose a Christmas one and after that we had a spate of Christmas ones, so I think you slot into their awareness." (OP:33),(OP:34),(OP:35),(OP:36)

E.F. linked acceptance with an openness to recognise the work of the Holy Spirit when she made the comment; "I believe that the Holy Spirit can work at whatever level a person is at." (EF:31)

U.V.'s comment links acceptance explicitly to pastoral communication:

"Deep conversations are difficult, obviously. I think it's a matter of reacting to the moment - to the way their mind is going." (UV:3)

It has been possible to isolate some motives for pastoral care. To a large degree however, it must be recognised that the pastors were eclectic in their motivation. They tended to build their models using aspects of different paradigms.

Having presented the information on motivation for pastoral care, the focus moves to an examination of two issues which arise from the experience of offering pastoral care to confused elderly people; the experience of God being at work in the pastoral relationship, and priorities in pastoral care.

2. The Experience of Pastoral Care

(a) God at Work

Fowler (1995) makes a plea that those involved in pastoral care begin to recognise again the actions of God in human affairs. In these interviews the experience of God being at work, in particular through the Holy Spirit, was raised on several occasions.

Some of the interviewees understood the Holy Spirit as being at work in the life of the confused elderly person. I.J.'s experience was of the calming power and presence of the Spirit:

"I think that it is "spirit based". The Spirit will provide. So, in the same way, you know, you come to deal with agitated folk, for whatever reason they're agitated - agitated because they're confused, agitated because of their illness, I've seen people change because I was there but, it is not me that creates the calmness the stillness. I would not have that much ego in me to say "See what I have done!"- it's the work of the Spirit to work through me." (IJ:13)

It was also clear from some of the interviews that the pastors believed that the Holy Spirit had a vital role in facilitating communication. E.F. comments:

"I believe that the Holy Spirit can work at whatever level a person is at. I can think of a lady who was in a hospital many, many times and her mind was not deteriorating, in fact, we were in communication and I gave her Communion and she was a tremendously vivacious Christian. ...However she made an extremely rapid deterioration and came into the ward, ...and I looked at her name on the list and thought "This can't be" and when I went to see her, she had made an extremely rapid almost disintegration, and I remember one of the nurses saying "Isn't it sad?". In fact, she was unconscious at the time and didn't recognise me at all - just these blank eyes. ...She did eventually, begin to respond a little bit to prayer and holding the hand. Well, I would believe, I think in my heart, that the Holy Spirit was working on her in her lack of capacity to understand and I still think that He must, and that He doesn't forsake a person as much enlightened by the Spirit as she was." (EF:31)

When asked if it was her theological belief which made her say that, rather than her experience, she replied; "Probably - I don't think He gives up on anyone". (EF:32) This raises questions about the inter-relationship between theology and practice or experience. In the case of dementia, is theological belief enough to sustain practice, even when experience is negative?

The Holy Spirit was often mentioned as being at work in and through prayer. Two examples illustrate pastors' experience of how through prayer and the work of the Holy Spirit communication took place:

"So this lady, I said a prayer with her. I just went over things which she's been through and things we'd talked about to help her to be able to trust a little bit more. You have got to pray so simply and then, at the end of the prayer, I didn't even look at her face at the time, I was just holding her hand and she was holding my hand so tightly and when I stopped, you know, there were tears on her face" (UV:26) "and you know, obviously something got through - you don't know what, but something that is positive and good." (UV:27) "You don't know whether she's tuning in or God is communicating in some way, or just giving some peace." (UV:28)

M.N. recounted the following example:

"There was one guy when I was in [City Name], now he was really confused, but I said we'd pray together and he said "OK" so I closed my eyes and he started praying and he just looked up at me at the end and said "I didn't know I could do that" and then he started talking again and it was all rubbish, but it was an amazing lucidity and it was the first time he had ever prayed with me. ...I thought "My, something's happening here, boy, this is amusing". So, you just don't know, I mean I don't know how something like that happens or what the process is, but I trust that God is in some way at work." (MN:17)

Thus, some of the pastors saw the Holy Spirit as being at work both in the life of the individual and in facilitating meaningful communication. There was also a recognition that the Holy Spirit was at work in the life of the pastor:

"After my own experience of the Spirit, in a more personal way, and of the gift of tongues, I felt that I've got something to give in this situation which is not me. You know before it was "Lord, help me to do what I can, okay?" Now it's "Thanks Lord, thanks, we go together and let me be open to you." I feel that I've something to bring to each person, no matter how tired I am. ...Certainly hospital visiting etc. took on a new dimension" (CD:27) "going prayerfully and trusting that God's Spirit is with you. I think that the Lord communicates through you. Communicates His love really, not in a sentimental way but in a ministering way." (CD:10)

C.D. described himself as speaking from a charismatic perspective. I.J. is a Roman Catholic priest who, speaking of hospital chaplaincy, said:

"When I took it on at first, you know I would get urgent calls in the middle of the night, I would go from here the two miles or so into the hospital wondering what am I going to say - how am I going to handle this? Now I don't. I just go there and let it happen. I think that it is "Spirit-based"."
(IJ:12),(IJ:13)

The Holy Spirit is thus seen ministering through the pastor, and as having a role in assuring the pastor of the efficacy of his intervention. On this point C.D. comments:

"There's more than me involved in this situation - I've found that tremendously helpful. If I was just going on the basis of what I could do, in a kind of mechanical way, I would get panicky because I would think because they can't hear me, we can't communicate or if we're not saying something sensible - if I was just going on that basis, I would become terribly frustrated."
(CD:3)

(b) Priorities in Pastoral Care

In the interviews, pastors were reluctant to agree wholeheartedly that this aspect of pastoral care was a priority. This is consistent with the outcome of the questionnaire which highlighted a division of opinion. Thus 44.4 % (n=124) of the respondents agreed that it was a priority, while 21.1 % registered disagreement, or strong disagreement.[4:1] Q.R. linked prioritisation with the degree of dementia shown by an individual. He said:

"There are people in severe dementia who I have visited in hospital and I have felt that it has been a total waste of time ...because they have failed to almost be aware that a person has been there, much less who I am or what I am doing there." (QR:35),(QR:36) "In terms of people with mild dementia, moderate dementia, I'm sure that I would be thinking of making them a priority - I think I would be saying what I want to do was to try include them." (QR:37),(QR:38)

The concept of basing priorities on the severity of dementia was not in accordance with O.P.'s thinking, she commented:

"I would always put the confused elderly on the same level with elderly non-confused so they get the same treatment and the same number of visits and the same pressies."(OP:45),(OP:46) "Much more of a priority would be trying to communicate with a Down's Syndrome woman, I would like to communicate with her because she's not in a degenerative state." (OP:50)

Thus for O.P. degeneration, or perhaps, lack of potential was a factor in rating priorities. In responding to the same question S.T. mentioned level of need as an important factor in assessing priorities:

"I think that really it is in response to the level of need rather than signalling out, well, this is a good group, I must be careful to spend a lot of time with them." (ST:12)

No-one in the interviews rated pastoral care of confused elderly people as a high priority, although they took it seriously as a pastoral task and responsibility. The question of priorities in pastoral care brings the relationship between theology and experience into sharp relief. While all of the pastors who were interviewed were able to put pastoral care of confused elderly people into a theological and pastoral framework, this area of pastoral care was not seen as a high priority. One reason for this may be negative experiences of pastoral care with this group. A further possibility is simply that with pressure of work only the most urgent, crisis situations are recognised as priorities. This is further evidence of the dynamic, cyclical relationship between theology, pastoral care and experience. Theological understanding informs pastoral care, and the experience arising from the pastoral care in turn impinges on theological reflection and pastoral practice.

Theological and pastoral perspectives on pastoral care of confused elderly people having now been reported, attention now turns to pastoral communication.

Pastoral Communication with Confused Elderly People

In this section the information elicited from the in-depth interviews (Stage 5) on aspects of pastoral communication, will be presented. The order in which these topics are presented, as well as the headings used, mirror the structure of the questionnaire (Stage 4).

1. Pastoral Communication

In this section the focus is on factors which, in the pastors' experience, enhanced communication with confused elderly people.

(a) Eye Contact

Throughout her interview E.F. spoke about the power of the eyes to communicate. She noted, "Eye-contact is very important" (EF:6), and she went on to make the following comments about a woman who had severe Alzheimer's Disease, which had rendered her unable to communicate verbally:

"I would say her eyes weren't happy, I felt she was struggling within the limitations of what was going on. I don't think I've ever seen such horror in a person's eyes before." (EF:33)

A factor which impinges on the ability to maintain eye-contact is that of being on the same level, physically, as the confused elderly person. One interviewee, I.J., spoke of his experience of the value, symbolically and practically, of being on the same physical level, as the confused elderly person. He said:

"The other thing which I would attempt to do is to get down to their level, I would sometimes sit on a foot-stool in front of them rather than stand, sometimes I would kneel beside their chair rather than be the priest dominating or whatever. I would get down beside them, you know some of these old bodies are all curled up in their chairs, so I would kneel down beside them or sit on a foot-stool and talk to them at that level." (IJ:16)

(b) Touch

The first formal question in the interview with O.P. was "What have you found to be most effective in communicating with people with dementia?". Her immediate response was "touch", she elaborated:

Many of the ministers spoke, almost in passing, of how they would naturally hold a person's hand when they were visiting them, to cite K.L.:

"I always hold the person's hand when I'm visiting them. When I'm leaving, sometimes just a squeeze or an extra hold of the hand helps you to think 'well, that has made some sort of communication.' (KL:6)

Touch therefore was almost universally recognised as a powerful tool in facilitating communication.

(c) Reality Orientation

A number of the ministers spoke of their understanding of the importance of introducing themselves when initiating communication with an confused elderly person. When asked if there were things which he had found to be particularly helpful in sparking even momentary understanding I.J.replied:

"Well certainly, my first introduction would be - even with that lady from the [Area Name], every time I call I have to re-introduce myself - that I would always start by saying, 'the priest'. " (IJ:16)

A.B., also a Catholic priest had had a similar experience; "just by asking "you know who I am? I'm a priest"- usually gets some sort of reaction". (AB:9)

Repetition in combination with reality orientation was stressed as helpful in facilitating meaningful pastoral communication by U.V. She said:

"I keep saying it's [UV] you know, the minister - I've been here before - I've seen your wife. You know you remind them of things. You've got to drive the conversation a lot, even if it takes three or four minutes. Sometimes, they'll be sort of indignant and say "I know you are!". " (UV:36)

In addition to introductions, reality orientation can also take the form of talking about the church by name. A comment by K.L. illustrates this approach:

"I talk about [Church Name] and about places in the church, because I'm here as their minister and try to help them to feel some sense of relating and belonging to the church, and this is sometimes easier through a building." (KL:3)

(d) Knowledge about Life-Story

Knowledge about the individual's life-story was seen as helpful in establishing a point of contact and perhaps even "meaningfulness" in the pastoral encounter. This is reflected by E.F. when asked if she found it helpful to know about the person's background she replied:

"Yes, very helpful, because then you were at least able to talk a little more knowledgeably about things, and not think "What am I going to talk about this time?" or "How am I going to approach this person?", particularly when some of them were very silent and withdrawn". (EF:2)

Most respondents felt that being able to talk about the past, either of the individual or the church, was comfortable for both themselves and the confused person. When they were talking about a life-story they were fairly sure of a response and appeared to believe that they were being understood. M.N. made this clear:

"I find it quite hard to remember things which would have communicated [enhanced communication]. Often, it is the familiar and being able to relate to people in the family whom you mention, or events which happened to them, or which are happening to them, and obviously some of these may be forgotten. Occasionally, they forget who I am, but I have experienced that, so I try to latch on to their memories - I have found that to be helpful." (MN:2)

The experience of I.J. backs this up, he commented:

"They do live very much in the present moment and the only thing which sometimes seemed to spark them off is the long-term memory, the child-hood thing you know. One lady, in particular who I can think of, happens to be from the [Area Name] which is my home base too, so if you can get her onto that - she'll talk about it as if its in the present. We both went to a local church in [Town Name] and, of course, she hasn't been in [Town Name]

for years, but I mean that's OK., you make that adjustment and at least there is a conversation there." (IJ:4)

U.V.'s comments indicate her belief that for the confused person their sense of reality may be based in the past. This reinforces the importance of the pastor knowing some of the confused elderly person's life-story:

"Occasionally, I go in and recall names of their relatives from the past. The ones which are more confusing I find, are the ones who sound completely credible and lucid, and sound completely fine, and you realise, from someone else afterwards, all the people who they've been talking about died about 20 years ago". (UV:2)

That knowledge of life-story forms a point of contact with the confused person seems obvious, but it is a point of significance. It may spark recognition or trigger memories for the confused person, and obtaining some feedback provides reinforcement for the pastor. Arising from the interviews it appeared that knowledge about life-story had three other significant implications. The first can be summarised by Feil's (1992) term "validation", the pastoral application of which is illustrated by this statement from E.F.:

"but because I knew something about his circumstances and they were very, very sad indeed, I would, very gently, sometimes bring in something about his past." (EF:4)

E.F. seems to indicate an understanding that, even in the case of a confused elderly person there may be a need for the person to raise issues from the past, or have those issues raised for them, in order that some resolution might be achieved. The attitudinal background to this statement also has significance, for it implies an underlying recognition that the individual's story is worth hearing and that people with dementia have valid spiritual and pastoral needs. An understanding that the person's life-story and concerns can be of present-day relevance is illustrated by C.D.:

"Often, with elderly women, there's a deep concern for their families, for their grandchildren, and it often shows. I remember an old lady who used to become, at about four o'clock in the afternoon, extremely restive because she needed to get the train to get home and feed these children. Eventually they had to tie her to the chair so that she wouldn't go for a walk...but there was obviously something from away back and as far as I could gather, she seemed to have total responsibility for quite a large family or extended family and this was still with her." (CD:20)

In the same vein M.N. told the following story:

"I suppose the one that stands out for me was here, in this area, about two years ago and I had to go and visit a lady whom the Social Services had referred to us, and who had said that she would like Communion. This lady had a reputation for liking her drink when she was younger, I think she still likes a drink actually. She'd had a few accidents and was immobile in bed, along with that she was confused. So I went to see her and she was living in extreme squalor and I visited her a lot. Eventually I said to her, "Well look, I'll give you Communion". We started the service and when we began singing, the woman just burst in to tears and she just wept and wept and wept and I understand it. I mean, she basically needed forgiveness. I think she'd found that she'd made a huge mess of her life and she knew she was coming to the end of it and she would repeat herself all the time and tell you the same story time after time; she was obviously very confused but it was a genuine sort of repentance and openness to God" (MN:8)

M.N.'s knowledge of this woman's life-story was crucial in his interpretation of her actions.

The second finding is that for some of the ministers the "spiritual" or "religious" history of the person was of significance. On one level this is illustrated by the following statement where past religious involvement was seen to provide a point of contact, A.B., a Roman Catholic priest comments:

"If it's Catholic people who have been practising all their lives, this will be a help to them. You can just say, "This is something to help you - the church's sacrament". You know, people of eighty or ninety, that generation, have a simple faith and they have never lost it" (AB:3)

From a Presbyterian tradition U.V. reinforces this view when she states:

"Obviously it's harder in the spirituality line if someone has no church background at all, because it's very difficult. You can talk about a lot of things, and roots and suchlike, but I think that people's faith, their grounding as a child, is so important if they do become confused, because they can go back to something they've trusted in." (UV:31)

The final part of U.V.'s comment implies that a faith history provides a grounding and a solid anchor for the person, even in the midst of confusion. For ministers coming from an evangelical background, knowing a life-history which involves conversion has other implications.

Another aspect of C.D.'s experience is that knowledge of the person's life-story, in the pastoral situation, is helpful because it facilitates memory cueing:

"I believe that with those who are confused or disoriented or disconnected in some way that if you can get to the key, I think that there are keys, and if you can get that key you can begin to follow through "(CD:21)
"At Christmas time I remember there was a lady who told me she had been to Ceylon with her husband. She told me about the boat trip, and my father was a merchant skipper and I know a bit about the whole kind of shipping attitude to life and I was able to latch on to that." (CD:13)

In summary, therefore, the interviewees consistently highlighted the helpfulness of their knowing something of the life-story of the person with dementia. This knowledge gave them a very practical point of contact, and in addition it alerted them to the potential existence of pastoral and spiritual needs. This understanding has theological implications, for it reveals a belief in the worth and personhood of the person with dementia. C.D. made this connection explicit:

"you hear about what they (confused elderly people) did, and you realise all these people are individuals with a long history and a story of their own, and I try to respect them on that basis." (CD:3)

Recognition of the importance of knowing aspects of the individual's life-story also has practical implications. It may well take time and effort for the minister to gather relevant information pertaining to the individual. One practical pointer may have been provided by a speech therapist at an earlier stage of the research who advocated use of a simple questionnaire which she gave to the relatives of patients with dementia, which, when complete, provided her with helpful family information, family names, and hobbies for example.

(e) Silence

The comment made by C.D. in which he noted the calming effect of pastoral visits on confused elderly people, along with O.P.'s account of sitting quietly, holding the hand of a confused person have already been given. E.F.'s experience reinforces those already mentioned, she said:

"I've learnt so much from the people who weren't able to communicate much, about silence. I've learnt a lot from them in the experience of just sitting quietly with someone who was unable to communicate something." (EF:13)

(f) Repetition

U.V, in particular, spoke of the helpfulness of repetition in facilitating meaningful communication. She spoke of repeating herself as a means of helping the confused person to understand her, and she then broadened the concept to getting the confused elderly person to repeat what she is saying. She explained:

"Sometimes to get people to repeat after you ... "Can you say these words after me?"- I do it with primary children - sometimes you've got to use children's tactics and say "Do you want to say the words after me?" And if they get lost, well, it's fine. Its just very short phrases "we thank you that you love us, and you are our friend"- and this is all not so much in public

worship, I'll do this in a Nursing Home, by a bed or something. I'll say "Do you remember hearing stories about Jesus? You know He still loves us" and the face lights up sometimes and this is great" (UV:46),(UV:47),(UV:48)

(g) Wearing a Clerical Collar

It is recognised that a number of issues impinge on the question of wearing a collar, apart from its usefulness in communicating with confused elderly people. These include gender, style of ministry and perhaps even theological perspective.

Despite these considerations the majority opinion, evidenced in the in-depth interviews, was that a collar, due to its familiarity as a symbol, had the potential to facilitate communication in this setting. Introducing the topic into the interview U.V. said:

"I wear a collar most of the time for my work. I think--even for giving people a boost they think "well, here's my minister". People find it a comfort, sometimes when they're frightened and things like that, to see a collar can be good. As long as its not used to pull rank or anything like that." (UV:23) "This chap who was confused, I went one time without my collar and he had no idea, but the other time, he would just be looking at the collar and pointing and it clicked." (UV:25)

A collar was understood as being important in aiding recognition and reality orientation. I.J. said:

"I would never go without my collar."(IJ:16) "If I go and say, "I'm a Catholic priest, ...yes I'm a Catholic priest, see the priest" (indicating his clerical collar). (IJ:14)

Two of the interviewees indicated that they would make a point of wearing a collar when visiting confused elderly people. This is indicative of their experience of its usefulness. K.L.. stated:

"I hardly ever wear a clerical collar, but I do try to wear a clerical collar when I go to visit folk who are confused, because I think that, sometimes, that helps them. It gives them some idea of what I am, if not who I am." (KL:3)

M.N. had a similar perspective. Speaking about wearing a clerical collar he said:

"I would normally and especially for the older folk. [wear a collar]. This is partly because I don't look very ministerial, so putting a collar on immediately puts me into that bracket and it does help them to focus. I mean the chap who is in hospital just now is an enormous man, [Man's Name], and he is not really well at all. His wife is still alive and I take her in to visit him and have got to know him quite well. When I go to visit him in hospital as soon as he sees the collar, he immediately twigs." (MN:3)

However, this positive opinion of a clerical collar was not unanimous. O.P. stated:

"I never wear a dog collar. I might, as I go in, say "Can I visit Mrs. So-and-so, I'm her minister", but I might not." (OP:25),(OP:26),(OP:27)

Although reporting that it was his custom to wear a clerical collar C.D.'s experience was that it was not always noticed:

"Sometimes people notice the collar - but they often don't notice the collar, they notice the beard first - but sometimes there's a reaction, a positive one." (CD:13)

(h) Reminiscence

O.P. chose the term "rehearse memories" to apply to reminiscence she said:

"With those who are in the earlier stages they like to rehearse memories. I would say "I am from - church", and they say "Oh church" and will talk about the past. I wasn't there, but I know enough to ask questions - not closed questions with a yes or no answer, but open ones" (OP:1)

G.H. expanded on the topic:

"It's no use referring to the present. Most of my ministry is with the elderly. ...So what I have tried to find out with old people is common ground for them, and common ground for them is music hall, railways, the things which went on in their life-time, good things and bad, their hobbies - with one chap it was leek growing and I would talk about leeks until the cows came home! This is what I find stimulates them, you've got to go back to their experience and bring out things. ...I often go in there [to a Residential Home], especially on a winter evening, and those people who are moving toward the dementia side will pull these things out and amaze other people, in the sense that you have hit on something here that they can really pull out and talk about and communicate on and give their experience. This is tremendous as it gives these people a different quality of life. Someone is interested in them, ...in the subjects which they are interested in." (GH:7)

In G.H.'s experience finding something from the past was often a key to meaningful communication. What held for conversation, was experienced by C.D. to be true in worship also:

"I have found, and it was actually when I was chaplain in a Geriatric Hospital, where there were a lot of folk with Alzheimer's and such like and I had to take services there, that what was quite helpful was, in fact, to use those things which were familiar from their childhood, basic things." (CD:2)

This finding was reiterated by I.J. who said:

"They do live very much in the present moment and the only thing which sometimes seemed to spark them off is the long-term memory, the childhood thing you know." (IJ:4)

M.N. continued:

"I find it quite hard to remember things which would have communicated. Often, it is the familiar and being able to relate to people in the family, whom you mention, or events which have happened to them, or which are happening to them and obviously some of these may be forgotten. Occasionally, they forget who I am, not so much the ones we have at present, but I have experienced that, so I try to latch on to their memories, I have found that to be helpful." (MN:2)

In the questionnaire respondents were asked if, in their experience, talking about the past was helpful in enhancing communication [2:18] p.450. The high percentage who responded positively to this variable, and to related variables concerned with knowing the confused elderly person's life story [2:6] p.444, are entirely consistent with the findings from interview analysis.

The issues presented in the following sections were not the subject of explicit questions in the questionnaire (Stage 4) but arose only in these in-depth interviews.

(i) Use of All the Senses

One of the areas to which E.F. referred when asked about facilitating meaningful pastoral communication with people who are confused, was use of photographs and pictures. She talked about using a photograph of her children to stimulate attention and understanding for the confused person:

"There is an immediacy about what you have to really communicate, mostly about things going on around, drawing their attention to something going on in the ward or people, or, because you know nothing about them at all, just to talk about one's own family. I tended rather to do that because, sometimes, a photograph of my children, anything which they could see to just bring their attention to something. You see, the other thing, as a hospital chaplain, I carried a whole lot of stuff around with me which might be helpful to anybody, little cards and suchlike." (EF:3)

E.F.'s experience was that using sight stimulated reminiscence. She continued to speak about one particular man:

"He would talk about cars, that would jog his memory and he would talk when he was stimulated a little bit and I would make him laugh because I was always telling him what a bad driver I was, and he would begin to talk a little bit. I would try to find cards with old cars on them." (EF:6)

Shamey (1993) asserts out that "faith memories" can be cued like this, indeed stimulation of general memories may have meaningful faith associations. A related area is Brown and Ellor's (cited by Shamey (1993) finding, that a feeling of well-being remains with the confused elderly person long after the ability to conceptualise that feeling has been lost. So, if, in the course of a pastoral encounter an confused elderly person can be enabled to feel well, or feel loved by God and the pastor, then Brown and Ellor maintain that the feeling of well-being remains.

E.F., however was not the only person to speak of photographs, C.D. told of the following situation:

"I'm just thinking of [Lady's Name], she has a photograph in her room of some folk and myself. I spoke to her about that, but she didn't really know who was in the photograph and I sometimes find in that sort of situation you can explore a wee bit." (CD:25)

It may be that their relatedness to a number of senses is one of the reasons for the meaningfulness of symbols and the sacraments for people who are confused.

(j) Music

The emphasis at this point will be on music and singing in one-to-one interaction. The use of familiar hymns and music in worship will be examined at a later stage as part of the section on Public Worship. Three of the ministers interviewed spoke of singing in this one-to-one context. It is notable that two of the three were women. One of the emphases in O.P.'s pastoral care of confused elderly

people was "reactivating the faith" which had been built up throughout the confused person's lifetime. Speaking of ways by which this might be achieved she said:

"Sometimes we do daft things like sing a wee verse of "Away in a manger" or "Jesus bids us shine" or "Jesus loves me", and I would just hold their hand and sing along with them. Sometimes it turns into "Auld Lang Sang" or something, but I think care is the overall thing." (OP:22)

U.V. told of how her Granny enjoyed music:

"In the place where my Grandmother is and other places round about here, they have a small room, about this size where there are seats all round, but there is a focal point, and they have a video and country dance music or something that they can take part in. I tell you it's so good for my Granny and she loves it. They have fiddle groups who come in and most of the residents just love it. Music is wonderful. Again its all sense, smell, touch." (UV:74)

U.V. then told of how she brought this love of, and enjoyment of music, into one-to-one interaction, both with her Granny and others. She speaks generally at first and then about her Grandmother:

"If you go back to childhood and talk about streets which were known to them and things like that, the memory can be triggered, or start singing a song (UV:2) - My Granny is so simplistic in her faith, you know, she'll start singing a wee song, she loves to sing "Jesus loves me" and when she sings, it's almost a "wee girl" voice. You can start singing things like that with her and "What a friend we have in Jesus" and some of the old mission hymns." (UV:29)

The evidence therefore would appear to suggest that music and singing are not just helpful in public worship, but also in one-to-one situations of pastoral care.

(k) Dance

Only one of the ministers mentioned dance, so it could not be claimed that it was a general theme. E.F. spoke of dance in the context of non-verbal communication:

"I've learnt so much from the people who weren't able to communicate much, about silence, that's another dimension which perhaps I have brought into the church situation - and other means of communication apart from speaking, music and dance, touch and eye-contact. I mean you can do a lot with movement can't you? , and things like that.- I have done a lot of one-to-one Communion with people who are very, very sick and realise how meaningful that becomes with as few words as possible. In a sense its more about the grace of God and just having to provide the symbols, the signs." (EF:42),(EF:43),(EF:44),(EF:45)

(l) Prayer

Prayer was mentioned by all of the ministers as being one aspect of the pastoral care which they offered to confused elderly people. The familiarity of ritualised, liturgical prayers was emphasised by I.J.:

"Oh, yes, that [prayer] can be a great touch into the past, into their memory, because, as you know, prayer can become a very habitual thing, so, certainly in Catholic terms, if you put some old prayer in front of these people, you know, just say a couple of words, the rest of it will come out! Perhaps it's a prayer that I wouldn't even remember myself, I mean we have a long Prayer of Sorrow, which I could never master as a kid and I certainly cannot master it as an adult, but some of these old people - I mean I will say "Oh, my God" and the whole thing will come out." (IJ:7)

Others, like C.D. spoke of informal extempore prayer. He told of one particular lady:

"I think that possibly the most distressing case is this lady whom I have at the moment. The Home she's in are very keen to keep her there, they're very fond of her, but she gets quite violent. When I see her, she's certainly not violent but there's this panic that comes over her. At first I thought that it's really the toilet she wanted, she was getting so distressed, but discovered that there's something else and , so, what I have done in her case is

just to pray quietly with her and certainly she seems to quieten a wee bit."
(CD:8)

U.V. sees her prayers as summarising the pastoral encounter, she explains:

"I always say a prayer and my idea of prayer is using what we've spoken about in the conversation ...such things like - "we thank you for the time we've had together and being able to talk together" (UV:50) ...So this lady , I said a prayer with her. I just went over things which she's been through and things we'd talked about, to help her to be able to trust a little bit more. You have got to pray so simply and then, at the end of the prayer, I didn't even look into her face at the time, I was just holding her hand and she was holding my hand so tightly and when I stopped, there were tears on her face."
(UV:26)

A similar view of prayer was evidenced by C.D. It is useful to note that he does not presume that prayer will be welcomed, nor does he impose it on the situation:

"It depends on the person but usually I'll say "We'll have a prayer before I go" and lots of folk will accept that. There are one or two folk who are not quite sure and I'll say "Would you mind if I pray?" and then they say something like "Oh well, if you want to!" (CD:24) There are one or two folk of course who don't want you to. But I think prayer focuses all we've talked about into "offering it to the Lord". - It's not a set prayer and I usually include what we've been talking about. ...I don't see why, as far as folk with Alzheimer's are concerned and those who are confused, that it shouldn't work with them, except of course in very extreme cases where the person doesn't seem to be quite latching on at all. Then I think, I would simply pray in the Spirit and perhaps have a formal blessing - the Aaronic blessing or say the Lord's prayer with them - that often rings bells and maybe I wouldn't be able to do anything other than that." (CD:25)

It is interesting that O.P. also said that at times she would substitute a blessing for extempore prayer, she spoke of visiting a very confused elderly person:

"I didn't say at the end, "shall we pray" which I think is almost a challenging thing and I did what I often do, I held her hand and said, "I have to go now, the Lord bless you and keep you, and be with us both until we see each other again" or "God be with you" or "the blessing of God be with you" . It's not a prayer, more of a blessing." (OP:56)

There were examples, for instance that previously cited from U.V. (above) or M.N. (in an earlier section), in which the pastors spoke of extempore prayer having a calming effect, on confused elderly people. E.F. told of one woman whom she knew well:

"She did, eventually, begin to respond a little bit to prayer, and holding her hand. Well I would believe in my heart, that the Holy Spirit was working on her in her lack of capacity to understand and I still think that He must, and that He doesn't forsake a person as much enlightened by the Spirit as she was." (EF:31)

E.F. spoke of other reactions to prayer:

"Tears, emotional tears often. I didn't get much aggressive behaviour, the Wards were fairly regimented and some of the doors were locked and in there, were some folk who were really affected. However, again, it was those short bursts of stimulation - it wasn't anything long term and of course, they didn't remember you again the next time you went". (EF:10)

(m) Humour

It was U.V. who initiated the topic of humour into the interview. She reported that she found humour helpful, both in interaction with the confused elderly person and in working through her own reactions. It is important to note that humour, in her thinking, was held in conjunction with a very strong view of the dignity of the confused individual and respect for the person. U.V. maintained:

"But you need humour, a lot of humour. But I do think you have to have the patience of Job sometimes. I have seen ministers going in and saying "I told you last week when I was up", but you know they can't help being like that. I get confused enough about things myself "(UV:36) ...You know I was just talking recently about the funny things which people with dementia do, and the behaviour seems obscure and embarrassing, but if you don't let it be embarrassing then you are better at dealing with the issue in hand." (UV:41)

Both U.V. and O.P. refer to their own human fallibility when they speak of pastoral care of confused elderly people, as if this enables them to empathise with confused elderly people. U.V.'s reference is in the quotation given above in which she comments, "I get confused enough about things myself". (UV:36) On the same theme O.P., citing an acquaintance said:

"I remember him saying that we are all handicapped, its the degree of it. We're all a bit imperfect and need the grace of God to make us perfect and make us whole. Perhaps because somebody is in a Geriatric Ward, it emphasises the gap between her and me which isn't really valid." (OP:23)

In summary, in this section the pastors told of practical aspects of communication, verbal and nonverbal which enhanced pastoral care. In Chapter 6, in which the results of the questionnaire are analysed, the possibility that pastors lacked confidence in their practice, in this area, was introduced. This possibility was raised as a potential explanation for the large number of uncertain responses recorded for some of the questions. On the basis of the interview analysis, it appears that a universal diagnosis of 'lack of confidence' would be difficult to maintain. Where the pastors have had positive experiences they are confident in their pastoral practice. This, however, does not prevent them asking questions and reflecting in a creative way. Thus for example, K.L., reflecting on an confused elderly man who is a member of his congregation and attends public worship on a Sunday, said:

"Until I had this interview with you, I am ashamed to say that after twenty-four-and-a-half years as a parish minister, I have never addressed the questions "What should we be doing on a Sunday morning to make worship more accessible for confused elderly people?" and I am ashamed of that actually - and I'm not just sure of how to meet it." (KL:29)

This example shows that uncertainty need not be an implication of lack of confidence in pastoral practice. That being said, some did give evidence of some uncertainty. M.N. spoke of his experience of prayer with an confused elderly man, when, to his amazement the man prayed lucidly:

"So, you just don't know, I mean I don't know how something like that happens or what the process is - but I trust that God is in some way at work." (MN:17)

Thus whether uncertainty arises out of lack of confidence or out of insecurity there may be value in further training. It is also important to note that some of these examples come from only one or two representatives, and so there are possibly large numbers of clergy who would not exhibit good practice. We now move to the next section and the subject of "Public Worship".

2. Public Worship

Although some of the ministers spoke about the attendance of confused elderly people at congregational worship on Sunday, and these comments will be reviewed, the main emphasis in their comments was on services of worship which were aimed at people with dementia in particular. The review of their comments will begin with those made about Sunday, congregational worship.

(a) Attendance of Confused Elderly People at Public Worship

Doubts were mentioned by I.J. about the value of bringing very confused people to congregational worship. He said:

" Those who are able, sometimes, can be taken out to church on Sunday as part of keeping their social life going, and arrangements would be made to take them out. Those who are really confused, they wouldn't have the

attention span for Mass and it would be putting them through an experience which they wouldn't really want." (IJ:17)

K.L., through talking with a carer, had had experience of some of the difficulties which confused people can encounter as part of "normal" Sunday worship:

"I have, I suppose on a Sunday morning, probably only one who is a regular worshipper and is a confused elderly person. His daughter is a good friend of mine and I know from her that he loves organ music, but he finds the number [of people] frightening. Obviously I wish he would find it more frightening as I wish numbers were bigger! I know he finds this difficult and I was thinking about how it would be possible for him to get the atmosphere of good singing without having to feel part of a crowd. Another thing is, the church he comes to is his daughter's church and not the one with which he is familiar and that's awkward for him as well. Until I had this interview with you, I am ashamed to say that after twenty- four and a half years as a parish minister, I have never addressed the questions "What should we be doing on a Sunday morning to make worship more accessible for confused elderly people?", and I'm ashamed of that actually, and I'm not just sure of how to meet it." (KL:29)

Some interesting comments were made by Q.R. He appears to be balancing what he understands as being an important theological message - that all are welcome to worship and valued by God, with underlying questions about whether or not attendance is of value to the individual, and the potential disruption which a confused person could cause. Speaking of an confused elderly woman who used to attend Sunday morning worship he made the following comments:

"She used to wander the streets and if there was anything on in the church she would come in, so she was at every service and a lot of meetings during the week. Up until the end she really seemed to know, although she was not understanding she was sufficiently taking part in things for it not to be too intrusive. But I would be pushed to say what she actually latched on to" (QR:8),(QR:9),(QR:10),(QR:11),(QR:12) "I wouldn't use the word "participate", she was present. I think a lot of the time she just sat there" (QR:18),(QR:19) "God loves them, they are part of the church. I think that's why I was glad when the lady I spoke to you about earlier wanted to come to church. Her behaviour was, on occasions, inappropriate, but we are wanting to say as a church that everybody's welcome here, whoever they are, and that

church isn't a place you stop coming to when you lose your respectability"
(QR:81),(QR:82),(QR:83),(QR:84)

Without doubt the most frequently mentioned topic with regard to worship in any context was familiarity. Familiarity it was claimed was a salient feature in enhancing understanding and participation of confused elderly people, and that familiarity applied to prayers, hymns, Bible readings and liturgy where that was familiar.

Both I.J. and Q.R. spoke of how the person's response to the Lord's Prayer helped them to gauge the individual's level of understanding. I.J. said:

"The "Our Father" would be very familiar, you know, once we get to the "Our Father" I would know whether or not I'd made contact - if there was a response coming, that is when it would come. The liturgy I would say at the Communion Service is about three minutes and if I could hold concentration for that I would be satisfied. The Mass, you know, if you are going to give Mass, you're looking at 25 minutes and that's a lot of time for a confused patient." (IJ:19)

Thus, in his experience, even the familiarity of the Mass was not enough to counteract concentration deficits. Q.R. also saw response to the Lord's Prayer as an indicator of the individual's level of confusion. He reported:

"I would sometimes get a clue as to how or where somebody is at, by simply praying the Lord's Prayer with them." (QR:44)

The Bible readings which the ministers had found to be meaningful for confused elderly people were also the familiar ones. K.L.'s comment is representative:

"I try to read the Bible, and when I do that I tend to read one of three or four well-known Psalms or one or two very well-known passages from the Gospels." (KL:4)

Due to his experience of the helpfulness of familiarity in enhancing understanding, K.L. commented that he tended to use what he perceived to be the most familiar Bible version when leading worship with confused people saying:

"I always, in that context, use the Authorised Version, which is not my normal practice." (KL:15)

Both Roman Catholic and Protestant clergy reported that the sacraments were powerful communicators. When asked if the Mass seemed to trigger memories for confused elderly people A.B. responded:

"Oh, very much so. The Mass is a very big thing in their lives and the symbols are very important for them, the candles, the alter, and the Priest in vestments, all of these are very important to them, and they remember." (AB:19)

G.H., an Episcopalian, spoke of his experience of the value of the sacraments:

"Back to [Town Name] where I ran 26 services a year. Every alternate Service except special occasions, such as Christmas, Easter and Whit was Communion - evening prayer and a celebration. The youngest was about 65-70, and the oldest was 104. We held it in the Dining Room. Yes, there were people who were confused and part of it they wouldn't follow. Two things they always followed, the Lord's Prayer and the receiving of the sacrament." (GH:9)

A Presbyterian minister, C.D. was in accord with the previous statements.

"The other thing are the sacraments, Communion. I feel more and more that for most people who have known this in a personal way, it is very helpful because it is something familiar. Now some folk come from traditions where it's not really at all that familiar and in some ways the Church of Scotland, because of our rather formal approach in the past where you might have the communion quarterly, or six monthly or annually, in some ways, people associate it, in their minds, with a very formal approach. But where Communion has a more personal meaning, I think it can be very helpful. Again, it's something familiar." (CD:4)

Another aspect of the theme of familiarity which was stressed by the interviewees was familiar music and hymns. Both of these had been found to be helpful in orientating the confused elderly person and enhancing understanding. E.F. commented:

"The ones in the Chapel situation obviously weren't able to articulate anything very much, it was all given to them. But they would sing. They each had a volunteer beside them who would turn the pages of the hymn-book for them, and they would often sit there, clutching the hymn-book. There was a response." (EF:25)

C.D. agreed:

"There is this great heritage of Christian song which is there and people have it, and I try to capitalise on that. Sometimes I will just repeat a Psalm, say Psalm 23 and just repeat it with them and say it as a prayer and that's helpful." (CD:14)

This review highlights the fact that familiarity was the overriding theme when the ministers were asked about formal worship with people who are elderly and confused. Familiarity, whether it be with regard to music, liturgy or scripture engendered meaningful communication, and facilitated worship.

(b) Reality Orientation and Worship

Although a number of the ministers spoke of utilising reality orientation to enhance the confused person's understanding in one-to-one communication, only two spoke of it directly in the context of services of worship. A.B. told of how he would introduce himself at the beginning of Mass:

"Just by asking, "You know I'm the priest" and it usually gets some reaction." (AB:9)

O.P. told of one instance in a service when she felt that it was important that the participants were aware of the season:

"One time it was Christmas and they didn't have any Christmas things because they wanted all these ones like "Oh love that will not let me go" and "Abide with me". And then I said very firmly, "It's Christmas time, I wondered if I could ask if [Man's Name] could choose one" as he was one of my elders, and they were all quite happy for him to choose, and he chose a Christmas one. (OP:34)

It is thus evident that some of the interviewees carried over the principle of reality orientation from one-to-one interaction into more formalised worship.

(c) Difficulties in Worship

(i) Mixed Abilities

By far the most commonly mentioned difficulty encountered by the ministers with regard to organising services was that of trying to cater for a group of people who had very different abilities and deficits. Referring to leading worship in a Residential Home O.P. made the following comment:

"There are a group of about 20, and they have differing, I don't know whether to use the word ability or disability. I mean some are there because they are maybe not just able to move, they have had a stroke, or they are very crippled with arthritis or maybe deaf, but they are all right mentally. But others are quite confused." (OP:32)

Constructing a service that would be meaningful for all participants became a major influence on ministers' attitudes, and practice, with regard to the structure and content of worship in this context. It is interesting that in response to similar conditions very different practices were evidenced. G.H. believed that the most appropriate service was a "normal Christian pastoral service", he described his practice thus:

"we have a system where a different organisation takes a Service for 35-40 minutes each Sunday. ...Now in that group which come down from the day room, from the four units you have got people as completely coherent as ourselves to the ones who are just in there prior to going to a Nursing Home. Now the type of service I run there is as near as we can to a normal pastoral Christian service, non-denominational because we have got primarily Church of Scotland people. We let the people choose hymns, we use open prayers with the Lord's Prayer and we give a standard sermon which I feel is important and end up with tea and biscuits. We don't use a standard liturgy such as we use in church for the Eucharist, unless they want Communion ...and then I would probably use a simplified form, right across the denominations. I think I speak for others, when I say we try to give a Christian service and a Christian sermon or address which is across the board. We find that even with people with dementia you just don't know where that level is of listening and reasoning. Just to refer to the lady in her eighties who passed on recently, she had already suffered a stroke and very bad dementia, that left her frustrated because if she sat here today she would understand what we were talking about but she could not communicate. She could speak but couldn't communicate, a lot of people get confused between the two. On the other hand, you don't know what is going in and at what level, you don't know when they shut off." (GH:8)

This very long quotation is included in its entirety as it raises a number of issues. The first concerns the use of liturgy. G.H. is an Episcopalian, who therefore comes from a rich liturgical tradition. In addition, practitioners contend that liturgy, due to its over-learned, familiar nature is useful in enhancing communication with confused elderly people (Clayton 1991). Yet G.H. rejects its use in place of open prayers and a simplified Communion. This is possibly due to the fact that his experience does not bear out the claims of the researchers or it may be that he feels constrained by practicalities. He is sharing worship with other denominations, and is in a context where another denomination is in the majority; it may be that he feels that he cannot use his liturgy out of respect for the others present. If this is the case it is a finding with large scale implications as many services in Nursing and Residential Homes appear to be undertaken on a shared basis. In this context, finding aspects of

worship which are familiar to all may be a difficult task. It could, therefore, be claimed that although familiar liturgy is important it is almost impossible to implement it, if ministers are normally in a situation where the participants are from different denominations.

Secondly G.H.'s comments highlight the importance of services of worship from a social point of view for the confused people, a point to which reference was made by other ministers, for example E.F. said:

"The going out of the Chapel was very important. We spoke to each person, so the line-up of wheel-chairs at the door was very important and the volunteers would tell us which ward they came from and it was always "How are you today?" and they would smile. There was a response." (EF:30)

Thirdly, G.H.'s attitude to the sermon is note-worthy. He includes it out of respect for the people who are confused and also because he contends that it is impossible to know how much the confused people are taking in. Both of these are laudable reasons. However his attitude to content and type of sermon would not be upheld by all of the researchers, or indeed, by the findings from the questionnaire[3:3] p.454 where 38.8% of the respondents (n=124) rated a sermon as unhelpful, or very unhelpful, in public worship with confused elderly people. This is an opinion shared by some of the other ministers in this survey. U.V. exemplifies a very different attitude to G.H.:

"Public worship is very difficult because it can be upsetting sometimes. The sermon isn't all that constructive for someone with dementia, but I feel in Nursing Homes a small service with hymns which people know and just a few words, even just to say "Jesus loves us" and then a short prayer." (UV:46)

In the interviews a tension is evidenced between formality and liturgy, which set the scene for worship in the confused people's minds, and which could almost be claimed to be reality orientation in themselves, and informality and simplicity which some of the ministers seem to feel intuitively is the right approach. If G.H. is illustrative of a predominantly formal approach, M.N. stresses informality:

"When I was in [City Name] I went to visit some residential homes on a regular basis where some, not all, but where some of the folk would have been confused. Again, it is the familiar hymns, keeping it simple, being informal and relaxed and to enjoy the time, I think that can be helpful."
(MN:6)

The other issue which ministers appear to be holding in balance with the value of liturgy is that of complexity. In response to the comprehension difficulties evidenced by confused elderly people, some ministers believe that communication and meaningfulness in worship is enhanced more through simplification, than by the familiarity of liturgy. I.J. said:

"Those who are really confused, they wouldn't have the attention span for the Mass and it might be putting them through an experience which they wouldn't really want. A simple Communion service with two or three minutes of concentration, if I can get that from them I would regard that as sufficient. ...I would use the same (liturgy) with them every time. I would say, basically, a short penitential rite from the beginning of the Mass and then simply say the "our Father"." (IJ:17),(IJ:18)

In his approach to the Mass I.J. thus seeks to combine familiarity and aspects of liturgy with simplicity. It thus appears that having to deal with people of differing abilities, is one factor in giving rise to varying approaches to worship with confused elderly people.

(ii) Disruptive Behaviour

Another difficulty which ministers mentioned in connection with leading worship with confused elderly people was that of disruptive behaviour. K.L. spoke of his experience:

"I have any number of experiences, of failures, of people interrupting, of people wanting out and being abusive during worship. I have to say that because I've been doing it for so long now it doesn't get to me at all - it probably did when I was younger." (KL:17)

When asked how he dealt with difficult behaviour he replied "Ignore it". C.D. said:

"Sometimes they can go completely crazy! I mean I remember folk who used to wander up and down and round about in the course of things. I used to have people with me from my congregation and at first they found this a bit difficult; but I think because I said "Look, it's OK., just let her do that" and I mean she might wander round and open doors and do various things, although there were staff around to keep things within limits, but I think you have to take folk as they are." (CD:7) "I think that, sometimes, people's reaction is to stand back, keep their distance and not get involved and keep everything as quiet as possible, but I think you have to accept them as they are, with inter-action where possible." (CD:6)

Dealing with what could be termed disruptive behaviour was also a factor in one-to-one situations. U.V.'s account is included, despite its length, as it highlights a number of facets of behaviour management:

"There's the violent behaviour and obviously you have to react to that as well, rather than saying "You can't do that", I've actually taken someone's hands firmly and said, "Now come on, you don't need to do that, I'm just here to talk to you." (UV:82) "Well, she got her walking stick and was going to hit me with it, and I said to her sternly "Do that again and I'll break your walking stick in half", she said "You wouldn't" and I said "I would". The fact that she started talking, it engaged her in something. They want to touch your face sometimes as well. Also, and I've only had this about two or three times ever, not with males, but with females, wanting to touch your whole body, and running their hands down your body and you don't know whether its a sexual thing or something like that. They'll sometimes take

your hand and put it on their breast or something," (UV:83) "and that can be uncomfortable and I sometimes don't know exactly how to deal with that." (UV:84) "I don't want them to feel uncomfortable about their bodies or anything like that, but I feel there's something sexual dysfunctioning here." (UV:85) "I just took hold of the person's wrists and hands, rather than reacting badly. I think that when the clothes start to come off a little bit of scolding is good." (UV:85) "There was an old man who used to annoy everyone in the place. He was quite confused but he'd catch you and say things like "let's see your chest". Probably he had been a bit of a Casanova in his day and it wasn't really out of disrespect for females either. The ladies were all so lady-like, and he would do indecent exposure all the time. So what I would do, until he started to behave himself, was to turn his wheelchair in the opposite direction! I would say, "This is not fair, other people don't like it". I found, sometimes, ignoring it as well was quite good, because it was an attention seeker." (UV:86)

U.V. was the only minister who referred to confused elderly people and inappropriate sexual behaviour. Her input, although not limited to worship and referring to a number of contexts, exemplifies different ways of dealing with difficult behaviour, speaking firmly, ignoring and physically moving the person. At another point in the interview she also spoke of using humour to diffuse what had the potential to be a difficult situation.

Having explored aspects of "difficult behaviour" the discussion will move to an examination of the minister's attitude to the participation of lay people in worship with confused elderly people.

(d) Lay Participation

The importance and value of lay people participating in the totality of pastoral care with confused elderly people was mentioned by half of the ministers. With regard to worship in a Residential Home, O.P. said:

"I don't do it on my own. I always go with a team of about four of us from the Kirk Session. One plays the piano, then two others look up hymn books for those who can read. Some will have a hymn book up to their noses reading, and others will have a hymn book and want it opened at the right place but not be able to read and some will hold it upside down." (OP:32)

E.F. spoke warmly about how she felt herself to be part of a team when she commented that: "the volunteers were so good as well. A great team." (EF:29)

Other ministers spoke of lay people's involvement in the running of clubs and Day Centres, A.B. exemplifies this:

"I have one or two parishioners who work with a club, run by the Episcopalian Church for confused elderly, and two or three of my parishioners work there." (AB:2)

(e) Participation in the Sacraments

In the questionnaire which preceded these interviews 79.9% of the respondents (n=124), rated Holy Communion as helpful, or very helpful for elderly, confused people [3:11] p.457. At that time it was noted that "this very positive view is interesting, as it may be indicative of an underlying theological opinion which does not exclude people with dementia from participation in this sacrament". Questions were therefore asked of the ministers in the in-depth interviews about their attitude to the admission of confused elderly people to the sacraments. The initial comments

come from the Roman Catholic participants who have a rich sacramental tradition. A.B.'s comments indicate his experience of the meaningfulness of the sacraments for confused people, at the same time he would wish to see some level of understanding before administering Mass to a confused person:

"There are certain sacraments which we can give, even if they are confused, even if a person is unconscious. Now this is what we call "anointing" obviously for Confession, where the strength of our Lord's grace is given to them, and they do find that this helps them physically. Not that it cures of course. I had a case the other day, I was certain that this old lady was going to die very shortly, and she was fine. So it's something which bucks them up, and whatever it is, some kind of psychological thing, just to give them absolution seems to be meaningful, and they definitely feel the benefit. That sacrament we give to a person even if they are unconscious or confused, because the Church's idea is that they do need a sacrament, an Absolution." (AB:4),(AB:5)

When asked if, with regard to Communion, the person would have to understand what was happening he replied:

"Oh yes, I would think so, I don't think that you could give it to them without them knowing." (AB:6)

I.J., the other Roman Catholic participant also sought some level of understanding prior to administration of the Eucharist. In response to the same question he said:

"Yes, if I go in and say "I'm a Catholic priest, are you sure you're a Catholic?" ...then it would depend on the sort of reaction I got from them. I'm sure the good Lord will understand that I sometimes take chances with His Presence, and as a Catholic priest I have always had a tremendous respect for our understanding of Christ's Presence. But I would always give the benefit of the doubt to the patient." (IJ:11) "If they live very much in the present moment, OK. Within that present moment they can recognise me as a priest, then I would minister to them to the extent of sharing Holy Communion with them. I wouldn't exclude them from Holy Communion simply because they have Alzheimer's." (IJ:2)

None of the Protestant ministers said that they would exclude people with dementia from Holy Communion. M.N. said:

"I mean it is difficult to know what goes on in people's minds isn't it? I don't have any problem with it. I mean if I know that they have been members of the Church and have been used to receiving Communion, then I have no problems, especially if they want it or their family want it. I mean I think that some people who are fully aware do not always understand what they are doing when they receive communion, so I don't think that there's a problem - certainly not for me." (MN:5)

K.L. spoke of a particular meaningful experience of sharing Communion with a confused person, and of his underlying theological understanding:

"I haven't any pictures in my mind of people taking Communion in Church, but I certainly have several experiences of taking communion with confused people in their own homes. That, I think has almost always grown out of them being already ill at home and taking Communion, and so this has been my practice and I have just carried on. However, I can think of having done it at the prompting of a husband, and indeed also of a wife, both of whom asked me to do it and I did it. I actually put the bread and wine into the person's mouth. My feelings about that I have to say, are not personal and pastoral but are bound up with what I believe about God and what I believe about the Lord's Supper and anticipation of the end. Therefore I believe exactly the same about that as I believe if you and I were having Communion together." (KL:20)

Despite the fact that all of the Protestant ministers thought that it was permissible, not all of them agreed that it was helpful, U.V. told this story:

"To go back to the two sisters I was telling you about. One would have driven you batty at one point, you know, to the extent of talking about different things during the service because she didn't really know where she was. ...I took home Communion to her and she wanted Communion, but she was quite confused. You know, going through the sacraments she was quite deaf as well and she kept saying "Eh?" and I'm quite loud so I would say "Have you got your hearing aid in Jean?", "Eh?". So we'd look for the hearing aid and get it, and start again. ...Then we got to the part with the bread and she was fine. I handed her the bread and said, "The body of Christ broken for you", "Is it blest" she shouted, "yes its blest [Lady's Name]". Then we do the wine after that. "I can't take wine for my stomach" I said "That's fine [Lady's

Name], you don't have to have it, its not alcoholic. She then said "Well you'll have to wait a few minutes, I'll have to go in and take some milk first, I want to take the wine." (UV:16)

Practical difficulties inherent in confused elderly people taking Communion were also mentioned by A.B. who commented;

"I've seen some being given it thinking that they would be all right, and they can't swallow." (AB:8)

The reason that the sacraments in general, and Holy Communion in particular, appeared to communicate meaning to the confused elderly people was touched upon by some of the ministers. I.J. spoke of the familiarity for elderly people of the "white cloth and a few candles" (IJ:8), whereas O.P. stressed its familiarity and symbolic nature. It is interesting too, that two of the ministers maintained what they believed to be the meaningfulness of Communion despite unexpected reactions to the elements. O.P. again spoke of a woman who drank deep from the cup and then took another draught because, she said, "it was good stuff and she was thirsty" (OP:37), and A.B. told of another woman who thought she was toasting in the New Year with the wine.

From this data it is clear that the majority of the ministers believed that Holy Communion was meaningful for the confused elderly person, and that it communicated something to them of the love and care of Christ.

3. Listening to the Confused Elderly Person

The primary focus of attention up to this point has been on communication as the pastor's initiative. This focus now shifts to the way in which the confused elderly person may be communicating, and to the pastor's willingness and ability to interpret that communication. Two issues which arose in the interviews are of particular relevance to this area. They are, the pastor's experience of confused elderly people expressing their feelings, and picking up cues, often non-verbal cues, from the person with dementia.

(a) Confused Elderly People Expressing their Feelings

When asked if they had been in a situation where someone who is confused has expressed anger, grief, or a feeling of being abandoned by people or by God, a number of the interviewees responded with instances to support their contention that they had. K.L. responded thus:

"Fear, most often, I'm very familiar with that. I don't have any memories of confused people abusing God at all. Quite often fear and sadness and despair, but the fear is very ephemeral, it comes and goes. I said to you earlier that I have almost no record of success in talking things through as in a normal pastoral situation" (KL:21) "You don't need to be a very good minister to know that there are things in the Gospel which relate to fear. I'm quite used to people wanting to hold on to you, a sort of security thing, particularly when going away, people are very anxious for that not to happen." (KL:22)

Realising that confused elderly people have real fears was also an issue which E.F. raised when she said that in small group situations, she would draw out "what their fears were". She spoke of using Bible readings to stimulate communication in a worship setting:

"Often I would read a Bible story which, perhaps, drew them in to that, or pick something which had been going on that day outside. I can remember one particular time, it was Armistice Day, Poppy Day, and that drew them out. Those who could communicate were sometimes very vociferous, ...so their fears would actually come out." (EF:24)

There was also recognition, as demonstrated by I.J. that the confused elderly person may feel guilt or concern about past sins. His approach illustrates that he recognises the validity of those feelings:

"So, if I am confronted by a confused person, who may really be going through agony because of something which is there I think that to say to them "Forget it" is not helpful at all. I may say that to a younger person, but to a confused person I think you have got to let them go through what was a tried and tested method for them, as laid down by the church, that they should confess their sins to the Priest, in the hope that they may find some calmness in the aftermath of confession." (IJ:25)

E.F. spoke of an old man who despite severe dementia was troubled by the death of his wife:

"I did get glimpses of recognition from the old man - he was in for two-and-a-half years of the five years I was there and he died in hospital. There were times of deep unhappiness with him, which he couldn't express in words, but he recollected sometimes his loss - it was through crying, I mean he would take my hand. I knew what was wrong, it was about his wife, so you know there were times, often, when he would not talk about it but indicate that there was something deeply painful." (EF:10)

The pastors told of other emotions being expressed in addition to fear and sadness. O.P. recalled one woman who was angry with her sister for "leaving her":

"it was a woman whose sister was a lovely, lovely person. The sister did most of the caring, but she got terminal cancer and died within six or seven months. The one who was left was very resentful, partly, I think because she was always cared for by the one who died. Sometimes she would say "Why did [Sister's Name] leave me?" not "Why did God take [Sister's Name]?" and sometimes I am very blunt and say "it was sad that she died" because I don't know whether she believes that [Sister's Name] walked out on her or whether she realises that she actually died. I don't know the right thing

to say so I tend to say fairly bland things, which nevertheless I believe to be true like, "we're all in God's hands." "(OP:6)

A.B. recounted how he had experienced confused elderly people asking questions of God:

"I have heard them say "I wonder why God does this?" which is natural you know, and I'll say something like "there must be some kind of reason which we can't, at the moment, understand". When a child of four or five weeks dies, that's a difficult one. But I find the older generation are very accepting in a Christian way. I have now, occasionally, been to hospital and been turned away - a lady just couldn't accept things - but in the end, I think, I got through to her a little." (AB:17)

(b) Picking up Cues

It therefore appears that a willingness to accept the confused elderly person as they are, and to let them take initiatives in communication is instrumental in opening up the possibility of meaningful interaction. Approaching the confused elderly person with that attitude may mean that the pastor will be open to interpreting the cues which the confused person gives them, rather than dismissing those signals as meaningless or simply as symptomatic of the condition. M.N. mentioned: "I suppose people who can't communicate verbally often can give you signals as well". O.P. gave a startling example of meaningful communication which happened because she was willing to pick up, and act upon, the cues being given to her by a respected confused elderly minister:

"Let me tell one story about my predecessor, the [Predecessor's Fullname], a lovely man full of vitality, full of life, wonderful bass/baritone voice, he played the piano - a great character. He had dementia and ended up a pathetic creature, tied to a chair and latterly he was in bed, three weeks before he died I visited him. He was in bed and I said "I'm going to go now [Predecessor's Christian Name], I will be in to see you again". I think he recognised who I was because he always used to say to me "I'm so glad that

you are my successor" I think he recognised the voice. On my going he suddenly lifted his right hand, he was prone, I expected him to say the Blessing but the words didn't come so I said it, "The Blessing of Almighty God, Father, Son and Holy Spirit", and he waited until I said "Amen" and then put his hand down. Now don't tell me that he didn't, at some spiritual level, understand what was going on, and yet he couldn't get a word out. I find that very moving, after saying good-bye I had to go outside and mop the tears up in the corridor. He died very soon after that." (OP:57),(OP:58)

This example illustrates how a minister was able to facilitate the occurrence of meaningful and truly pastoral communication, through realising that the cue which they were being given was meaningful and picking up on it.

As a result of the findings from the questionnaire (Stage 4), the questions "How do pastors know or assess that meaningful pastoral communication has taken place?", and "How do they know that the individual with dementia is, or is not, assured of the love of God?", were raised. Analysis of these interviews has highlighted some answers to these questions.

The first possibility is that "knowing" is the work of the Holy Spirit as indicated by C.D. "I think you sense" (CD:12). The second possibility is that, in these pastors' experience, the confused elderly person reacted to communication in various ways. In some instances there were tears (UV:26), squeezing of hand (MN:19), or the person might, unexpectedly, join in saying the Lord's Prayer, as described by QR: "I would sometimes get a clue as to how or where somebody is at by simply praying the Lord's prayer with them" (QR:44), or overt cues as described by O.P.(OP:58),(OP:57). All of these instances, and there are many more examples in

the text, illustrate the finding that confused elderly people can communicate in many different ways.

Families and Carers

It has been repeatedly asserted that the focus of this research is on the confused individual rather than their family or carers. This is not meant to belittle or ignore the devastating effect which dementia has on the family circle of the sufferer, but rather is in recognition of the fact that much research has already been done in this area. However, that being maintained, it was found that this subject could not be totally neglected, and it became necessary to assess whether or not ministers felt that pastoral care aimed at the confused individual was worthwhile in itself, or whether the better approach was "systems pastoral care", as described by E.M. Pattison (1972). According to this model, pastoral care is focused on the family, in the hope that its benefits will be felt, indirectly, by the confused individual. Families were also relevant because, anecdotally, there was evidence that for some ministers, families were a motivating factor in their pastoral care of confused elderly individuals. They visited, so that the families would feel that their loved one was still important and valued by the church. Therefore in the questionnaire (Stage 4) the ministers were asked to rate the level of their agreement with the statements; "I find that the most effective way of caring for confused elderly people is to support the carers" [4:7]

p.464, and "I prefer visiting confused elderly people when somebody else is there" [4:16] p.468.

At the interview stage, the occurrence of the issue of families was also analysed . A conclusion drawn from the analysis of responses concerning families was that "there are strong indications that a systems approach is the pastoral response of a number of these pastors." It was felt desirable therefore to explore this issue further at the interviews.

For S.T. a priority in pastoral care was the family of the confused elderly person. He made this clear in his comments:

"It might be that more time needs to go the wider family, and to the generation below them rather than with the actual person, the problem might very well present itself as "What will we do with Mum?",[or] "What are we going to do with Dad?", because the person themselves might not be aware of what is going on. So the priority is more likely to be the family or the next generation or whatever." (ST:13),(ST:14)

The needs of the family were also emphasised by Q.R.:

"My own interpretation is that the suffering is caused to the people who know them and who feel they've lost them, that the person themselves is mercifully beyond the state of awareness." (QR:70),(QR:71),(QR:72) "That's certainly how I perceive the situation, so to see somebody suffering from severe dementia I don't worry about the person, I do worry, I do feel for the family." (QR:73) "So there is a question about what we are trying to do when they are very severely demented? When they are living at home I think there is a great ministry to their family because again you are saying that you're with them in what is a very difficult and demanding situation." (QR:80),(QR:81)

The belief that a pastoral visit made a difference for the family, whether or not it was meaningful for the person with dementia, was also mentioned by K.L. who said:

"Whether, in fact, it's always a great thing for the visited person is another matter altogether. I'm also quite clear that for the visited person's family, it is very important." (KL:8)

The same point was made by U.V.:

"I find its more difficult for families than for the actual person with dementia, especially if the person is fairly young, and the husband isn't a husband any longer, or hasn't been for a few years, and the person changes from someone that someone has been depending on, to being someone who is totally dependent. People can't handle that, and its sometimes easier for an outsider to be able to accept them at the level they're at- whereas if you are emotionally involved, it is really difficult." (UV:4)

The perception that the person whom they love has changed or gone, and the subsequent role changes which may arise from that, was one of the difficulties for the family which was raised most frequently by the ministers. It is illustrated by U.V.'s comments above and by Q.R.'s aside that families feel that they have "lost" their loved one. E.F. put it this way:

"Sometimes relatives find it impossible to cope with them because they have deep feelings when the character of someone changes." (EF:35)

One story which U.V. told is effective in highlighting role changes brought on by dementia within a family:

"My Session Clerk's wife's mother stayed with them for long enough, with dementia. She would talk to [Session Clerk's Wife's Name] as if she were someone else. She would say, "Oh, you are so nice to me, you know my daughter's not" and it was terribly funny. [Session Clerk's Name], my Session Clerk is super and she would tell him to get off the 'phone! I mean I was in their house one time, and they were on the 'phone to someone and she said "You've been on the 'phone long enough, this isn't your house." (UV:33)

S.T., in telling of one particular pastoral situation highlighted other difficulties which the family and friends may face:

"One is a bachelor, and it would be friends more than family who are keeping more and more of a part up, for instance - at the present moment he gives someone a lift to church, that person is now afraid to travel in the car with them. The other is a husband and wife of many years. She has a family history of dementia. Certainly two older members of her family, probably both sisters have already died with dementia, and her husband is now scared stiff about admitting the fact that she clearly has Alzheimer's and is over-protective and not quite ready yet to accept, he knows that this is likely to be the beginning of the end." (ST:16),(ST:17)

An additional difficulty sometimes encountered by families is that others do not recognise, or appear to believe the extent of the illness. S.T., again, speaking of the husband and wife to whom he had previously referred said:

"the woman, the sufferer herself, she delights in company, she is bright and alert. The pity is that you go over every conversation three times in every twenty minutes. But it is animated and excited while it lasts." (ST:19) The problem is that this can give the impression that everything is all right to visitors with the result that the husband feels that he has to battle on alone." (ST:20)

These comments illustrate that dementia has wide-scale effects, on the individual, the primary carer and extending to family and friends.

Summary

These in-depth interviews have brought a great deal of pastoral experience and expertise to light. As was the case with the questionnaires (Stage 4) the pastors' insights have a high level of correlation with the research findings presented in the literature review. In the chapter which follows, the evidence from each stage will be integrated, with the aim of developing a theological basis and a practical method

which have the potential, when utilised, to enhance pastoral communication with confused elderly people.

CHAPTER EIGHT

**THE DEVELOPMENT OF A THEOLOGICAL BASIS FOR THE
PASTORAL CARE OF CONFUSED ELDERLY PEOPLE**

THE DEVELOPMENT OF A THEOLOGICAL BASIS FOR
PASTORAL CARE OF CONFUSED ELDERLY PEOPLE

Introduction

In this chapter, having undertaken a wide-ranging literature review, implemented the research design, and presented the study's findings, we now turn to the task of integrating the research results with theoretical perspectives. As the purpose of this study is to provide a means whereby the pastoral care of confused elderly people may be enhanced, the aim of these final chapters, is to develop a pastoral and theological basis or model and a method, based upon the research findings, which informs the pastoral care of this group.

Underlying the research, influencing both theory and method, has been an assertion of the dynamic inter-relationship between theory and practice. The first focus of this discussion, therefore, will be an examination and development of that theoretical position in the light of the research findings.

Theology and Practice

In the introduction to this study, the relationship between theological understanding and pastoral practice was introduced as a theme. It was claimed there but also in the literature review, that there are weaknesses both in models which understand pastoral care as applied theology and those which describe pastoral care

as being rooted in the application of the social sciences. Neither model was seen to provide a satisfactory basis for the integration of theory and practice.

Reference was then made to alternative models. Whitehead and Whitehead (1983) developed a tripartite model of theological reflection in which tradition, cultural information and personal experience are inter-related. Green (1990) developed a spiral model of theological reflection. According to this paradigm, an initial experience is explored using prior feelings and prejudices, as well as information and insight from related disciplines. There is then a stage of reflection, which in turn, feeds into response. The model is cyclical insofar as it recognises that the response results in experience, and thus the cycle begins again. These models, in common with that developed by Fowler (1995) have significant strengths, in that through active and on-going reflection, theology and practice are fundamentally related. The result is that theological understanding cannot remain purely cerebral, but is necessarily transformed into an 'owned' theology.

Review of the literature therefore indicates that theology and practice are integrally, reciprocally and dynamically inter-related. It is the task of this section to examine whether or not that theoretical contention holds true in the light of the research findings in this study.

The research findings which relate to this topic are as follows:-

1. The Pastors' Responses indicated that Theology and Practice were Integrally Inter-related in their Pastoral Care

Three aspects of this relationship were evidenced by the comments made by the respondents.

(a) Theological understanding influenced practice

This could also be described as an 'owned' theology being worked out in pastoral care. Some comments made by K.L. illustrate this point:-

"I need no persuading that the elderly, the housebound, the intellectually limited whose contact with the world is brief are every bit as precious and as valuable to God as people who are the chief office bearers in the congregation ...What I think I am there to do is for a moment to help them feel they're not alone, for a moment I hope to help them feel part of a congregation, and because God is better at this than I am, helping them to be reminded that they belong to God and that nothing, even their lack of understanding, can remove them from His care." (KL:10)

It is clear that the pastor's understanding of the worth of the confused elderly person, which emerged in this study as a dominant theme in pastors' thinking, not only motivates, but provides the content for, the pastoral care which he or she offers.

(b) Experience led to theological reflection

In the interviews (Stage 5) there was evidence that the ministers did reflect theologically on their experience of offering pastoral care to confused elderly people. A series of comments made by U.V. exemplify this. Her experience of pastoral care had prompted her to explore and reflect theologically on whether or not the faith of the confused person remains, despite the devastation of the disease. She said:

"I've had a few discussions about it with colleagues, is the soul awake to anything, and that brings in spirituality. There are certain things, not necessarily things that are "churchy" which cause emotions, and to me emotions come from the soul."
(UV:87),(UV:88)

Relating this to Green's (1990) spiral model there is evidence of the experience leading to reflection and exploration, which in turn led to response. In this case her reflection led to reinforcement of the efficacy of pastoral care of confused elderly people. Experience, therefore leads to theological reflection.

(c) Pastoral practice led to theological reflection and thence to response

The interviews (Stage 5) provided evidence of experience prompting theological reflection. M.N.'s comments make the continuing link back to practice explicit:

"I do feel quite strongly that when I go to visit folk who are severely confused that to a large extent it isn't the person, because the person is just slowly draining away and the body is still ticking. Now that is maybe a wrong picture, but its a helpful one for me as I am ministering." (MN:16)

It seems to be that his pastoral experience leads him to a theological perspective, with which he is not completely happy, but which is sufficient to inform his pastoral practice. It could be claimed this illustrates that, in this case, pastoral practice is the primary influence on theology, rather than the reverse.

Such comments are sufficient to illustrate the fact that, in practice, the inter-relationship which was described theoretically in the literature review, (Chapter 1), is maintained. The claim that theology and practice are integrally, reciprocally and dynamically related is supported. Theology was seen to inform practice, and practice has the power to inform and alter theological formation. This has direct relevance to theological and pastoral training. Fowler (1995) contends that:

"on-going interpretations of scripture and tradition, in correlation with present situations can fuel processes of change in church practices". (6)

This claim was reinforced by the evidence from interview analysis. If practice is to change then both scripture and/or, theology and experience will have a part to play. Practice therefore must be informed by a strong theological base and maintained by positive experience.

2. The pastors' responses indicated some dissonance between theological opinion and pastoral experience, with regard to pastoral care of confused elderly people.

K.L. was honest enough to admit that, at times, his experience of pastoral care of confused elderly people raised theological questions for him:

"There is a real theological issue about when death happens. People are always saying, "That's not my mother", they have some perception that death has happened, and yet ... I find it hard when they want me to affirm that this person, has, in any sense, entered into a life of glory." (KL:30),(KL:31) " I would also want to set it in the context of a conviction that I have here...about the place of confused people being absolutely certain in terms of the Gospel--in no sense do we belong to God in terms of our abilities or our capabilities". (KL:34)

Thus, theologically, K.L. was encountering difficulties in holding together an affirmation of the value of the confused person in the sight of God, with his pastoral experience of their suffering and diminishment in personhood.

3. The pastors' responses indicated the importance of theological understanding in the interpretation of experience.

The third aspect to this relationship, which must also be borne in mind in the construction of any model, is the role of theological understanding in the interpretation of experience. The interviews contain a number of examples, the first to which reference will be made comes from E.F., who spoke of a woman who experienced a rapid mental deterioration due to dementia:

"I can think of a lady who was in hospital many, many times, and her mind was not deteriorating, in fact we were in communication and I gave her Communion and she was a tremendously vivacious Christian ...However she made an extremely rapid deterioration and came into the ward,...and I looked at her name on the list and thought "This can't be" and when I went to see her, she had made an extremely rapid, almost disintegration, and I remember one of the nurses saying, "Isn't it sad?". In fact she was almost unconscious at the time and didn't recognise me at all, just these blank eyes...She did eventually, begin to respond a little bit to prayer and holding the hand. Well, I would believe, I think in my heart, that the Holy Spirit was working on her in her lack of capacity to understand...He doesn't forsake a person as much enlightened by the Spirit as she was." (EF:31)

Objectively when on the ward, E.F. was simply confronted by a woman "with blank eyes". However, in the light of her theological understanding, or perhaps more accurately in the light of her faith, she saw a response and claimed with complete sincerity that the Holy Spirit was at work. Thus, a theological understanding which

stressed the value of the individual and the on-going work of the Holy Spirit was sufficient to inform pastoral practice. A further example of theological understanding being instrumental in the interpretation of an outwardly devastating situation was provided by O.P:

"at this place (a Residential Home), a lovely woman, now dead, who was a missionary for twenty-seven years, I think, and was an Elder in our congregation. She became confused and I remember the minister of a neighbouring church phoning me up and saying would I take a service? and I said "yes, you've got one of ours there now." He said "that lady, I couldn't get out of her what she'd done or where she'd come from, but I was aware that here was a woman who could pray"." (OP:39)

Again, this minister was confronted with a confused woman who communicated very little verbally, yet the situation was given meaning by a theological understanding which allowed for retained spirituality.

In summary, these are three facets of the relationship between theology and pastoral care which emerged during the interviews:

(1) Theology and practice are integrally inter-related, with the potential for both to be altered by the interaction. Thus, while theological understanding was seen to motivate practice, experience of pastoral practice also affected theological understanding.

(2) There was evidence of some dissonance between theological opinion and pastoral experience. It could, therefore, be claimed that theological belief in isolation was not sufficient to maintain pastoral practice for all of the ministers.

(3) Theological reflection was seen to be pivotal in the interpretation of pastoral situations. This was true particularly with regard to pastoral encounters which were reported by the informants to have been meaningful.

The Case for the Development of a Model and a Method

These findings have implications both for understanding pastoral practice and for pastoral education and training. If a simple spiral model of theological reflection is taken as a guide, these findings imply that there is necessity for input at the levels of both "experience" and "reflection" for change, or maintenance of pastoral practice.

This assertion has obvious implications for the development of a model to inform the pastoral care of confused elderly people. Any model which is going to have a significant impact on pastoral care must have a strong theological base. However, the findings from this research indicate that theology in isolation will not be enough to maintain pastoral practice. If theology is not consistent with pastoral practice, it is unlikely to become an 'owned' theology. An understanding of the complexities of the relationship between theology and practice makes clear the futility of developing a model which stresses the worth of the confused elderly individual, and the possibility of retained spirituality, without providing a method whereby those theological truths may be experienced in practice. Therefore, in addition to coherent theological perspectives, the pastor must also be provided with a practical method of facilitating pastoral practice, in order that his or her experience of offering pastoral care to this population is enhanced.

The claim that a two-pronged approach is necessary, that the enhancement of pastoral communication demands attention being given not simply to the development of communication techniques but also to theological perspectives, is strengthened by evidence from two additional areas in this study. These are the experience with which this study began, and the evidence from the questionnaires (Stage 4).

(a) The experience with which this study began

This research was given impetus by the fact that pastors related that the pastoral care of confused elderly people was an area within which they were encountering difficulties. Having undertaken intensive investigations, it now becomes possible to address that experience. This research indicates that the difficulties being experienced by pastors are on two levels. Firstly practical, as they grapple with the communication difficulties caused by dementia. Secondly theological, as it becomes apparent that some traditional theological models are inadequate, when faced with the realities of dementia.

Theological models which rely strongly on memory will be obviously problematic. In these cases faith is built on memories of God's dealings with His people in the past, as recounted in scripture and also in the faith stories of each particular congregation. The Old Testament is full of instructions to the people to remember what God has done in the past, how he brought the children of Israel out of slavery in Egypt, for example. This model of faith requires that individuals remember the One in whom they have faith, and that they remember a corpus of

belief, tasks which may be impossible for confused elderly people, whose memory has been undermined.

An alternative understanding of faith is that through their relationship with God, and their openness to the work of His Spirit, individuals are gradually transformed so that they become more Christ-like. This understanding is reflected in 2 Corinthians 3;19, where the writer speaking of followers of Jesus, claims:

"And we, who with unveiled faces all reflect the Lord's glory, are being transformed into His likeness with ever-increasing glory, which comes from the Lord who is the Spirit."

(New International Version)

Despite the fact that this model has strengths when applied to the experience of dementia, in that it stresses the possibility of the on-going work of the Holy Spirit in the life of the individual, it too, is basically problematic for the confused elderly person. This model demands a decision to put self aside, yet often self is of increasing importance for the confused elderly person as the disease renders them more ego-centric.

It thus appears that as they offer pastoral care to confused elderly people, pastors are not only encountering communication difficulties, they are also grappling with difficulties in correlating traditional theological models with their experience of confusion in elderly people. Information gained from the interviews (Stage 5), indicates that these theological difficulties compounded their doubts and concerns about the efficacy of pastoral care in this context. This experiential perspective gives

additional impetus to the claim that the development of practical ways of enhancing pastoral communication with confused elderly people must go hand in hand with the development of theological perspectives, which adequately address this area.

(b). Evidence from the questionnaires (Stage 4)

The case for the development of a strong theological base in addition to practical techniques for enhancing communication is further strengthened by an examination of the responses to the questionnaire (Stage 4). These responses indicate the need for a model to guide pastors' thinking and practice. In response to the questionnaire (Stage 4), 44% (n=124), of the respondents agreed, or strongly agreed, with the statement that "pastoral care of confused elderly people was a priority for them", [4.1] p.461, whereas 22% (n=124), disagreed. If, as this thesis suggests, the pastoral care of confused elderly people is a vital area of pastoral concern, the 22% (n=124) rating for "is not a priority" is significant. It begs the question why is it not seen as being important enough to be a priority for such a large number. A number of reactions are possible to that question. One is the negative view of ageing, discussed in the literature review, which pervades society and may therefore affect pastors and cause them, due to their undeniable busyness, to place elderly people low on their list of priorities. Another possibility is that they have had negative experiences of offering pastoral care to confused people, when perhaps they were confronted by uncharacteristic behaviour such as swearing, or by no response at all. Also there may be a lack of expectation that their pastoral care will make any

difference to the confused individual. Any, or all of these reasons, may lead to the pastor questioning the value and aims of pastoral care in this context.

Yet a further factor must be seen in combination with this apparent ambivalence among approximately one fifth of the respondents, and that is the high response rate to the questionnaire (Stage 4) (79.5%). This may be due in part to practical issues already discussed, questionnaire presentation, covering letter and such like. However, it may also indicate a level of interest or practical concern about pastoral care of confused elderly people. Taking these two responses together it seems that there is potential for meaningful theological, pastoral and practical input into this area. A model which holds true theologically, and which also makes the theoretical efficacy and pastoral aims of intervention clear, may provide pastors, whose high response rate indicates that they are genuinely concerned about confused elderly people, with a deeper understanding of the needs of confused elderly people. This model could also provide a framework which gives pastors security and helps them to shape their pastoral care.

The inter-relationship between theology and practice has been a consistent theme throughout this research. It now emerges as a foundation stone of its findings and of the discussion which follows. A stated aim of this research was the enhancement of pastoral communication with confused elderly people. Acknowledgement of the relationship between theology and pastoral practice means, that if this aim is to be achieved, a bi-lateral approach must be taken. Thus a practical

method for the enhancement of pastoral communication must be developed in addition to a theological basis or model.

As this research developed a search was made for one theological model which would hold together, and encapsulate the themes and struggles which were becoming apparent. Metaphors such as the biblical picture of "becoming like a child" were explored along with insights which were emerging from Liberation Theology. These, and others were considered in isolation. However, it became obvious that to try and fit the research findings to one model, although an attractive concept, would be to lose some of the richness which was emerging. It has already been stated that many traditional theological models have significant inadequacies when applied to dementia. The theological issues raised by the pastoral care of confused elderly people are at the cutting edge of theological thinking, concerning questions like, "Who are we?" Is there an essential spirit which remains despite the ravages of dementia? It became clear that any attempt to develop a tidy theological model in response to questions of that magnitude would be foolhardy.

However, the need remained to develop an adequate theological base. In response to that need what will be attempted is the development of a series of cameos, scriptural pictures, which give insight into the experience of dementia and impetus and motivation for pastoral care.

Two basic issues, personhood and spirituality, must first be addressed. They emerged in the research as major theological concerns and, as such, they form the context for the search for images or cameos which will illuminate this area.

Personhood

Goldsmith's (1996) observation, serves to re-orientate the discussion on this area:

"we are left with the unresolved question as to whether there is still a 'person' remaining as the illness advances, or does the very notion of dementia destroy what makes someone a person?" (20).

In the literature, differing opinions on the nature of personhood were uncovered (Chapter 3). The tension was discovered between approaches which define personhood in terms of criteria, and therefore having the potential to diminish or cease before physical death, and those which see personhood as being synonymous with life.

In this study a similar tension was highlighted between some pastors' experience of the deterioration which dementia brings, and a strong theological affirmation of the person's worth in God's sight with a resultant desire to illustrate that love in sensitive pastoral care. Two of the questions which arise from this tension are:

1. Did the pastors understand dementia as leading to a diminishment of the individual's personhood?
2. Experientially and theologically does personhood relate to worth?

1. Does Dementia Result in a Diminishment of Personhood?

M.N. was the only interviewee who was explicit about his opinion that dementia altered the personal status of the individual. The following quotation makes this clear:

"I do feel quite strongly that when I go to visit folk who are severely confused that to a large extent, it isn't the person, because the person is slowly draining away, and the body is still ticking."
(MN:16)

This statement supports McGregor and Bell's (1993) assertion that personhood is necessarily damaged by dementia.

In addition to this explicit reference there were other comments made by some pastors which infer an experience of a change in personhood. Q.R. spoke of carers' experience:

"suffering is caused to the people who know them and who feel they have lost them" (QR:70),(QR:71) "and that they are left with what appears to be the physical shell but the person they knew is no longer there." (QR:74)

It could also be claimed that doubts which some of the pastors articulated about the value of offering pastoral care to such people indicate that they have experienced confused elderly people to be less than fully persons. M.N. commented:

"if you have been there for twenty minutes or half an hour in total silence, you can't help feeling, "What's the benefit of me staying?", especially when you have a lot of other places to go."
(MN:19)

There is therefore explicit and implicit evidence in the interviews of some pastors' experience of a diminishment in the personhood of the confused elderly individual. However, there appears to be a level of inconsistency between that experience and theological assertions. There was no evidence in the interviews of pastors affirming theologically that personhood had been diminished. Even M.N. who made the statement cited at the beginning of this section, is wary of putting his experience that "the person is just slowly draining away" into a theological context. He ends that statement with "now that is maybe a wrong picture, but it's a helpful one for me as I am ministering" [MN:16].

Thus, although the pastors spoke in the interviews of changes in the personalities of confused elderly people, of carers' experience that death had somehow occurred and of spiritual changes resulting from dementia, none of them spoke theologically of these changes as being a diminishment of the confused elderly individual's personhood. This may be indicative of a dissonance between experience and theological assertion. There are significant theological and ethical implications if it is asserted that the confused elderly individual's personhood has been eroded by dementia. A theological assertion that personhood has been diminished is logically based on a criteria governed view of personhood, which has ramifications for the way in which a number of groups, mentally handicapped individuals for example, are viewed. Pastors may be encountering difficulties in attempting to put an experience that the confused elderly individual is less than they once were into a theological context. Value judgements based on "less" raise the question of who sets the

criteria. Is cognitive ability the primary criterion for judging who is fully human? If it is claimed that the confused elderly person is less than they once were, it could be asked why do we not say that children are less fully persons because they are less than what they will be? Ethically if it is claimed that personhood is diminished it raises questions about euthanasia. Thus there are many reasons why taking the step of saying that the personhood of the individual with dementia has been diminished by the condition, is a step which the pastors are unwilling to take.

Yet, exploring the 'diminishment' model further highlights the advantages of this reasoning. Firstly, it is consistent with the experience that the confused elderly person is not the person they once were, because of the profound physical and mental changes which result from the disease. Secondly, it is supported philosophically by those who maintain a criteria governed view of personhood. It could be argued that people with severe confusion have ceased to be fully persons. Thirdly, it can be maintained that even in response to diminishment of personhood, the Christian response is one which stresses love and care, and maintains the dignity of the confused person. Thus in the light of diminished personhood, the Christian can offer pastoral care which reveals aspects of the Kingdom of God. An argument for euthanasia is therefore undermined because no matter what the personal status of the confused elderly individual they remain of value to God.

The weaknesses of this approach must also be recognised. Along with those already mentioned, there is the question of power. Within this model the carer is

giving care to the powerless recipient; there seems little potential for mutuality or the possibility of the carer receiving from the confused person. Secondly, as has been stressed previously, accepting this model does raise ethical questions about the personal status of other groups whose level of cognitive functioning is compromised.

It could be claimed that implicit in some of U.V.'s comments about her Granny is the experience of retained personhood:

"she doesn't want to be told that she has to wear something like a hospital gown, just because its convenient. They say "Well, we've got to look after her" and I thought, "The whole thing is, do we look after her as an animal or as a person?" (UV:94) I hate it when people say something like "She's been awfully confused today", it's as if the person is not a person and that is so difficult". (UV:58)

An affirmation of retained personhood could also be made on the grounds of the pastors' emphasis on the importance of knowing the individual's life-story.

It must also be acknowledged that just as a dissonance was uncovered between experience and theology, when pastors described dementia as resulting in a diminishment of personhood, a parallel dissonance exists when it is maintained that personhood is unaffected by dementia. A theological affirmation of retained personhood is difficult to maintain in the light of pastors', and, in particular, carers' experience. How can it be asserted that the person is not less than they once were when their personality has changed, when they are incontinent and uncommunicative? It could well be claimed that a tidy theological belief in maintained personhood

creates guilt for the carer, who day and night is confronted with a reality that speaks to them of the person being diminished by dementia.

In summary, therefore, the pastors gave evidence in the interviews of experience both of a diminishment of, and preservation of, the personhood of the confused elderly individual. There was a reluctance to put the experience of diminishment into a theological context. This may be the result of a gap between a 'learned' theology and an 'owned' theology, or the result of a difficulty in acknowledging the extent of the changes which dementia can bring.

These experiences may be held together if it is maintained that changes have occurred, which are radical, but which in ultimate, theological terms should not be described as a diminishment of the individual.

2. Is there a Relationship between Personhood and Worth?

If the evidence from the interviews on the personhood of the confused elderly person must be acknowledged to be equivocal, it is unequivocal on the issue of the confused person's worth in God's sight. No matter what doubts or questions they might have had on personhood, all of the interviewees affirmed the value of the individual and a belief in God's love for them. The evidence from the interviews thus indicates that theologically the pastors did not relate personhood to worth. This is illustrated by the following comment made by Q.R:

"In the eyes of society this person may be a cabbage, but in God's eyes they are not. They are still somebody who has value because our value doesn't depend on our own ability". (QR:78)

The overriding emphasis in the interviews was that the presence or effect of dementia has no relevance to the individual's position before God, but rather that the individual remains the subject of God's love, both precious and unique. Theologically it is affirmed that even if the personality and intellectual abilities of the individual with dementia have changed, even diminished beyond recognition, the person continues to be loved and recognised as being of value, by God. This is a point of great pastoral importance. The individual with dementia is of value, not because of what they once were, or due to their past achievement, but as they are now.

This emphasis is reflected by current researchers into the area of dementia. Treating the person with dementia with dignity and actively listening to them is at the root of the validation theory which has been developed by Naomi Feil (1992). No matter what the individual's weaknesses, or the objective "status" of their personhood, Kitwood (1993 b) stressed that people with dementia should be treated as persons:

"Instead of seeing a set of deficits, damages, and problem behaviours awaiting systematic assessment and careful management which effectively turn the person into an object, we need to work on the basis of seeing the person as a whole." (1993 b :16)

From the methodological and theoretical perspective which underlies this study, it is interesting to note that researchers and clinicians approaching the area of dementia from different angles, namely psychology and theology, come to similar conclusions. The inter-relating of psychological, clinical insights with theological

ones, the fusing of these horizons, enriches both disciplines, and impinges directly on practice.

Thus, even if it is claimed that personhood is diminished, the person should be treated as if it has not, and everything possible should be done in terms of environmental manipulation to ensure that the dignity and value of the individual with dementia is maintained and indeed enhanced. This has obvious pastoral implications, and is strengthened by the comment made by Goldsmith (1996)

"...if it is true that the condition of the person can be affected by - relationships, and that this can be for good or ill, then it becomes very important that we understand our own role." (27)

There was evidence in the interviews that pastors understood the importance of treating the confused elderly people with dignity and respect. This was reflected in the fact that 73% (n=124) of the respondents disagreed, or strongly disagreed, with the statement in the questionnaire "It is difficult to have any meaningful religious element in a visit with confused elderly people" [4.5] p.463. The comments made by I.J. about Confession also illustrate his willingness to take the concerns of the confused individual seriously:

"For someone who is confused and has got this niggle in the back of their mind, again I think too in terms of older people who would be very aware of the Catholic doctrine of dying in mortal sin condemning them to hell, it could be very, very difficult. So, if I have got someone like that, I think I would have to take that very seriously. I would say "That is O.K.", and I would hear their Confession. And I mean it might be a total jumble sort of thing, but I need to try to let them have the experience of removing this thing. The experience of Confession." (IJ:21)

Thus I.J's theological assertion of the value of the confused elderly individual is seen to be an 'owned' theology and is expressed in treating the confused individual with dignity and in taking their needs seriously.

In summary, researchers imply that the objective status of the individual's personhood should not alter the way in which that person is treated, which is with respect and dignity. What is true psychologically in this area can also be put into a theological framework. Pastorally the interviews provided evidence that despite some questions about personhood the pastors stressed the worth of the confused elderly person. Moreover the evidence was that this theological assertion was worked out in pastoral practice.

Spirituality

The direct evidence which is available, although admitted to be limited, suggests that dementia is a physical condition which brings about spiritual changes. Robert Davis, a minister from Florida, who wrote of his experience of Alzheimer's Disease claimed that even in the midst of physical and mental deterioration , " the worst personal loss was the spiritual change that suddenly came to me" (1989;121). In the interviews (Stage 5) pastors also gave evidence that dementia does affect spirituality. (This evidence is presented in Chapter 7). These experiences raise profound theological questions concerning the effect of mental deterioration on spirituality.

The first task undertaken will be to place the discussion into an Hebraic conceptual framework of the view of the person. The second will be to review the evidence available from experience and theology. These will then be inter-related in an attempt to reach some synthesis.

It will be recalled that the divergence of opinion which exists concerning the nature of the individual was reviewed in the literature review. Within this discussion a holistic Hebraic understanding will be assumed. Study of the use of the Hebrew *nephesh*, in conjunction with an appraisal of Genesis chapter 2, leads to the conclusion that any conception of the soul as a separate part or division of our being is invalid. To quote Colwell's definition given in the *"New Dictionary of Theology"* (1988) "the human person is a 'soul' by virtue of being a 'body' made alive by the 'breath' (or Spirit) of God" (29). The evidence to be reviewed comes from experience and scriptural and theological insight.

1. Experience

The experience of the effect of dementia on spirituality which comes from pastors, carers and the individuals themselves shows a remarkable uniformity in the report that dementia evokes changes in the individual's spirituality. There is divergence on the nature of those changes.

From the perspective of someone with a mild to moderate level of Alzheimer's Disease, Davis (1989) reports changes in spirituality rather than a total loss. He reports alterations in the things which made his faith meaningful, for example he reports differences in his musical taste, and obviously aspects of his faith which were intellectually challenging moved out of his reach.

The model of *change* rather than *loss* could also be used to describe the experience of some of the pastors in this study, who, even in severe cases of intellectual deterioration, saw some glimpses of a retained spirituality. It is recognised that those reports are subjective, but perhaps there is a place for subjectivity in recounting belief in the work of the Holy Spirit. An assertion of change rather than death of spirituality was also supported by a number of the findings from the questionnaire (Stage 4). 73% of the respondents (n=124) disagreed with the statement "It is difficult to have any meaningful religious element in a visit with confused elderly people" [4.5] p.463. In addition, 84% (n=124) indicated their experience of confusion impinging on the individual's relationship with God, when they said that "they were not surprised when confused elderly people were angry with God"; [4.6] p.463; 58% (n=124) implied the potential for the on-going work of the Holy Spirit when they responded that "confused elderly people can be assured of the love of God" [4.14] p.467. Taken together these statistics indicate an awareness of spirituality in the confused elderly person which is altered, but not missing.

An alternative experience was also evidenced by one of the interviewees, namely the death of all that was spiritual in the confused individual [KL:26]. This was evidenced even in situations where the confused elderly individual was reported to have a deep level of spiritual maturity prior to the onset of the dementia.

Therefore, in summary, there was a universal experience of change, but a difference in the reported nature of that change, whether it was complete loss, or whether even in severe dementia glimmers of spirituality are retained.

2. Scripture and Theology

The bulk of the scriptural evidence appears to indicate the potential for on-going spirituality, even in dementia when the individual's cognitive processes are undermined. The Book of Wisdom (3;1) reflects Jewish Diaspora thinking, "the souls of the virtuous are in the hands of God, no torment shall ever touch them."

Furthermore, scripture teaches that God does not abandon His people. Images of God's guidance of the children of Israel, the protection of His people like a mother hen, and Biblical passages like " You are mine, you are precious to me, you are honoured and I love you" (Isaiah 43, 1-4) speak powerfully to that truth. Wesley (1755) in his comments on 2 Peter 1;4 " Ye may become partakers of the Divine nature" notes that this means believers are "being renewed in the image of God, and having communion with him, so as to dwell in God, and God in you". However we accept or interpret that statement today, it does cast significant doubt on the

likelihood of God ceasing to dwell in that person due to no fault of their own but purely to a lack of cognitive acuity.

So, the research findings indicate a change, but not complete loss of spirituality. This finding in itself raises questions such as, "which is the real person?" Is it too simplistic to claim that the spirituality of the person with dementia is not less than it once was, but just different? There will be an attempt to throw some light on these issues in the chapter which follows, through the development of cameos, as we search for pictures which can be applied to the experience of dementia. Consideration of each of these cameos leads to the development of a pastoral response which provides a framework for the pastoral care of confused elderly people.

CHAPTER NINE

A THEOLOGICAL BASIS FOR PASTORAL CARE

OF CONFUSED ELDERLY PEOPLE

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ELDERLY PEOPLE

The Development of Cameos

The findings from this research indicate the necessity for the development of a theological basis or model, for pastoral care of confused elderly people, in tandem with a practical method for facilitating pastoral communication. Having reviewed the evidence on two of the central theological issues raised by pastoral care of people with dementia, namely, personhood and spirituality, the task of developing this model will now be undertaken.

The theological basis develops out of the research findings and takes the form of four scriptural cameos or pictures; the sufferer, the child, the prisoner and the representative. These cameos provide significant theological insights when applied to the experience of dementia. Each cameo also gives rise to a pastoral response, namely, presence, sustenance, release, and advocacy.

1. The Sufferer

"They went to a place called Gethsemene, and Jesus said to his disciples, "Sit here, while I pray." He took Peter, James, and John along with him and he began to be deeply distressed and troubled. "My soul is overwhelmed with sorrow to the point of death," he said to them. "Stay here and keep watch."

(Mark 14; 32-34 New International Version)

The picture of Jesus and his disciples in the Garden of Gethsemene

(Matthew 26;36-46, Mark 14;32-41) resonates with some of the struggles and challenges raised by an attempt to offer pastoral care to confused elderly people.

It is a picture of intense suffering and questioning as Jesus anticipates the manner of his death, and in the context of a loving relationship with His father lays His feelings, His doubts, fears, and questions before God. He is honest to the point of admitting His desire that the present situation would be different - "My father , if it is possible, take this cup from me." (Matthew 26;39)

In the search for a theological model there is a temptation to begin to view the experience of dementia with detachment, and to forget the reality of intense suffering and loss both for the individual and their carers. Dementia is a devastating illness. The turmoil of early diagnosis, the rupturing of relationships, the altering of personality which may ensue as the disease progresses will all cause profound grief. This cameo confronts us with the reality of suffering and gives permission to the individual and those who love and care for them to be open with God about that suffering.

The concept of Jesus understanding us, and of being alongside us in our sufferings, combined with a resultant desire to follow that example emerged in the comments to the questionnaire, (Stage 4) [5:4], p.472. It was also evident in the in-depth interviews (Stage 5) as a significant motivation for pastoral care. U.V.'s comments make this clear:

"Jesus got alongside people. He wasn't issuing prayers all the time. It was a working conversation in life. It was being there, as love in flesh, and to me that's what the ministry is all about." (UV:78)

The cameo of Gethsemene gives insight into the reality of Jesus' humanity and his suffering, and leads to an approach to pastoral care in which the agony of dementia is acknowledged and shared with others and with God. And in the context of His anguished suffering what does Jesus ask of His disciples - that they "stay here, and keep watch with me" (Matthew 26;38). In a powerful way this cameo from the life of Jesus gives insight into the ministry of presence in pastoral care. Indeed it could well be claimed that a ministry of presence is one of the most effective means of pastoral communication in this context.

The empirical findings from this research bear this claim out. This is exemplified by the respondents' stress in the interviews (Stage 5) on their experience of the importance of touch and of sitting quietly with the confused elderly person.

From the pastors' experience, touch emerged as a significant form of communication. E.F. commented:

"Touch is very, very important because you can communicate all sorts of things that way, whether consciously or unconsciously. I can think of this particular old man to whom touch was very important indeed. I think there was probably more achieved at each visit with touch, than with anything else."
(EF:6)

O.P.'s anecdote about the importance of presence is intensely challenging. When, on sharing her frustration with a nurse that she felt her pastoral visit with a confused person was meaningless, the nurse encouraged her to simply sit quietly with the confused elderly person for just ten minutes. O.P. recounts that the nurse told her as he left, "She'll be different tonight because you have given her time." (OP:55)

This cameo thus has profound implications for practical theology. It underlines the prophetic nature of pastoral care. If pastors are to be true to their vocation, there is a responsibility to swim against the tide of activism and obvious productivity, and to recognise the significance of presence. As they sit with the confused elderly person in silence, or facing a tirade of abuse, they witness to the integrity of the spirit of the confused person. In their being and their actions they reveal aspects of God who accepts and loves people unconditionally. God who sits where we sit, God who waits and weeps with us.

2. The Child

"At that time the disciples came to Jesus and asked, "Who is the greatest in the Kingdom of heaven?" He called a little child and had him stand among them. And he said: " I tell you the truth, unless you change and become like children, you will never enter the Kingdom of Heaven."

(Matthew 18: 1-3 New International Version)

The cameo which illustrates Jesus' attitude to a child may help us to understand some aspects of the experience of offering pastoral care to confused elderly people. In exploring this picture the claim is not being made that an confused elderly person is rendered child-like by the disease, nor that they should be treated like children, nor indeed is a developmental model being mistakenly applied.

However, it is not too great a hermeneutical leap to see parallels in Jesus' teaching on children with confused elderly people. Indeed Davies and Allison (1991) claim that in the Gospels the evangelists showed a shift from the real child to the metaphor of the child which symbolises the Church. Thus they point out that in verses 10-14 of chapter 18, Matthew is using "little ones" as a designation for believers. Weber (1979) reinforces this understanding by pointing out that in Luke "little child" is later assimilated with "the least among my disciples". Thus, in the Gospels, Jesus was understood as using a vulnerable, seemingly unimportant, and often despised child as a metaphor for weak and poor members of the Church; in particular, members who through weakness, were rendered dependant on others to be sustained and cared-for. Dependency, one aspect of the metaphor of the child will now be examined in depth.

"Unless you become like little children you will never enter the Kingdom of heaven" (Matthew 18:3 NIV) The precise meaning of Jesus' teaching has been open to a wide variety of interpretations. Weber (1979:28) sees the child in this context as a metaphor for "objective humility", saying that children are not necessarily more humble than adults, but being dependant they look for help from adults as a matter of course. He continues:

"To receive God's Kingdom like a child means to beg and claim this Kingdom like a child claims food and love. It means to receive with empty hands." (28)

The fact that dementia renders people dependant on others cannot be denied. This is not to say that the relationship between confused elderly people and pastors is necessarily unidirectional. The issue of reciprocity and the importance of expectancy, that the pastor can receive in the pastoral relationship will be discussed in a later section. The discussion on dependency takes place within a context where the reality of "mutual responsibility and mutual need" (Campbell 1986:1) are recognised. There need not be a tension between honest recognition of dependency, and a desire to encourage and affirm independence and autonomy. Facing the reality of dementia demands that it must be recognised that in the later stages of the condition in particular, confused elderly people may be in a position of depending on others for physical as well as emotional and spiritual care. The disease places them in a position of receiving with empty hands.

So what is the Church's pastoral response to the recognition of that dependency? Returning to the metaphor of the child, it is clear that Jesus commends those who are poor, weak and dependant, to the disciples' love and care. This is a continuation of Old Testament teaching, where, in the prophets for example, there are calls to be charitable to orphans because God Himself is their defender (Ezekial 22:22). God is the Father of the fatherless (Psalm 68;5). Thus a biblical response to the reality and recognition of dependency is love and care. Through the actions of the caring individual and community the dependant person is sustained, physically and spiritually.

Thus a biblical response to dependency is to sustain the dependant individual. The literature on maintenance or sustaining as a motive for pastoral care has been reviewed (Chapter 4). Indeed, Clebsch and Jaekle (1967) claim that sustaining has been an aim of pastoral care throughout the development of the discipline. This is reflected in their definition of pastoral care as:

"helping acts done by representative Christian persons directed towards the healing, sustaining, guiding, and reconciling of troubled persons whose troubles arise in the context of ultimate meanings and concerns." (4)

The pastoral response of sustaining the confused elderly person brings the discussion back to the nature of pastoral care. Sustaining is not a problem solving, change oriented response. It is possible that the difficulties reported by some pastors in offering pastoral care to confused elderly people stem from a problem solving approach to pastoral care, in which change is the desired outcome. It was illustrated in Chapter 4 that change is a central motive in a number of models of pastoral care. It

was claimed there that change can even be seen as a motive in the work of some practical theologians who actively sought to move away from a "task-oriented" approach to pastoral care. Thus change as a motive is even evidenced in Pattison's (1988) definition of pastoral care as:

"that activity, undertaken especially by representative Christian persons, directed towards the elimination and relief of sin and sorrow and the presentation of all people, perfect in Christ to God." (18)

The expectation of overt change as a result of pastoral care of confused elderly people is obviously problematic. Therefore, in addition to making inadequacies in some traditional theological models apparent it becomes clear that pastoral care of confused elderly people highlights weaknesses in some traditional models of pastoral care.

Sustaining should be recognised as a strong option, not a weak choice or the last resort in pastoral care. The pastoral response of sustaining requires the depth of integrity that is described by Campbell (1986) in addition to commitment to God, whose love is consistent and does not seek for response, and commitment to the confused individual. Pastoral care of this quality cannot help but disclose the purposes and actions of God in human affairs, and must become an impetus towards transformation, if not of the situation of the person with dementia, of attitudes towards them. Through an active commitment to sustaining individuals who have been rendered dependent, one of Lambourne's aims of pastoral practice, as described by Foskett and Lyall (1988) is brought nearer to fulfilment, that is:

"the building up of a community of faith, hope and love in which women and men were enabled to attain their full potential as human beings." (4)

A pastoral response to dependency is to sustain. The theoretical and experiential findings elicited by this research indicate that the confused elderly person may be sustained by two means, namely, practical care, and memory.

1. The Sustaining Potential of Practical Care

Through practical acts of caring the confused elderly person and their carers can be sustained or supported. It is difficult to under-estimate the significance of practical care. Involvement of the congregation in practical aspects of pastoral care of confused elderly people recurred as a theme in the interviews (Stage 5), where O.P., for example, spoke of members of the congregation visiting confused people in their own homes and of congregational involvement in worship in residential homes.(OP:32)

U.V gave a simple but telling example of thoughtful practical care offered to her Granny:

"At my brother's wedding, my Granny was so confused...We thought my friend J is the best one to sit beside her, because he'll help her with her food and, whereas some other relatives will want to feed her, John will cut up her food and then hand the fork to her." (UV:70)

This quality of pastoral care is not only revelatory, it is a means whereby the confused individual's continuing membership of the church and that particular congregation is given practical expression, and as such it is more likely to be

understood by the confused person. Thus through practical care the confused elderly individual is sustained not only practically, but also in relationships, which are meaningful in themselves as well as being deeply symbolic.

2. The Sustaining Potential of Memory

The findings from this research indicate that the confused elderly person can be helped to remember for themselves. The radical effect of dementia on cognition and on memory is acknowledged. However the empirical evidence gathered in this research indicates that all of the experience gained in the confused person's life-time is not lost to the disease. This claim is made on the following grounds:

1. Many of the pastors in the questionnaire (Stage 4) and in the interviews (Stage 5) stressed the value of knowing the confused elderly person's history . They provided information and anecdotes which suggested that knowing about the confused person's life and faith history provided a way of accessing meaningfulness in the pastoral encounter. This evidence implies that although affected by dementia all memory and experience may not be lost.

2. One of the most strongly supported research findings was that over-learned material was helpful in accessing faith memory for the confused elderly individual. That over-learned material is familiar because of a life-time's experience of saying the Lord's Prayer or the Twenty-third Psalm. Thus the importance of over-learned material indicates that all experience is not lost.

3. In the literature review, the debate about whether dementia is the result of a loss of memory or a difficulty in accessing intact information was introduced. The empirical evidence from this research could be taken to support the argument for an accessing difficulty. This claim is made on the grounds that it appears that faith memories can be accessed through familiar liturgy, use of smell for example. It may be that some memories, perhaps recent ones in particular are totally lost, but the fact that some can be accessed indicates that they are not all lost.

If the research shows that some memories can be accessed through familiar material, symbols, the senses and through reminiscence, then the community of faith must have a role in this. Members of that community may have access to faith memories of which the pastor is unaware, and there may be value in the congregation making efforts to incorporate confused elderly members of the congregation into worship. This may be achieved through their physical presence, by bringing taped services to their home or hospital, being involved in services on the hospital ward or in the residential home and through remembering confused members and their carers regularly in public prayers. In all of these activities to cite Gunter (1997) "grace has been incarnationalized into a helping, healing, challenging, convicting, calling presence" (6).

Thus one activity which belongs to both God and the community in the partnership of pastoral care for confused elderly people is that of remembering. There are many biblical references which speak of God remembering His people,

Psalm 136;23 for example, "for the One who remembered us in our low estate". God remembers people, and there is a timeless quality to that remembering. He remembers people as they were, as they are and as they shall be.

(a) Faith in the Past: Sustained by the Past being Remembered

As dementia undermines memory it is others who must do the remembering for the confused elderly person. Davis (1989), while in the early stages of Alzheimer's Disease, makes a heartfelt plea that people remember him as he was. That they remember his strengths and his personality before they were devastated by Alzheimer's Disease. On a cold objective psychological level, we can read implications on personhood into that plea, an understanding that the changes brought about by the disease are not really him. On an intuitive level, his desire that he be held in the individual and collective memory of his family and community of faith is easily understood. Pailin (1986) suggests that eternal life consists of being held in the memory of God. Whatever one's theological response to that contention it does serve as an illustration of God remembering people as they were. However, the congregation has an important part in this too. The community are the keepers of the memory of the person as they were. They can make that memory real to the confused elderly person through their presence, and through telling and re-telling the stories of the individual and of the faith community of which they are a part, through reminiscence. As that remembering takes place the objective fact that the confused person is a part of the faith community becomes felt by the community and the

individual. It becomes a subjective reality. They are sustained and supported, their identity confirmed by that remembering.

(b) Love in the Present: Sustained by the Present being Remembered

There is also a present tense aspect to God's remembering. He remembers people as they are now. This affirms the value which God places on the individual, which is independent of cognitive functioning, or level of achievement.

Affirmations of the value which God places on the individual who is confused were the strongest, most consistent feature of the interviews (Stage 5). None of those interviewed were in any doubt that God values the confused elderly person, as they are now. Each of the pastors interviewed stressed their belief that the value which God places on the individual is not dependant on their ability to respond to Him, to grapple with theological belief, partake in acts of faith, or even recognise the presence of God. His love, and the value of the individual is completely unconditional. This theological affirmation gives practical impetus to pastoral care, as those involved in that care are driven out to be channels of that love into the brokenness and dependency of dementia.

Responses made by the pastors in the interviews made clear their understanding that one aspect of the pastoral response to dementia is to help confused elderly people to feel that they are of value to the congregation and God, not because of past achievements, but as they are now, and that they are remembered

as they are now. Q.R. expressed this simply when he said " I want them to know that God loves them, that they are part of the church." (QR:81)

(c) Hope in the Future: Sustained by the Future being Remembered

God's remembering transcends time, so it is possible to talk about remembering the future. He remembers what we will be. No matter what the details of our eschatological views this raises the issue of hope for the confused person. So human beings too are invited to remember the future, to remember our future hope.

What is the nature of hope for the confused elderly person? Travis (1988) explains hope in the following way:

"To hope means to look forward expectantly for God's future activity. The ground of hope is God's past activity in Jesus Christ, who points the way to God's purposes for his creation". (321)

The relevance of the broader socio-political implications of hope (as developed by Pattison (1994), Bloch (1986) and Moltmann (1967) , among others) to the confused elderly person are not discounted . They will be discussed in a later section on Advocacy. However the focus here is on hope as applied to the individual.

Travis' (1988) definition makes it clear that the past plays a role in hope. This is emphasised by Becker (1978) when he claims:

"Against this backdrop of remembered care, guidance, and love given by the Lord, of remembered love, friendship and care from "significant others," reality and responsibility can be faced without plummeting one into anxious despair." (189)

In the literature review (Chapter 3) it was claimed that two aspects of the nature of hope were problematic for the confused elderly person. These are, its active nature, and the role of memory. However there are indications in this research that although an intellectual understanding of hope may be beyond the confused elderly person, hope can be made real for the individual with dementia. This can be achieved through the resources of the faith community, through hymns, bible readings and liturgy. So hope can be made possible, even in dementia, through the remembrance of God, perhaps His love and presence in particular. As the individual is enabled to remember God's love they may be enabled to feel what is an objective reality, that they are held secure in that love whatever the future may hold.

Summarising this section, the cameo of the child is a reminder that Jesus entrusts those who are rendered weak and dependant into His disciples' care, in order that they might be sustained. The confused elderly person may indeed be dependant on others for many aspects of their well-being and care. It is suggested that they may be sustained through practical care, by the realisation of the sustaining potential of memory.

3. The Prisoner

" By the rivers of Babylon we sat down and wept when we remembered Zion - How can we sing the songs of the Lord while in a foreign land?."
(Psalm 137; 1&4 New International Version)

In the distress resulting from their experience of captivity in Babylon, the Children of Israel cried out "How can we sing songs of the Lord while in a foreign land?" The image of being in a foreign, or strange, land is used extensively in writing about dementia (Jewell (1996), Goodall (1996) and Shamey (1993)). In this study a number of pastors described their understanding of dementia as captivity or imprisonment. E.F. for example, referred to "something being trapped inside the body". O.P. also made an explicit link with the metaphor of imprisonment:

"I wondered if people who are demented can't also hear something locked into that bit of them that's in prison. Maybe they can hear things like that, maybe they also retain pictures of the glistening crocuses or the dancing daffodils". (OP:61)

There is not yet sufficient evidence to prove or disprove whether this pastoral experience holds true cognitively. That evidence exists to support both views of dementia as an accessing problem and a loss of cognitive information was illustrated in Chapter 2 of the literature review, by an examination of the evidence on the nature of confrontation naming difficulties in dementia. However, even if the cognitive evidence is equivocal, the fact remains that a number of the pastors' experience of spirituality in dementia was that of imprisonment. To be specific, their reflection was that although something of the spirit of the person remained, it was made captive within the body, by dementia.

A biblical, and pastoral response to the experience of imprisonment is to bring release. When Jesus set forth goals of his ministry in Nazareth, as recounted by Luke, he made this clear:

"The Spirit of the Lord is upon me, because he has anointed me to preach good news to the poor. He has sent me to proclaim freedom for the prisoners and recovery of sight for the blind, to release the oppressed, to proclaim the year of the Lord's favour."

(Luke 4; 18-19 New International Version)

This text has been taken by liberation theologians as a *raison d'être* for their approach, and their reflections have been pivotal in enabling the church to interpret Jesus' teaching in a social, as well as a spiritual context. It is used here, however, with regard to the way in which the pastors in this study applied the image of imprisonment to the spirituality of confused elderly people. In that context how can pastors respond to the experience of imprisonment and bring release?

This research has been useful in highlighting a number of keys which have the potential to unlock the prison of dementia even momentarily. A number of these have already been discussed. They include touch, familiar, over-learned material, such as the Lord's Prayer and Twenty-third Psalm, and reminiscence which is made possible through shared life experience or knowledge of the confused elderly person's life story. Another significant 'key', is the use of symbols.

Symbols are a means of communicating deep meaning, yet they do not rely on language memory or intact intellectual processes. In situations, therefore, when

language is inadequate, symbols like a cross appear to have the power to express and communicate meaningfulness.

The usefulness of symbols as a tool in pastoral communication with confused elderly people was reflected by the research findings. When questioned on Holy Communion, 80% (n=124) of the respondents to the questionnaire (Stage 4) rated it "as helpful or very helpful in worship with confused elderly people" [3.11] p.457. "Wearing a clerical collar" [2.17] p.449, which acts as a symbol for many people, was rated as helpful by 67% (n=124) of respondents. When asked if, "in their experience, use of symbols like a cross, enhanced communication" [3.15] p.459, 69% (n=124) responded that it was helpful or very helpful. It is clear therefore that the empirical data gathered in this research indicates that, in pastors' experience, symbols enhance pastoral communication.

Part of the explanation for this may lie in research findings from child development studies. Bruner (1978) asserts that a child may develop a concept before he has the ability to attach a label to that concept. He writes:

"Before they (infants) can make verbal distinctions in speech, they have sorted the conceptual universe into useful categories and classes, and can make distinctions about actions and agents and objects." (8)

This is paralleled by research findings concerning the nature of the language deficit in dementia, and Alzheimer's Disease in particular. It is commonly reported, (Bayles et al 1992) that word finding difficulties are a feature of the language deficit in dementia. When errors occur in naming, the error response is likely to be

semantically similar to the target. Thus, for example, Thompson (1981) reports a subject who, when shown a bell, said 'gong'. Furthermore he claims that people with dementia can demonstrate through gesture the meaning or function of objects which they cannot name. These findings suggest that, as Bruner (1978) claims to be the case in the developing child, the concept is intact, even if the confused person is unable to label that concept. The empirical findings from this research do indicate that symbols have the power to access concepts for the confused elderly person. The positive response to a clerical collar reported in the questionnaires (Stage 4) has already been noted. During his interview K.L. made these comments on the same issue:

"I hardly ever wear a clerical collar, but I do try to wear a clerical collar when I go to visit folk who are confused, because I think that, sometimes, that helps them. It gives them some idea of what I am, if not who I am."

(KL:3)

Thus K.L, in his aside, "it gives them some idea of what I am, if not who I am" indicates his experience that the pastor in himself, or herself, has a symbolic significance.

In summary, some pastors in this study described the effect of dementia on spirituality as imprisonment. A biblical, pastoral response to imprisonment is to bring release. This research has highlighted a number of keys which in pastoral experience, and upheld by insights from speech and language therapy, have the potential to release the individual, even momentarily, from the prison of dementia. Symbols were chosen as an example because they emerged as a feature in the interviews (Stage 5)

and because they have received considerable attention and study from a linguistic and cognitive perspective.

4. The Representative

"When the Son of Man comes again in his glory, and all the angels with him, he will sit on his throne in heavenly glory. All the nations will be gathered before him, and he will separate the people one from another as a shepherd separates the sheep from the goats. He will put the sheep on his right and the goats on his left. Then the King will say to those on his right, "Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me." Then the righteous will answer him, "Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?" The King will reply, "I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me."

(Matthew 25; 31-40 New International Version)

Who does Jesus choose as his representatives? The prisoner, the sufferer, the child, those who are seen by others as being powerless and marginalised.

Three of the participants in the interviews (Stage 5) referred to issues which relate to the powerlessness which can be a by-product of dementia. E.F. said the following:

"they were being looked after very well. However I would say that very little was being asked of them, so they weren't being stimulated into being able to try to do things for themselves, ...and most of them would just sit or lie on their beds." (EF:4)

Undeniably dementia results in a decreasing ability to make autonomous decisions. That being admitted, systems or situations which deny confused elderly people the opportunity or means of making those decisions of which they are able, must be recognised as contributing to their powerlessness, and by definition therefore oppressive.

Dementia is a situation of powerlessness, voicelessness, and marginalisation. It is people in just such a situation that Jesus called his representatives. It would be impossible to raise these issues, and make these statements, without referring to insights from liberation theology. Reference to liberation theology is also important in the on-going dialogue with understandings of the nature of pastoral care, which runs through this study. Insights from liberation theology counter an exclusive individualism which distorts pastoral care, and ensures that pastoral practice be placed within a context in which the effect of socio-political dimensions is acknowledged.

Pattison (1994), arising from his experience of pastoral care with people who are mentally ill, applies insights from liberation theology to practical theology and pastoral care. His thesis is that there is a need to counter-balance the individualism which has dominated approaches to pastoral care, and this develops into a stress on the need to change the social structures which foster mental illness, or indeed the oppression of women. The application to confused elderly people is limited in that

regard, although aetiological factors are diverse in dementia, socio-economic factors are not regarded as being primary among them.

Where Pattison's (1994) thinking can be applied to pastoral care of confused elderly people is with regard to response. Although "liberation theology is socio-culturally specific, and does not seek to be universalisable" (Pattison 1990;210), a formative insight is that a biblical and pastoral response to powerlessness is advocacy. If the powerless are Christ's representatives, then advocacy is not just a duty, it is a response which springs from love.

Advocacy is fast becoming a recognised principle in care for people with dementia. In an article entitled *Speaking out for advocacy*, Killeen (1996) contends that people with dementia need advocacy both on a one-to-one basis, and on a political level, to help them make decisions at transitional points in life, to ensure that their legal rights and entitlements are observed, and to help them make their voices heard about the services which they receive. This article concludes with the statement; "obstacles to communication must not be allowed to undermine the rights of people with dementia." (22)

It is not without significance that in response to the questionnaire (Stage 4), when asked to make additional comments [5:4] p.472, 3 of the respondents (46 pastors in total made comments in this section) mentioned themes related to political dimensions of pastoral care of people with dementia. Of these respondents, 2 noted

lack of nursing and residential care provision for people with dementia, the other wrote of his or her experience of a lack of respite care. These responses indicate that advocacy is being undertaken as an appropriate pastoral response to the experience of dementia.

Indeed, the response of advocacy for the confused elderly person can be understood and applied on a number of different levels. The pastor may feel that they have a role in being an advocate, for the confused individual, in prayer, when the person with dementia is bereft of conventional language and may have lost the ability to pray with words. They may feel that they have a role as advocate in expressing the confused person's value and worth in the community, perhaps, as Pattison (1994) and the examples above suggest, on a political level. In the literature review negative attitudes to ageing were reviewed, advocacy might be instrumental in undermining those attitudes. There may also be a role for advocacy on a congregational level as the community becomes involved in this area of pastoral care. Killeen (1996) also raises the possibility of self-advocacy for individuals with dementia. She applies this in particular to situations where an early diagnosis has been given, and suggests that people be given the opportunity to express their views about their future care. However, she contends that at all stages of severity people should be given an opportunity to make their feelings known. It may be, therefore, that there is potential for pastors to facilitate this self-advocacy. Through advocacy, transformation can be re-introduced as an aim of pastoral care for confused elderly people, as pastoral care

becomes transformative within a systems model, on a societal level and in a prophetic sense.

Summary

The complexity of theological and pastoral issues impinging on pastoral care of confused elderly people, combined with the richness of experiential evidence elicited by the research meant that to select one model as a theological basis to guide and inform pastoral care, would have inevitably led to over-simplification.

The four cameos or pictures which emerged - the sufferer, the child, the prisoner and the representative, all threw their own particular light on pastors' experience of pastoral care of, and communication with, confused elderly people. Each in turn, following theological and experiential reflection, gave rise to a pastoral response, presence, sustenance, release and advocacy.

Having developed and applied this theological basis it now becomes necessary to look at the development of a method for enhancing pastoral communication with confused elderly people. Specifically, this requires an examination of the evidence which has arisen from the research on this issue.

CHAPTER TEN

THE DEVELOPMENT OF A METHOD

THE DEVELOPMENT OF A METHOD

Pastoral Communication with Confused Elderly People

Introduction

This research has brought to light a huge amount of practical experience on pastoral care of confused elderly people. The information used in this section arises from the data from each of the stages. This ensures the integration of theoretical perspectives, practical experience, linguistic theory and pastoral concerns, and leads to the formulation of a basis or method for enhancing pastoral communication with confused elderly people.

The Research Process

One of the tasks which ran through Stages 1 (literature review), 2, (structured interviews with speech and language therapists), and 3 (structured interviews with multi-disciplinary group) of the research, was the construction and refinement of a list of communication principles which, it was hoped, would have the potential, when implemented, to enhance pastoral communication with confused elderly people. The product of this process of correlation between theoretical and experiential perspectives is included in the Appendix as "List 3" (p.406) In the questionnaire (Stage 4) and the in-depth interviews (Stage 5) pastors' experience of the usefulness of these communication principles was explored. The development of a method for enhancing pastoral communication with confused elderly people thus demands the integration of the insights contained in List 3 with the feedback elicited from pastors

through the questionnaire and in-depth interviews. It is to this task that attention turns in the section which follows.

The Development of a Method

In the questionnaire, a number of items received levels of agreement of 70% or more. In the in-depth interviews, pastors also responded to them positively based on their pastoral experience. They are, therefore, regarded as theoretical insights based on developments with speech and language theory which have been proven to hold true in pastoral practice. These items are presented in Table 10.1.

The large number of items in this table should not be ignored. Throughout the research there was a consistent finding of high levels of correlation between the insights and expertise from the different professions. The results from this study indicate that whether through instinct, or based on knowledge gained through experience, pastors are doing many of the 'right things' with regard to enhancing pastoral communication with confused elderly people. That being said, there are gaps, as might be expected, in the pastors' knowledge and there were indications that some of the pastors were not confident in this area of their pastoral practice. In the interviews (Stage 5), a number of the pastors evidenced feelings of inadequacy with regard to the pastoral care of this population. In addition, in the questionnaires (Stage 4) the largest number of general comments (n=10) concerned a desire for additional training in this area [5.4] p.472.

Table 10.1: Pastor's experience of communication with confused elderly people:

The percentages given are for those who rated the features given as helpful or very helpful in enhancing communication. In all cases n=124.

71 - 80%	81 - 90%	91 - 100%
Talk about the past (79.9%)	Listen to their stories (87.1%)	Familiar hymns (90.3%)
Holy Communion (79.9%)	Sit facing the person (83.9%)	Lord's Prayer (90.3%)
Knowledge of hearing (79.8%)	Know something about their lives (83.9%)	
Maintain calm tone (78.2%)	Know names of family members (80.6%)	
Identify oneself (78.2%)		
Maintain eye contact (76.6%)		
Use short sentences (75%)		
Don't correct rambling (74.2%)		
Know what behaviour to expect (76.2%)		

This research, therefore, has brought to light the fact that pastors may be misperceiving the effectiveness of their input with confused elderly people. In response to this, it is vital that pastors are encouraged, and are affirmed in their already good practice. Of course, additional training may also be of use to them.

Another group of communication techniques were developed out of the literature review and speech therapists insights, (Stages 1 and 2) and tested on the multi-disciplinary group (Stage 3), but was not included in the questionnaire. Whilst not wishing to raise matters which relate primarily to method, it is well worth reiterating that the decision not to include them was made for three reasons. Firstly, the responses of the multi-disciplinary group (Stage 3) indicated that they were not familiar with them, the commonest responses at that stage were ambivalence, surprise or theoretical agreement, with the caveat that they "had never tried that". On the basis of these responses it was felt that pastors may not have been familiar with them and would register a high level of uncertainty. The second reason was the length of the questionnaire, some items had to be omitted to avoid becoming cumbersome and discouraging a high response rate. Thirdly, some were not amenable to a questionnaire format because in order to be unambiguous, further explanation would have been required. These items, however, have potential to be included in training of pastors. They are, avoiding humour and sarcasm, avoiding changing the subject too quickly, avoiding pronouns, being alert to fatigue, reminding the confused elderly person about the topic of conversation, using familiar words, avoiding implications and analogies, and making topics of conversation as concrete as possible, giving the confused person time to process what has been said and allowing them time to respond, encouraging the confused person and being aware of non-verbal communication.

The third group of responses of which mention should be made at this point is the group with which the majority of pastors registered active disagreement, both in the questionnaires (Stage 4) and the interviews (Stage 5). These will therefore be discarded in the development of a method for enhancing pastoral communication and care. They were, use of drama [3.13] p.458, including a sermon in worship [3.3] p.454, and writing words in an effort to encourage comprehension [2.16] p.449. Fewer than 20% of the respondents to the questionnaire (n=124) agreed or strongly agreed with these items.

In order to develop a basis for a method of pastoral communication with confused elderly people, the integration of these research findings, with insights from the literature review and discussion, is demanded. This task will be the focus of the following chapter.

CHAPTER ELEVEN

A METHOD FOR ENHANCING PASTORAL COMMUNICATION

WITH CONFUSED ELDERLY PEOPLE

A METHOD FOR ENHANCING PASTORAL COMMUNICATION
WITH CONFUSED ELDERLY PEOPLE

Introduction

The principles for enhancing communication with confused elderly people were developed on the basis of speech therapists' expertise and tested on a multi disciplinary group. In general, the pastors' experiences and insights with regard to communication with confused elderly people, affirmed those gleaned from the speech therapists (Stage 2) and the multi-disciplinary group (Stage 3). This is a significant research finding.

In practical terms this means that many of the communication principles presented in List 3 (Appendix 1, p.406) will be repeated here. The difference is that at this point in the research it can be affirmed that their usefulness in enhancing pastoral communication has been tested, and affirmed, in a pastoral context.

The experience of the three groups is similar, but not identical. Thus, while the findings indicate that many of the pastors had already developed good practice and should be affirmed in this, good practice is not universally applied. There is still the potential therefore, for training, and the application of speech therapists' expertise to the pastoral context.

In addition to this, the experiences of the three groups are not identical with regard to the context of communication. This is a vital point. Whilst there is a level of universality with regard to experiences of communication across the three groups, the clergy's communication takes place, mainly, in a pastoral context. This assertion has significant implications. They are, firstly, that pastoral communication is informed and motivated by a pastoral and theological understanding. The initial aim of this study was to develop a list of communication principles which could be used by pastors to enhance their care of confused elderly people. However, at an early stage, it became evident to the researcher that this approach was not adequate because it ignored the pastoral context. As a result, the decision was made to develop a theological basis for pastoral communication, in addition to the communication principles. Subsequent research findings affirmed the validity of this approach. This research has shown that the pastor's attitude to the confused elderly person is influenced by his or her theological perspective, and by his or her understanding of the nature of pastoral care. Theology and practice go hand in hand.

Secondly, the pastoral context is distinctive because it is one in which the action of God is recognised and affirmed. Fowler (1995) makes a plea that those involved in practical theology would be willing to talk about the actions of God in human affairs. In the interviews (Stage 5) a number of the pastors in this study did just that. The action of God is not limited to specifically pastoral contexts, however, in a pastoral context it is recognised that God and human beings are working in partnership.

In summary, the method which is presented is the result of the integration of insights from the three groups which took part in this research. It is therefore the further distillation of the literature, research findings and discussion. The communication principles are presented here in list form as recommendations for good practice. As such, they constitute a theoretical and practical basis for enhancing pastoral communication with confused elderly people. It is, of course, recognised that this basis has potential for adaptation and illustration, in order to utilise it in pastoral training.

Background Knowledge

1. This research indicates that pastoral communication with confused elderly people will be enhanced if the pastor is aware that dementia:
 - (a). has different forms
 - (b). is progressive, but will progress in distinctive ways depending on aetiology
 - (c). results in cognitive changes
 - (d). results in behavioural changes
 - (e). results in spiritual changes
 - (f). affects the individual's ability to communicate

2. This research indicates that pastoral communication with confused elderly people will be enhanced if the pastor has some background knowledge of the individual with dementia. In particular if the pastor knows:

- (a) the names of family members
- (b) aspects of their life-story
- (c) aspects of their faith history
- (d) their level of hearing acuity
- (e) their level of visual acuity
- (f) the nature of the condition which is causing confusion
- (g) the level of severity of dementia
- (h) whether or not the confused elderly person is being given drugs which could affect their behaviour or responsiveness

Helping the Confused Person to Understand

1. The Physical Context of Communication

This research suggests that the pastor should:

- (a) sit in a quiet area free from distractions like television and radio
- (b) sit facing the confused person so that he or she can pick up on all the available nonverbal cues
- (c) sit in good light, but not in front of a window where the confused person may be dazzled
- (d) sit or position oneself so as to be on the same level as the confused person to encourage and facilitate good eye contact

2. Reality Orientation

The pastor should alert the confused elderly person to his or her presence and identity by:

- (a) touching the person and using their name to alert them
- (b) giving their own name clearly, and the name of the church which they serve
- (c) indicating or even lifting the confused person's hand to touch his or her clerical collar, or other significant religious symbols, such as a Cross, or a Bible

3. Specific Communication Skills

This research indicates that pastoral communication will be enhanced if the pastor:

- (a) refrains from using humour and sarcasm
- (b) avoids changing the subject too quickly
- (c) avoids pronouns
- (d) uses short, simple sentences
- (e) re-orientates the confused person by reminding them about the topic of conversation
- (f) uses familiar words
- (g) avoids implications and analogies
- (h) makes subjects of conversation as concrete as possible
- (i) speaks slightly more slowly
- (j) is aware of tone of voice
- (k) avoids writing

- (l) is willing to use simple, easily understood gestures
- (m) re-states critical facts in a conversation using either explanation or anecdote
- (n) prays, if appropriate
- (o) is aware of body language

Enabling the Confused Elderly Person to Express Himself or Herself

1. This research indicates that the confused elderly person's ability to express himself or herself may be enhanced if the pastor:

- (a) allows the person to tell his or her stories
- (b) does not correct if the person rambles
- (c) uses closed questions, eg. "Do you mean 'X'?"
- (d) encourages the confused elderly person to use gestures.
- (e) uses forced alternatives, eg. "Is it a knife or a fork?"
- (f) uses sentence completion, eg. "Knife and ?" (with rising intonation).
- (g) uses phonemic cueing, the initial sound of the target word being given to the person with dementia.
- (h) encourages talking around the target word. It is not vitally important that the confused elderly individual calls a "bell" a "gong".
- (i) gives the person with dementia time and encouragement.
- (j) moves on if a target word cannot be produced, if the confused person is pressurised they will be less likely to produce the word. As time goes on, they may forget what they were trying to say.

2. This research indicates that faith memories may be accessed for confused elderly people. Potential keys to faith memories were found to be:

- (a) smell
- (b) symbols
- (c) familiar Bible readings
- (d) familiar liturgy
- (e) familiar songs and hymns

Interpreting what the Confused Elderly Person is Communicating to you

This research indicates that the pastor's ability to understand the confused elderly person will be enhanced if :

- (a) the pastor recognises that at every level of severity the confused person may communicate, verbally and nonverbally
- (b) the pastor is willing to pick up the confused elderly person's cues, and not dismiss his or her actions as random
- (c) asks for the statement to be repeated
- (d) tells the confused person that he or she does not understand
- (e) does not, necessarily, correct facts
- (f) is alert to the confused elderly person's tone of voice
- (g) listens for any grammatical clues which the confused person may give in the syntactical structure of their sentences. The structure of words, for example the endings -ed, -er, -est, and suffixes in-, un-, are usually preserved until the late stages of the condition, as is the structure of sentences.

(h) gives reassurance

(i) reduces the use of open questions, and encourages turn-taking, in order to help re-orientate the overly talkative person with dementia.

Public Worship

This research indicates that in planning and leading public worship with confused elderly people the pastor should:

(a) select familiar hymns

(b) select short, familiar Bible readings

(c) make use of familiar liturgy

(d) use familiar prayers

(e) select themes which are relevant to the spiritual needs of the person with dementia

(f) use concrete illustrations which encourage reminiscence

(g) use familiar symbols

(h) omit a sermon

(i) use all the senses

(j) include others from the congregation

(k) include confused elderly people in Holy Communion or the Eucharist.

These recommendations, constituting a distillation of the literature, research findings and discussion, thus provide the basis of a method, which pastors could apply to enhance the pastoral care of confused elderly people.

CHAPTER TWELVE

CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

A number of conclusions, theoretical, theological, pastoral and practical, can be drawn from this research. One of the most noticeable aspects of the research was the consistency in findings between the various groups from whom data was sought.

1. Theoretical Conclusions

- (a) Theology and practice are integrally, reciprocally and dynamically inter-related.
- (b) There is a body of knowledge derived from speech and language therapy, concerning communication with people who have dementia, which lends itself to application to a pastoral situation.
- (c) Enhancement of pastoral communication with confused elderly people demands the development of a theological basis or model in addition to a practical method.

2. Theological Conclusions

- (a) The pastors in this study affirmed the view that God loves the confused elderly person, as they are now.
- (b) The pastors in this study affirmed the view that God values the confused elderly person, as they are now.

(c) Pastoral care of confused elderly people raised theological questions. These included dilemmas about the nature of the individual, personhood, hope and suffering.

(d) Recognition was made of the confused elderly individual, as a person with dignity. This recognition is a way of showing his or her value in the sight of God.

3. Pastoral Conclusions

(a) The findings reflected theological and pastoral experiences across the denominations

(b) Confused elderly people have spiritual needs which may change as the condition progresses.

(c) Confused elderly people themselves, as well as their families and carers, are a valid focus of pastoral care.

(d) Some pastors find the pastoral care of people with dementia difficult, both practically, and in terms of the fact that it raises profound theological questions for them.

(e) Some traditional motives for pastoral care, such as proclamation, are limited when applied to the experience of dementia. However motives such as presence, sustenance, release and advocacy are informative.

(f) Pastoral care of confused elderly people provides an opportunity for ministers and others to exercise their gifts and become involved in an area of pastoral care which is difficult, and may provide very little overt positive feedback, but which is

transformative and an act of witness to God whose love is for all, including the voiceless and those marginalised by dementia.

(f) There is a need for training in this area.

4. Practical Conclusions

(a) The pastors' experiences and insights with regard to communication with confused elderly people affirmed those gleaned from the speech therapists and the multi-disciplinary group.

(b) Many of the pastors have developed good practice with regard to communication, but they were largely unaware that it could be described as such.

(c) Communication, verbal and nonverbal, has the potential to bridge the gap between confused elderly people and those seeking to offer them pastoral care.

Recommendations

The basis for a method for enhancing pastoral communication with confused elderly people, described in Chapter 11, contains many explicit and detailed recommendations. These will not be repeated. However, some general recommendations arise from the research.

1. Recommendations for Pastoral Care

(a) It is recommended that pastoral care of confused elderly people be recognised as an important area of pastoral concern.

(b) It is recommended that pastors work actively to promote the dignity of the person with dementia. This approach is advocated in recognition of the fact that the status of the individual's personhood is controversial. However, the research findings from this study reinforce the claim made elsewhere (Goldsmith 1996, for example) that environmental manipulation in general, and development of relationships in particular, have the potential to improve the individual's feeling of well-being.

(c) This research highlights the potential for specialised chaplains for confused elderly people. They would have specific responsibility for pastoral care of people with dementia at every stage of the condition, and for their carers. They would also have a responsibility for training and supporting both ministers and lay people. They should also be advocates for this group within congregations, the church and society.

(d) It is recommended that there should be increased lay involvement in the pastoral care of confused elderly people. Working in partnership with the pastor, they should develop relationships with the confused elderly person through regular visiting, and should be a link between the family and the rest of the congregation. It is strongly recommended that these lay visitors receive training.

(e) Although not the focus of this study, the pastoral, emotional and practical needs of carers were recognised by several of the participants. In the light of this recognition, it is strongly recommended that pastors be aware of these needs. When appropriate, allowing for confidentiality, these could be communicated to the congregation, in order that the carers receive the necessary emotional and practical support.

(f) It is recommended that the Church examine ways in which it can support clergy who are exercising this difficult ministry.

2. Recommendations for Training

(a) It is recommended that training be provided in pastoral care of, and communication with, confused elderly people for:

(i) theological students

(ii) those involved in pastoral care , ordained and lay

(iii) hospital chaplains

(b) In addition to focusing on a theological basis and practical method for pastoral communication with confused elderly people, it is recommended that training should include the practical and spiritual needs of carers, and of the pastors themselves.

(c) It is recommended that one aspect of in-service training be affirmation of good practice where it exists.

3. Recommendations for Research

(a) It is recommended that further research be carried out on the pastoral care of people with dementia. This could focus on:

(i) ascertaining the spiritual needs of people with dementia directly, or,

(ii) further investigation of triggers which may have the potential to access faith memories for the confused person.

(b) There is potential for further research focused on the experiences and perceptions of the confused elderly people themselves. The challenges and difficulties inherent in such a suggestion are acknowledged. However, there is developing interest and expertise in interviewing confused elderly people. Research of this type would be helpful in avoiding of the pitfall of imposing views on people with dementia, or presuming that their feelings are understood. There is also the potential for the making of comparisons between the experiences of pastors and those of confused elderly people.

(c) It is recommended that research be done on the optimum time for training to be given to ministers.

(d) This thesis is data rich. All the information which is contained in the transcripts from the in-depth interviews, for example, has not been utilised. There is thus potential for further research based on analysis of this information.

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APPENDIX I

Lists of Communication Principles (Stages 1,2 and 3)

LIST 1

Developed from literature review and used in structured interviews with speech and language therapists (Stage 2)

The following is a list of suggestions which, it is hoped, will help pastors' to communicate with people with dementia.

A. Preparation

1. Be aware of the nature and course of dementia.
2. Think through some of the issues which people with dementia may be facing.
3. Find out about the confused person from the people who know him best.
4. Be aware that the visit is worthwhile.
5. Remember that when you visit a confused person communication is taking place whether you like it or not.
6. Allow for "bad days".

B. The Context

1. Ask permission to see the person from the hospital staff or caregivers
2. Find somewhere quiet to talk away from television and radio.
3. Feel comfortable in the situation.
4. Sit in the same area on every visit.

C. To increase the likelihood of being understood by the confused person

1. Know about the persons hearing.
2. Identify yourself very clearly.
3. Sit so that good eye-contact can be maintained.
4. Watch out for fatigue.

5. Remember that the person with dementia may have difficulty understanding humour and sarcasm.
6. Use "over-learned" material.
7. Talk about concrete topics rather than abstract ones.
8. Don't change the subject quickly.
9. Talk about the past - in particular the individuals life.
10. Use short, simple sentences.
11. Avoid pronouns
12. Remind the person about the topic of conversation.
13. Repeat sentences, phrases and words.
14. Be alert to your tone of voice.
15. Be realistic about the persons capabilities.
16. Writing will probably not be helpful.
17. Pray if appropriate.

D. Encouraging the confused person to express themselves

1. Encourage the use of alternative ways of getting the message across.
2. Encourage talking around the target word.
3. Use closed questions.
4. Use specific strategies - for example forced alternatives, phonemic cueing or sentence completion.
5. Leave the target quickly if the person is not successful.
6. Reward messages which are communicated.
7. Offer alternative endings to incomplete sentences.

E. Understanding what the confused person says

1. Remember that it takes a confused person a long time to say anything.
2. If the person produces meaningless sentences tell them that you have not understood.
3. If the person repeats an idea or phrase tell them, distract them, or change the subject.
4. If the person talks too much you can emphasise verbally the need to take turns, reduce use of open questions and give re-assurance.

F. Public Worship

1. Use ritual
2. Use symbols
3. Choose familiar hymns and short familiar bible readings
4. Choose relevant themes
5. Remember that it isn't always necessary to have a sermon
6. Keep it short.

LIST 2

Developed from literature review and interviews with speech and language therapists: Used in interviews with related professionals and carers (Stage 3)

Pastoral Communication with confused elderly people

the aim of this study is to help ministers and pastors communicate more effectively with confused elderly people. During the last number of years there has been a growing interest, in all aspects of confused elderly people, and extensive research has been carried out on the effects of the disease, on speech and language. The list which follows has been based on the findings of these investigations, and on feedback from speech and language therapists working in this area. It is hoped that the implementation of these suggestions would enhance pastoral communication.

1. PREPARATION:

The potential for effective pastoral communication may be increased if the minister is able to **prepare** for the visit. What follows is a list of suggestions which may be of help in this preparation:

A. Some awareness as to the nature and course of dementia may be helpful. this knowledge helps the pastor to know what to expect in terms of behaviour and the progression of the disease. In addition it enables the pastor to distinguish between, behaviour which is characteristic of the disease, and behaviour which is occurring as a result of particular anxiety or distress which the person may be experiencing.

B. It may also be useful to have thought through some of the issues which confused elderly people may be facing. In the early stages in particular people may be grappling with questions about suffering and the nature of god, or wondering about a link between sin, sickness and punishment. Even in the later stages, when more deeply affected by the illness, people may need to be reminded of gods unconditional love and presence, and affirmed as an individual who is of worth.

C. It may well be useful to find out about the confused person before they are visited. this includes finding out about their personality, hobbies and interests as well as their christian beliefs and practice. If the confused elderly person is in hospital, or in a residential or nursing home this information may be obtainable from the staff. Some professionals who work with confused people obtain relevant information from a questionnaire (see appendix for an example), and it may be possible to have access to this information. Alternatively it may be possible to ask the family.

D. Pastoral communication may well be enhanced if the pastor knows the level of severity of the persons illness. It may well be however, that the family are not the most reliable informants in this area. Understandably they may have unrealistic expectations about their relatives abilities.

E. In addition to this practical, factual preparation a degree of mental preparation may also be helpful. The vast majority of pastors are heavily over-burdened with work. It is therefore understandable that the thought that "visiting confused elderly people is a waste of time" - or something similar, will cross many pastors minds. It cannot be denied however that confused elderly people have genuine pastoral needs. The feedback that the pastor gets when he offers care may not be positive. The person may have forgotten your last visit, or may not recognise you. It may therefore be helpful to alter the criteria by which we assess the usefulness of our care. When involved with confused elderly people it may be unreasonable to expect a long term change to occur, as a result of a visit or series of visits. The effect of a visit may just be for the moment. It may be that God by his spirit uses that moment to remind the person of God's love and presence. That in itself is worthwhile. Bearing this in mind, can empower, encourage and enable the pastor to be genuinely interested, warm and patient.

F. Pastors are valid and important members of the team of people who are caring for the confused elderly person. Care staff and family members will be glad to see pastors making a real effort to communicate. Pastors can therefore feel comfortable in the situation. This too is important as the confused person will pick up your relaxation.

G. It may be helpful to bear in mind that when visiting a confused person communication is taking place whether we like it or not. Frequent glances at a watch, not sitting down, lack of eye contact are all communication. If one visits and feels afraid, bored or embarrassed, that in itself is communication at a very deep level. As a result we may leave the confused person feeling isolated or worthless. This is of particular importance in that recent research has found that even if a confused elderly person with alzheimer's disease does not appear to understand, all of the elements in a conversation, the feelings that the encounter evokes are real and lasting.

H. Many of us vary in mood to some degree from day to day. It may be helpful, as preparation is made for a visit, to remember that on the day, or at the time when you choose to visit, the person may be tired or unwell. They may be on new drugs which are making them feel drowsy, or which are increasing their confusion.

2.Context:

The **context** in which the visit takes place will affect the usefulness of the pastoral encounter. It is suggested that the following may create a helpful environment in which pastoral care can take place:

A. If the person is in hospital, it is a professional courtesy to ask permission from the hospital staff to visit. This does not deny the fact that the pastor is an important member of the care team. It does however give the pastor the opportunity to ensure that he or she is calling at an appropriate time. If the pastor calls at a meal time, or at a time when the person is usually taken to the toilet, they are likely to be distracted. In addition making an initial contact, with ward staff, enables the pastor to find out how the person is today.

B. It is important to find somewhere quiet to talk, away from distractions like television and radio. Some researchers have found that it is helpful to sit in the same area on every visit. It is claimed that this reinforces continuity, and enables the confused person to identify the pastor more readily, as they associate them with a particular place.

C. It has been found that the confused person finds it easier to understand what is being said if the speaker sits with the light on their face. This aids lip reading and enables the person to pick up every available non-verbal cue. People with dementia are relatively good at picking up non-verbal cues like gesture, facial expression, gaze and body language. Appropriate use of all of these may help them to tune into the meaning of the conversation.

3. Being understood:

The pastor may find it useful to implement the following strategies which are aimed at **helping the confused person to understand what is being said:**

A. Find out about the persons hearing. if they use a hearing aid, are they wearing it at the moment, and is it turned on. If the person is hard of hearing, instead of shouting, it is more helpful to add a little volume, and speak slightly more slowly.

b. touch the person, and use their name to alert them, and to gain and hold their attention. This may also help the pastor to gain and maintain eye contact.

c. it will help the confused person, to follow the content of your conversation, if they are sure who you are. Don't take it for granted that they remember you, even if you know them well. It may be most helpful to identify yourself very clearly, and to put yourself in context. It will help the confused person if they are given every possible clue, name the church clearly, name church activities and members. it may also help them to identify you if they are given relevant non-verbal clues - indicating ones' clerical collar or a bible or a cross for example.

d. be alert to fatigue. If the person does get tired you can just sit quietly for a time.

e. the person who is confused may have difficulty understanding humour and sarcasm. it is much better to say "it is raining heavily" than to say "its raining cats and dogs".

F. people who have dementia, often find it easier to remember things which they learnt long ago, then they do to remember recent events. Pastors may well have noticed this in church congregations, where even the most confused person may join in the singing of a well known hymn. Or they may say the lords prayer or a psalm. The pastor can use this "over-learned" material to help the person understand and to make conversation meaningful. If choosing hymns and bible readings for a service it may well be best to concentrate on well known ones. In one to one conversation it may well be appropriate to say the Lords prayer. The repetition of that prayer may create a spark of recognition for even the most confused person.

g. it will help the confused person, to follow the conversation, if the speaker does not change the subject too quickly. it has been found that it takes confused elderly people time to tune into the subject of a conversation, and time to process what is being said. If the subject is changed quickly or the speaker goes off at a tangent, even if the progression seems logical to you, it is likely that you will lose the confused persons attention and understanding. therefore it may be useful to introduce new topics of conversation directly, even to go as far as saying "lets talk about the church now"

h. it may help if short, simple sentences are used. for example "i am from st. patrick's" rather than "rev.jones from st. patrick's ,who usually comes to see you is away on holiday, so i have instead."

i. it will help the confused person to follow if pronouns are avoided. A sequence like, "mr brown was in church on sunday, he was looking very well and he said that -" is difficult for the confused person. by this stage they may well have forgotten, to whom "he" is referring. therefore although it often sounds cumbersome it is more helpful to repeat the subjects name. "mr. brown was in church on sunday. mr brown was looking well. mr brown said that -".

j. it may also be helpful to remind the confused person about the topic of conversation. this can be done directly by using a phrase like, "you remember we are talking about cars" or by repeating sentences, words and phrases.

k. a difficulty in understanding may be overcome if you re-state and paraphrase what has been said. The same idea stated in a different way may be better understood.

l. it may make things easier for the confused person if well known, everyday words are used rather than infrequently used ones. for example, friend instead of acquaintance.

m. it is best to say what you mean, and not to employ implications, for example "I'm too busy to talk", rather than "do I look as if I've got nothing to do?"

n. It will help the confused person to understand if analogies are avoided. For example "keeping this house clean is like painting the forth bridge".

o. it will help the confused person to follow the conversation if the speaker assumes that previously given information is being gradually forgotten. to overcome this, one can, re-state critical facts using either explanation or anecdote.

p. some researchers have found that confused elderly people remain sensitive to the tone of voice being used by the speaker, especially if it contains reprimand or criticism. Therefore it may be important to remain alert to the tone of voice you are using.

q. it may be helpful to enhance what you say with appropriate gestures. being physically expressive may increase the confused persons ability to understand.

r. if meaningful pastoral communication is to take place, it is important that the pastor, be realistic about the confused persons capabilities. a confused elderly person may appear to understand more than they really do. this is due to the fact that the "social" aspects of language are relatively preserved by the disease. they may answer appropriately when asked questions like "how are you?". they may try to mask the extent of their difficulties, for example, they may change the subject if they cannot understand. they may use appropriate eye-contact, they may nod. This might be because they are picking up non-verbal signals rather than really understanding what is being said. it becomes helpful therefore to keep language simple, even when you are being given all the right cues. this may be particularly hard if you knew the person well before they became ill. There can be a very real emotional component for the caring pastor who can , understandably, find it difficult to believe that their loved and responsible congregation member and friend, has been so deeply effected by the disease. it will be helpful for the confused person, if the pastor tries to keep the relationship as it has always been. One way of doing this is to avoid talking to the person as if their role in life had altered.

s. sadly, writing words down does not provide an easy way around comprehension problems. The confused person may not be able to recognise or understand the written word. it may also help to be aware of the fact, that ability to read a word aloud, does not imply that the confused person understands the meaning of that word. that being said some practitioners have found that a combination of the verbal and written word may be helpful, and writing can help in overcoming the effects of a profound hearing loss.

t. in appropriate situations, the language and posture of prayer may be a powerful means of pastoral communication, even to the most confused person.

u. it is when the **subject** of the conversation is considered, that the pastor encounters one of the crucial difficulties in this area. there is little doubt that confused elderly people, find concrete topics easier to understand than abstract ones. It is best to base

the conversation on that which is familiar and directly observable. it is very difficult for a confused elderly person to follow, complex logical argument or philosophical or logical discussion. however the pastor is often dealing with that which is abstract and unobservable - love, guilt fear of death, for example. if communication is going to be both meaningful and pastoral the pastor must recognise this potential difficulty and do all that he or she can to earth the conversation and make what is abstract concrete. the pastors presence in itself may be for the confused person a concrete expression of the churches care and by extension of the love of god. in this situation the "well-worn" phrase which has become religious jargon may be usefully employed for it may trigger meaning. it may be helpful to use familiar bible stories and even use an illustrated bible.

it may well be helpful to talk about the past, in particular the individuals life. reminiscence is very important. talking about their life may help the confused person to see that their life was and is valued and important. by reminiscing the person may also remember important points in their own faith story and relationship with god. this may lead to reassurance that god continues to be with them and continues to love them.

4. self-expression:

one of the most common symptoms of dementia is difficulty in meaningful self-expression. it can be very difficult for these people to find words or name objects. Yet, it can enhance self-worth if the confused person experiences success in communicating a message. in addition if the confused person is distressed it may be very helpful for them to be able to express what is on their minds. The following are offered as suggestions which may enable the confused person to **express themselves**:

- a. the confused person may find it easier to communicate, if they are given time and encouragement by the listener.
- b. encourage talking around the target word, and description of the item, that cannot be named. Reward the person for communication. it is not vitally important that they called the "bell" a "gong" , or that they didn't use a noun at all, but said "to call with it". Communication took place and that is of paramount importance.
- c. if the person is struggling to find a particular word it may help if you use closed questions. "is it an x, or a y?". "do you mean x?" . it is necessary to take care, when asking closed questions, that you are not leading the person to say what you want them to say . also you might be on totally the wrong track, and confusing the person, with irrelevant closed questions.
- d. it may also be helpful to use clues to help the person e.g. if it's an animal - you're talking about something that you eat.
- e. it may help the confused person if they are encouraged to demonstrate, what they are trying to say, with gesture.

f. in some cases it may be appropriate and helpful to use specific strategies. if you know the word, that the person is trying to say, and you feel that it is important for their self-confidence to actually say the word, it is possible to implement the following strategies:

- a) forced alternatives; like closed questions, "is it a knife or a fork?"
- b) sentence completion; knife and (with rising inflection)
- c) phonemic cueing; the initial sound of the word is presented to the person.

g. if the strategies described above are not successful then it is better to move or give the person the word if you know it, on rather than struggling to find the word. this claim is made for two main reasons. the first is that if the confused person is pressurised, then they are less likely to produce the word. the second is that as time goes on, the person may forget what they are trying to say. in both cases the outcome is that the person feels demoralised.

5. understanding:

having enabled the confused person to express themselves the pastor must try to **understand what the confused person has said.** this can be quite a difficult task. the speech of confused elderly people has been found to contain meaningless, as well as, inappropriate utterances. it can also be characterised by repetition of phrases like "i want to go home" or "where is mother?". an already complicated picture may then be complicated, yet further, if the confused person is disorientated in time, place or person.

- a. as has been pointed out a confused elderly person remains sensitive to intonation patterns in a speakers voice. it may help the pastor to understand what the person is trying to communicate if they listen to the intonation patterns in the speech of the confused person.
- b. there may well be a place for responding to what you feel is being said, not necessarily what is being literally said.
- c. if the person produces meaningless sentences, you can tell them that you have not understood. there may however, be little to be gained from trying to correct the facts.
- d. it often takes the confused person a long time to say anything. the pastor can give them time, and may even wish to say "i'm in no rush" or something similar, if the person is getting upset.

e. if the person continually repeats themselves, you can try to break the cycle by telling them, or you can distract them, or you can change the subject.

F. if the person is rambling, or gets confused, you can tactfully bring them back to the topic with a reminder or a question. for example, you were talking about your wedding. was the service in the church?"

g. Dementia can make some people more talkative. if the person talks too much, you may feel that it is appropriate to emphasise the need to take turns, reduce use of open questions and give reassurance.

h. there are positive things which the pastor may like to listen out for, to give him or her clues as to the meaning of what is being said. the structure of words, for example the endings -ed, -er, -est, and suffixes, in-, un-, are usually preserved until the late stages of the disease, as is the structure of sentences.

6. public worship:

one specific situation in which the pastor may find themselves, is leading services of **public worship** on a hospital ward, or in a home where there are a number of confused people. many of the suggestions made above may be applied to services of worship. in addition the following suggestions are offered:

a. the confused person may find considerable meaning in ritual. therefore it may help to use familiar liturgy and ritual acts, like the sharing of the peace and communion.

b. symbols which are clear and concrete and require minimal interpretation may be used. for example, a shepherds staff, or the bread and wine on the communion table.

c. Choose familiar hymns and familiar short bible readings.

d. choose relevant themes, and if possible, have the theme clear in most of the elements of the service. a persons fears and concerns may not have gone just because they are confused, therefore it is still important to deal with topics like death, forgiveness and jesus' care and concern for the sick.

thus a possible order of service might include a number of short scripture readings, with brief comments, hymns and a time of prayer, with the lords prayer and the sharing of the peace, all built round a central theme.

E. it may not be necessary to have a sermon.

f. at times it may be appropriate to encourage participation, in responses and in "feedback" during comment on bible passages.

g. the most appropriate length may be about half an hour.

LIST 3

Developed from literature review, interviews with speech and language therapists and related professionals and carers : Used in construction of questionnaire (Stage 4)

Pastoral communication with elderly confused people

The aim of this study is to help ministers and pastors to communicate more effectively with people with dementia. During the last number of years there has been a growing interest in all aspects of dementia, and extensive research has been carried out on the effects of the disease on speech and language. The list which follows has been based on these investigations and on feedback from speech and language therapists and others who have experience in this area. It is hoped that within these findings there are insights which may be helpful in pastoral communication.

1. Preparation

The potential for effective pastoral communication may well be enhanced if the pastor is able to prepare. It is hoped that the following would help in that preparation.

a. Awareness as to the nature of dementia

This knowledge helps the pastor to know what to expect in terms of the persons behaviour and the likely progression of the disease. Pastorally it may help to distinguish between behaviour which is characteristic of the disease, and that which may be occurring as the result of particular anxiety or stress which the person may be experiencing.

b. Reflection on the issues which people with dementia may be facing.

In the early stages of the disease people may be grappling with questions about suffering and the nature of God, or perhaps wondering about a link between sin, sickness, and punishment. Even in the later stages of the disease when the person is more deeply effected they may be comforted by being reminded of Gods unconditional love and Presence. They may be encouraged if the pastor is able to affirm them as an individual who is of worth.

c. Finding out about the person with dementia.

It may well help the pastor to trigger meaning and memory if they know about the person. This may include finding out about their personality, hobbies and interests

before they became ill, as well as their Christian beliefs and practice. This information may be sought from the family or care professionals. (See appendix for a questionnaire)

Knowledge about the severity of the persons illness may also be helpful. It may well be however that the family are not the most reliable informants in this area. Understandably they may have unrealistic expectations about their relatives abilities.

d. Realistic Expectations

The feedback which the pastor gets when he or she offers care to the confused elderly person may not be positive. It is possible that they may have forgotten the last visit, or the pastor may not be recognised. It may therefore be helpful to alter the criteria by which the usefulness of care is assessed. When involved with people with dementia it may be unreasonable to expect a long term change to occur as a result of a visit or series of visits. The effect of a pastoral encounter may be just for the moment. It may be that God by His Spirit uses that moment to remind the person of His Love and faithfulness. That in itself is worthwhile. It may be that bearing this in mind can empower and enable the pastor and free him or her to be genuinely interested, warm and patient.

e. Being aware of the breadth of communication

Frequent glances at a watch, not sitting down, lack of eye-contact are all acts of communication. It is possible to communicate boredom, or anxiety or embarrassment inadvertently. As a result the confused person may be left feeling isolated or worthless.

Recent research suggests that even if a person with dementia does not understand much of a conversation the feelings which that encounter evokes are real and retained. This makes it vital that the act of pastoral communication is positive and affirming for the confused person.

f. Being aware that people vary from day to day

On the day that the pastor chooses to visit the person may be tired or unwell. They may be on new drugs which are making them drowsy or increasing their confusion.

2.Context

It is suggested that the following may create a helpful environment in which pastoral care can take place.

a. Asking permission to visit

This may be most applicable in a hospital or nursing home. Asking permission does not deny that the pastor is an important member of the care team. It is however seen as a professional courtesy. In addition it gives the pastor an opportunity to ensure that they are calling at an appropriate time. For example if the pastor calls at a meal time, or a time when the person is usually taken to the toilet then they are likely to be distractible. Making an initial contact with the ward staff also enables the pastor to find out how the person is today.

b. Finding a quiet place, away from distractions

It may help the confused person if they are away from television and radio. Some researchers suggest that it is helpful to sit in the same area on every visit as this reinforces continuity, and enables the confused person to identify the pastor more readily as they are associated with a particular place.

It has been found that the confused person finds it easier to understand what is being said if the speaker sits with the light on their face. This aids lip reading and enables the person to pick up every available non-verbal cue. People with dementia are relatively good at picking up non-verbal cues like gesture, facial expression, gaze and body language. Appropriate use of all of these may help them to tune into the meaning of the conversation.

3. Helping the confused person to understand

It is suggested that the following may help the confused person to understand what is being said.

a. Finding out about the persons hearing

If the person uses a hearing aid are they wearing it and is it turned on? If the person is hard of hearing it has been found that adding a little volume and speaking slightly more slowly is more effective than shouting.

b. Alerting them to your presence

It may be useful to touch the person and use their name to alert them, and to gain and hold their attention. This may also help the pastor to gain and hold eye contact.

c. Identifying yourself

It will help the confused person to follow the content of the conversation if they are sure who you are. Don't take it for granted that they remember you even if you know them well. It may help the confused person if you put yourself in context and give them every possible clue as to your identity. It may be useful to name the church clearly, or name church activities or members. It may also help them to identify you if they are given non-verbal clues - indicating a clerical collar, or a Bible or a Cross for example.

d. Being alert to fatigue

If the person does get tired just sit quietly for a while.

e. Avoid humour or sarcasm

The person who is confused may find it difficult to understand humour or sarcasm.

f. Avoiding changing the subject too quickly

It has been found that it takes people with dementia time to tune into the subject of a conversation and time to process what is being said. If the subject is changed quickly, or the speaker goes off at a tangent, even if the progression seems logical to the speaker, it is likely that the confused persons understanding and attention will be lost. It may therefore, be helpful to introduce new subjects directly, even to go as far as saying "Lets talk about the church now".

g. Using short simple sentences

"I am from St. Patrick's" rather than "Rev. Brown from St. Patrick's who usually comes to see you has gone away on holiday so I have come instead".

h. Avoiding Pronouns

A sequence like, "Mr. Jones was in church on Sunday, he brought his children. He was looking much better and he said to me that he - " is very difficult for the

confused person. By this stage they may well have forgotten to whom "he" is referring. Therefore although it often sounds cumbersome it is helpful to repeat the subjects name - "Mr. Brown was in church on Sunday. Mr. Brown brought his children etc."

i. Reminding the person about the topic of conversation

This can be done directly by using a phrase like "You remember we were talking about cars" or by repeating sentences, words or phrases. Alternatively restating and paraphrasing may be helpful. The same idea stated in a different way may be better understood. It may well be that the confused person gradually forgets previously given information, even in the course of a conversation, to overcome this one can try re-stating critical facts using either explanation or anecdote.

j. Using well-known words

For example, friend instead of acquaintance.

k. Avoid implications

It is better to say what you mean and not to employ implications. For example, "I'm too busy to talk" rather than "Do I look as if I've got nothing to do?"

l. Avoid analogies

" I have a lot of cleaning to do " rather than "keeping this house clean is like painting the Forth Bridge".

m. Being aware of tone of voice

Some researchers have found that people with dementia remain sensitive to the speakers tone of voice, especially if it contains reprimand or criticism.

n. Using gestures

For example pointing to a collar.

o. Being realistic about the confused persons capabilities

A person with dementia may appear to understand more than they really do. This is because "social" aspects of language are relatively preserved by the disease. They

may therefore answer appropriately when asked "how are you?". They may try to mask the extent of their difficulty by changing the subject if they cannot understand. They may use appropriate eye-contact, they may nod. This may be because they are picking up non-verbal signals rather than really understanding what is being said. It will help the person to understand if language is kept simple, even if the speaker is being given all the right cues and is therefore tempted to make things more complex. This may be especially difficult if the pastor knew the person well before they became ill. There can be a very real emotional component for the caring pastor who, understandably can find it difficult to believe the extent of their friends difficulties. It will be helpful for the confused person if the pastor tries to keep the relationship as it has always been. One way of doing this is to avoid talking to them as if their role in life has altered.

p. Avoid writing

The confused person may not be able to understand or recognise the written word. The confused person may be able to read a word aloud but this does not mean that they understand the meaning of that word. That being said some practitioners have found that a combination of the verbal and written word may be helpful.

q. Prayer

In appropriate situations the language and posture of prayer may be a powerful means of pastoral communication and care even to the most confused person.

r. Concentrate on subjects which are concrete, familiar and observable

It is very difficult for a person with dementia to follow complex logical argument or philosophical discussion. However the pastor may be dealing with subjects which, by their nature, seem abstract - like love, forgiveness and peace. If conversation is going to be both meaningful and pastoral the pastor can try to do all that they can to earth the conversation and make what could be abstract concrete. The pastor's presence may in itself be a concrete expression of the church's care and, by extension of the love of God. It may be helpful to use familiar Bible stories or an illustrated Bible. Being alert to all triggers of meaning will enhance pastoral care. A particular smell or a hymn may bring recognition.

s. Talking about the past

Reminiscence is important. Talking about their life may help the confused person to see that their life was and is valued and important. Through reminiscence the person may also remember important points in their own faith story. This may lead to reassurance as they remember that God loves them now as he did then.

4. Enabling the confused person to express themselves

One of the most common symptoms of dementia is a difficulty in meaningful self expression. It can be very difficult for the person to find words or name objects. Yet self expression enhances self worth, and may enable the person to express fears or concerns. It is suggested that the following strategies may help the confused person to express themselves.

a. Giving the person time

Wait for a response, hesitation may be due to a lack of understanding or, an inability to frame a reply.

b. Encouragement

It is not vitally important that the person calls the bell a gong or described it with a phrase like "to call with it". If communication took place it should be encouraged.

c. Using closed questions

If a person is struggling to find a particular word one could ask "Is it an X or a Y?" or "Do you mean X?" A word of caution however, it is possible to lead the person to say what you want them to say using closed questions, or you may be misunderstanding what the person wants to say and be confusing them with irrelevant questions.

d. Encouraging the confused person to use gesture

e. Using specific strategies

If you know the word that the person is trying to find and you feel that it would be helpful for them to produce it, then it may help if one of the following strategies are implemented.

- 1) Forced alternatives; "Is it a knife or a fork?"
- 2) Sentence completion; Knife and (with rising inflection)
- 3) Phonemic cueing; the initial sound of a word is presented.

If the strategies outlined above are not successful then it is better to give the person the word or move on rather than struggling further. This suggestion is made

for two reasons. Firstly, if the person feels themselves to be under pressure then it is less likely that they will be able to produce the word, and secondly, as time goes on the confused person may forget what they were trying to say. In both cases the outcome would be that the confused person feels demoralised.

5. Understanding what the confused person has said

Understanding the speech of a person with dementia can be quite a difficult task. Their speech has been found to contain meaningless as well as inappropriate utterances. It can also contain repeated phrases - " I want to go home" for example. An already complicated picture may be made yet more difficult if the person is disorientated in time, place or person.

It is suggested that the following may help the pastor to understand the speech of a person with dementia

a. Asking for the statement to be repeated

b. Telling the person that you don't understand

There may be little to be gained from trying to correct the facts. However if the person continually repeats themselves it may be possible to break the cycle by telling them. Alternatively one could distract them or change the subject.

If the person is rambling they can be tactfully brought back to the subject with a question or a reminder, for example, "you were talking about your wedding. Was it in the church?".

c. Being alert to the tone of voice

d. Listening for grammatical clues

The structure of words, for example the endings -ed, -er, -est and suffixes, in-, and un- are usually preserved until the very latest stages of the disease, as is the structure of sentences. Listening for these may help the pastor to tune into the meaning of what is being said.

There may well be a place for responding to what the pastor feels is being said rather than what is literally said.

6. Public Worship

Many of the suggestions made above can be applied to a service of public worship in a hospital or residential home. In addition the following suggestions are offered.

a. Use " over-learned" material

People who have dementia often find it easier to remember things which they learnt long ago than they do to remember recent events. Therefore when choosing hymns and Bible readings it may be most helpful to concentrate on very well known ones. The Lords Prayer or the Twenty-third Psalm may create a spark of recognition for even the most confused person.

b. Ritual

The person with dementia may find meaning in familiar liturgy and ritual acts, like the sharing of the Peace or Communion.

c. Symbols

Symbols which are clear and concrete and require minimal interpretation may be helpful. For example, a shepherds staff or the Bread and Wine on the Communion Table.

d. Highlighting relevant themes

If possible link the theme into most of the elements of the service. The person with dementia may be concerned about issues like death and forgiveness and Jesus care and concern for the sick.

e. Encouraging Participation

People may be helped by being able to participate, in responses and in feedback during comment on Bible passages.

In summary therefore a possible order of service might include a number of short Scripture readings with brief comments, hymns and a time of prayer with the Lords Prayer, all built round a central theme. It may not be necessary to have a "sermon". The most appropriate length may be half an hour.

APPENDIX II

Pastors' Questionnaire (Stage 4)



PASTORAL COMMUNICATION WITH
CONFUSED ELDERLY PEOPLE.

PASTORAL COMMUNICATION WITH CONFUSED
ELDERLY PEOPLE

During the last number of years there has been a growing interest in all aspects of dementia, and extensive research has been carried out on the effects of the disease on speech and language. Arising from this the aim of this study is to explore with ministers and pastors how we can be enabled to communicate more fully with confused elderly people.

It would be of tremendous help if you would complete the following questionnaire as fully as possible.

Please indicate how much of your working week is spent with confused elderly people.

(Please tick the appropriate box)

All of my working week.

About three quarters of my working week.

About one half of my working week.

About one quarter of my working week.

Less than one quarter of my working week.

No regular contact.

YOU HAVE ANSWERED "NO REGULAR CONTACT" PLEASE GO
TO QUESTION FOUR ON PAGE FOUR

Where do you meet with confused elderly people?

(Tick one box per line)

	Yes	No	
Person's own home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carer's home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Residential/Nursing home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Yes	No	
Hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Yes	No	
Church Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Church Activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>(please specify)</i>			<input type="checkbox"/> <input type="checkbox"/>
_____			<input type="checkbox"/> <input type="checkbox"/>

Do you lead services of worship at which confused elderly people are present?

(Tick appropriate box)

Yes

No

If "Yes", where do they take place? (Please tick)

Residential/Nursing home	<input type="checkbox"/>	<input type="checkbox"/>
Hospital ward/Chapel	<input type="checkbox"/>	<input type="checkbox"/>
Church/Chapel	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>(Please specify)</i>		<input type="checkbox"/> <input type="checkbox"/>

PLEASE GO TO SECTION TWO

If you have no regular contact with confused elderly people at the moment have you ever had?

(Tick appropriate box)

Yes

No

If "No" please go to Section Five.

If "Yes" where?

(Tick one box per line)

Yes No

Person's own home

Carer's home

Residential/Nursing home

Yes No

Hospital

Hospice

Yes No

Church Services

Other Church Activities

Other *(Please specify)*

SECTION TWO Pastoral Communication with confused elderly people.

The following are statements which concern pastoral communication with confused elderly people.

(Please respond by circling the number which best corresponds with your experience.)

1 2 3 4 5
 Strongly Agree Agree Uncertain Disagree Strongly Disagree

For example, you have found that maintaining eye-contact makes it much easier to communicate with confused elderly people then you would circle "1". If, on the other hand, you find it very unhelpful you would circle "5".

On my experience I have found it easier to communicate with confused elderly people if I

	Strongly agree					Strongly disagree					
	1	2	3	4	5	1	2	3	4	5	
maintain eye-contact	1	2	3	4	5						<input type="checkbox"/>
I am sure about their degree of confusion	1	2	3	4	5						<input type="checkbox"/>
know about their hearing	1	2	3	4	5						<input type="checkbox"/>
hold their hand	1	2	3	4	5						<input type="checkbox"/>
identify myself clearly	1	2	3	4	5						<input type="checkbox"/>
know something about their lives	1	2	3	4	5						<input type="checkbox"/>
speak slowly	1	2	3	4	5						<input type="checkbox"/>
correct them when they ramble	1	2	3	4	5						<input type="checkbox"/>
use familiar gestures (ex. pointing)	1	2	3	4	5						<input type="checkbox"/>
ask them questions	1	2	3	4	5						<input type="checkbox"/>

SECTION TWO Pastoral Communication with confused elderly people.

From my experience I have found it easier to communicate with confused elderly people if I

	Strongly agree		Strongly disagree			
	1	2	3	4	5	
know what behaviour to expect from a confused elderly person	1	2	3	4	5	<input type="checkbox"/>
know the names of close family members	1	2	3	4	5	<input type="checkbox"/>
sit quietly at times	1	2	3	4	5	<input type="checkbox"/>
don't repeat myself	1	2	3	4	5	<input type="checkbox"/>
use short simple sentences	1	2	3	4	5	<input type="checkbox"/>
write down key words	1	2	3	4	5	<input type="checkbox"/>
wear a clerical collar	1	2	3	4	5	<input type="checkbox"/>
talk about the past	1	2	3	4	5	<input type="checkbox"/>
speak loudly	1	2	3	4	5	<input type="checkbox"/>
don't move the person	1	2	3	4	5	<input type="checkbox"/>
sit facing the person	1	2	3	4	5	<input type="checkbox"/>
maintain a calm and even tone of voice	1	2	3	4	5	<input type="checkbox"/>
listen to their stories	1	2	3	4	5	<input type="checkbox"/>

SECTION THREE Public worship

The clergy are concerned with people's participation in public worship. Based on your experience with confused elderly people, how helpful are the following elements to this group?

1	2	3	4	5
Very helpful	Helpful	Uncertain	Unhelpful	Very unhelpful

(Please circle the appropriate number)

	Very helpful				Very unhelpful	
Singing familiar hymns	1	2	3	4	5	<input type="checkbox"/>
Familiar Bible readings	1	2	3	4	5	<input type="checkbox"/>
Sermon/homily	1	2	3	4	5	<input type="checkbox"/>
	Very helpful				Very unhelpful	
Extempore prayer	1	2	3	4	5	<input type="checkbox"/>
Lord's prayer	1	2	3	4	5	<input type="checkbox"/>
Times of silence	1	2	3	4	5	<input type="checkbox"/>
Sharing the peace	1	2	3	4	5	<input type="checkbox"/>
	Very helpful				Very unhelpful	
Using the same order	1	2	3	4	5	<input type="checkbox"/>
Using a standard liturgy	1	2	3	4	5	<input type="checkbox"/>
Using one version of the Bible consistently	1	2	3	4	5	<input type="checkbox"/>

SECTION THREE Public Worship contd

Based on your experience with confused elderly people how helpful are the following elements of public worship to this group?

	Very helpful					Very unhelpful
	1	2	3	4	5	
Holy Communion						<input type="checkbox"/>
Other sacraments						<input type="checkbox"/>

	Very helpful					Very unhelpful
	1	2	3	4	5	
Drama						<input type="checkbox"/>
Visual aids						<input type="checkbox"/>
Symbols (<i>ex. cross or a candle</i>)						<input type="checkbox"/>
Other (<i>please specify</i>)						<input type="checkbox"/>

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

SECTION FOUR Pastoral care of confused elderly people.

The following are statements which raise issues surrounding the provision of pastoral care to confused elderly people.

(Please rate the statements by circling the appropriate number.)

1 Strongly Agree	2 Agree	3 Uncertain	4 Disagree	5 Strongly Disagree		
			Strongly agree	Strongly disagree		
Pastoral care of confused elderly people is a priority for me.	1	2	3	4	5	<input type="checkbox"/>
It can be difficult to know what to say to confused elderly people.	1	2	3	4	5	<input type="checkbox"/>
At times I am embarrassed by what confused elderly people say or do.	1	2	3	4	5	<input type="checkbox"/>
If I had more time I would visit confused elderly people more frequently.	1	2	3	4	5	<input type="checkbox"/>
It is difficult to have any meaningful religious element in a visit with confused elderly people.	1	2	3	4	5	<input type="checkbox"/>
I am surprised when confused elderly people express anger with God.	1	2	3	4	5	<input type="checkbox"/>

SECTION FOUR Pastoral care of confused elderly people.

The following are statements which raise issues surrounding the provision of pastoral care to confused elderly people.

Please rate them by circling the appropriate number)

	Strongly agree					Strongly disagree					
I find that the most effective way of caring for confused elderly people is to support the carer(s).	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I am relieved when the visit is over.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I visit confused elderly people out of a sense of duty.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I often feel that pastoral visits make no difference to confused elderly people.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
	Strongly agree					Strongly disagree					
I enjoy visiting confused elderly people.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I generally delegate the pastoral care of confused elderly people to others.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
At times I put off visiting confused elderly people.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I find it difficult to be sure that confused elderly people can be assured of the love of God.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>
I find it easy to make confused elderly people understand me.	1	2	3	4	5	1	2	3	4	5	<input type="checkbox"/>

SECTION FOUR Pastoral care of confused elderly people.

The following are statements which raise issues surrounding the provision of pastoral care to elderly confused people.

(Please rate them by circling the appropriate number)

	Strongly agree					Strongly disagree	
I prefer visiting confused elderly people when someone else is there.	1	2	3	4	5	<input type="checkbox"/>	
I find it difficult to assess the level of peoples confusion.	1	2	3	4	5	<input type="checkbox"/>	

SECTION FIVE

At some later date would you be willing for me to meet with you to discuss some of the issues arising from this questionnaire?

If you would please tick this box

THANK YOU FOR YOUR HELP.

Please return the questionnaire in the envelope provided by Friday 8th. October)

**Rev. Heather Morris
5 Sorrell Drive
"The Brambles"
Old Carrick Road
Newtownabbey
Northern Ireland
BT37 0XR**



1st September 1993

DEPARTMENT of CHRISTIAN ETHICS
and PRACTICAL THEOLOGY

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Dear colleague,

I am writing to ask you to help with a piece of research currently being undertaken in this Department. The area of research is Pastoral Communication with Confused Elderly People and is being undertaken by the Revd. Heather Morris, a Ph.D. student who is a Methodist minister in Belfast.

Prior to ordination, Mrs Morris was a speech therapist and in her research she is exploring whether insights from her previous training can be adapted to help ministers function more effectively in this difficult area of pastoral ministry. I know that both as a parish minister and as a hospital chaplain I always felt less than adequate in this aspect of my work.

We hope that the outcome of this research will be very practical and will present us with guidelines which will enhance ministry to those who suffer from this distressing condition. As part of the research it is important to explore the views and insights of ministers currently involved in this ministry and to this end I invite you to complete the enclosed questionnaire and return it to Mrs. Morris.

Thank you for your help.

Yours sincerely,

Revd. Dr. David Lyall.

HEAD OF DEPARTMENT Professor Duncan B Forrester
Senior Lecturer Dr J I H McDonald
Lecturers Dr M S Northcott Dr D Lyall Mr R Tongco Revd D C Weber

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CENTRES OF WORK:

Grosvenor Hall, Belfast

Craigmore Adolescent Home,
Millisle, Co. Down

Childhaven Conference Centre and
Holiday Home, Millisle, Co. Down

Castle Rocklands House and
Bungalows for Senior Citizens,
Carrickfergus, Co. Antrim

11th October 1993

Dear colleague,

PASTORAL COMMUNICATION WITH CONFUSED ELDERLY PEOPLE

A few weeks ago, Revd Dr D Lyall invited you to take part in the above research. Since your responses are very important to the success of this study, I would appreciate the return of your completed questionnaire as soon as possible. A copy is enclosed, in case you have mislaid the original.

Should you feel unable to assist with this project, please return the questionnaire in the envelope provided. Any comments you wish to make will be appreciated.

Thank you for your help.

Yours sincerely,

Revd. Heather Morris

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APPENDIX III

Presentation of Questionnaire Results (Stage 4)

RESULTS

Outcome of Analysis of the Questionnaires (Stage 4)

SECTION 1

Areas of Responsibility

1. Please indicate how much of your working week is spent with confused elderly people

[1.1] Percentage of working week spent with confused elderly.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
75%	2.00	1	.8	.8	.8
50%	3.00	1	.8	.8	1.6
25%	4.00	8	6.5	6.5	8.1
<25%	5.00	89	71.8	72.4	80.5
0%	6.00	24	19.4	19.5	100.0
	9.00	1	.8	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	5.089	Mode	5.000	Std dev	.601
Valid cases	123	Missing cases	1		

2. Where do you meet with confused elderly people?

[1:2 (a)] meet at person's own home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	83	66.9	83.0	83.0
NO	2.00	17	13.7	17.0	100.0
	8.00	24	19.4	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	1.170	Mode	1.000	Std dev	.378
Valid cases	100	Missing cases	24		

[1:2 (b)] meet at carer's home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	41	33.1	41.0	41.0
NO	2.00	59	47.6	59.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.590	Mode	2.000	Std dev	.494
Valid cases	100	Missing cases	24		

[1:2 (c)] meet at residential/nursing home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	93	75.0	93.0	93.0
NO	2.00	7	5.6	7.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.070	Mode	1.000	Std dev	.256
Valid cases	100	Missing cases	24		

[1:2(d)] meet at hospital

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	81	65.3	81.0	81.0
NO	2.00	19	15.3	19.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.190	Mode	1.000	Std dev	.394
Valid cases	100	Missing cases	24		

[1:2 (e)] meet at hospice

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	21	16.9	21.0	21.0
NO	2.00	79	63.7	79.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.790	Mode	2.000	Std dev	.409
Valid cases	100	Missing cases	24		

[1:2 (f)] meet at church services

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	63	50.8	63.0	63.0
NO	2.00	37	29.8	37.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.370	Mode	1.000	Std dev	.485
Valid cases	100	Missing cases	24		

[1:2 (g)] meet at other church activities

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	46	37.1	46.0	46.0
NO	2.00	54	43.5	54.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.540	Mode	2.000	Std dev	.501
Valid cases	100	Missing cases	24		

[1:2 (h)] meet at other places

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
social gathering	1.00	5	4.0	20.0	20.0
clubs for elderly	2.00	5	4.0	20.0	40.0
womens organisations	3.00	3	2.4	12.0	52.0
youth activities	4.00	1	.8	4.0	56.0
daycare centre	5.00	4	3.2	16.0	72.0
alz group on premise	6.00	5	4.0	20.0	92.0
church meetings	7.00	2	1.6	8.0	100.0
	88.00	24	19.4	Missing	
	99.00	75	60.5	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.680 Mode 1.000 Std dev 2.116

* Multiple modes exist. The smallest value is shown.

Valid cases 25 Missing cases 99

[1:2 (i)] meet at more than one other place

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Social gathering	1.00	2	1.6	1.6	1.6
	88.00	24	19.4	19.4	21.0
	99.00	98	79.0	79.0	100.0
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 95.290 Mode 99.000 Std dev 12.880

Valid cases 124 Missing cases 0

3. Do you lead services of worship at which confused elderly people are present?

[1:3 (a)] does minister lead worship for confused elderly people

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	92	74.2	92.0	92.0
NO	2.00	8	6.5	8.0	100.0
	8.00	24	19.4	Missing	
Total		124	100.0	100.0	
Mean	1.081	Mode	1.000	Std dev	.274
Valid cases	100	Missing cases	24		

If "yes" to question 3, where do they take place?

[1:3(b)] residential/nursing home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	74	59.7	80.4	80.4
NO	2.00	18	14.5	19.6	100.0
	8.00	32	25.8	Missing	
Total		124	100.0	100.0	
Mean	1.196	Mode	1.000	Std dev	.399
Valid cases	92	Missing cases	32		

[1:3 (c)] hospital ward/chapel

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	15	12.1	16.3	16.3
NO	2.00	77	62.1	83.7	100.0
	8.00	32	25.8	Missing	
Total		124	100.0	100.0	
Mean	1.837	Mode	2.000	Std dev	.371
Valid cases	92	Missing cases	32		

[1:3(d)] church/chapel

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	37	29.8	40.2	40.2
NO	2.00	55	44.4	59.8	100.0
	8.00	32	25.8	Missing	
Total		124	100.0	100.0	
Mean	1.598	Mode	2.000	Std dev	.493
Valid cases	92	Missing cases	32		

[1:3 (e)] other place of worship

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Communion at home	1.00	4	3.2	57.1	57.1
holy communion service	2.00	1	.8	14.3	71.4
Own homes	3.00	2	1.6	28.6	100.0
	88.00	33	26.6	Missing	
	99.00	84	67.7	Missing	
Total		124	100.0	100.0	
Mean	1.714	Mode	1.000	Std dev	.951
Valid cases	7	Missing cases	117		

[1:3 (f)] worship at more than one other place

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Own house	3.00	1	.8	33.3	33.3
Prayer	4.00	2	1.6	66.7	100.0
	88.00	32	25.8	Missing	
	99.00	89	71.8	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	3.667	Mode	4.000	Std dev	.577
Valid cases	3	Missing cases	121		

4. If you have no regular contact with confused elderly people at the moment have you ever had?

[1:4 (a)] past experience with confused elderly

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	17	13.7	73.9	73.9
NO	2.00	6	4.8	26.1	100.0
	8.00	101	81.5	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.261	Mode	1.000	Std dev	.449
Valid cases	23	Missing cases	101		

If "Yes" where?

[1:4(b)] person's own home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	12	9.7	70.6	70.6
NO	2.00	5	4.0	29.4	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.294	Mode	1.000	Std dev	.470
Valid cases	17	Missing cases	107		

[1:4 (c)] carer's home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	5	4.0	29.4	29.4
NO	2.00	12	9.7	70.6	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.706	Mode	2.000	Std dev	.470
Valid cases	17	Missing cases	107		

[1:4(d)] residential/nursing home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	14	11.3	82.4	82.4
NO	2.00	3	2.4	17.6	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.176	Mode	1.000	Std dev	.393
Valid cases	17	Missing cases	107		

[1:4 (e)] hospital

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	13	10.5	76.5	76.5
NO	2.00	4	3.2	23.5	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.235	Mode	1.000	Std dev	.437
Valid cases	17	Missing cases	107		

[1:4 (f)] hospice

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	1	.8	5.9	5.9
NO	2.00	16	12.9	94.1	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.941	Mode	2.000	Std dev	.243
Valid cases	17	Missing cases	107		

[1:4 (g)] church services

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	10	8.1	58.8	58.8
NO	2.00	7	5.6	41.2	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.412	Mode	1.000	Std dev	.507
Valid cases	17	Missing cases	107		

[1:4 (h)] other church activities

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
YES	1.00	9	7.3	52.9	52.9
NO	2.00	8	6.5	47.1	100.0
	8.00	107	86.3	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.471	Mode	1.000	Std dev	.514
Valid cases	17	Missing cases	107		

[1:4 (i)] other places

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Club for elderly	2.00	2	1.6	100.0	100.0
	88.00	108	87.1	Missing	
	99.00	14	11.3	Missing	
Total		124	100.0	100.0	
Mean	2.000	Mode	2.000	Std dev	.000
Valid cases	2	Missing cases	122		

SECTION TWO

Pastoral Communication with confused elderly people

In my experience I have found it easier to communicate with confused elderly people if I....

[2.1] maintain eye contact

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	49	39.5	42.6	42.6
Agree	2.00	46	37.1	40.0	82.6
Uncertain	3.00	18	14.5	15.7	98.3
Disagree	4.00	1	.8	.9	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.774	Mode	1.000	Std dev	.806
Valid cases	115	Missing cases	9		

[2.2] certainty of degree of confusion

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	29	23.4	25.2	25.2
Agree	2.00	38	30.6	33.0	58.3
Uncertain	3.00	36	29.0	31.3	89.6
Disagree	4.00	10	8.1	8.7	98.3
Strongly Disagree	5.00	2	1.6	1.7	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.287	Mode	2.000	Std dev	.998
Valid cases	115	Missing cases	9		

[2.3] know about their hearing

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	51	41.1	44.3	44.3
Agree	2.00	48	38.7	41.7	86.1
Uncertain	3.00	11	8.9	9.6	95.7
Disagree	4.00	4	3.2	3.5	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.748	Mode	1.000	Std dev	.836
Valid cases	115	Missing cases	9		

[2.4] hold their hand

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	45	36.3	39.5	39.5
Agree	2.00	39	31.5	34.2	73.7
Uncertain	3.00	26	21.0	22.8	96.5
Disagree	4.00	3	2.4	2.6	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.912	Mode	1.000	Std dev	.898
Valid cases	114	Missing cases	10		

[2.5] identify self clearly

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	49	39.5	42.6	42.6
Agree	2.00	48	38.7	41.7	84.3
Uncertain	3.00	15	12.1	13.0	97.4
Disagree	4.00	2	1.6	1.7	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.765	Mode	1.000	Std dev	.809
Valid cases	115	Missing cases	9		

[2.6] know about their lives

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	59	47.6	51.3	51.3
Agree	2.00	45	36.3	39.1	90.4
Uncertain	3.00	6	4.8	5.2	95.7
Disagree	4.00	3	2.4	2.6	98.3
Strongly Disagree	5.00	2	1.6	1.7	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.643	Mode	1.000	Std dev	.840
Valid cases	115	Missing cases	9		

[2.7] speak slowly

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	30	24.2	26.1	26.1
Agree	2.00	54	43.5	47.0	73.0
Uncertain	3.00	25	20.2	21.7	94.8
Disagree	4.00	5	4.0	4.3	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.070	Mode	2.000	Std dev	.856
Valid cases	115	Missing cases	9		

[2.8] correct when they ramble

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	3	2.4	2.6	2.6
Agree	2.00	5	4.0	4.3	7.0
Uncertain	3.00	15	12.1	13.0	20.0
Disagree	4.00	44	35.5	38.3	58.3
Strongly Disagree	5.00	48	38.7	41.7	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	4.122	Mode	5.000	Std dev	.975
Valid cases	115	Missing cases	9		

[2.9] use familiar gestures

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	19	15.3	16.5	16.5
Agree	2.00	40	32.3	34.8	51.3
Uncertain	3.00	40	32.3	34.8	86.1
Disagree	4.00	12	9.7	10.4	96.5
Strongly Disagree	5.00	4	3.2	3.5	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.496 Mode 2.000 Std dev 1.003

* Multiple modes exist. The smallest value is shown.

Valid cases 115 Missing cases 9

[2.10] ask them questions

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	13	10.5	11.3	11.3
Agree	2.00	32	25.8	27.8	39.1
Uncertain	3.00	34	27.4	29.6	68.7
Disagree	4.00	27	21.8	23.5	92.2
Strongly Disagree	5.00	9	7.3	7.8	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.887 Mode 3.000 Std dev 1.130

Valid cases 115 Missing cases 9

[2.11] know what behaviour to expect from confused elderly

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	32	25.8	27.8	27.8
Agree	2.00	58	46.8	50.4	78.3
Uncertain	3.00	16	12.9	13.9	92.2
Disagree	4.00	8	6.5	7.0	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.026	Mode	2.000	Std dev	.883
Valid cases	115	Missing cases	9		

[2.12] know names of close family members

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1.00	54	43.5	47.0	47.0
Agree	2.00	46	37.1	40.0	87.0
Uncertain	3.00	11	8.9	9.6	96.5
Disagree	4.00	4	3.2	3.5	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.696	Mode	1.000	Std dev	.786
Valid cases	115	Missing cases	9		

[2.13] sit quietly at times

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	27	21.8	23.7	23.7
Agree	2.00	55	44.4	48.2	71.9
Uncertain	3.00	28	22.6	24.6	96.5
Disagree	4.00	4	3.2	3.5	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
Total		124	100.0	100.0	

Mean 2.079 Mode 2.000 Std dev .789
 Valid cases 114 Missing cases 10

[2.14] don't repeat

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	1	.8	.9	.9
Agree	2.00	5	4.0	4.5	5.4
Uncertain	3.00	37	29.8	33.0	38.4
Disagree	4.00	51	41.1	45.5	83.9
Strongly Disagree	5.00	18	14.5	16.1	100.0
	8.00	7	5.6	Missing	
	9.00	5	4.0	Missing	
Total		124	100.0	100.0	

Mean 3.714 Mode 4.000 Std dev .821
 Valid cases 112 Missing cases 12

[2.15] use short simple sentences

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	31	25.0	27.2	27.2
Agree	2.00	62	50.0	54.4	81.6
Uncertain	3.00	20	16.1	17.5	99.1
Disagree	4.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
Total		124	100.0	100.0	

Mean 1.921 Mode 2.000 Std dev .693
 Valid cases 114 Missing cases 10

[2.16] write down key words

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	8	6.5	7.3	7.3
Agree	2.00	13	10.5	11.9	19.3
Uncertain	3.00	46	37.1	42.2	61.5
Disagree	4.00	29	23.4	26.6	88.1
Strongly Disagree	5.00	13	10.5	11.9	100.0
	8.00	7	5.6	Missing	
	9.00	8	6.5	Missing	
	Total	124	100.0	100.0	
Mean	3.239	Mode	3.000	Std dev	1.053
Valid cases	109	Missing cases	15		

[2.17] wear a clerical collar

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	33	26.6	28.9	28.9
Agree	2.00	51	41.1	44.7	73.7
Uncertain	3.00	17	13.7	14.9	88.6
Disagree	4.00	9	7.3	7.9	96.5
Strongly Disagree	5.00	4	3.2	3.5	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
	Total	124	100.0	100.0	
Mean	2.123	Mode	2.000	Std dev	1.032
Valid cases	114	Missing cases	10		

[2.18] talk about the past

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	41	33.1	35.7	35.7
Agree	2.00	58	46.8	50.4	86.1
Uncertain	3.00	13	10.5	11.3	97.4
Disagree	4.00	3	2.4	2.6	100.0
	8.00	7	5.6	Missing	
	9.00	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.809	Mode	2.000	Std dev	.736
Valid cases	115	Missing cases	9		

[2.19] speak loudly

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	5	4.0	4.4	4.4
Agree	2.00	19	15.3	16.7	21.1
Uncertain	3.00	38	30.6	33.3	54.4
Disagree	4.00	38	30.6	33.3	87.7
Strongly Disagree	5.00	14	11.3	12.3	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	3.325	Mode	3.000	Std dev	1.035
* Multiple modes exist. The smallest value is shown.					
Valid cases	114	Missing cases	10		

[2.20] don't move the person

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	15	12.1	13.4	13.4
Agree	2.00	27	21.8	24.1	37.5
Uncertain	3.00	54	43.5	48.2	85.7
Disagree	4.00	15	12.1	13.4	99.1
Strongly Disagree	5.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	5	4.0	Missing	
Total		124	100.0	100.0	
Mean	2.643	Mode	3.000	Std dev	.909
Valid cases	112	Missing cases	12		

[2.21] sit facing the person

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	44	35.5	38.6	38.6
Agree	2.00	60	48.4	52.6	91.2
Uncertain	3.00	9	7.3	7.9	99.1
Disagree	4.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	3	2.4	Missing	
Total		124	100.0	100.0	
Mean	1.711	Mode	2.000	Std dev	.648
Valid cases	114	Missing cases	10		

[2.22] maintain a calm and even tone of voice

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1.00	36	29.0	31.9	31.9
Agree	2.00	61	49.2	54.0	85.8
Uncertain	3.00	15	12.1	13.3	99.1
Disagree	4.00	1	.8	.9	100.0
	8.00	7	5.6	Missing	
	9.00	4	3.2	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.832	Mode	2.000	Std dev	.680
Valid cases	113	Missing cases	11		

[2.23] listen to their stories

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	60	48.4	52.2	52.2
Agree	2	48	38.7	41.7	93.9
Uncertain	3	6	4.8	5.2	99.1
Disagree	4	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	1.548	Mode	1.000	Std dev	.639
Valid cases	115	Missing cases	9		

SECTION THREE

Public worship

The clergy are concerned with people's participation in public worship. Based on your experience with confused elderly people, how helpful are the following elements to this group?

[3.1] singing familiar hymns

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	83	66.9	72.8	72.8
Helpful	2	29	23.4	25.4	98.2
Uncertain	3	1	.8	.9	99.1
Unhelpful	4	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	

Mean 1.298 Mode 1.000 Std dev .531
 Valid cases 114 Missing cases 10

[3.2] familiar bible readings

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	67	54.0	58.3	58.3
Helpful	2	32	25.8	27.8	86.1
Uncertain	3	15	12.1	13.0	99.1
Unhelpful	4	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	

Mean 1.565 Mode 1.000 Std dev .751
 Valid cases 115 Missing cases 9

[3.3] sermon/homily

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	7	5.6	6.1	6.1
Helpful	2	14	11.3	12.3	18.4
Uncertain	3	45	36.3	39.5	57.9
Unhelpful	4	34	27.4	29.8	87.7
Very Unhelpful	5	14	11.3	12.3	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.298 Mode 3.000 Std dev 1.038
 Valid cases 114 Missing cases 10

[3.4] extempore prayer

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	12	9.7	10.5	10.5
Helpful	2	38	30.6	33.3	43.9
Uncertain	3	48	38.7	42.1	86.0
Unhelpful	4	8	6.5	7.0	93.0
Very Unhelpful	5	8	6.5	7.0	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.667 Mode 3.000 Std dev 1.001
 Valid cases 114 Missing cases 10

[3.5] Lord's prayer

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	81	65.3	70.4	70.4
Helpful	2	31	25.0	27.0	97.4
Uncertain	3	3	2.4	2.6	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 1.322 Mode 1.000 Std dev .522
 Valid cases 115 Missing cases 9

[3.6] times of silence

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	10	8.1	8.8	8.8
Helpful	2	20	16.1	17.7	26.5
Uncertain	3	48	38.7	42.5	69.0
Unhelpful	4	30	24.2	26.5	95.6
Very Unhelpful	5	5	4.0	4.4	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	3.000	Mode	3.000	Std dev	.991
Valid cases	113	Missing cases	11		

[3.7] sharing the peace

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	13	10.5	11.9	11.9
Helpful	2	24	19.4	22.0	33.9
Uncertain	3	43	34.7	39.4	73.4
Unhelpful	4	22	17.7	20.2	93.6
Very Unhelpful	5	7	5.6	6.4	100.0
	8	7	5.6	Missing	
	9	8	6.5	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	2.872	Mode	3.000	Std dev	1.072
Valid cases	109	Missing cases	15		

[3.8] using the same order

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	33	26.6	28.9	28.9
Helpful	2	51	41.1	44.7	73.7
Uncertain	3	26	21.0	22.8	96.5
Unhelpful	4	3	2.4	2.6	99.1
Very Unhelpful	5	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.018	Mode	2.000	Std dev	.841
Valid cases	114	Missing cases	10		

[3.9] using a standard liturgy

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	21	16.9	18.4	18.4
Helpful	2	37	29.8	32.5	50.9
Uncertain	3	46	37.1	40.4	91.2
Unhelpful	4	8	6.5	7.0	98.2
Very Unhelpful	5	2	1.6	1.8	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.412	Mode	3.000	Std dev	.929
Valid cases	114	Missing cases	10		

[3.10] using same version of the bible consistently

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	19	15.3	16.7	16.7
Helpful	2	43	34.7	37.7	54.4
Uncertain	3	43	34.7	37.7	92.1
Unhelpful	4	8	6.5	7.0	99.1
Very Unhelpful	5	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.377 Mode 2.000 Std dev .876

* Multiple modes exist. The smallest value is shown.

Valid cases 114 Missing cases 10

[3.11] holy communion

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	43	34.7	37.1	37.1
Helpful	2	56	45.2	48.3	85.3
Uncertain	3	16	12.9	13.8	99.1
Unhelpful	4	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 1.784 Mode 2.000 Std dev .708

Valid cases 116 Missing cases 8

[3.12] other sacraments

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	13	10.5	13.7	13.7
Helpful	2	21	16.9	22.1	35.8
Uncertain	3	52	41.9	54.7	90.5
Unhelpful	4	8	6.5	8.4	98.9
Very Unhelpful	5	1	.8	1.1	100.0
	8	7	5.6	Missing	
	9	22	17.7	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.611 Mode 3.000 Std dev .867
 Valid cases 95 Missing cases 29

[3.13] drama

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	3	2.4	2.8	2.8
Helpful	2	16	12.9	15.0	17.8
Uncertain	3	59	47.6	55.1	72.9
Unhelpful	4	21	16.9	19.6	92.5
Very Unhelpful	5	8	6.5	7.5	100.0
	8	7	5.6	Missing	
	9	10	8.1	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.140 Mode 3.000 Std dev .863
 Valid cases 107 Missing cases 17

[3.14] visual aids

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very helpful	1	15	12.1	13.3	13.3
Helpful	2	48	38.7	42.5	55.8
Uncertain	3	38	30.6	33.6	89.4
Unhelpful	4	9	7.3	8.0	97.3
Very Unhelpful	5	3	2.4	2.7	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
Total		124	100.0	100.0	

Mean 2.442 Mode 2.000 Std dev .916
 Valid cases 113 Missing cases 11

[3.15] symbols

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Very Helpful	1	25	20.2	22.3	22.3
Helpful	2	61	49.2	54.5	76.8
Uncertain	3	23	18.5	20.5	97.3
Unhelpful	4	2	1.6	1.8	99.1
Very Unhelpful	5	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	5	4.0	Missing	
Total		124	100.0	100.0	

Mean 2.045 Mode 2.000 Std dev .764
 Valid cases 112 Missing cases 12

[3.16] other elements of public worship

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Young People	1	6	4.8	27.3	27.3
Music	2	3	2.4	13.6	40.9
Simple Worship	3	1	.8	4.5	45.5
Smell	4	2	1.6	9.1	54.5
Participation of POT	7	2	1.6	9.1	63.6
Memory aids	8	1	.8	4.5	68.2
Laughter	9	1	.8	4.5	72.7
Pictures	11	1	.8	4.5	77.3
Rosary Beads	12	1	.8	4.5	81.8
Part of Normal Congregation	14	1	.8	4.5	86.4
Encourage participation	15	1	.8	4.5	90.9
Good atmosphere	16	1	.8	4.5	95.5
Collar	17	1	.8	4.5	100.0
	88	7	5.6	Missing	
	99	95	76.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 6.318 Mode 1.000 Std dev 5.584
 Valid cases 22 Missing cases 102

[3.17] public worship at more than one other place

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Music	2	2	1.6	25.0	25.0
Touch	5	1	.8	12.5	37.5
Reminiscences	6	1	.8	12.5	50.0
Participation of others	7	1	.8	12.5	62.5
Memory aids	8	1	.8	12.5	75.0
Hand clapping	10	1	.8	12.5	87.5
Video	13	1	.8	12.5	100.0
	88	7	5.6	Missing	
	99	109	87.9	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 6.625 Mode 2.000 Std dev 3.777
 Valid cases 8 Missing cases 116

SECTION FOUR

Pastoral care of confused elderly people

The following are statements which raise issues surrounding the provision of pastoral care to confused elderly people. Each statement is rated by the respondent as detailed below:-

[4.1] Pastoral care of confused elderly people is a priority for me.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	9	7.3	8.0	8.0
Agree	2	46	37.1	40.7	48.7
Uncertain	3	31	25.0	27.4	76.1
Disagree	4	25	20.2	22.1	98.2
Strongly Disagree	5	2	1.6	1.8	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
	Total	124	100.0	100.0	
Mean	2.690	Mode	2.000	Std dev	.964
Valid cases	113	Missing cases	11		

[4.2] It can be difficult to know what to say to confused elderly people.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	17	13.7	14.8	14.8
Agree	2	53	42.7	46.1	60.9
Uncertain	3	8	6.5	7.0	67.8
Disagree	4	33	26.6	28.7	96.5
Strongly Disagree	5	4	3.2	3.5	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
	Total	124	100.0	100.0	
Mean	2.600	Mode	2.000	Std dev	1.153
Valid cases	115	Missing cases	9		

[4.3] At times I am embarrassed by what confused elderly people say or do.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Agree	2	13	10.5	11.2	11.2
Uncertain	3	12	9.7	10.3	21.6
Disagree	4	66	53.2	56.9	78.4
Strongly Disagree	5	25	20.2	21.6	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.888 Mode 4.000 Std dev .872
 Valid cases 116 Missing cases 8

[4.4] If I had more time I would visit confused elderly people more frequently.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	13	10.5	11.2	11.2
Agree	2	44	35.5	37.9	49.1
Uncertain	3	37	29.8	31.9	81.0
Disagree	4	20	16.1	17.2	98.3
Strongly Disagree	5	2	1.6	1.7	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 2.603 Mode 2.000 Std dev .959
 Valid cases 116 Missing cases 8

[4.5] It is difficult to have any meaningful religious element in a visit with confused elderly people.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	2	1.6	1.7	1.7
Agree	2	8	6.5	6.9	8.6
Uncertain	3	15	12.1	12.9	21.6
Disagree	4	52	41.9	44.8	66.4
Strongly Disagree	5	39	31.5	33.6	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----		
Total		124	100.0	100.0	
Mean	4.017	Mode	4.000	Std dev	.951
Valid cases	116	Missing cases	8		

[4.6] I am surprised when confused elderly people express anger with God.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Agree	2	3	2.4	2.6	2.6
Uncertain	3	7	5.6	6.1	8.8
Disagree	4	60	48.4	52.6	61.4
Strongly Disagree	5	44	35.5	38.6	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----		
Total		124	100.0	100.0	
Mean	4.272	Mode	4.000	Std dev	.695
Valid cases	114	Missing cases	10		

[4.7] I find that the most effective way of caring for confused elderly people is to support the carer(s).

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	23	18.5	20.5	20.5
Agree	2	52	41.9	46.4	67.0
Uncertain	3	27	21.8	24.1	91.1
Disagree	4	9	7.3	8.0	99.1
Strongly Disagree	5	1	.8	.9	100.0
	8	7	5.6	Missing	
	9	5	4.0	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.223	Mode	2.000	Std dev	.898
Valid cases	112	Missing cases	12		

[4.8] I am relieved when the visit is over.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	3	2.4	2.7	2.7
Agree	2	31	25.0	27.4	30.1
Uncertain	3	34	27.4	30.1	60.2
Disagree	4	36	29.0	31.9	92.0
Strongly Disagree	5	9	7.3	8.0	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	3.150	Mode	4.000	Std dev	1.002
Valid cases	113	Missing cases	11		

[4.9] I visit confused elderly people out of a sense of duty.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	1	.8	.9	.9
Agree	2	26	21.0	23.0	23.9
Uncertain	3	23	18.5	20.4	44.2
Disagree	4	46	37.1	40.7	85.0
Strongly Disagree	5	17	13.7	15.0	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
Total		124	100.0	100.0	
Mean	3.460	Mode	4.000	Std dev	1.035
Valid cases	113	Missing cases	11		

[4.10] I often feel that pastoral visits make no difference to confused elderly people.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	6	4.8	5.3	5.3
Agree	2	16	12.9	14.0	19.3
Uncertain	3	26	21.0	22.8	42.1
Disagree	4	46	37.1	40.4	82.5
Strongly Disagree	5	20	16.1	17.5	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
Total		124	100.0	100.0	
Mean	3.509	Mode	4.000	Std dev	1.099
Valid cases	114	Missing cases	10		

[4.11] I enjoy visiting confused elderly people.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly agree	1	6	4.8	5.3	5.3
Agree	2	28	22.6	24.6	29.8
Uncertain	3	47	37.9	41.2	71.1
Disagree	4	30	24.2	26.3	97.4
Strongly Disagree	5	3	2.4	2.6	100.0
	8	7	5.6	Missing	
	9	3	2.4	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	2.965	Mode	3.000	Std dev	.911
Valid cases	114	Missing cases	10		

[4.12] I generally delegate the pastoral care of confused elderly people to others.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	1	.8	.9	.9
Agree	2	10	8.1	8.8	9.7
Uncertain	3	2	1.6	1.8	11.5
Disagree	4	59	47.6	52.2	63.7
Strongly Disagree	5	41	33.1	36.3	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	
Mean	4.142	Mode	4.000	Std dev	.895
Valid cases	113	Missing cases	11		

[4.13] At times I put off visiting confused elderly people.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	1	.8	.9	.9
Agree	2	40	32.3	35.4	36.3
Uncertain	3	19	15.3	16.8	53.1
Disagree	4	34	27.4	30.1	83.2
Strongly Disagree	5	19	15.3	16.8	100.0
	8	7	5.6	Missing	
	9	4	3.2	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.265 Mode 2.000 Std dev 1.142
 Valid cases 113 Missing cases 11

[4.14] I find it difficult to be sure that confused elderly people can be assured of the love of God.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	2	1.6	1.7	1.7
Agree	2	17	13.7	14.8	16.5
Uncertain	3	24	19.4	20.9	37.4
Disagree	4	37	29.8	32.2	69.6
Strongly Disagree	5	35	28.2	30.4	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
		-----	-----	-----	
Total		124	100.0	100.0	

Mean 3.748 Mode 4.000 Std dev 1.099
 Valid cases 115 Missing cases 9

[4.15] I find it easy to make confused elderly people understand me.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	3	2.4	2.6	2.6
Agree	2	11	8.9	9.6	12.2
Uncertain	3	42	33.9	36.5	48.7
Disagree	4	48	38.7	41.7	90.4
Strongly Disagree	5	11	8.9	9.6	100.0
	8	7	5.6	Missing	
	9	2	1.6	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	3.461	Mode	4.000	Std dev	.891
Valid cases	115	Missing cases	9		

[4.16] I prefer visiting confused elderly people when someone else is there.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	8	6.5	6.9	6.9
Agree	2	21	16.9	18.1	25.0
Uncertain	3	29	23.4	25.0	50.0
Disagree	4	45	36.3	38.8	88.8
Strongly Disagree	5	13	10.5	11.2	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	3.293	Mode	4.000	Std dev	1.103
Valid cases	116	Missing cases	8		

[4.17] It is difficult to assess the level of peoples confusion.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Strongly Agree	1	8	6.5	6.9	6.9
Agree	2	43	34.7	37.1	44.0
Uncertain	3	32	25.8	27.6	71.6
Disagree	4	30	24.2	25.9	97.4
Strongly disagree	5	3	2.4	2.6	100.0
	8	7	5.6	Missing	
	9	1	.8	Missing	
		-----	-----	-----	
	Total	124	100.0	100.0	
Mean	2.802	Mode	2.000	Std dev	.989
Valid cases	116	Missing cases	8		

SECTION FIVE

Personal details

[5.1] what age are you?

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
20-30	1	2	1.6	1.6	1.6
31-40	2	24	19.4	19.7	21.3
41-50	3	36	29.0	29.5	50.8
51-60	4	42	33.9	34.4	85.2
61-70	5	16	12.9	13.1	98.4
70+	6	2	1.6	1.6	100.0
	9	2	1.6	Missing	
	Total	124	100.0	100.0	

Mean 3.426 Mode 4.000 Std dev 1.052
 Valid cases 122 Missing cases 2

[5.2] How many years is it since you were ordained?

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
1-10	1	30	24.2	24.6	24.6
11-20	2	35	28.2	28.7	53.3
21-30	3	34	27.4	27.9	81.1
31-40	4	19	15.3	15.6	96.7
40+	5	4	3.2	3.3	100.0
	9	2	1.6	Missing	
	Total	124	100.0	100.0	

Mean 2.443 Mode 2.000 Std dev 1.121
 Valid cases 122 Missing cases 2

[5.3] What other occupation have you had other than ministry?

Value Label	Value	Frequency	Percent	Valid Cum	
				Percent	Percent
None	1	44	35.5	36.4	36.4
Accountant	2	2	1.6	1.7	38.0
Social Worker	3	6	4.8	5.0	43.0
Banker	4	5	4.0	4.1	47.1
Administrator	5	8	6.5	6.6	53.7
Teacher	6	10	8.1	8.3	62.0
Factory Worker	7	1	.8	.8	62.8
Civil Servant	8	2	1.6	1.7	64.5
University Lecturer	9	3	2.4	2.5	66.9
Publishing	10	1	.8	.8	67.8
Surveyor	11	2	1.6	1.7	69.4
Sales	12	5	4.0	4.1	73.6
Probation officer	13	2	1.6	1.7	75.2
Police	14	2	1.6	1.7	76.9
Librarian	15	1	.8	.8	77.7
Armed Forces	16	5	4.0	4.1	81.8
Nurse	17	2	1.6	1.7	83.5
Educational Research	18	1	.8	.8	84.3
Research Scientist	19	1	.8	.8	85.1
Driver	20	1	.8	.8	86.0
Decorator	21	1	.8	.8	86.8
Journalist/Media	22	2	1.6	1.7	88.4
Engineering	23	4	3.2	3.3	91.7
Solicitor/advocate	24	3	2.4	2.5	94.2
Carer for Mentally ill	25	2	1.6	1.7	95.9
Counsellor	26	1	.8	.8	96.7
Farming/Agriculture	27	2	1.6	1.7	98.3
Artist	28	1	.8	.8	99.2
Industrial chemist	29	1	.8	.8	100.0
	99	3	2.4	Missing	
	Total	124	100.0	100.0	

Mean 8.132 Mode 1.000 Std dev 8.360
 Valid cases 121 Missing cases 3

[5.4] If you would like to make any other comments about the pastoral care of confused elderly people please do so below.

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Family member	1.00	3	2.4	6.5	6.5
Being beside	2.00	3	2.4	6.5	13.0
Rewarding	3.00	4	3.2	8.7	21.7
Nature of pastoral relationship	4.00	2	1.6	4.3	26.1
Training	5.00	10	8.1	21.7	47.8
Lay visitors	6.00	3	2.4	6.5	54.3
Holy communion at home	7.00	1	.8	2.2	56.5
Relatives/carers	8.00	6	4.8	13.0	69.6
Euthanasia	9.00	1	.8	2.2	71.7
Reassurance/love	10.00	1	.8	2.2	73.9
Small worship in Res. Home	11.00	2	1.6	4.3	78.3
Church day centre	12.00	2	1.6	4.3	82.6
Embarrassed relative	13.00	1	.8	2.2	84.8
Respite care	14.00	1	.8	2.2	87.0
Lack of provision	15.00	2	1.6	4.3	91.3
Touch clerical collar	16.00	2	1.6	4.3	95.7
Chocolate	17.00	1	.8	2.2	97.8
Music	18.00	1	.8	2.2	100.00
	99.00	78	62.9	Missing	
	Total	124	100.0	100.0	

Mean 7.413 Mode 5.00 Std dev 4.707
 Valid cases 46 Missing cases 78

[5.5] denomination of pastors

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Roman Catholic	1	11	8.9	8.9	8.9
Presbyterian	2	73	58.9	58.9	67.7
Episcopalian	3	37	29.8	29.8	97.6
Methodist	5	3	2.4	2.4	100.0
	Total	124	100.0	100.0	

Mean 2.282 Mode 2.000 Std dev .728
 Valid cases 124 Missing cases 0

APPENDIX IV

Pastors Interview Data (Stage 5)

In these transcripts every effort has been made to protect anonymity. Therefore, the initials used to denote the interviewees do not refer to their real names. In addition all identifiable information has been removed.

INTERVIEW WITH AB

H.M. The Church has given me a few years off now - I have a little boy of two, and I'm attached to the Belfast Central Mission, which is right in the middle of Belfast, but I lived in Dublin previously. Do you have Irish connections, yourself?

AB:1 My father was a convert from the Church of Scotland, my grandmother was from [Irish County Name] and I'm always interested in Ireland, I must say - a beautiful country.

H.M. Indeed it is - can I ask you do you have folk who are confused within your Parish?

AB:2 Not many. I have about twenty people confined to their houses, very few of them actually confused. I have one or two Parishioners who work with a Club, run by the Episcopalian Church, for confused elderly and two or three of my Parishioners work there. I have no connection with that particular Club but have a Club here for confused, vulnerable elderly and I sometimes visit them. It's not as often as I should but they are looked after, they do really well there. The problem is that I'm just part-time and it's difficult to know what is wrong with a person - I don't always have that information, so I tend to treat them from the spiritual point-of-view, with the sacraments and that.

H.M. With the sacraments - it's something I'm interested in exploring - some people have said that, with the symbolism of just having the bread and wine, something might get through.

AB:3 That's true, if it's Catholic people who have been practising all their lives, this will be a help to them. You can just say "This is something to help you - the Church's sacrament". You know, people of eighty or ninety, that generation, have a simple Faith and they have never lost it.

H.M. Have you had situations, you know with someone who is very confused or withdrawn, and you've been able to give them a sacrament and seen them respond?

AB:4 Oh yes, there are certain sacraments which we can give, even if they are confused, even if a person is unconscious. Now that is what we call "anointing" obviously for Confession, where the strength of our Lord's grace is given to them and they do find that this helps them, physically.

H.M. Right, right.

AB:5 Not that it cures, of course. I had a case the other day, I was certain that this old lady was going to die very shortly and she was fine. So it's something which bucks them up and whatever it is, some kind of psychological thing, just to give them absolution seems to be meaningful and they definitely feel the benefit. That

sacrament we give to a person even if they are unconscious or confused because the Church's idea is that they do need a sacrament, an absolution.

H.M. So, with regard to Communion, they would have to understand what was happening

AB:6 Oh yes, I would think so, I don't think you could give it without them knowing

H.M. Right, right.

AB:7 You see, there's the swallowing - that's a problem.

H.M. Oh yes, of course.

AB:8 I've seen some being given it, thinking they would be all right and they can't swallow.

H.M. You were saying about trying to make sure they understand. Do you do that just by asking them?

AB:9 Oh yes, just by trying to get through to them in some way. Oh yes, just by asking "you know who I am, I'm a Priest" and it usually gets some sort of reaction.

H.M. Yes, yes - have you found, as you visit folk, that there are things that seem to make it easier for them to understand. Some folk have said that the collar is a help, as a sign of recognition, or perhaps touch?

AB:10 It depends on the person, I would say, some are more direct than others. This is a working-class Parish, I come from that class myself. Things have changed since I was ordained, forty years ago now, but when I introduce the sacrament and try to tell them everything will be all right, that is usually sufficient.

H.M. Exactly, exactly. Would you ever be in a situation of needing to do a Mass on the Ward, or anything like that, with folk who are confused?

AB:11 We do in the Parish. I find it awfully difficult. I do the Mass once a month. They're all elderly and some are very confused - they're all in a circle around the Altar. I have an Anointing Mass, I anoint them all and then have the Mass, this is a new thing which has come from Vatican Two, I find that very helpful, both for any Nurses who are there and the old people.

H.M. Do you find that as folk are in this situation, especially with regard to confused folk, that they do seem to understand that something special is going on?

AB:12 Oh, I think so. I think, too, the way the Nurses are now-a-days, they wouldn't just bring a person down, willy-nilly.

Often, they ask them beforehand if they'd like to come to a Mass, otherwise they wouldn't put any pressure on them. They do come down voluntarily and generally I would say they are more-or-less alert, when they come to the Masses.

H.M. Right, right. Some of the people who are writing in America have said that the effect of coming in to a situation where there is an Altar set out, that even very confused people seem to realise that something is happening there.

AB:13 Yes, if I see a person whom I don't know, I would usually ask "Which Parish do you come from?" or ask them about themselves - are they married and about their family, I find this very helpful.

H.M. Exactly, when you are visiting, say, the house-bound folk and the old folk in the Parish, can I ask just for the reasons for doing it, within your own thinking, especially with some who are very confused? Some people have said to me that, really, they go into a situation where someone is confused in their own home, and maybe stay for a while, and leave, and wonder was their any point?

AB:14 I get that myself. You see, lay people could take care of them, but the older folk won't accept this. My main reason for visiting them is that some Priests leave it entirely to the lay people. Now the older generation like to see a Priest and he's always most welcome and when they meet together for Mass in the Church during Lent, from a practical point-of-view, they meet with friends and make new ones and some have never been out for a whole year. The Parishioners volunteer to bring them by car. They come to the Mass and have their cup of tea afterwards. These people - their prayers help us.

H.M. Yes, thank you. In the questionnaire, quite a large percentage of the people who responded said that they feel their visits made a difference to the confused. I'm just wondering how you know it makes a difference?

AB:15 Well, the reaction you get - you know they seem thankful. It depends on the person himself, some are very shy, of course. Generally, they just show some form of appreciation. Some might want to make an offering to the Church.

H.M. Would you have been in the situation, either in the hospital or Parish where someone has been agitated or anxious and you have found, through one of the sacraments, that you have been able to calm her and help her?

AB:16 It is difficult to say - but yes, I do find that the sacrament can definitely calm them - even as soon as a Priest comes I do think it calms them.

H.M. Yes, thank you. Would you ever have been in a situation, where some confused person has expressed anger, even anger at God, because of the situation they're in?

AB:17 I have heard them say "I wonder why God does this?" which is natural, you know, and I'll say something like "there must be some kind of reason which we can't, at the moment, understand". When a child of four or five weeks' dies, that's a difficult one. But I find the older generation are very accepting in a Christian way. I have now, occasionally, been to hospital and been turned away - a lady just couldn't accept things - but in the end, I think, I got through to her a little.

H.M. Yes, yes - indeed. Have you found, with say, Mass, forgive my ignorance, would there be a set liturgy?

AB:18 No, no, there isn't. Strangely enough, there isn't. What I'm inclined to do is to cut down the first reading, because it's difficult for them and I would use a shortened Mass.

H.M. Right, right. Do you find for folk who have grown up in the Church, that using that set form of Mass, it does seem to trigger memories for them?

AB:19 Oh, very much so. The Mass is a very big thing in their lives and the symbols are very important for them, the candles, the Altar and the Priest in vestments, all of these are very important to them and they remember.

H.M. Yes, I think you are so much richer than we are in terms of symbols because that is one of the things which has come through, things like the candles, the Cross and the Cup - all of these seem to evoke memories.

AB:20 Yes, these things are really central for them.

H.M. That's tremendous. That's covered most of the things. I really appreciate your help.

INTERVIEW WITH CD

H.M. Can I start by asking you, do you have folk in your congregation who are confused?

CD:1 One or two. Our age level is quite high. Now we have several 80 or 90 year olds who are, in fact, very vigorous and are in the congregation, but we have had one or two who have become quite severely confused. I can think of one who is mildly confused, but not to the extent that we can't communicate. We have a lady in one of the Old Folks' Homes who is getting confused and I think she just about recognises me but there are quite advanced problems there, because after a minute or two she gets panicky and starts calling for folk and obviously there is something there which troubles her. She is the most severe.

H.M. Are there things which come to mind that you have found to be most effective in helping you to communicate, with both the moderately affected and more severely affected folk?

CD:2 Well, with the moderately affected folk, I think it is just a matter of keeping steady and trying to follow the drift of where they are and not worrying if they ask the same thing over and over again. That's not too difficult. I have found, and it was actually when I was Chaplain in a Geriatric Hospital, where there were a lot of folk with Alzheimer's and suchlike and I had to take Services there, that what was quite helpful was, in fact, to use things which were familiar from their childhood, basic things. I always included the Lord's Prayer and I found that the most confused people often latched on to that and would say it with me. I always used the Aaronic Blessing and the same thing happened and people could sing hymns and obviously all of this had a calming effect and also they were enjoying it. But I found in one-to-one conversations that if I could try to suspend the whole business of time and space, and listen to them and talk myself into what they're coming at, and in that way, I found we got into a conversation which became very interesting, although it wasn't directly related to here and now. When you latched on to who they were thinking about, like their mother or their home, things began to open out and that was the way I handled it.

H.M. So you would actually go in and talk to them about their mothers or home or whatever.

CD:3 Yes, or at least listen until they came out with something - you know, I would say "yes" and "no" but I would try to say "yes?" with a question-mark in my voice so that they began to talk quite a bit. I feel it is so important to treat people as people and I've been so surprised, many a time, by some old folk who are really out of touch and yet you hear about what they did, and you realise all these people are individuals with a long history and story of their own and I try to respect them on that basis. I was very fortunate, my first parish was in [Scottish Isle Name], and the people there on the whole are not vociferous and you can sit for 20 minutes without saying anything and I got used to that and so I don't find silences uncomfortable and I do try

to pray inwardly, you know just to listen to God's Spirit, so that there's more than me involved in this situation - I've found that tremendously helpful. If I was just going on the basis of what I could do, in a kind of mechanical way, I would get panicky because I would think because they can't hear me, we can't communicate or if we're not saying something sensible - if I was just going on that basis, I would become terribly frustrated.

H.M. You see, that raises an issue which is very exciting for me as it's in line with something which I've been thinking about recently, you know, how God's Spirit can be moving in a situation, obviously beyond anything which we can expect and wondering too, in conjunction with that, if there can be something present of the spirit of the individual which could be in communion with God, even when mind and body have deteriorated, if you can see what I'm getting at. Is there anything which that brings to mind with you?

CD:4 Well, my own view is that the Spirit operates now and that we can have the gifts of the Spirit and I have found that the gift of tongues is helpful, not to pray aloud, but to be praying whilst I'm with the person or speaking with them. I've found this very helpful. In some ways there's an analogy here with the person who is unconscious or in a operation or in some sort of trauma, obviously we're operating on the basis of Faith here, but I have certainly found that particular gift to be very helpful in these situations. The other thing too, are the sacraments, Communion. Now, if I remember rightly, I don't know if we ever had it in the last hospital I was in, but I feel, more and more, that for most people who have known this, in a personal way. it is very helpful because it is something familiar. Now some folk come from traditions where it's really not all that familiar and in some ways the Church of Scotland, because of our rather formal approach in the past where you might have the Communion quarterly or six-monthly or annually, in some ways people associate it, in their minds, with a very formal approach. But where Communion has a more personal meaning, I think it can be very helpful. Again, it's something familiar.

H.M. Yes, and it brings together all the symbolism of the past.

CD:5 That's right - although I had a very funny experience with this. I was asked to take Communion in that last hospital, before I was Chaplain, with folk who were members and there was this old lady who was totally confused. I set out the Communion elements, when all of a sudden she cried out something which indicated she thought it was some kind of New Year celebration!

H.M. Oh, yes - (laughter).

CD:6 With violent people, I just kept them at arm's length or ready to jump if they lashed out but tried never to be shocked! I do know of someone who got onto the wave-length of someone like that once - they were quite firm with them, but they didn't bully them, they didn't say "What are you doing this to me for?" and, in fact, it worked in that case. I think we should be quite positive in our approach to folk who are confused, I mean sensitively so. I think that, sometimes, people's reaction is to

stand back, keep their distance and not get involved and keep everything as quiet as possible, but I think you have to accept them as they are with inter-action, where possible.

H.M. But it opens us up to vulnerability.

CD:7 It does and sometimes they can go completely crazy! I mean I remember folk who used to wander up and down and round about in the course of things. I used to have people with me from my congregation and at first they found this a bit difficult; but I think because I said "Look, it's okay, just let her do that" and I mean she might wander round and open doors and do various things, although there were Staff around to keep things within limits, but I think you have got to take folk as they are.

H.M. I think it's coming through a lot that, if you're willing to do that and find what's meaningful for them, it's amazing what can open up.

CD:8 Yes, yes, that's certainly been my experience. However, I think that, possibly the most distressing case is this lady whom I have at the moment. The Home she's in are very keen to keep her there, they're very fond of her, but she gets quite violent. When I see her, she's certainly not violent but there's this panic which comes over her. At first I thought that it's really the toilet she wanted, she was getting so distressed, but discovered that there's something else and, so, what I have done in her case is just to pray quietly with her and certainly she seems to quieten a wee bit - but I really don't know.

H.M. It's interesting, isn't it, that quite a high percentage of folk said that they felt their visits made a difference, even with the most confused. One of the things which I'm trying to pick up is, what is it that makes us feel that we've made a difference?

CD:9 You mean is it wishful thinking? (laughter)

H.M. Or are there specifics?

CD:10 I realise that one wants to feel one has made a difference - I don't know, I think that if it doesn't and I believe it does. I think I would speak on two levels. One is that there is one person who has taken time who is not part of the Staff or Establishment, just to sit down and perhaps the physical touch of a person's hand - I think that this inevitably makes a difference. In the other sense, going prayerfully and trusting that God's Spirit is with you. I think that the Lord communicates through you, communicates His love really - not in a sentimental way but in a ministering way. These are the two things which I would think seem to make a difference.

H.M. Yes, I understand.

CD:11 Certainly, on the whole, where one is in a position to give time to this sort of thing, quite often the Staff, if they are in a position to notice, will often say, "You know, that's made a difference".

H.M. Can I tell you about a Minister who told me a story about a woman who had been a missionary in India, I think, for all of her life but she was now very, very confused. She was in a Home in a neighbouring Parish and the Minister of that particular Parish rang to see if this Minister could come and take a Service. The Minister said "Oh yes, you've got a woman from us with you there" and the Minister who was ringing said "Well, that's very interesting, I tried to talk with her but she couldn't tell me her name or anything about herself, but I knew that this was a woman who could pray". I'm wondering if you have had an experience like this, with folk with whom you've felt there's something here in relationship with God. Or, on another level, whether folk have told you about their Faith or have expressed anger with God because of the situation they're in?

CD:12 I can't remember a situation where folk have expressed anger but I have had several situations when I've realised that they have a relationship with God and there's no doubt about it, that that makes a great difference - and I think you sense there's something's happening because there's a reciprocal response.

H.M. Yes, yes.

CD:13 At Christmas time, I remember there was a lady who told me she had been to Ceylon with her husband. She told me a lot about the boat trip and my father was a Merchant Skipper and I know a bit about the whole kind of "shipping" attitude to life and I was able to latch on to that, because otherwise she wasn't quite on this planet! Sometimes people notice the Collar - but they often don't notice the Collar, they notice the beard first - but sometimes there's a reaction, a positive one. On the whole, I haven't had much in the way of negative reaction in Old Folks' Homes, but another generation might produce that because things have changed. So many folks in Old Folks' Homes at present have had a Christian background, whether they've been practising Christians or not and therefore, on the whole, my experience has been that they're friendly towards Ministers.

H.M. Yes, but we might see changes in another generation.

CD:14 Oh, yes. Also, there is this great heritage of Christian song which is there and people have it and I try to capitalise on that. Sometimes I will just repeat a Psalm, say Psalm 23 and just repeat it with them and say it as a prayer and that's helpful.

H.M. Just cueing in to something.

CD:15 Yes, yes.

H.M. Now there will obviously be big individual variations and it'll depend on the person you're visiting, but in general, for you, why bother visiting someone who is very confused?

CD:16 Because they're just the same as any other person and ought to have the same kind of pastoral care.

H.M. So your reasons for pastoral care for the person who is confused would be the same as for any other member of your congregation?

CD:17 Yes, yes - I mean I'm talking about this in theory, because I'm one of those people who never gets to the end of their pastoral visiting, who never does enough and, in some ways, I get on very well with people, although I would be quite shy initially and I don't find the visiting the easiest part of my work. I find it takes an awful lot out of me, although I enjoy it in the actual practice. Having said all that. I'm trying to indicate that I'm not an expert, I haven't got it together. This aspect of my Ministry I've never, ever, got together in a sense that is really satisfactory, as far as I'm concerned. At the same time, I feel it is part of the care of souls, if you like, and whoever the person is - it's basically a mission to share my Faith with whoever. I find folk like that quite interesting - it's quite a challenge.

H.M. Yes. It's interesting to hear you say that, in that quite a few folk have said to me that they can see the theory of it and see the validity of folk in that they would affirm, as you were saying, people's value and identity before God, but they still found the visits to those who were confused were the ones which didn't get done at the end of the day - you know, that just slipped off the visiting list!

CD:18 No. I think I can honestly say, they're not ones who slip off my list!

H.M. That's encouraging for me! (laughter). Another area which I'd like to bring up is that of trying to understand what the individual who is confused, is trying to communicate. You've touched on that already when you spoke of getting into their situation. Do you think it's possible, on a practical level and also on a spiritual level, to assess someone's concerns when they're confused?

CD:19 You mean for me to actually latch on to whatever they're concerned about? I think it is, but I have the feeling it's a long process, you know one might latch on to something and find that that's actually a blind alley. I can't honestly say whether I know I have ever actually got to the root.

H.M. You were saying earlier about getting into conversation on interesting things.

CD:20 Yes, yes I think it has been more that things have opened up and they've enjoyed it - that I've enjoyed it - although, mind you, often with elderly women there's a deep concern for their families, for their grandchildren and that often shows. I remember an old lady who used to become, at about 4 o'clock in the afternoon, extremely restive because she needed to get the train to get home and feed these children. Eventually they had to tie her to the chair so that she wouldn't go for a walk - but there was obviously something from away back and as far as I could gather, she seemed to have had total responsibility for quite a large family or extended family and this was still with her.

H.M. Right, right.

CD:21 I think I'm also fortunate, in a way, that my wife had a total breakdown about ten years ago now and she's totally recovered from it and they reckon, at the time, that it was to do with an awful lot of stresses which had come on, over a number of years, and it just came to a head. However, in that experience, because she was in a psychiatric hospital for two-and-a-half months, and in the initial period when she was very upset, I was sitting with her for days at a time even before they committed her to hospital, and I wrote to the hospital at the time and said, you know - certain things, which you may not recognise and think they are delusion or whatever, but in fact they aren't, because an awful lot of it she was relating back to her own childhood in [Country Name] and her relationship with her father and so on and I knew, from what she was saying, exactly where she was, you know, all through. Now, in fact, with more experience of all sorts of things including manifestations of God's Spirit which we see in [City name] and so on, I'm awfully glad that I was aware enough to know that there was a lot mixed in here. It wasn't all mental illness, do you see, and I believe that with people who are confused or disorientated or disconnected in some way, that if you can get into the key, I think there are keys, and if you can get that key you can begin to follow through.

H.M. Yes, yes.

CD:22 But as I say, it's this whole business of taking them - of taking what they are saying seriously and not imposing upon them what appears to be sensible now. I mean if they think they're back in 1928 or something with their mother, obviously that doesn't relate to now, but if you go back with them to there, there's a whole lot of things which all fit into place. I've always been interested in history, so I carry bits and pieces, details, about in my mind and I can think myself into these kind of situations, so I can talk about things as they were then, to a certain extent, you know - because of my historical imagination.

H.M. What you're saying is picking up on all sorts of theories which are coming up about, you know, validating where the person is and being willing to go back, because there may be issues which are unresolved and perhaps just listening may help. Specifically, have you found when you've been willing to do that, that the person has been helped or that, perhaps, Faith issues for them have arisen?

CD:23 Not that I can remember, except, maybe, in one or two cases where the folk actually had a Faith which was still very much with them - but not otherwise, I don't think. I think I have found this to be the case more with people who were disturbed, but not out of touch - people who would be confused in the normal run of daily life but wouldn't actually be labelled "confused"; also in pastoral caring for folk suffering from alcoholism and things like that, the kind of phobias and fears and so on which we all carry to a certain extent, but I've found with folk in that kind of circumstance, going back with them and praying with them and so on, we've got onto something which they've been able to deal with and come through. I'm not so sure, you see, that we don't categorise folk too much because there is such a fine line between sanity and insanity, shall we say, and I think quite a lot of what one uses with normal

people, actually also works with those who don't seem to be normal provided you get it into context, into their wave-length.

H.M. So what sort of things are in your mind here?

CD:24 Well, what we've been talking about, to use your jargon, validating people, letting them talk to you rather than going with a prescribed agenda. There are certain things which I set round pastoral visits anyhow in that, when I go into a house I suppose the way it works is we talk about things generally, until I feel that folk are reasonably easy, and then I almost always pray. It depends on the person, but usually I'll say "We'll have a prayer before I go", and lots of folk will accept that. There are one or two folk who are not quite sure and I'll say "Would you mind if I pray?" and then they say something like "Oh, well, if you want to!" and I feel like saying "Let's start again!"

H.M. Yes, yes (laughter).

CD:25 But no, I usually accept that. There are one or two folk, of course, who don't want you to - But I think prayer focuses all that we've talked about in to "offering it to the Lord" - it's not a set prayer and I usually include what we've been talking about and I tend to approach all the pastoral work rather like that, you know in the hospital or whatever. I don't see why, as far as folk with Alzheimer's are concerned and those who are confused, that it shouldn't work with them - except, of course, in the very extreme case where the person doesn't seem to be quite latching on at all. Then, I think, I would simply pray in the Spirit and perhaps have a formal blessing - the Aaronic blessing or say the Lord's Prayer with them - that often rings bells and maybe I wouldn't be able to do anything other than that. I'm just thinking of [Lady's Name], she has a photograph in her room of some folk and myself. I spoke to her about that, but she didn't really know who was in the photograph and I sometimes find in that sort of situation you can explore a wee bit, but then if nothing is coming - often I would just take her hand or place a hand on her shoulder and just pray a blessing on her. You know, I'm not - I mean, I think if I were less inhibited I would touch more. I was brought up in the sort of Scottish tradition. My mother was very loving towards us but we were still all quite reserved, you know "men didn't do these things". And I have tried with my family for it to become natural for us to hug one another. I felt I had to break that kind of inhibition and sometimes, of course, in a situation of crisis, I have a tendency to stand back and then go in - I don't withdraw to run away but I stand back to think, as it were. This seems to be my way of coping, but sometimes it's the wrong thing to do - but I find, yes, to touch a person is helpful.

H.M. Yes - right. as a researcher, can I ask you about praying in the Spirit, and what difference this makes to a situation?

CD:26 It makes all the difference in the world. I've always prayed with people and always prayed in a hospital, if I could. Actually, I took it from a senior Minister who once said "If you don't pray in folk's homes, how are they ever going to start

praying?" You see some people would say now the Minister shouldn't do that, because he's expected to - but this senior Minister said to me that he did, because he felt it was his responsibility to lead folk, and not to pray in an elaborate fashion, but very simply. So, I've always done that and I've always believed that the Lord works in these things.

H.M. Yes, yes - that's a good idea.

CD:27 But after my own experience of the Spirit, in a more personal way, and of the gift of tongues, I felt that I've got something to give in this situation which is not me, you know before it was "Lord, help me to do what I can", okay? Now, it's "Thanks Lord, thanks, we go together and let me be open to you", so that's the difference and that definitely takes, well - the hassle out of it, because I feel that I've something to bring to each person, no matter how tired I am - in the middle of the afternoon, I'm usually very sleepy - that's another problem of mine! (laughter) In fact, I remember a colleague of mine and he wasn't well for a while and he said to me "You know, I just feel like crawling out of here or something"! (more laughter). But that's the marked difference it made and certainly hospital visiting etc. took on a new dimension.

H.M. So it's not just your own resources

CD:28 That's right, that's right, and me clocking up my visits! Also, I think, I would hope to be more aware with regard to the person I should go and see at any time. I mean, I used to hear Ministers saying "If a name comes to mind, never neglect it". Now, I find in practice, it can take something like three weeks to do something about it, but I'm beginning to recognise that the Lord knows what he's doing, so if he's giving me a prompt, he also knows the time-scale in which it has to be done, and I think that that makes things more positive too. I feel I'm going when I should be going - when I can be of most help, and this doesn't apply particularly to those with Alzheimer's, but there have been times when folk have said "That was the right time".

H.M. Now the last question and I can almost guess your response! In the comment section, at the end, one or two people say that pastoral care of folk with Alzheimer's made them think of euthanasia. Would that raise any issues with you or, apart from euthanasia, would you feel that there were other ethical issues involved here?

CD:29 Yes, it makes me think about it, but I'm not tempted to it. One of the reasons, I think, is that "looking on" is possibly more distressing than what the person, herself, is feeling. They may be confused, but if they are not "distressed confused", well fine, keep them happy with people to look after them and care for them. I do feel very strongly that our lives are not ours to - You see, we live with this, although at some distance. My father-in-law was seriously injured in a car crash, about 35 years ago, and he suffered great damage at the time. However, just when he was beginning to make a recovery, there was an experimental brain operation done which went wrong and he had a stroke and has been sort of, semi-registrative, ever since. Now, he's 85.

H.M. Right

CD:30 and has been in a wheel-chair or bed all these years. He can't move around, can't speak properly, has a lot of difficulty communicating and has had to suffer many frustrations, such as personality changes, all very difficult. My mother-in-law is 82 or 83 and looks after him up to now and she's managed - it's just amazing what she has been able to do, but she has been left with this now. My wife and I often talk about it and often pray for Dad's release.

H.M. Yes, yes, I know

CD:31 -but the thing is, I think, you know there are two things. One is that the person himself doesn't really want to go and they're hanging on and constitutionally, they're strong enough to hang on. The other thing is that Mum [Family Surname] just wouldn't know what to do. He's been her life - all her life really, in many ways, I think she is holding onto him as tightly as anybody else. I wonder if we're a bit arrogant, you know, we do make judgements about people's quality of life - and yet, when you're actually in a situation, you don't think about that, you get on with it and deal with it. Dad was a very fine Christian. Since we've been involved more, as it were, in expecting God's Spirit to act, in practical ways, I think we've become more aware of how people can affect their lives by a will to live or a will to die and we wonder sometimes - going back over Dad [Family Surname]'s life - (a long story, sorry). My wife's going out to [Country Name] in March and it's going to be very difficult, it may be her last time. She's going to see the situation which will have deteriorated; they're not getting much medical help, really not much care, although there's care available. The trouble with Mum [Family Surname] is that she would get care for two days and then say "thank you very much, its all right, I'll look after him"

H.M. She'd manage, yes

CD:32 and as a result, folk find it very difficult to help her and she has fallen off people's lists, you know. Then, he wasn't expected to live more than ten years and the compensation he got was niggardly. They were very poor to start with and in some ways they're better off since he's been ill, but it's beginning to eat into their resources and there's all of this - so, you know, you do ask questions about euthanasia but I think it's a very dangerous road because I'm quite sure people would get even more fearful and very frightened. Also, the ones that get it may even start accusing their families, I mean they do that when families start trying to get them into Homes, and I think it would just make the situation worse. Mind you, on the other hand, there was an old lady who had just seen her husband die and it was quite a brief illness but he deteriorated very quickly and she said that, in the end, you know, she prayed that God would take him and that was good, because she was letting him go; but at the same time, she said to me "that's why I'm all in favour of euthanasia when people get to this stage" - well, it wasn't the time to disagree with her just then.

(tape recording has now come to an end. Heather continues speaking herself and makes the following comments):

We continue talking about euthanasia, saying that life is too valuable and that we are sometimes arrogant and that life is not our own. He then talked about Homes and said he felt it was very important that Homes took the spiritual needs of people seriously because folk who were elderly were coming from a background where Faith was important, when there were the big Services and they went to hear the preachers and this might not be understood by folk who are younger and from a post-Christian era and actually running those homes. He found with funerals, when sometimes families did not know Church backgrounds, as the person may have been in the Home for 30 years or so, they did not always take enough care with funeral arrangements. He felt it was important, if he knew such persons were on the list, to actually do something about this and find out the Church connections and Parish Ministers. He talked about situations when his Elder had told him not to go into the Home because the Elder could run the Service very well. Then, when he did go in for funeral Services, he found that he wasn't known. So, it was very important that the Staff knew the Parish Minister. He indicated that this whole situation was partly the Church's fault.

Lastly, he felt that the Staff should do their best to regard Services as something special - there is something happening in a Service so they shouldn't be wandering in and out. There should be Guidelines given, they shouldn't be moving people around and they shouldn't be having conversations in a corner. He had a Home where this was a particular problem and it made things very difficult, although some Staff were very good.

Heather said how much she had appreciated this interview.

INTERVIEW WITH EF

H.M. Can I ask have you encountered many folk who are confused?

EF:1 In the A [Hospital Name], we dealt with people who came in who were very confused in some of the geriatric wards and some of them belonged to in-patients, as they had other things wrong with them, who had some other surgical problem or some long-term illness, either Alzheimer's or whatever. Strangely enough, although it was an acute hospital, they were in for as long as two years and they just got stuck there, often with no stimulus particularly apart from the love and the care of the Ward - small Wards. Others were in for short term, but they would return again because the problem arose again and most of them were elderly. They would return and I would think "Oh, there's [Lady's Name] again" and I would know what the situation is. Some of them, I would know a great deal about their background, others I would know nothing.

H.M. Did you find it helpful when you did know something about their background, when you did have that information?

EF:2 Yes, very helpful, because then you were at least able to talk a little more knowledgeably about things, and not think "What am I going to talk about this time?" or "How am I going to approach this person?", particularly when some of them were very silent and withdrawn.

H.M. When you were visiting the very withdrawn and confused folk, were there things which you found were most helpful, things which you could do or things which happened in the environment that really helped you to communicate?

EF:3 Well, you know, there is an immediacy about what you have to really communicate, mostly about things going on around, drawing their attention to something going on in the Ward or people, or, because you know nothing about them at all, just to talk about one's own family. I tended rather to do that because, sometimes, a photograph of my children - anything which they could see to just bring their attention to something. You see, the other thing, as a hospital Chaplain, I carried a whole lot of stuff around with me which might be helpful to anybody, little cards and suchlike.

H.M. When you say you showed them a card or a picture of your family, what sort of reaction did you get?

EF:4 Varied, varied - I remember one particular man who was a great pal - I don't think he remembered me from one time to another, because he got progressively worse - but, you know, his eyes said a lot and he would take the things and look at them and hand them back to me and I would say "this is for you" and he would take it and talk about it a little bit. If it happened to be a simple little poem, I would read that to him, whether he remembered it or not and I think that was stimulating - a little

bit - but because I knew his circumstances and they were very, very sad indeed, I would - very gently, sometimes - bring in something about his past. He didn't get many visitors - often such people didn't get visitors and they were being looked after very well. However, I would say that very little was being asked of them, so they weren't stimulated into being able to try to do things for themselves - so it was difficult - and most of them would just sit or lie on their beds.

H.M. Right, right - and would there be much reaction to you reading to them?

EF:5 No, very, very little reaction sometimes, except the eyes - you know.

H.M. Right - sorry to be pushing you - but just specifically the eyes?

EF:6 Oh yes, yes, the eye-contact is very important and touch. Well, from the point of view of a Chaplain anyhow, touch is very, very important - because you can communicate all sorts of things that way whether, it's consciously or unconsciously.

I can think of this particular old man to whom touch was very important indeed. I think there was probably more achieved, at each visit, with touch, than anything else. He would, occasionally, talk through touch. He couldn't remember anything about his past life except that his wife had died, he could remember that and in fact he got very, very, much worse when his wife died and she died in another Ward, that was how I got to know him. I pushed him round to see her, sometimes - but he would talk about cars, that would jog his memory and he would talk when he was stimulated a little bit and, I would make him laugh because I was always telling him what a bad driver I was, and he would begin to talk a little bit and I would try to find cards with old cars on them. These were fairly short interviews, I mean they were bedside sort of things. Perhaps, sometimes, when I had more time, I would see this particular man more often. Others were less responsive.

H.M. Right, right.

EF:7 and quite difficult.

H.M. Just thinking of those less responsive ones, did you find things like reading the Bible helpful?

EF:8 I did occasionally, just a Psalm - not much, just a few verses - because the Psalms say a lot about life and people's reactions and also offer comfort - particularly if I knew anything about the background.

H.M. Indeed - right.

EF:9 I also prayed with them, just little prayers.

H.M. Did people become quiet when you prayed?

EF:10 Yes and tears, emotional tears often. I didn't get much aggressive behaviour, the Wards were fairly regimented and some of the doors were locked and in there, were some folk who were really affected. However, again, it was those short burst of stimulation - it wasn't anything long term and of course, they didn't remember you again the next time you went. I did get glimpses of recognition from the old man - he was in for two-and-a-half years of the five years I was there and he died in hospital. There were times of deep unhappiness with him, which he couldn't express in words, but he recollected sometimes his loss.

H.M. Well, would that have been through crying or words..?

EF:11 It was through crying, I mean he would take my hand - I knew what was wrong, it was about his wife - so, you know there were times, often, when he would not talk about it but indicate that there was something deeply painful.

H.M. Right, yes.

EF:12 But most of the time, he wasn't like that, he was - he just sat there, sometimes he wasn't so well, physically, and it wasn't unusual to sit there, just holding his hand actually.

H.M. Yes, yes - one of the statistics which came up is that 53% of folk who responded said that they thought their visits made a difference, would you agree with that? Would you have experiences to back it up?

EF:13 Well, I mean, the way I feel about it, I suppose, is that it was very worthwhile. I've learnt so much from the people who weren't able to communicate much, about silence. I've learnt a lot from them in the experience of just sitting quietly with someone, who was unable to communicate something sometimes..... or nothing. They, from my point of view, are very worthwhile people in the community. Often, we will know a bit about their lives and trying to grow something out of that, sometimes, even if there is very little response, is worthwhile.

H.M. Just to home in on people being worthwhile in the community, could you pick up for me a theological list of reasons under "why bother?" I mean with regard to folk who are very confused and who perhaps don't realise that you're there.

EF:14 I suppose it's this "image of God" thing which I find important. I find God's likeness in people - whoever they are - it's very seldom to be found and something "offering", and I find that that probably is offering in their weakness and the fact that they are doing something for me, which I didn't expect, inside me, the fact that they are - everyone's different and they are left by God and the very practicalities of the way the Cross related to people, whoever they were - I think I'm drawn - perhaps this is why I love hospital Chaplaincy so much - I'm drawn by the brokenness which seems to be in all people and that's, in essence, to me, the heart of

God in people - their brokenness and their powerlessness and a weakness which so often - well - we ignore at our peril.

H.M. Yes, yes.

EF:15 Whether it's the chap lying on the ground out there, because he can't find any place to live and doesn't want to anyhow, perhaps, and can't communicate and can't remember from one phrase to the next what the last phrase was and it's this, sort of powerless present - that makes them important

H.M. Right, yes.

EF:16 -and yet it's redeeming. My daughter is heavily involved in riding for the disabled and some of those kids are absolutely, totally, so disabled, that all they can do is lie across the pony and feel the movement and it's extraordinary how [Daughter's Name] comes back with her face alight and says "they were great today!" and - it's redeeming

H.M. Yes, yes.

EF:17 and also the way in which the Nurses responded in the Wards when [Man's Name] died, they were extremely kind and loving - I never heard a bad word at all - they were exceedingly loving and helpful in the Wards particularly. The two Wards where he and his wife finished up were very bright places. They were both extremely well cared-for and comfortable and spoken to as adults of worth, they weren't treated like children.

H.M. Yes - it's interesting that one person, said that at the heart of his difficulty with Ministry with folk who are very confused, is that he affirms, wholeheartedly, their worth in the sight of God, that they are precious to Him and therefore it is right that he should visit and be used by God in that situation. But, on the other hand, he found it very, very hard to see how faith in God was a reality for them in that moment, because the only hope that he could see for them, was after death. You know, the momentary glimpses and the momentary recognition were, perhaps, the only remembrances of God's presence and love and weren't really enough and he was trying to hold these two things together and finding it very, very difficult and I think that that might be an underlying thing for folk.

EF:18 Yes, when this man eventually died, I took his funeral - and I think the freedom aspect of death was helpful to talk about, you know the Nurses came - yes, I don't know, I felt that the people I was closest to - grasped the love of God in some way, I mean through all sorts of areas - through the Nurses and others. I think there was a sense of something going on. They weren't agitated, they were peaceful and calm.

H.M. Right. How did this come about, do you think?
Was it through your care, your presence, through the practicalities, like the flowers?

EF:19 I think a lot of it was through the handling and the care.

H.M. Right, right.

EF:20 and as I said there was a lot of kindness. There was the love of God there. I just felt we were walking on holy ground.

H.M. Really, really.

EF:21 I mean you were at the battle-front. It was an acute hospital, so you could be in a quiet ward where people were being looked after well and looking bright and cheerful and the next minute would be in a mental state and questioning inside themselves about what's going on - and this could be someone whom you knew extremely well. It was a place of tremendous contrast and I did feel very close to some.

H.M. A tremendous privilege. Were you in a situation of leading Worship with those who were confused?

EF:22 Yes, occasionally, not often in that hospital. Well, I took part with the Presbyterians in Sunday Worship sometimes, and the patients were moved down to the Chapel for this. They were moved in wheel-chairs by volunteers and we would have a good old sing-song and a few prayers and I gave a very short address. Then, in another hospital, very occasionally, there would be confused people and in a Day Room I would have "small group" type of Worship, perhaps there would be six people.

H.M. What would be most helpful in those situations?

EF:23 In the small group, it was informality and drawing out of them, if they were able, what their fears were and praying about them.

H.M. Did folk articulate those fears?

EF:24 Yes, they did, yes. Often I would read a Bible story which, perhaps, drew them in to that - or pick something which had been going on that day outside. I can remember one particular time, it was Armistice Day, Poppy Day, and that drew them out. Those who could communicate were sometimes very vociferous, they actually did say quite a lot, but there again we were in a sort of area where they were apprehensive anyway - they were not in their normal surroundings, so their fears would actually come out, particularly about relatives at home and, anyone who was slightly confused, would sit there and listen and it may have jogged their memories a bit and they would say "Amen" very loudly. (laughter).

H.M. So maybe there was something going on.

EF:25 I think there was and they would say "thank you". The ones in the Chapel situation obviously weren't able to articulate anything very much, it was all given to them, but they would sing. They each had a volunteer beside them who would turn the pages of the hymn-book for them and they would often sit there clutching the hymn-book. There WAS a response and the other Chaplain had a good singing voice, so it was quite a little concert, you know, it was good.

H.M. Was there ever a sharing of the Eucharist there?

EF:26 Yes, once a month.

H.M. And did the confused folk partake?

EF:27 Yes, they partook, everyone did and I think it was helpful to them.

H.M. Right, were there many responses? Folk have said that the strongest symbolism of all may well be taking the bread and the wine. Were there instances where you saw some confused folk partake and realised that that was meaningful?

EF:28 I would need to think about that - there were tears, I mean it may not necessarily be someone suffering from Alzheimer's, it could be a stroke patient and they are very, very tearful anyway.

H.M. Surely, yes. Would it be possible to follow that up, I mean how did you deal with it when someone started to cry?

EF:29 Just put my arms around them and cuddle them! I think "touch" again and the volunteers were so good as well. A great team.

H.M. Right.

EF:30 The going out of the Chapel was very important. We spoke to each person, so the line-up of wheel-chairs at the door was very important and the volunteers would tell us which ward they came from and it was always "How are you today?" and they would smile, there was a response - quite a lot.

H.M. One person told me a lovely story about how they had a woman in their congregation who was very, very confused and who had been a missionary and a very committed Christian most of her life. However, now she couldn't even tell her name, or anything, and couldn't remember being overseas. This woman was in a neighbouring Parish and the Minister from that Parish rang the woman's Minister to ask if he would go and take a Service in the Home where this woman was and he said "Of course, I will, anyhow you have Mrs. [Lady's Surname] there, she's one of ours". The Minister in that Parish said "That's very interesting, I didn't know who the woman was, I was talking to her yesterday, she couldn't tell me her name or anything about herself, but I was aware that this was a woman who could pray". That set up so many questions for me, if it's possible when so much deterioration of the mind is

going on, if underlying that, there's a possibility that something of the Spirit is still there and if, by implication then, the Holy Spirit can be working at that sort of level.

Would you think that that's a possibility from your experience - or just my wishful thinking?

EF:31 Difficult to know, isn't it, whether it's wishful thinking or what - I would have thought and, speaking from my own experience, I believe that the Holy Spirit can work at whatever level a person is at. I can think of a lady who was in a hospital many, many times and her mind was not deteriorating, in fact, we were in communication and I gave her Communion and she was a tremendously vivacious Christian. I suppose she was in her late fifties, early sixties. She told me a lot about what she felt about the Church she is now in and we had some good conversations. She actually sent me a book and a letter, later on. However, she made an extremely rapid deterioration and came in to the Ward - one of the Wards which I was describing and I looked at her name on the list and I thought "this can't be" and when I went to see her, she had made an extremely rapid, almost disintegration, and I remember one of the Nurses saying "Isn't it sad?" In fact, she was unconscious at the time and didn't recognise me at all - just these blank eyes - she made a very, very slow recovery. A tremendous loss, for me too, because we had had a good relationship in a Chaplain/patient sort of way. She did, eventually, begin to respond a little bit to prayer and holding the hand. Well, I would believe, I think in my heart, that the Holy Spirit was working on her in her lack of capacity to understand and I still think that He must, and that He doesn't forsake a person as much enlightened by the Spirit as she was - she was a tremendously praising person.

H.M. Right, right - is it your theology belief which makes you say that, rather than your experience?

EF:32 Probably, probably - I don't think He gives up on anybody

H.M. No, no.

EF:33 and I wouldn't believe He can. We don't know what happens, we haven't experienced that. I would say her eyes weren't happy, I felt that she was struggling within the limitations of what was going on. I don't think I've ever seen such horror in someone's eyes before - but I've seen it in my father's actually, I think there was a bit there as well, something about being trapped inside the body - but I don't believe that the Spirit of God would abandon in any way - in the end, she died. It's a difficult one.

H.M. Very difficult and yet it's an issue which must be running along there and yet, it can never be pinned down. The last question is just an ethical one. A person said to me that, for them, pastoral care of folk who are very, very confused raised the question of euthanasia in their minds. Would that echo for you at all?

EF:34 Not for me. No, I think it's part of my faith that anyone who is unable to help themselves is so precious. I have confused feelings about people who are

suffering intense pain. I know that people will be given large doses of diamorphine. I know that and I know that that goes on to help the pain and we know that it accelerates death and in some cases, it is actually right. Regarding people who are confused, I would say I am against it from the point-of-view of what's left in society. I have heard too many old people saying things like "I feel a burden to my family and I wish I could die", but that's not the answer. So I see it as a very dangerous area in which to get involved, because of the preciousness of these people to God. I think it's up to society to look after them and to bring out the best in them and I think tremendous things can be done for them, in fact, one of the women in my Church is doing tremendous things for them at a Day Centre and stimulating them, and enabling them.

H.M. Yes, yes.

EF:35 So, I think that the quality of life is important. Sometimes, relatives find it impossible to cope with them because they have deep feelings when the character of someone changes. I do think that the family have a responsibility, if possible to provide for people so that they are seen to be worth a lot.

H.M. Exactly - yes. Finally, would you like to put yourself within the theological spectrum for me, if you don't mind giving yourself a label, where would you put yourself?

EF:36 I admit to being very strongly evangelical and whether you would call it moving on, or whether you would call it going in a different direction along the path-way and I'm sure I still have fairly strong evangelical tendencies. I have gained a lot from the Church tradition which I'm in and I suppose I'm half-way now - I can fit in almost anywhere (laughter).

H.M. I know the feeling (laughter).

EF:37 and it's the hospital work which has done it to me, leading me away from one direction. In fact, my evangelical friends would probably say that I've stepped back, but I don't regard it like that, I regard it as accommodating a whole lot more that I'd missed out on.

H.M. Sure, sure.

EF:38 I believe that the hospital work has done this for me.

H.M. Right, right.

EF:39 working in the ecumenical dimension has been tremendous, it's a great team and I enjoy working with the Presbyterians and the Catholics and all the other folk who come in. I was in the Evangelical Church for twenty-five years and I suppose the tremendous thing was the dimension of prayer, which was really powerful and the healing Ministry.

H.M. Yes, right.

EF:40 So I missed that - but in moving I got a tremendous combination. (laughter).

H.M. That is a wonderful help. Thank you very much indeed.

EF:41 I feel sadly lacking in being able to contribute in a wider sort of sphere.

H.M. It's the specifics of experience which I'm looking for and you have been so helpful.

EF:42 I've learnt so much from the people who weren't able to communicate much

H.M. Yes

EF:43 about silence, that's another dimension that perhaps, I've brought into the Church situation and other means of communication apart from speaking.

H.M. Such as music and things like that

EF:44 Yes - music, dance, touch and eye contact. I mean you can do a lot with movement, can't you, and things like that?

H.M. Right, yes.

EF:45 I have done a lot of one-to-one Communion with people who are very, very sick and realise how meaningful that becomes with as few words as possible. In a sense, it's more about the grace of God and just having to provide the symbols, the signs.

H.M. It's moving into an area of non-verbal communication in Pastoral Care in a situation where words are not the most helpful. It's an area which, just recently, I've been trying to think more about and it's so ALIEN to everything.

EF:46 Last week, I was in contact with a woman who is verging on Alzheimer's and it's not unusual to have a little Communion Service which she desperately needs and she is from a very Catholic background and has to see all the symbols. So you get all the symbols out and in the past she has been a very deeply spiritual woman and very devout. So we have the symbols and the bread and the wine and she loves the silver Cup and she likes to pick it up and look at it - she is at home.

H.M. Yes, yes.

EF:47 However, it's nothing to stop at the most critical part of the Service and have a long discussion - and you have to allow for that.

H.M. Yes, yes. Thank you so very much.

INTERVIEW WITH GH

H.M. Can I start by explaining the background to the research? I was a speech therapist before I went into the Ministry.

GH:1 That's very interesting because the other lady whom I thought you were when you phoned up, [Lady's Full Name], is the Dean's wife, who is a senior speech therapist with [Hospital Name] - she's Irish!.

H.M. Getting in everywhere.

GH:2 I don't know her maiden name, she's a lovely girl.

H.M. So, then, when the Church gave me permission to be without Pastoral charge, for my little boy's sake, I decided just to do some study as well, just to impose a bit of discipline primarily and chose pastoral communication with people who are confused, because it is a developing area with speech and language therapy.

Also chatting with friends very informally, a lot of them said to me that they found difficulties in this area, in that they were going to visit folk who were very confused and really felt quite inadequate for lots of different reasons. So this all raised questions for me about whether or not there were things in speech and language therapy and theory which could be applied or handed on to Ministers which would help them in this area of trying to care for folk with dementia, so that's where it all started off.

GH:3 And how long ago is that?

H.M. That was three years ago, this is the fourth year. I have been doing lots of interviews and then a questionnaire and this is now following up, trying to pick up on some of the areas which are coming out of the questionnaire, just to throw back questions and some of the results and see if they make sense. Do you have folk with dementia in your Parish with whom you have contact?

GH:4 Yes, we have. In fact, I lost one a fortnight or three weeks ago. We have several in here, we have a dementia awareness group which meets through the social work organisation, that's [Residential Home Name]. Now [Residential Home Name] is a residential home run by the [Scottish District Name]'s District Council and it is looked after obviously by Wardens, a Senior Warden and three juniors and care assistants. It is divided into five units, they're using four units at the moment, each unit for eight people. They've all got their own bedroom and a communal lounge, dining-room and kitchen - there is a main kitchen down below where food is prepared. We have people in this home with dementia and people who go in for respite care suffering from dementia, it is purely a residential home. The first unit at the bottom is being re-vamped at the moment by the Health and Social Work Authority under the new documents which came out, and that will take eight people

but it goes further than the dementia unit, because in charge will be a qualified registered Mental Nurse around the clock, and care assistants. So that's [Residential Home Name].

H.M. Right, that's most interesting.

GH:5 We have two Nursing Homes, one is a private home run by an organisation based at [Town Name]. We have another nursing home which is seven miles up the coast run by Mr. & Mrs. [Surname], again this is a private nursing home which can take 20 people. Now with the hospital policy at the moment - although we haven't got a hospital, you know in England the nearest hospital is ten miles away but in Scotland the nearest hospital is 44 miles away and so is the mental hospital. We're getting a geriatric day hospital here, which is going to help but quite a few of us feel that it shouldn't be just a DAY Hospital. Within these two nursing homes, the Health Board have bought two beds each so that we have four nursing beds for people coming out of hospital who can be nursed. The majority of these, obviously, are at the retirement end of the population, for example I saw a gentleman there last week who is in respite care and he's continually on an enhanced air device.

H.M. Yes, I understand.

GH:6 However, we have a dementia group which meets here regularly. One of my parishioners is very involved in this for the simple reason that her mother is in that state and we have several people who are moving into a dementia area, into Alzheimers, it's coming to that. I lost one twelve months ago with advancing dementia as I would call it, as a layman to that subject, and we have got various people through the community. I wouldn't say that it's any more than other communities. I came from the coast to here, from [Area Name], prior to that from [Area Name] and I would say that the ratio is all about the same.

H.M. From any part of your experience, have you found things which are particularly helpful when you are seeking to communicate with someone with dementia?

GH:7 Yes, it's no use referring to the present. Most of my Ministry is with the elderly, all right I have been in a school this morning but most of my Ministry is with people older than myself. So what I have tried to find out with old people is common ground for them and common ground for them is music hall, railways, the things which went on in their lifetime, good things and bad, their hobbies - one chap was leek-growing and I would talk about leeks until the cows came home! This is what I find stimulates them, you've got to go back into their experience and bring out things.

Also there are some in community residences - we have two sets of flats, warden controlled, one Council and one the Housing Association and British Legion, where there are communal rooms where they meet and have bingo, dominoes, cards and where they sit and talk. I often go in there, especially on a winter evening and those people who are moving towards the dementia side will pull these things out and amaze other people in the sense that you've hit on something here which they can

really pull out and talk about and communicate on and give their experience. This is tremendous as it gives these people a different quality of life, someone is interested in them, in them, in the subjects they're interested in. I found over my years in dealing with the elderly, for about 20 years, that they teach you so much and it's not only the completely coherent elderly but even those who have only a limited part of memory left who can teach you so much, when you pick on the right subject.

H.M. That's very helpful, thank you. Would you be in a situation of leading Worship in. say. some of the Homes?

GH:8 I take a monthly Service in [Residential Home Name]. Let me go back. Predominantly, of course with Scotland so that the national Church takes precedence over everything! Therefore the parish Minister, as he's called, takes Services in various places. So there's a precedent for a Service. [Residential Home Name], run by the Board of Social Work, have a system where a different organisation takes a Service for 35-40 minutes each Sunday. The Methodist take the first Sunday you will be pleased to know, I take the second Sunday, the third Sunday is a group of singers and the fourth Sunday is the Salvation Army. Now in that group which come down from the Day-room from the four units, you have got people as completely coherent as ourselves to the ones who are just in there prior to going to a Nursing Home. Now the type of Service I run there, is as near as we can to a normal pastoral Christian Service - non-denominational because we have got primarily Church of Scotland people. We let the people choose hymns, we use open prayers with the Lord's Prayer and we give a standard sermon which I feel is important and end up with tea and biscuits. We don't use a standard liturgy such as we use in Church for the Eucharist. unless they want Communion in Church and then I would probably do a simplified form, right across the denominations. I think I speak for others, when I say we try to give a Christian Service and a Christian sermon or address which is across the board. We find that even with people with dementia you don't know where that level is of listening and reasoning. Just to refer to the lady in her eighties, who passed on recently, she had already suffered a stroke and very bad dementia, that left her frustrated because if she sat here today she would understand what we were talking about but she could not communicate. She could speak but couldn't communicate, a lot of people get confused between the two. On the other hand, you don't know what is going in and at what level, you don't know when they shut off.

H.M. That is very helpful. Have you experience of folk who are very confused taking Communion, would you agree with that?

GH:9 Oh yes. Back to [Area Name], where I ran 26 Services a year. Every alternate Service except special occasions, such as Christmas, Easter and Whit, was Communion - evening prayer and a Celebration. The youngest was about 65-70 and the oldest was 104. We held it in the Dining Room. Yes, there were people who were confused and part of it they wouldn't follow. Two things they always followed. the Lord's Prayer and the receiving of the sacrament. In different ways, we got over a lot of it by administering straight into their mouths. i.e. the Cup and the Host. Those who wanted to take it in their own way were given it in their own way but no one

was ever so confused that it was thrown back and if it had been, it wouldn't have bothered me. One lady did bite a piece off and said "Thank you very much". You've got to accept at whatever level they come. Even if it is administered by intinction, I have never had anyone who has not wanted it and it is up to the person as to whether or not they want to have it, no matter what level of confusion they have reached.

H.M. On a more spiritual level one of the issues which I'm trying to look at is whether or not it's possible, when mind and body are gone or at least very deteriorated, to ascertain if something on a spiritual level can still be going on. What got me unto this thought was a story a Minister told about a person who was in a Nursing Home who had been a Missionary most of her days and who was now very confused. When a stranger came in to visit this woman, he told the Minister that she hadn't been able to tell him her name, or what she'd done, or who she was but on some level, he was aware that this was a woman who could pray. This got me wondering about whether or not others have had experience of people who are confused and yet there is still something spiritual there, something still there so that they have a relationship with God? Would you have any experiences like that to either back that up or have questions about it?

GH:10 Discussion about it, I would think yes. In the sense that I've known many stroke victims. Now, whether in clerical terms a stroke can be allied to any type of dementia, I wouldn't know, but a lot of the outward appearances would suggest it. I think and I know from dealing with people who have had strokes, providing you can get in to them, i.e. by writing something for those who are deaf and provided others can hear, you can get a certain communication from them by eyes, facial expression and things like that and I think these can be very positive and you can build up a communication relationship with them. So following on from that if they have a communication relationship with you, there is a thought process and if there is a thought process, it is quite possible that there can be a spiritual process.

H.M. Yes, I see what you mean.

GH:11 I would go as far as to say that, if you take the ultimate end of dementia, which is prior to clinical death, I'm certain that that is there, provided they can receive you with a sense, I'm sure they can also communicate. There are all sorts of cases where people who have been stricken by some illness which has affected the brain or the motivation parts rather than the automotive system of the body have prior to death, communicated in fantastic ways. So the way I operate is that, until a person is pronounced clinically dead there is always a method of communication which they can use. It might not be standard communication which we normally accept. It might be a difficult area to work with but I think there is that communication still there. It might be if you examined a lot of people over long periods of time that the spiritual side of communication could be of a higher level than we communicate spiritually. Different people, as you well know, communicate spiritually in different ways. As I often tell people, some of my finest prayers I've said when I've been doing my hobby, which is woodwork, especially when things are going wrong!

H.M. (laughter) Exactly, I know what you mean.

GH:12 A lot of people with dementia spend a great deal of time on their own and there must be something which keeps them going, perhaps a will to live or a will to get better, spiritual support or whatever, and a lot of that would be drawn from their own experience of life, as I said earlier, and their own experience of whatever kind of faith they had and they will draw on that to support them, i.e. the store which is in their mind and they will pull that out to support and help and nourish and keep them going. To a certain extent, as far as a number of people are concerned, who do not have the good fortune to be in a Nursing Home or residential home, it's like a prison sentence for them and wherever they live becomes like a cell. They need something, some form of communication - perhaps from television, records, radio, the stimulation is needed. I know that some folk do not seem to have that depth of stimulation, those who sit at the window or just watch blank walls and suchlike, but one thing which we do not know is the activity which may be going on inside and there's got to be more than just automotive activity which keeps the will to live alive, to get up every morning and keep going, even if that will is as small as a mustard seed.

H.M. This is interesting as it brings to mind a lady in New Zealand who is at the forefront of working with people who are confused and this is a very strong point with her. She talks about "cueing the faith memories". Would you have specific experiences of times when something has clicked?

GH:13 Oh yes, very much so. I would have experienced this quite a bit when I was working in [Area Name]. I used to try to go back in time and use sermons which depict the various parts of the year. I remember mentioning Sir Harry Lauder and it was surprising the way in which people clicked in on that. Other things which have occurred like that are, when you do something in Worship say at Christmas, with kids and carol singing, it can be the talking point for the rest of the week. It is things like this which people pick up on and make their whole life and if you can go back in time to things which you can remember or which have been passed on to you by your parents, things like Old Time Musicals which I like very much and mention folk like Maximillian and someone says "Oh yes, I remember seeing him at the Hippodrome" and you set a trend going which they might not even have thought of for 20 or 30 years.

H.M. Yes, exactly. Another thing which came out of the Questionnaires was that a high percentage said they felt their visits made a difference to the individual who was confused. I wonder would you feel that this was true in your case and also why you feel the visits were worthwhile, or not, as the case may be?

GH:14 Not that easy, my dear. Obviously, the worthwhile ones are the reactions you see in people - the level of communication will come from them - these are the good ones. At the time it did something for them and I think this is the important thing.

You're trying to do a pastoral activity, through the love of God, for someone else. The down side is the sense of pity and sadness which you can't show.

H.M. A couple of people have said to me, look if you can prove to me that visiting someone who is very confused is worth it, then I'll do whatever you tell me to do in terms of speech and language skills; but they have huge doubts about whether or not visiting people who are confused is really a good use of their time in a busy week.

GH:15 Oh, I have no doubt, I have no doubt that it is a good use of their time - even a five-minute visit is a change of face and a change of scenery. Unless you can know what is going on inside them, you can never put the worth on it. Just the value of the face on the other side of the door ought to be enough.

H.M. Can I ask in general, what your understanding of pastoral work is - your understanding of the pastoral charge which you have?

GH:16 Pastoral care from the ecclesiastical sense is for the care of the souls. The pastoral side to me is trying to meet the needs, within the resources which are available to me. To me it's all about meeting the needs of the people. The pastoral ministry in the three places in which I've been has been similar, sickness, dementia, family break-up, mental illness, chemotherapy, ministry to the dying or whatever happens to people, the main thing is that you feel you're able to respond with the love of God and your own Christian philosophy.

H.M. Another question which may be a difficult one - if you could put yourself within the structure of theological thinking, where would you place yourself? That is, if you're happy to do that!

GH:17 Yes, yes, I'm happy to do that with you by all means, my dear! In some respects of theological thinking, it is very modern. My tradition basically is Anglo-Catholic, stemming from my childhood. It is very traditional in the sense that, where certain eminent clergymen of the Anglican Church, the Roman Church and the non-Conformist (no disrespect) have come out against traditional thinking, I have thought through and have pronounced my own thoughts on it, scripturally, - but then again, I'm for the ordination of women, then again I will give Communion to any baptised person, then again I will marry divorced persons, I will christen, baptise, any child. I would be happy to let any other denomination use my Church, I'm ecumenical in very many respects, I'm a man for unity, not uniformity - I prefer my own ways of celebrating the rites of the Church but I do not decry anyone else's. I dress in a certain way because I feel comfortable that way. I feel that ordained people who have a pastoral charge in the community should identify themselves. I'm not one for stating theology in academic terms. The Church is where the people are. I will help regardless of denomination - obviously, I will ask if they have consulted their own Minister. My theology is very practically based, I'm a practical person. My spirituality is practical in that sense as well.

H.M. It is interesting to hear you speak of identifying yourself within the community because I think that that is important to confused people as well, a number of them have said that the "collar" is very helpful and has made a difference and has somehow clicked with them.

GH:18 I think it is an identification of the Christian Church - this is the important thing.

H.M. Thank you very much indeed. Now, on to the last question! Have you ever been in a situation with someone who is confused, when they have expressed a very definite sense of feeling abandoned by God and angry with God because of the way they are?

GH:19 I think this is sometimes the case for those with terminal illnesses as well. Yes, this is hard, because we all lose God. Yes, I do think people lose God and this is partly because they have lost part of their life. The people who lose God tend to be the people who are isolated - they haven't got the stimuli which they were used to, within a community life. Such people often don't talk about faith but they see in others, perhaps, what they would like to have themselves, spiritual gifts. I think that those people who have lost God have lost him because they haven't got other people around them, people who can stimulate them and their spiritual side which is still there. I think there are times when people get so low, they just cannot pick themselves up and it is only through people like us, through our communication, that they can manage to do this. I believe it is important to keep the level of communication going, on their wave-length, as much as we possibly can.

H.M. That is tremendously helpful. Thank you very much indeed.

INTERVIEW WITH IJ

H.M. May I explain the background to what I'm doing, just to fill you in. I was a speech therapist before I went into the Ministry. I'm a Methodist Minister now and the Church has given me a few years off - I have a little boy of two, and they have given me permission to be without Pastoral Charge. While I was off, I wanted to do some study and friends at home told me about how inadequate they felt when they were working with folk who are very confused, they just found that that was a difficult area and I began to wonder if there were things from speech therapy practice, because this is an area which is growing in speech therapy, which could be applied and could be handed on to people who are working in Parishes with folk who are confused and which might help them, really, to be used more fully by God in that situation. That is where everything started - and so we picked just, randomly, a few folk who had responded to the questionnaires to talk to about their experiences. For example, do they feel their visits make a difference, what sort of things have they found to be most helpful as they speak with them in their homes or in the hospital ward or when taking Mass? Can I ask, first of all, would you have folk who are confused, within your Parish?

IJ:1 I have, now not an awful lot to be honest. I have one or two. I have two Parishes, one here and another about two miles out towards the city. Now the other Parish, [parish name], is one of those areas where there has been a mushrooming of old folks' Homes. I think I have six at the present time. Now, to a greater or lesser extent in those six Homes, in the sense that I don't have an awful lot of Catholics in them, but obviously I would meet people there suffering from alzheimers, so much more there than in their own homes. I have one or two still at home and I would find that a much more difficult problem because my visits to the old folks' Homes, I suspect to those who still have full faculties, is a joy - or maybe not - (laughter), but for those who have a tremendous commitment to the Church, I think it's a joy for them, when the Priest takes the time to come and see them, or the Minister or whatever. I suspect the alzheimer patient in the hospital has such a short attention span that my visit, really, would not have any great effect, either "pre" or "post" in the sense that, if the Staff were to say "your Priest will be in to see you today", it wouldn't make any difference, you know "when is today - when is tomorrow?" and equally within seconds of leaving them, they really wouldn't remember. But, as a Priest, I wouldn't say that I can just sideline them or side-track them, I think they still need pastoral care.

H.M. Right, right.

IJ:2 and if they live very much in the present moment, OK. within that present moment they can recognise me as a Priest, then I would minister to them to the extent of sharing Holy Communion with them. I wouldn't exclude them from the sacrament of Communion, just simply because they have Alzheimer's.

H.M. Right, right.

IJ:3 However, in terms of the effect which my visit would have on them, I think that would be limited if not exactly nil.

H.M. Yes, right.

IJ:4 They do live very much in the present moment and the only thing which sometimes seemed to spark them off is the long-term memory, the childhood thing you know. One lady, in particular whom I can think of, happens to be from [area name in Scotland] which is my home base too, so if you can get her on to that - she'll talk about it as if it's the present. We both went to a local Church in [City Name] and, of course, she hasn't been in [City Name] in years, but I mean that's OK., you make that adjustment and at least there is a conversation there.

H.M. Exactly, yes.

IJ:5 But, otherwise, she's really being lifted out of the environment she remembers and she's stuck here and I think that, sometimes, she forgets she's in [City Name]. So, as I say, I would minister to them even though they're living totally in the present moment, and if I can get that reaction from them, then I would invite them to share in the Communion, if they wanted.

H.M. Right. You were saying about offering pastoral care to someone who is very confused, can I ask you about your reasons for that?

IJ:6 I think everybody who is drawing breath has the human dignity - and nobody chooses to have cancer, nobody chooses to have diabetes, nobody chooses to have Alzheimer's - I do find it difficult, in an open room situation I can find it embarrassing. You know if I have to talk to you and there are three or four folk round about who are watching us, it is very difficult and I think sometimes I might opt out of that, and OK. sometimes, shame on me, I opt out because of my embarrassment. Sometimes I would opt out, because for the poor soul who is getting confused, this means little or nothing. So in an open room situation, I would find difficulty. But if I can have someone, on their own, in their own room, or in a corner of their home, I would talk to them as long as I felt I was of any help to them - but I don't think I can say "so you have cancer, so I'm not talking to you - you have Alzheimer's so I'm not talking to you" - I think they have a human dignity which has to be observed.

H.M. Right, right. Can I ask about the place of sacraments, because that's something which is very much of interest to me as you have a much richer tradition in all of this than we have. Have you found, either on a one-to-one basis, or in a hospital, that being able to administer the sacraments, really does make a difference?

IJ:7 Oh, yes, that can be a great touch into the past, into their memory because, as you know, prayer can become a very habitual thing, so, certainly in Catholic terms, if you put some old prayer in front of these people, you know just say a couple of

words - the rest of it will come out! Perhaps it's a prayer that I wouldn't even remember myself, I mean we have a long Act of Sorrow, which I could never master as a kid and I certainly cannot master it as an adult, but some of these old people - I mean I will say "Oh, my God - " and the whole thing will come out, so you have got that side of it. So there is that aspect of it and I think the other one too, for Catholics, is the Holy Communion because they're very much more tied together than the Protestant tradition would be. The basic function of my visit would be Communion, I mean I would always take Holy Communion with me on my visits, both to old folks' Homes and hospitals. I would never be without it - I wouldn't always administer it. Sometimes they would say "Oh, the next time you're about Father". But I would always have it with me and would always offer the opportunity. Certainly, if they have been committed Church members, Holy Communion to the sick would be something which they have known since they were kids. I was taught as a kid how to prepare a Table in a sick-room for a Priest coming with Communion.

H.M. Right, right.

IJ:8 now, we have moved on a bit from there, I would very seldom find a Table prepared as per the 1940's - but the old people would still be aware of it, you know the white cloth and a few candles - because it is something which they would have been taught in their school Catechism.

H.M. Yes, the symbols have power, don't they?

IJ:9 Oh yes. The other side of that, of course, is what we would have called "The Last Rites", you know this anointing of the dying, as it was, but the whole purpose of that sacrament has been changed round, it really is a sacrament to sick now, not a sacrament to dying, but I would think twice about administering it to a semi-comatose patient.

H.M. Right.

IJ:10 If I could talk with the patient and know that he and I share an understanding that this is a sacrament of the sick, then I would administer the sacrament. If I hadn't had time to talk with the patient about it and if I felt the patient still had some awareness, I would be a bit doubtful about it, just in case he said to himself "Oh, my God, this is IT - it's the Last Rites!" and it's not any more. Even with the Alzheimer patient, I would be careful of that one, just in case I would create a wrong impression.

H.M. Oh yes. With Communion, do people need to have an element of understanding?

IJ:11 Yes, if I go in and I say "I'm a Catholic Priest" "Are you sure you're a Catholic?" - you know, I get this type of thing. "Yes, I'm a Catholic Priest - see, the Priest" (indicating his clerical collar). Then, it would depend on the sort of reaction I got from them. I'm sure the good Lord will understand that I sometimes take chances

with His Presence and, as a Catholic Priest, I have always had a tremendous respect for our understanding of Christ's Presence - but I would always give the benefit of the doubt to the patient. I would do the same with mentally handicapped children, you know the Down Syndrome child or whatever, I would talk to the parents and if the parents are willing to work, a little, with the child, then I would admit the child to the sacrament without any great difficulty.

H.M. Right, right. Would you have been in the situation when, after administering one of the sacraments, a real change took place. Perhaps in the case of someone confused, or agitated or anxious and the administration of the sacrament, or perhaps just your visit, brought calm?

IJ:12 I am very wary about that sort of question - but I've seen it, yes I've seen it. I've found myself standing beside a bed saying words which weren't mine. Now I can talk to you on those terms but I would be wary of getting up in front of my Parish and saying "Look - I've had this experience". Oh, yes, it has happened, that's the Spirit of the Lord. You know, it's a matter of the words being given to you at that moment. Apart from these old folk, I have the [Hospital Name] as part of my duties, and I took that on even though it's not my natural habitat - I would rather have a big secondary school than a hospital. When I took it on at first, you know I would get urgent calls in the middle of the night, I would go from here the two miles or so into the hospital wondering what I am going to say - how am I going to handle this? Now, I don't. I just go there and I let it happen

H.M. Right, right.

IJ:13 I think that that is "spirit based". The Spirit will provide. So in the same way, you know, you come to deal with agitated folk, for whatever reason they're agitated - agitated because they're confused, agitated because of their illness, I've seen people change because I was there but it is not me that creates the calmness, the stillness. I would not have that much ego in me to say "See what I've done!" - it's the work of the Spirit to work through me.

H.M. Yes, yes - I understand what you mean - you see that is the huge area which, at the end of the day, would be impossible for me to put my finger on in that there is always that dimension in which we don't know what is happening, but the Spirit is at work and who knows

IJ:14 Well, you see, if I stand up and tell my people this, some will understand exactly what I'm saying, because the Spirit will work through them too; but some will say "Who the heck does he think he is?" (laughter), or some others will say "No, I wouldn't be involved in that type of thing" and, to be honest, ten years ago maybe twenty, I would have been hesitant to say "That's the Spirit working", but now I have no doubt - that's the Spirit working.

H.M. Right, right.

IJ:15 So, if I can let the Spirit work through me, He will be present and yes, I have seen changes in some situations.

H.M. Yes, thank you. Can I ask about practical things which you have found helpful when you go in to visit someone who is very confused - I'm thinking of introductions here and things like touch - and the collar, and perhaps the familiar words of the liturgy. Are there things which you have found to be particularly helpful in sparking, even a moment, of understanding?

IJ:16 Well, certainly, my first introduction would be - even with that lady from the west of Scotland every time I call I have to re-introduce myself - that I would always start by saying "the Priest" and I would never go without my collar. Invariably, she would say "Catholic, are you sure?" and I would say "Would you like Holy Communion?" "Are you sure you're Catholic?" and we could be talking for maybe five minutes and she's still not very sure of this guy. So I would keep on that line and I think as soon as I start the prayers she would know because, obviously, the "Hail Mary", she would pick that up. The other thing which I would attempt to do is to get down to their level, I would sit on a foot-stool in front of them rather than stand, sometimes I would kneel beside their chair rather than be the priest dominating or whatever. I would get down beside them, you know some of these old bodies are all curled up in their chairs, so I would kneel down beside them or sit on a foot-stool and talk to them at that level.

H.M. Yes, yes, and of course that gets the eye contact going as well. Now with regard to Mass.

IJ:17 No, I wouldn't have Mass - there aren't nearly enough of them in any one Home. As I say, I have got six old folks' institutions but I think there are four Catholics in one of them but the others have only got one and there aren't really any significant numbers. Those who are able, sometimes, can be taken out to Church on Sunday as part of keeping their social life going and arrangements would be made to take them out. Those who are really confused, they wouldn't have the attention span for the Mass and it would be putting them through an experience which they really wouldn't want. A simple Communion Service, with two or three minutes of concentration, if I can get that from them, I would regard that as sufficient.

H.M. Just with regard to that two or three minutes - would there be a set liturgy for that?

IJ:18 I would use the same with them every time. I would say, basically, a short penitential rite from the beginning of the Mass and then simply say the "Our Father".

H.M. Right, right.

IJ:19 The "Our Father" would be very familiar, you know, once we get to the "Our Father" I would know whether or not I'd made contact - if there was a response coming, that is when it would come. The liturgy I would say at the Communion

Service is about three minutes and if I can hold the concentration for that, I would be satisfied. The Mass, you know if you are going to give Mass, you're looking at twenty-five minutes and that's a lot of time for a confused patient.

H.M. Right, yes, yes. Can I ask what symbols, the candles and suchlike and even the white cloth on the table. In your experience, would you find that the presence of the symbols there could, perhaps, spark something off in their minds?

IJ:20 Very rarely would have happen now. You see I work on the theory that it is good to keep in contact with all the Staff in these Homes and hospitals and I wouldn't make demands on them at all. I would try to make myself a willing partner with them as part of the social care for these people. So if someone were to take seriously ill, my hope would be that the Staff would phone me. Now I don't want to be the "fuss-pot". so I wouldn't insist on any of these things, so very rarely in Home or hospital would there be anything approaching the Table with the white cloth or whatever, and I wouldn't make an issue of it. To be honest, I wouldn't make an issue of it when visiting Parishioners in their own homes. Occasionally, yes, I would have everything set out for me and the candle waiting to be lighted but that would be the exception, rather than the rule. I think we've become, some would say lax, others would say more comfortable with the Priest visiting. You know the Priest coming with Holy Communion is distinct from the Priest just visiting the sick person.

H.M. Yes, that's excellent, thanks. The other area that I'm thinking about is, is it possible with someone who is confused to actually assess their concerns? I'm wondering have you been in a situation where someone has been noticeably anxious, fearful or angry?

IJ:21 Oh, you would get occasional scruples, yes, yes, and - I'm not sure that I can do a lot about that. Scruples are hard to deal with, even when someone is in full possession of their faculties. I would sit down with them and say "OK., I, as your Minister, will take responsibility for all of this, you must listen to what I say and you must do what I say" - that's the standard Catholic approach to scruples. I take it on my shoulders, now you forget it. That can be hard enough for someone, even when they are in full possession of their faculties and for someone who is confused and has got this niggle at the back of their mind, again I think too in terms of older people who would be very aware of the Catholic Doctrine of dying in mortal sin condemning them to hell, it could be very, very difficult. So, if I have got someone like that, I think I would have to take that very seriously. I would say "That is OK." and I would hear their Confession. And I mean it may be a total jumble sort of thing, but I need to try and let them have the experience of removing this thing. The experience of Confession. Indeed, it may well be that when I go back next time, it would happen again but, as I say, I can understand.

H.M. Oh yes, yes.

IJ:22 Most of them would be a generation ahead of me and I was brought up in the Doctrine of "if I die in mortal sin, I'm lost forever" - it's a pretty severe option for

them. I mean the "mortal sin" element will step out to them, you know missing Mass on a Sunday - these old dears are in Homes, they're missing Mass every Sunday and suddenly all of that can create problems.

H.M. Equally with that concept of mortal sin and its implications, must be the relief which must come.

IJ:23 That I hope would be so - if it comes out, it is moved on.

H.M. Yes, exactly. You know coming through a lot of the research is the power of liturgy and the power of symbolism and the power which comes from being able to confess.

IJ:24 Yes - this is what I was brought up to do, to confess my sins and in the confession of my sins, with sorrow, I can find forgiveness. That's the Catholic theory of the sacrament.

H.M. Right, right.

IJ:25 So, if I'm confronted by a confused person, who may really be going through agony because of something which is there, I think to say to them "forget it" is not helpful at all. I may say that to a younger person, but to a confused person I think you have got to let them go through what was a tried and trusted method for them, as laid down by the Church, that they should confess their sins to the Priest, in the hope that they may find some calmness in the aftermath of confession.

H.M. That's very, very helpful, and those are the main areas which I'm interested in covering and I really appreciate your time and openness. To be honest, it gives me a good insight into another tradition and to the power within the sacrament. Thank you very much indeed.

IJ:26 You're most welcome.

INTERVIEW WITH KL

H.M. Can I ask you, first of all, do you have folk who are confused in your congregation?

KL:1 Yes, we do.

H.M. Do you have many?

KL:2 No, I think probably I have about between six and ten, but of course, there are degrees of confusion.

H.M. Can I ask if you have found certain things which are particularly helpful when you visit them. You know things which you have found seem to break through the confusion or which seem to bring a spark of recognition or meaningfulness?

KL:3 I wish I could say that I had all sorts of clever insights, but most often I go away thinking I haven't really made any sort of breakthrough. But obviously, from time to time, there are moments when things are happening. I hardly ever wear a clerical collar, but I do try to wear a clerical collar when I go to visit folk who are confused because I think that, sometimes, that helps them. It gives them some idea of what I am, if not who I am. Invariably, I try to talk about people whose names they will know and I always talk about our congregation by name - I talk about [Church Name] and about places in the Church, because I'm here as their Minister and try to help them to feel some sense of relating and belonging to the Church and this is sometimes easier through a building.

H.M. Yes, yes.

KL:4 I wouldn't say "always" because I'm not very good at being consistent, but I try to read the Bible and when I do that, I tend to read one of three or four well-known Psalms or one or two very well-known passages from the Gospels.

H.M. Right - right.

KL:5 I wouldn't say that in any of these I have any confidence that they always open doors.

H.M. Surely, surely. I think that what you're saying would highlight a lot of what others have said that things like reading the Bible, prayer, and the collar, they do sometimes seem to spark some sort of recognition or meaning for folk. Can I ask you, specifically, when you're visiting someone like that, what is it which makes you feel "that broke through"?

KL:6 Sometimes there's a smile of recognition, that helps. I always hold the person's hand when I'm visiting them. When I'm leaving, sometimes just a squeeze or an extra hold of the hand helps you to think "well, that has made some sort of communication". Sometimes, just occasionally, I try to say something pathetically amusing and you get..... just a flicker - but by no means, is this often.

H.M. Yes, yes.

KL:7 Also, sometimes just talking about families can be helpful. But I would have to say to you that my general record of visiting confused people is rather low - I don't feel I'm good at it.

H.M. But what you're saying is echoing 99% of what others have said to me - (laughter). I mean that was really part of my reason for undertaking this - I'm a Methodist Minister and friends at home said to me that they found this very, very difficult and really were wondering at the back of their minds, "I'm doing this because I know that it's part of my pastoral task but is it a waste of time"?

KL:8 I don't think I ever think it's a waste of time - maybe I'm just too insensitive, but it never occurs to me not to do it. I'm absolutely certain that it's right to do it, I feel it's my duty and I wouldn't consider striking that person off the list. That it should be done for God and for the Church, I feel is quite essential. Whether, or not, it's always a great thing for the visited person is another matter altogether. I'm also quite clear that for the visited person's family, it is very important.

H.M. Yes, absolutely. We've been touching on it already, can I ask you, in general, what is your understanding of the pastoral task of the Minister?

KL:9 My understanding of that task is neglected!! (laughter) I'm more guilty than most! But here are my thoughts on it.

H.M. Right.

KL:10 One is that I need no persuading that the elderly, the house-bound, the intellectually limited whose contact with the world is brief are every bit as precious and as valuable to God as people who are the chief office bearers in the congregation. I cannot ever see the pastoral task of the Minister with confused people as one of healing or solving or bringing light or even talking things through. I don't find myself able to speak on that sort of level at all with confused people. What I think I'm there to do is for a moment to help them to feel they're not alone, for a moment I hope to help them to feel part of a congregation, and because God is better at this than I am, helping them to be reminded that they belong to God and that nothing, even their lack of understanding, can remove them from God's care.

H.M. Absolutely, yes - thank you. That's encouraging because some research from America tells us that feelings which are evoked by conversation or by pastoral visiting remain, even if a person has forgotten who you were and all about your visit by the

time you reach the front door. So evoking such feelings as that they are remembered by God and loved by God is very valid.

KL:11 Right. That's encouraging.

H.M. Just thinking about worship - are you in a situation in which you lead worship in Nursing Homes or residential Homes?

KL:12 No, I have no responsibility for that.

H.M. In the past, you would have had that responsibility?

KL:13 Yes, yes.

H.M. What was helpful in leading Worship then? Would you have planned an Order of Service in a particular way and were there things which you would always have included or left out?

KL:14 I always made sure that I had a pianist with me, someone who could play well and if possible someone who would sing.

H.M. Right, right.

KL:15 I always, in that context, used the Authorised Version which is not my normal practice. I found it good to be short, brief, and before or after Worship, just to hold people's hands. In normal Worship, on Sundays, in our congregation, people always greet each other by holding each other's hands but I think I would be uncomfortable doing that with confused people.

H.M. Sure - right. Part of the rationale in the interviews is to try and search for examples of good experiences and bad. Can you think of a good experience of Worship where confused people were present? I'm searching for whatever it was which made that experience good? Or if a bad one comes to mind more easily.....

KL:16 I have had a terrific experience with the mentally handicapped, but that's maybe a different thing.

H.M. No, it's not, because you're working with a lot of the same issues.

KL:17 Four years ago, I took the funeral of a young handicapped lad of twenty-two and there were a great many of his friends present. During it, we played a piece of music which [Man's Name] had loved and at the end of it, there must have been twenty-five people who were laughing and clapping as it came to the end. How can I explain it - but I'm clear that it wasn't just the music but it was [Man's Name] himself whom they were laughing and clapping about. I have any number of experiences, of failures, of people interrupting, of people wanting out and being abusive, during

Worship. I have to say that, because I've been doing it for so long, it doesn't get to me at all - it probably did when I was younger.

H.M. So how do you deal with that if someone does prove to be difficult?

KL:18 Ignore it.

H.M. Do you find that distracts the other folk or are they happy enough to stay with you?

KL:19 My experiences of leading Worship are ten years in the past so I wouldn't be able to make any contribution on that.

H.M. Right, that's grand. Have you experience of people who are confused taking Communion, how would you feel about that?

KL:20 I certainly have. I haven't any pictures in my mind of people taking Communion in Church, but I certainly have several experiences of taking Communion with confused people in their own homes. That, I think has almost always grown out of them being already ill at home and taking Communion, and so this has been my practice and I have just carried on. However, I can think of having done it at the prompting of a husband and indeed, also of a wife, both of whom asked me to do it and I did it. I actually put the bread and wine into the person's mouth. My feelings about that, I have to say, are not personal and pastoral but are bound up with what I believe about God and what I believe about the Lord's Supper and anticipation of the End, therefore I believe exactly the same about that as I believe if you and I were having Communion together.

H.M. So its validity stands independently. One of the other areas which I am concerned about is whether or not it is possible to assess the needs of a confused person. I'm just wondering if you have been in a situation where someone who is confused has expressed anger or grief or the feeling of being abandoned or frightened by anyone - or by God?

KL:21 Fear, most often, I'm very familiar with that. I don't have any memories of confused people abusing God at all. Quite often, fear and sadness and despair, but the fear is very ephemeral, it comes and goes. I said to you earlier that I have almost no record of success in talking things through as in a normal pastoral situation in which you discuss the options available and suchlike.

H.M. I think that's probably an impossible task. When you are in a situation when someone is fearful, you know in the situations you have just mentioned, how did they express this fear or how did you pick it up?

KL:22 They just keep saying it all the time, I'm afraid. You don't need to be a very good Minister to know that there are things in the Gospel which relate to fear. I'm quite used to people wanting to hold on to you, a sort of security thing particularly

when going away, people are very anxious for that not to happen. I had an extreme experience, some years ago, with someone who would never come out from under the covers of her bed.

H.M. How did you deal with that?

KL:23 My memory is always more my inadequacy - she didn't live very long after she became like that.... but I didn't touch her - I didn't shout "Are you in there?" I don't remember much more - (laughter).

H.M. We have already touched on this - 53% of the people who responded said that they felt that their visit made a difference to the individual who was confused and to the family and relations. I'm just wondering, we have already talked a little about it, if there were instances when you have come away thinking "Yes, that did make a difference" or in some special way, God was at work in that encounter?

KL:24 I think I would agree with that and say "Yes, 53% of the time" (laughter). I don't think you can possibly say that every visit rings a bell for people - every visit doesn't - I think I'm more confident about reading the Bible and saying a Blessing, than I am about saying "It was good to see [Man's Name] yesterday". I think I'm more confident that that might have some significance. I think I'm more confident that being close to someone and holding their hand and giving them a wee kiss and a smile, is more significant than what I say.

H.M. Right - right.

KL:25 That isn't to do with any empirical evidence or because I have seen results, it's just intuition, hunches and what I believe about God and what I believe about people.

H.M. Yes, yes - this is the difficulty that there isn't any sort of, quantifiable information somewhere - all the time we're dealing with people's experiences and feelings and for me, that's what I'm really trying to get at.- folks just feeling that something like that is happening, that they're being used by God in the situation. One person told me a story about a Minister in a neighbouring Parish ringing him up and talking about someone who was in their congregation and in a Home in the Parish and the woman who was in the Home was very, very confused and not able to tell the Minister her name even, but the Minister who visited her told the other Minister that he was aware at some level, that this was a woman who could pray and it's that, that sort of deep intuition or hunch, that something is still there despite the continuing disintegration.

KL:26 Well, I'm sure that is true, but actually, just last week I was visiting an older man from the congregation, who was, in the best sense, very spiritual but that seemed to be all dead.

H.M. Right - right. One person said that the issue of caring for folk who were very, very confused raised for them the issue of euthanasia, would that ever cross your mind?

KL:27 It crosses my mind - it doesn't actually cross my mind for people who are very confused because it seems to me that it's a much more live issue when people are able to be responsible for their own decisions, I think I am quite far away from people who are not responsible for their own decisions. I think that there are issues in euthanasia which seem more grey to me now, than fifteen years ago. Fifteen years ago, I think I was fairly resolute against all forms of euthanasia and now I have to say more in terms of what would introduce unfair family pressures and family dynamics rather than what I believed about God and life. I think I'm still there but I would want to listen to, and have some understanding, of people who feel strongly that euthanasia could be a Christian option.

H.M. Right, right.

KL:28 However, for me, people who have Alzheimer's disease or the confused elderly would not be the people for whom I would argue the case.

H.M. Right, right. That's grand, thanks. Do you think that, in general, the Church treats confused elderly people well, I'm wondering this with regard to the normal Sunday services, for example?

KL:29 I have, I suppose on a Sunday morning, probably only one who is a regular worshipper and is a confused elderly person. His daughter is a good friend of mine and I know from her that he loves the organ music, but he finds the number frightening - obviously I wish he would find it more frightening, as I wish the numbers were bigger!! (laughter). I know he finds this difficult and I was thinking about how it would be possible for him to get the atmosphere of good singing without having to feel part of the crowd. Another thing is, the Church he comes to is his daughter's Church and not the one with which he is familiar and that's awkward for him as well. Until I had this interview with you, I am ashamed to say that after twenty-four-and-a-half years as a Parish Minister, I have never addressed the questions "What should we be doing on a Sunday morning to make Worship more accessible for confused elderly people?" and I am ashamed of that actually - and I'm not just sure of how to meet it.

H.M. Yes, it's a difficult one because a number of the researchers say that the things which are helpful are the familiar things like the music and you picked up on that and the familiar Bible readings. Can I just ask you, specifically, to finish off and you've already touched on it a bit - about theological issues which, for you, surround the pastoral care of these people?

KL:30 This will sound extremely naive, but there are theological issues about the relationship of God to suffering and that has two aspects, the aspect of the suffering

of family and what I perceive, but do not know, to be the suffering of the confused person. Thomas Aquinas said six hundred years ago, that that was the central theological issue. The second is a theological issue about the role of Ministry to people which, in general, I perceive as moving towards healing and light. I have no perception of that, as I said to you before, in these terms. Third, there is a real theological issue about when death happens. People are always saying "That's not my mother", they have some perception that death has happened and yet

H.M. Their mother is sitting there

KL:31 Exactly, exactly - I mean I have fairly orthodox views about death and resurrection and so I find it hard when they want me to affirm that this person has in any sense, entered into glory

H.M. Yes, yes

KL:32 I find that just a difficult issue. I do not have, I think I do not have sort of, a heavily interventionist view of God. I do not perceive of God as moving in to situations and altering things to suit His Will on a kind of random pattern, but I do find it quite hard to have any view of God at all at work in the situation of the decaying life of a confused, elderly person. As it happens, no one in my family is in that position, but I would not find it easy to affirm what faith in God means for my mother in that situation. Is that confusing for you? (laughter).

H.M. No, it's not. You're actually saying some very helpful things. But, specifically, your last point there about finding it hard to affirm what faith in God is.

KL:33 What I mean by that is that I, generally, have some kind of conviction about the purposes of God as bringing people to immortal light or wholeness and I can only speak in terms of "after death" with regard to an elderly person and that's why I find the other view upsetting.

H.M. Yes, yes - and the idea, therefore, that momentarily there might be a recognition or a remembrance of God or his Presence really isn't enough - or is it?

KL:34 It's all there is. I certainly would not want to minimise that. I think that's quite important. I would want to set it in the context of a conviction that I have here, which is as real as the uncertainties about which I spoke earlier, about the place of confused people being absolutely certain in terms of the Gospel and of the death and resurrection of Jesus and of belonging in the body of Christ; in no sense do we belong to God in terms of our abilities or our capabilities and my weaknesses may be in the view I have of God and the much more serious weaknesses of these people. So I have that clear conviction and I believe in it firmly, without reservation really, and that is as real and important as any hesitations and doubts which I may have, beside the bed.

H.M. Exactly, yes, yes..... and these are two very hard concepts to hold in tandem because they are really contradictory.

KL:35 Yes, yes.

H.M. That's very helpful for me just thinking it through, in that this is an issue which is being brought up a lot and yet no one has articulated it clearly like that.

KL:36 That's because I'm MORE confused about it (laughter).

H.M. You have been able to pin-point some very helpful issues for me and maybe this is what is at the root of people's perception of themselves as being inadequate, which is often said to me and this may be because people are desperately trying to hold these two things together.

Thank you so very much, this has been most helpful.

INTERVIEW WITH MN

H.M. Can you tell me, first of all, have you many folk who are confused in your congregation or is it mostly through the Project, that you would have them?

MN:1 We have a few who are just beginning to become confused and I would say we have two in early stages and one who isn't suffering from dementia so much, but who has had strokes and the memory has been affected and he has become quite aggressive. He is actually in hospital but he gets visited regularly.

H.M. When you're visiting folk who are confused, are there things which you find have been particularly helpful in trying to communicate with them or just to care, pastorally, for them?

MN:2 I find it quite hard to remember things which would have communicated. Often, it is the familiar and being able to relate to people in the family, whom you mention, or events which have happened to them or which are happening to them and obviously some of these may be forgotten. Occasionally, they forget who I am, but I have experienced that, so I try to latch on to their memories - I have found that to be helpful.

H.M. That's very helpful. Would you wear your collar always, when visiting? People have said that even the collar can be a link in.

MN:3 I would normally and especially for the older folk. This is partly because I don't look very ministerial, so putting the collar on immediately puts me into that bracket... (laughter) - and it does help them to focus. I mean the chap who is in hospital just now is an enormous man, [Man's Name], and he is really not well at all. His wife is still alive and I take her in to visit him and I have got to know him quite well. When I go to visit him in hospital as soon as he sees the collar, he immediately twigs.

H.M. How do you find with reading the Bible, do the folk link in with that at all - have you had experiences when you've read a passage and folk have really quieted down or perhaps you have just felt that something is happening here?

MN:4 I think that, generally, when I visit the house-bound I would take Communion which would be the tradition and what they're used to and I would use the Prayer Book service and, of course, there are all the memories in that. They'll sometimes say "Oh, I can't read it because I can't see so well", but they don't need to read it because they remember it from away back and it's turning on the switches again. So that's quite important. I think that, in the Episcopal Church, there's less a tradition of people reading scripture for themselves, which I think is a really unfortunate thing. So here, my experience has been that people are less familiar with scripture, so that's not the thing which switches them on. In my last Church, there was much more of a tradition of individual reading and often that was a trigger and

you would see people mouthing the words. But as I say, here it is the words of the old prayer book that switches people on.

H.M. Have you experience of folk who are confused taking Communion, would you have problems with that - or are you happy with that or have there been times when you have felt it was particularly meaningful or maybe not so?

MN:5 I mean it is difficult to know what goes on in people's minds, isn't it? I don't have any problem about it. I mean if I know that they have been members of the Church and have been used to receiving Communion, then I have no problems and especially if they want it, or their family want it. I mean I think that some people who are fully aware do not always understand what they are doing, when they receive Communion - so I don't think that there's a problem - certainly not for me.

H.M. Can I ask about Worship in general, would you have had experience, either here or in previous Parishes, of leading Worship when there have been a number of confused people present and again, were there things which you have found to be helpful or not helpful?

MN:6 I mean my experience has not been here, but when I was in [City Name] I went to visit some residential Homes on a regular basis, where some, not all, but where some of the folk would have been confused. Again, it is the familiar hymns, keeping it simple, being informal and relaxed and to enjoy the time, and I think that can be helpful. Again, it would be keeping to the familiar and not trying to introduce new-fangled things or even feeling that you must have a great message. I think it's simply a matter of allowing God to minister and trusting that the Holy Spirit will be at work in some way. I always find it difficult in those kind of situations because there is this thing of, "how much are people actually taking in?" but God loves people of whatever shape and form and it is His work and if He wants to get through, He'll get through and you have to trust in that.

H.M. This is one of the areas that I'm very interested in, in that it started from a story of one Minister who told me of a Parishioner of theirs, who was in a Home in a neighbouring Parish and the Minister of that Parish went to see this woman who was in the Nursing Home. She had been a missionary and a tremendously committed Christian, but she couldn't tell you her name now and couldn't remember that she had been overseas, nothing at all. The Minister who visited her said "You know, she couldn't tell me her name, I didn't know anything about her, but I knew that this was a woman who could pray" - and that excited me, in that I began to wonder if, when mind has disintegrated, is spirit still there and therefore is the Holy Spirit still ministering, still working, at some level? Now, that's extremely difficult to quantify.....

MN:7 Yes, absolutely.

H.M. but, people have told me stories like that which encourage me to think, just as you were saying, that God is working in the situation. Would you have any experiences when, maybe you have been surprised by a reaction and thought "Well, God is doing something here"?

MN:8 Yes, I suppose the one that stands out for me was here, in this area, about two years ago and I had to go and visit a lady whom the Social Services had referred to us, and who had said that she would like Communion. This lady had a reputation for liking her drink when she was younger, I think she still likes a drink actually. She'd had a few accidents and was immobile in bed, along with that she was confused. So I went to see her and she was living in extreme squalor and I visited her a lot. Eventually, I said to her "Well, look, I'll give you Communion". We started the Service and when we began singing, the woman just burst out into tears and she just wept and wept and wept and I understand it, I mean she basically needed forgiveness, I think she'd found that she had made a huge mess of her life and she knew she was coming to the end of it and she would repeat herself all the time and tell you the same story time after time; she was obviously very confused, but it was a genuine sort of repentance and openness to God. She died some months after that, but it was very moving - I was in tears as well. So I have seen confused people but that is the big example for me. This lady was eighty-five and why, on earth, she was allowed to stay in a place like that, I will never know - but that was where she died.

H.M. Was she able to speak about her feelings, or put words on those tears?

MN:9 Yes, she talked about her husband, she was estranged from her children. When I first met her, she was terribly embarrassed because when I went to see her, she was living with a guy, she was eighty-five and he was ninety. I said "Oh, living in sin, oh dear" (laughter) and she was terribly embarrassed about all of that. I think she just felt that her life had gone completely to pieces, her children had disowned her through the drink and so on. I think it was just a complete sense of inadequacy and loneliness and a sense of having abandoned God - because on the run-up to Christmas or Easter maybe, when she opened the door she just burst into song, singing hymns, from the days when she was a choir-girl at [Church Name] and she was remembering back - she could remember very lucidly details of the Church and of being a choir-girl. I think really - what she said to me was that she had abandoned God. I think that, in that sort of situation when people know they're coming to near the end of their life, they get this real desire to get things right.

H.M. Yes, yes.

MN:10 I feel that part of my job is to reassure them that that is possible, no matter what you have done, we might abandon Him but He is not going to abandon you - so that was really a privilege to be able to share in someone's life like that.

H.M. Could I ask you what, theologically, gets.....

MN:11 Oh, dear, theologically..... (laughter)

H.M. No, no - it's just in a situation in which someone is very confused and you're maybe not getting much reaction, theologically why are you there?

MN:12 My feeling about that is that Jesus seemed to spend a lot of time with people who would have been regarded as hopeless cases, people who other folk would have shied away from. I suppose in our society we do shut folk away with Alzheimer's, it's like death, when someone is dying we don't know what to say or what to do in that situation. Jesus would have always got alongside folk and ministered to them and generally brought healing to that situation and I suppose my belief is that my job is to do that; not necessarily to have them restored to full memory or clarity of mind, but a matter of sharing Jesus' love, because that is what He would have done. As to what is actually happening, I don't know, but in a lot of a minister's job, you don't know what the effect is and often you don't see the fruit and you hope that by being there and speaking that a positive, lasting effect, is taken from it.

H.M. Yes, yes, that is very helpful. One person said to me that he felt he was there, for the same reason as always, following in the steps of Jesus and doing what he wanted, affirming the worth of a person and God's love for them in their situation, but borne alongside that and felt almost equally as deeply, was just the huge question that with someone who was very confused, the only hope that he could see was after death and the glimmers of understanding are those moments when we're aware that God is working. He really felt they weren't enough and he felt this constant struggle between just wondering "What is faith in God for this person who seems so isolated and lost - what is my role in that situation?" and yet, alongside those questions was this, that they ARE worth it and this is where Jesus would be. Would that ring bells for you, at all?

MN:13 I mean I think about the people whom I know who have become confused, whom I have known previously when they weren't confused and who were sharp as nails, very bright and very intelligent. I mean I would hate that to happen to me, but I see people who are suffering and I think that because God has suffered that he is, in some way, in that suffering, you know the folk that I deal with are generally godly, Christian folk who are suffering and it's always a great problem "Why do Christians suffer?" and I suppose it's being there and being able to say to the person, but to the family and try to somehow make sense of a situation which is difficult to make sense of - you know, the suffering Servant, Jesus being in there and taking it all on board. It's just another element of the human predicament, if you like, and it's good to be there and alongside that. I mean that's an easy thing to say and it's an easy thing to think, but when you're in the situation, it's quite hard to grasp that. I mean I do struggle with it, I struggle with it a lot, especially when it's people whom I have known, you know great people.

H.M. Yes, yes. When talking with friends at home, some of them said to me "You know I go in to someone who is confused and I theologically know why I am there, I want to be there, but I hold their hand and there is no reaction at all. I say a prayer and I go, and in my heart of hearts I wonder was that a waste of time?". Now,

going alongside that, is that 53% of those who responded to the questionnaire said that they felt their visits made a difference and were worthwhile. What do you think yourself - where would you be in this?

MN:14 It's a question of whether or not it makes a difference to the person and that's a different question to whether or not it makes a difference.

H.M. I know what you mean. Let's narrow it down to whether or not it makes a difference to the person.

MN:15 I just don't know - really. I think it's an impossible situation to know about, although what I try to think is - if it is a person I know, would the person I know want me to be doing this.

H.M. Right, right.

MN:16 And if it is someone I know, then generally I know they would want me to be sitting by their bed praying with them, even though they're not aware. I do feel that quite strongly that when I go to visit folk who are severely confused that to a large extent, it isn't the person, because the person is just slowly draining away and the body is still ticking. Now that is maybe a wrong picture but it's a helpful picture for me as I am ministering. So what I try to think of is, would the person that I remember and love want me to be here and most of the time they would and whether or not it makes a difference doesn't matter to me really, because I'm not going to know that. I mean sometimes I might, sometimes you get a flash and people respond and sometimes they'll even start praying.

H.M. Even some who are very confused?

MN:17 Yes. There was one guy when I was in [City Name], now he was really very confused, but I said we'd pray together and he said "OK." so I closed my eyes and he started praying and he just looked up at me at the end and he said "I didn't know I could do that", and then he started talking again and it was all rubbish! (laughter) - but it was an amazing lucidity and it was the first time - I mean I had known him for quite a while - and it was the first time he had ever prayed with me and I asked a few people afterwards had he ever prayed aloud before and no one had ever heard him pray aloud and it must have been thirty years since he was inside a Church. I thought "My, something's happening here - boy, this is amusing". So, you just don't know, I mean I don't know how something like that happens or what the process is - but I trust that God is in some way at work.

H.M. Yes, and this has been backed up by your experience too.

MN:18 Well, I've got something there which I can base it on really.

H.M. Again, thinking about someone who is quite far progressed in confusion, do you think it is possible to pick up on their feelings if they're not able to articulate.

You see, recently I've been wondering if - we're so used to talking and that is the way we undertake so much of our pastoral care - but can pastoral care be non-verbal in a situation where words are of very little use to a person who is very confused. Would you have had situations where "touch" has been helpful or "eye contact" or "music" or something like that?

MN:19 Well - there have been times when it has been a case of "being there" rather than "speaking" because you can't have a conversation with some folk and yet it has been quite clear that they didn't want you to go. You know if it is a lady, I would take her hand and give her a peck on the cheek and she just wouldn't let my hand go - and obviously wanted me to stay. But, I mean, if you have been there for twenty minutes or half-an-hour in total silence,(laughter) - you can't help feeling "What's the benefit of me staying?" especially when you have a lot of other places to go.

H.M. Exactly - yes.

MN:20 I suppose people who can't communicate verbally, often can give you signals as well. I mean I have had some experience of people with learning difficulties and often they're very good at giving you non-verbal communication, from the way they sit, facial expression and so on, and to some extent, confused folk would do this as well. I try to be sensitive to this.

H.M. That's very helpful.

MN:21 Again, it depends on how confused they are - I've been to see some folk where there just doesn't seem to be any response at all - and at that point I just wonder, you know, how long is the right length of time to stay without being rude.

H.M. That's a very, very difficult one.

MN:22 I don't have anyone just at that stage at present, but there is someone who is going that way.

H.M. Lastly, can I ask you, would you mind telling me where you would be in the theological spectrum?

MN:23 I would be an evangelical charismatic.....

H.M. Right, right.

MN:24 Catholic - literal (laughter) - I'm not very good at labels (more laughter) - I mean, basically, I would be conservative evangelical - and charismatic.

H.M. Right, right.

MN:25 I think I'm probably a mixture in terms of the way I ought to be pastorally, because whenever I visit I always pray with people, I always invite the Holy Spirit to

minister to people and give me wisdom as to know how to BE in that situation and what to say and what to do. At the same time, I'm often listening, rather than speaking, to where people are at - I mean my natural inclination is to be directive - certainly in terms of counselling and pastoral care, because I think, from Ministers, that's what people are looking for - I think - I mean people don't come to a Minister "Now tell me" or "What I hear you saying..." (laughter) - people DON'T come to a Minister for that, what we try to do is to have other people in the Church who are listening counsellors, non-directive, but my job is not to do that. Obviously some people come to me and it's quite obvious that they've got the answer within them and they don't need me to tell them, so it's just a case of opening up. So from that point of view, I'm probably not your typical evangelical, because I would expect most evangelicals not to be quite as open about that. So I think that, theologically, I'm a mixture. (laughter).

H.M. This has been a great help. Thank you very much indeed.

INTERVIEW WITH OP

Following an explanation regarding the background to the research and my reasons for wanting to interview her, I asked for her permission to tape the interview. Permission was granted.

H.M. Can I start by asking you, what have you found to be most effective in communicating with confused elderly people?

OP:1 Well I would say touch - with those who are very confused, unless they don't want that, and they will let you know if they don't. I have one lady who rocks a lot and I would often sit and hold her hand and even rock with her. With those who are in the earlier stages they like to rehearse memories. I would say " I am from my Church" and they say " Oh - church" and will talk about the past. I wasn't there but I know enough to ask questions - not closed questions with a "yes" or "no" answer, but open ones. Maybe this is way off your question but

H.M Go ahead.

OP:2 like maybe this is a question - I am perfectly certain I visit a lady who has some form of dementia and I think she has an overlying depression.

H.M.. Right

OP:3 and something is masking the other, maybe it's drug induced, maybe its part of the Alzheimer's, that I feel that this woman is depressed as well as confused I think that's hard for her - I strayed a little.

H.M. No but I think you're right because depression is so often there and how do you get to grips with that?

OP:4 That's right.

H.M. Especially when understanding is limited.

OP:5 it's bad enough visiting someone who is depressed and who is healthy and youngish and has memories - but somebody who is confused and depressed , what sort of hell is that they are going through?

H.M. Yes, we were just talking about the hell they may be going through. Have you been in the situation where someone is confused and has expressed those sort of feelings of sadness, perhaps anger at God or at other people, or fear or frustration?

OP:6 Yes it wasn't directed against God. It was a woman whose sister was a lovely, lovely person that the sister did most of the caring, but she got terminal cancer and died within six or seven months. The one whose left was very resentful partly I think because she was always cared for by the one who died. Sometimes she would say

"why did [Sister's Name] leave me?" not "why did God take [Sister's Name]?" and sometimes I am very blunt and say it was sad that she died because I don't know whether she believes that [Sister's Name] walked out on her or whether she realises that she actually died. I don't know the right thing to say and I tend to say fairly bland things, which nevertheless I believe to be true that we're all in God's hands and whether we're alive or dead we're in God's hands and

H.M. Yes.

OP:7 I don't know whether that helps.

H.M. Does she react to that?

OP:8 Yes, she's one of the ones who rocks a lot and she tends to rock at me and then she'll change the subject quite a lot.

H.M. Yes, yes.

OP:9 She has a measure of understanding. She's another person who has got another illness and I think she's never been discussed with anyone, I think she has a kind of Parkinson's because she shakes a lot.

H.M. Right.

OP:10 She's in a nursing home now.

H.M. Yes, yes. Obviously there's going to be huge differences depending on the individual and the need and that sort of thing. In very general terms could you sort of put your finger on what the message is that you're trying to communicate by visiting her - a very general question.

OP:11 I think generally its a sense of care that the church still cares and I feel very strongly that this is not a one person job and nor is it one kind of caring. In other words, it shouldn't just be the minister and it shouldn't just be visits and so we have a visiting team, I also have a pastoral assistant just now which is absolutely wonderful.

H.M.. Right.

OP:12 Because he does a lot more of the routine visiting, simply because I'm a convenor of an assembly committee.

H.M.. Right.

OP:13 As soon as I stop that, then he goes, then I go back to doing it but he does it at the moment. Also, of course, there are the Elders. Starting off from January there will be daffodils at Easter then there are flowers in June, and I actually send a picture

postcard to every single one of my old folk when I'm on holiday. It's automated now in that I get a print out of labels.

H.M. Right.

OP:14 before I go and then as soon as I get there I go to the supermarket and get 120 cards and with ones who have dementia I don't really say much, I just say having a lovely time hope you a keeping well love [OP].

H.M. right

OP:15 And I put a little sticky label of who I am on the card so that the nurse or next of kin knows and then the next thing will be harvest and then Christmas presents in fact last night our Youth Group - thirteen of them wrapped one hundred and twenty Christmas presents that I had bought.

H.M. Right.

OP:16 In fact they will be delivered by the Elders and I have signed all the Christmas cards, so they have more than just the visit which can be forgotten very quickly.

H.M. Right.

OP:17 So they have the card which they can hold in their hand or the soap and face flannel. One of the nurses will say "good, where did you get this from?"

H.M Right.

OP:18 That's that sort of thing.

H.M. Yes, yes, there's backing up all the time then

OP:19 That's right, the overall thing is care. As well as that the visiting team visit once a month,

H.M. Right.

OP:20 and when it works, and it works most of the time not every time all these folk get a visitor once a month. They could be the same person.

H.M. Right.

OP:21 So they all are having a better relationship with that person than with the minister. In fact, I can't get round the wards, but the overall thing is of care and they will take the monthly magazine even though they can't read it. The idea is that if a sister or daughter or granddaughter comes in she will say "Oh the church has given

you a magazine" to try to get them to feel that we haven't forgotten them and we still care about them.

H.M Yes.

OP:22. If it comes down to a theological message I don't think you can actually say anything new to a confused mind, but what you can do is reactivate the faith that has been built up during their intellectual prime or during their childhood. Sometimes I've seen me hold hands with them and say the Lord's Prayer and bits out of the commandments or Psalm 23 or bits of St John and sometimes we do daft things like sing a wee verse of "Away in a Manger" or "Jesus bids us shine" or "Jesus loves me". That's what comes out and I would just hold hand and sing along with them and sometimes it turned into Auld Lang Sang or something, but I think care is the overall thing.

H.M. Yes, yes, it's lovely to hear you say you have the courage to sing along. I don't know if that is a woman's thing. At an earlier stage of interviews I was talking to nurses about their perception of how ministers related to people who were confused on the ward and a lot of them said we just feel that they are ill at ease. We feel they are not comfortable in the situation and to hear of someone being at ease to the extent of actually singing is hopeful.

OP:23 I remember [Colleague's Name] saying that we are all handicapped, it's the degree of it. We're all a bit imperfect and need the grace of God to make us perfect and make us whole. Perhaps because somebody is in a geriatric ward, it emphasises the gap between her and me which isn't really valid. Why not? said the Lord.

H M. Yes exactly.

OP:24 Any nurse wouldn't really necessarily know that I was a minister.

H M. Right.

OP:25 I never wear a dog collar.

H.M. Right, right.

OP:26 I might as I go in say "can I see Mrs so-and-so, I am her minister".

H M. Surely.

OP:27 But I might not.

H.M Right, yes, interesting, do you take worship or do you lead worship in a psychiatric or geriatric ward?

OP:28 I have never been asked to.

H.M. Right, right.

OP:29 So although I do take it regularly in an extra care nursing home -

H.M. Right, right.

OP:30 which is in a neighbouring parish and we have one very good member who is there. Before that, a retired missionary who was one of our Elders was there and I used to take services there and I've taken communion there.

H.M. Right, right.

OP:31 But never the big hospital wards.

H.M. Sure, sure in those sort of situations are there things that you find particularly helpful. Are there things that you think the more confused require picking up on or is meaningful for them?

OP:32 Yes, obviously there are a group of about twenty and they have differing needs, I don't know whether to use the word ability or disability, I mean some are there because they are just not able to move, they've had a stroke or they are very crippled with arthritis or maybe very deaf but they are all right mentally. But others are quite confused. Again I don't do it on my own. I always go with a team of about four of us from Kirk Session. One plays the piano, then two others look up hymn books for those who can read. Some will have a hymn book up to their noses reading and others will have a hymn book and want it opened at the right place, but not be able to read and some hold it upside down. I always go with a sketched out Order of Service and hymns chosen but if somebody says, they know its a service. They are aware that it's a service even though it is in the sitting room because they have been told or the nurses tell them , if somebody says I want Abide with Me, or I want O Perfect Love or I want Away in a Manger then that's what we have.

H.M. Right.

OP:33 Because if that's what is religious for them then we pick up on it

H.M. Right.

OP:34 And I think one time it was Christmas and they didn't have any Christmas things because they wanted all these ones like "Oh love that will not let me go" and "Abide with me" and then I said very firmly " its Christmas time and would Mr [Man's Surname] choose one" as he was one of my Elders and they were all quite happy for him to choose and he chose a Christmas one.

H.M. Right.

OP:35 And after that we had a spate of Christmas ones so we did.

H.M. Yes, yes.

OP:36 So I think you slot into their awareness.

H.M. Yes, yes.

OP:37 And you mustn't be embarrassed about really funny responses to the Bread and Wine like the time the woman drank deeply from--- it was Sainsbury's Red Grape Juice in fact and she said "it was good stuff I'm thirsty" and she took another great dram.

H.M. Theological significance there, too, isn't there.

OP:38 And I mean if she was getting, why not?

H.M. Exactly, exactly. So you wouldn't have a problem with people who are very confused taking -

OP:39 No, no not at all because I think that they are aware of what's going on in a strange way. I said earlier that at this place a lovely woman now dead who was a missionary for twenty-seven years, I think, and was an Elder in our congregation. She became confused and I remember the minister of a neighbouring church phoning me up and saying would I take a service and I said yes you have got one of ours there now. He said that lady, I couldn't get out of her what she'd done or where she'd come from, but I was aware of the fact that here was a woman who could pray. You know for all that her mind was disintegrating and deteriorating right up to the day she died there was a woman in communion with God. It was an awe inspiring thing, because I sometimes think if my body and mind goes, how much of my soul is there to have a relationship with God.

H.M. Yes, yes.

OP:40 It is big enough to stand the physical and mental deterioration that inevitably happens.

H.M. Right.

OP:41 But that woman had a communion with God it was lovely, lovely.

H.M. Yes, yes.

OP:42 No I have no problem sharing communion with people who are confused. I'd have much more problems if any were violent but I mean I've never had that experience.

H.M. Surely.

OP:43 I'd find that a difficult one to do.

H.M Yes, it's interesting you recounting about the woman in communion with God which underlies the next big area, which is that folk have said to me if you can prove to me that this is worth it, this is a good way for me to spend my time, then I will do whatever you tell me to do. Every technique that is coming from the speech and language thing I'll do, if you can prove that its worth it. Now in a way you have answered it already because of that story with the woman which is tremendous. It was reflected too, as I was saying 44 percent of the people who responded said that pastoral care of confused people was a priority for them.

OP:44 Really.

H.M. Now, maybe that's reflected by the fact that the question in the questionnaire on that creates a bias, but its a bigger percentage than expected to say really that it was a priority. I'm just wondering, in your experience, is it, does it, warrant being a priority and why?

OP:45 I'll have to be honest and say that at the moment it isn't and that's tied up with being convenor of an Assembly Committee which takes a huge amount of time. A huge amount of time, I find that difficult. I would love to able to say that it was a priority. It isn't, but I would always put the elderly confused on the same level with the elderly non-confused.

H.M. Right .

OP:46 So they get the same treatment and the same number of visits and the same pressies.

H.M. Right, right.

OP:47 And things like that.

H.M. Yes, yes.

OP:48 I was just thinking on Sunday for example - much more of a priority would be trying to communicate with a Down Syndrome woman who has just come to the congregation.

H.M Right.

OP:49 Her mother died and she has just come to stay with her sister who's a member of our congregation. This is a woman in her fifties and she comes to Church every Sunday and gives every evidence that she just loves it.

H.M. Right.

OP:50 I would like to be able to communicate with her because she is not in a degenerative state just at the moment. So however, that is way off your question.

H.M. Its interesting, I'm just wondering why she's a priority - a higher priority is it because she's not degenerating, is it to do with potential.

OP:51 Yes, and also because she's never joined, joined the Church, I wonder whether she shouldn't be allowed if she wants it, the ritual of Confirmation.

H.M. Right.

OP:52 And I don't know whether she would be prepared to stand up in Church and say "I love Jesus" - instead of all the questions that are normally put at Confirmation, I'm quite clear she couldn't be linked with the same new Communicants class.

H.M. Sure.

OP:53 It would need to be an individual session. I suspect that so often happens in The Church of Scotland she will just come to Church and be accepted but will never be assumed to be a member and I think that will be sad because I think her name should be on the roll as a member. We may do it by resolution of the Kirk Session which is - but that's a priority for me to talk to her sister who is an Elder and to talk to her and she probably has no understanding of membership because she goes every Sunday, and enjoys it and is much petted by the congregation, so she probably feels she is part of it anyway.

H.M. Yes, yes exactly.

OP:54 Anyway.

H.M. Another statistic was that 53 per cent said that they felt that their visit made a difference to the person - this is an area I tried to pick up on because I'm interested in knowing what feedback ministers get when they are going in. What makes people feel it makes a difference?

OP:55 Well I remember once in the hospital I saw this woman who didn't recognise me and was in quite a lot of rocking backwards and forwards and I had a busy time, check list of people to see and things to do, you know the usual pressure and I thought this is a useless visit. And the woman herself got up in a restless way and went off to do something else and I spoke to the charge nurse and said I think its a waste of time there and she said "why don't you just hold her hand and time yourself for ten minutes" and she said "we no longer have the time to do that, and we used to and if she doesn't want it then you know that, but in our experience she will respond to that." When she came back I put out my hand and she took my hand and I spoke quite softly about things that had been going on in church, like we had a Coffee Morning on Saturday and lots of people came there was a lovely baking stall Oh we had such a nice service on Sunday because we lit the Advent Candle, and there was a

parade of the Boys Brigade. I just talked stroking her hand and it did soothe her, and I literally timed it for ten minutes and the last five minutes was just silence. What she said didn't make sense to me just unconnected words, but the charge nurse left me out and said "she'll be different tonight because you have given her time".

H.M. Right.

OP:56 And that, that was okay for the feel good factor for me I hope it was the feel good factor for her too. I didn't say at the end shall we pray which I think is almost a challenging thing and I did what I often do, I held her hand and said "I have to go now the Lord bless you and keep you and be with us both until we see each other again" or "God be with you" or "the blessing of God be with you" it's not a prayer more of a blessing and -

H.M. Very interesting

OP:57 Well I think - well you don't know you just don't know. Let me tell one story about my predecessor, [Predecessor's Full Name], a lovely man full of vitality full of life, wonderful bass/baritone voice, he played the piano - a great character. He had dementia and ended up a pathetic creature tied to a chair and latterly he was in bed and three weeks before he died I visited him. He was in bed and - I said I'm going to go now [Predecessor's Christian Name], I will be in to see you again. I think he recognised who I was because he always used to say to me " I'm so glad that you're my successor' I think he recognised the voice. On my going, he suddenly lifted his right hand, he was prone, I expected him to say the Blessing but the words didn't come so I said it "The Blessing of Almighty God, Father, Son and Holy Spirit and he waited until I said Amen and then put his hand down. Now don't tell me that he didn't at some spiritual level understand what was going on.

H.M. Yes, yes.

OP:58. And yet he couldn't get a word out. I find that very moving - after saying good-bye I had to go outside - and mop the tears up in the corridor. He died very soon after that.

H.M. That's the great unknown, - that God is at work in encounters .

OP:59 Yes, this other lady, it was a wild, rainy, windy day and when I went to visit her she was just curled up in the foetal position, and I just sat with her that's one of things I have to do. Then I thought poor soul, and her mum had died, so just then the sun came in. It was very March weather you know showers and I spoke to her about the things I'd seen in the grounds and I said maybe next week I'd pop in and you'll be a bit better and we could go for a walk and I said the crocuses are lovely, fantastic opening wide in the sun and glistening yellow they are so lovely and then I talked for ten minutes and left because I just said ten minutes is enough and she never batted an eyelid never spoke.

H.M. Right.

OP:60 - Months later when she was as well as she could be, I met her and she said, remember that time you came and talked about the crocuses. I felt very humble because I thought that was a wasted visit and that she hadn't heard me and that she hadn't wanted me there because she lay with her eyes closed - and it was a lesson to me that depression can suck people into such depths that they are not able to respond, but their hearing is still there, and she stored it away and she remembered the glistening crocuses.

H.M. Right, right.

OP:61 There's sometimes I wondered if people who are demented can't also hear something locked into this bit of them that's in prison. Maybe they can hear things like that, maybe they also retain pictures of the glistening crocuses or the dancing daffodils, the sun on the water you know.

H.M. Yes, yes.

OP:62 Maybe they can, I don't know.

H.M. Yes.

OP:63 But I said to her, you remember that and she said of course I did. Maybe she didn't like to be reminded .

H.M. Exactly, yes, yes.

OP:64 Sorry we strayed.

H.M. No, it is terrific. I'm aware of your time now because are you rushing on.

OP:65 Well tonight I've got this rather jolly party where all the couples I married last year are coming up for a cup of coffee - I've got about twenty couples.

H.M. Oh that's lovely it is indeed yes, yes.

OP:66 I've got to take the cats to the vet.

H.M. Then I shall potter on thank you so much I really appreciated that.

OP:67 Thank you.

INTERVIEW WITH QR

H.M. Thank you for filling in the questionnaire, can I ask you first of all, do you have folk who have who are confused in the congregation.

QR:1 It changes, I think at the time I filled in the questionnaire I was thinking of one lady in particular who had moderate dementia and who was going down hill.

H.M. Right.

QR:2 And she then developed severe dementia, went into care and died during the summer.

H.M Right

QR:3 I'm trying to think whether we - there are always people I come across with dementia. There is one lady I know, who is in residential care at present, who has severe dementia. I'm not immediately thinking of people who have moderate dementia. There is nobody who regularly attends worship at present who suffers from dementia.

H.M. Right - in working with those folk, maybe in particular the first lady you spoke of , what were the things that you found most effective when you visited - things that you thought were getting through to her? Perhaps that your were there, or that you represent the Church or maybe something about God.

QR:4 It was an interesting case because there was a lady who started coming around to Church, just about the time I came here.

H.M. Right.

QR:5 So as far as I'm aware she was a person who didn't have any Church background.

H.M.. OK.

QR:6 So I suspect her age would have been in her eighties. It's unlikely she had not had some exposure.

H.M. Yes.

QR:7 As a child.

H.M. Sure.

QR:8 So, I'm not sure what it was which was perhaps resonating with something deep within her. She was living with her family at that time. I think it was a son and his family in a small council house. There was lot of pressure on the family unit. She used to wander the streets and if there was anything on in the Church she would come in.

H.M Yes.

QR:9 So she was at every service, and she was at a lot of meetings during the week

H.M. Right

QR:10 Up until the end she really seemed to know - although she was not understanding, she was sufficiently taking part in things.

H.M. Right.

QR:11 For it not to be too intrusive.

H.M. Yes, yes.

QR:12 But I would be pushed to say what she actually latched on to.

H.M. Right.

QR:13 Yet she joined the church. I was running a class for people thinking of membership, I also had a class at that time for two adults with learning difficulties.

H M. Right.

QR:14. And people who didn't - so there was a cross section.

H. M. Yes, yes.

QR:15 And I decided at the end of the day that what was best for her, in terms of her dignity, was to not ask her to stand at the front.

H.M. Right.

QR:16 In case she did something which would have caused her, maybe without her realising properly, to really wonder what was going on.

H.M. Sure.

QR:17 So she was admitted by resolution, by the Kirk Session, rather than by a profession of faith.

H.M. Sure, and at those classes was she able to participate and play a part?

QR:18 I wouldn't use the word participate, she was present.

H M. Right.

QR:19 I think a lot of the time she just sat there.

H.M. Right, but at least she was there?

QR:20 She was there.

H.M. And made the effort?

QR:21 Yes.

H.M Would you lead worship at residential homes, where there would be folk who are confused? Would you have that as part of your work?

QR:22 I don't have any homes like that within the parish.

H.M. Right.

QR:23 Though sometimes one or two of the homes, if they have one of our members who is currently in it, would invite me to come along. The problem doing that is you only know the one person.

H. M. Yes.

QR:24 And I have no idea about other people.

H.M. Surely, surely.

QR:25 Where I am involved is - we rang the Chairman of the Management Committee of the Club for Dementia.

H.M Right.

QR:26 A club which is across the road in the Community Centre.

H.M. Right, right.

QR27 Which runs two days a week, for about four hours, 10am - 2pm.

H.M.. Right, right.

QR:28 But that doesn't have any religious component to it.

H.M. Right, right.

QR:29 It is just part of our involvement in the community.

H.M. Would you call over, from time to time, or do you have much contact that way?

QR:30 I should do it more often than I get round to it, we get a grant effectively from the [Government Office Name] and we employ a co-ordinator to run.

H.M. Right.

QR:31 So then the Committee which manages it is not hands on, its a step back.

H.M. Right, one of the things that folk have been saying to me a lot is if you can prove to me that ministry with folk who are confused is worth it - good use of my time, then I'll do whatever you tell me to do in terms of speech and language techniques. But a lot of them are coming to me and saying, "really in my contact with people who are confused, its hard for me to say well, that's good". More of the time they were coming away saying "well I think that was a waste of my time" in as far as they can judge.

QR:32 Sure.

H.M. Would you echo anything like that? Do you think it is worth it - can it be a priority in a busy person's life?

QR:33 Yes, I think I would want to say that. I would feel it important to distinguish the degree of dementia.

H.M. Right.

QR:34 There are people with severe dementia who I have visited in hospital, and I have felt that it has been a total waste of time.

H.M. Right.

QR:35 Because I don't even think that they understand, they have failed to almost be aware that a person has been there, much less who I am.

H.M. Sure.

QR:36 Or what I'm doing there and I can think of a number of people one lady in particular, who was a integral part of this church some years before I came. Somebody who had given an enormous amount to the church and I was very sad to

go to see her in hospital, and as far as I was aware feel that she had lost so complete touch with reality.

H.M. Right.

QR:37 And nothing I did seemed to get through to her, in terms of people with mild dementia, moderate dementia, I suppose I would say, it was a waste of time but I'm sure that I would be thinking of making them a priority.

H.M. Yes.

QR:38 I think, I would be saying, what I want to do was to try and include them.

H.M. Right.

QR:39 In what we were doing.

H.M. Surely.

QR:40 Rather then singling them out as a special case.

H.M. Right yes, that takes a lot of effort sometimes doesn't it?

QR:41 Yes, and I'm also not sure that it's actually helping them.

H.M. Right.

QR:42 I think, I think particularly when a person has mild dementia and they are aware in one sense of being not quite there. To just be given the message that they are welcome - as they are in the life of the church, is very affirming to them in their unsettledness.

H.M. Yes, right.

QR:43 I think in terms of visiting people, in their own homes, what I would be trying to do, is to find things that they were familiar with.

H.M. Right.

QR:44 I would sometimes get a clue as to how or where somebody is at by simply praying the Lord's Prayer with them.

H.M. Sure.

QR:45 And quite a lot of people that I have a memory of, who I think were confused and by the time I got into it (Lord's Prayer), they were beginning to say it

with me, which suggested that I had been able to find something to connect with them.

H.M. Right and meaningful for them - at that point in time.

QR:46 Yes.

H.M. Yes, someone was saying to me yesterday they had an experience with a woman who was very, very confused and again like the lady you were talking of was very involved in the life of the church and how she had got to a very advanced stage of dementia and wasn't able to say anything. She told of how another minister had gone to visit her and how he recounted the story afterwards. He said to her I couldn't get anything out of her, I didn't know her name, I didn't know her, but I was aware that this was a woman who knew how to pray and somehow, even in the confusion, he could sense that she was a woman in communion with God. At some level her relationship with him was still intact. Have you ever come across anything like that - it's a rare sort of example?

QR:47 No probably once you've left.

H.M. It struck me because it was the first time I had come across someone actually articulating that, and obviously that's hopeful for me.

QR:48 Yes.

H.M. Yes.

QR:49 I think that it's this old business of finding something that you can connect to.

H.M. Yes, yes.

QR:50 If there's somebody who, has been a fairly nominal church member and, has never been particularly involved in the church, they are not like somebody you know an awful lot about.

H.M. Sure, yes.

QR:51 So it then becomes very difficult to make any kind of connection with them.

H.M. Right, yes.

QR:52 Another lady, who was in that category, who I happen to know lived up in the flats, the high flats.

H.M. Right.

QR:53 And somehow the idea came about speaking about the view that she used to have.

H.M Right.

QR:54 And it was just a flicker that said to me, "I made a connection there".

H.M. Right.

QR:55 But unfortunately, I didn't know anything more about her.

H M. Sure.

QR:56 - to be able to do anything more, and we just quickly lost her.

H.M Yes, I think you're right. Just trying to work with a person where they are, or those things which were meaningful to them, like the Lord's Prayer or Psalm Twenty-three.

QR:57 Yes.

H.M. The other side is that folk could just tune in, even for a short moment in time

QR:58 Yes, sure.

H.M Yes, I was amazed that 53% said felt that their visits made a difference to the person who is confused.

QR:59 Yes, yes.

H.M Which again is hopeful, can you think of visiting someone in particular and maybe talk about the feedback that they gave you which makes you think "well, maybe that did ring a bell"?

QR:60 I think this lady who lived in the flats - I visited her before she went into a residential home, I think my visit made a difference because she was suffering. Her dementia was causing her feelings of paranoia.

H.M. Right, right.

QR:61 And she was, she was hiding money in her house, she was telling me that somebody had got keys to her house and was coming in and taking her money and her daughter, who I suspect was looking after her, she couldn't trust her anymore.

H.M Right.

QR:62 It was only as the conversation went on that I that actually was able to see that there was a problem there.

H.M. Right, right.

QR:63 It was afterwards that somebody confirmed that she was suffering dementia.

H.M. Right, right.

QR:64 But I think the very fact that at that stage she understood who the minister was and where I was coming from, made her feel that I was somebody she felt able to trust.

H.M. Right .

QR:65 She felt able to talk about her fears.

H.M. Sure, yes.

QR:66 And I think that made a difference to her.

H.M. And your whole representative function I'm sure was important. That is one very sad thing that has come through from case histories I have been reading. Folk, who were very committed Christians, would have interpreted their confusion and interpreted their failing faculties as punishment, and all those things that folks so often connect with suffering.

QR:67 Yes.

H.M. Because they felt that God was against them. I'm sure therefore that ministers have a huge part in representing that they are not forgotten by God and that He still loves and cares for them. Someone I was talking to said that for them as they ministered with and cared for folk who were very confused, that those situations raised in their minds questions about euthanasia. Has it ever crossed your mind that there are any other ethical issues that spring to mind that you can think of?

QR:68 No I don't, dementia doesn't raise questions - even the prospect of euthanasia in my mind.

H.M. Yes.

QR:69 I may be wrong in thinking this, but my feeling is that dementia is at its most disturbing state when its mild.

H.M. Right.

QR:70 But by the time it's becoming moderate people are less aware that they are forgetful, and by the time it's severe its almost as if they are in a wee world of their own. They can often appear, and its only appearance, quite happy. My own interpretation is that the suffering is caused to the people who know them

H.M Right.

QR:71 And who feel that they've lost them.

H.M. Surely.

QR:72 That the person themselves is mercifully beyond the state of awareness.

H M. Right, right.

QR:73 And you may tell me the scientific researches show that, that's right - but that's certainly how I perceive the situation. So to see somebody suffering from severe dementia I don't worry about the person I do worry, I do feel for the family.

H.M Right.

QR:74 And that they are left with what appears to be the physical shell, but the person that they knew is no longer there.

H.M Right.

QR:75 And I think particularly, for a spouse, that can be dreadfully disturbing.

H.M It's interesting. It's difficult to find proof about what someone in the very late stages of dementia is thinking, or hearing or seeing. That's the problem, really, that it just doesn't exist and I think your are right about stages of "happy confusion". Others have said that sometimes they have come across folk who have expressed anger, are agitated within themselves even in very severe dementia. Have you ever come across anything like that? Perhaps folk expressing anger at God or at people or being depressed?

QR:76 No, I can't.

H.M Right, yes, maybe you have seen people further on than I would with dementia. What's the message that we are trying to communicate to them as ministers? What's the purpose in visiting someone who is very confused?

QR:77 I think when the person becomes, is at the stage were they no longer know who you are or have been, I think the purpose is either to assuage your own guilt or to say something to their family.

H.M Right.

QR:78 Or perhaps to say something to the home because they're usually in residential care by that time. In the eyes of society this person may be a cabbage, but in God's eyes they are not. They are still somebody who has value because our value doesn't depend on our own ability.

H.M Right.

QR:79 And the fact that a minister bothers to visit somebody in that situation is making that kind of statement.

H.M Yes.

QR:80 So there is a question about what we are trying to do, when they are very severely demented. When they are living at home I think there is a great ministry to their family.

H.M Right.

QR:81 Because you are saying that you are with them in what is a very difficult and demanding situation. While the person is still able to understand who you are, when you come, you are making a statement that they still matter, that God loves them, they are part of the church.

H.M. Yes, absolutely,

QR:82 I think that's why I was very glad when that lady who I spoke about earlier, wanted to come to church.

H.M. Right.

QR:83 Her behaviour was on occasions inappropriate but we are wanting to say, as a church, that everybody's welcome, whoever they are.

H.M. Right, yes.

QR:84 And that the church isn't a place you stop coming to, when you kind of lose your respectability.

H.M. Yes, yes.

QR:85 And that's hard to get across.

H.M. It is, yes, do you think the churches cater enough for folk who maybe have failing faculties or maybe have learning disabilities?

QR:86 I don't think it's so much what you do. I think it's the attitudes of the people here .

H.M Yes, yes.

QR:87 Me, I'm not a great believer in kind of radically changing what you do to meet the particular need of the people.

H.M Right.

QR:88 Particularly on a Sunday morning. My idea would be that this is the people of God who gather for worship.

H.M Yes.

QR:89 And not everybody's going to find out each bit is appropriate. It is the being together in God's House.

H.M Right.

QR:90 Whoever we are - that is important too.

H.M Yes.

QR:91 So the adults with learning difficulties may have a bible study which is very very basic, and geared at their level and when they come to church, they may not understand a word of the sermon, but its the being there.

H.M Right, right.

QR:92 The inclusiveness that I feel is important.

H.M Right, and I suppose that the folk can feel accepted if they come into that atmosphere - that they are welcomed there.

QR:93 And then that applies across the board. I don't think we're there yet because people, people who have all kinds of problems with their lives, they could come into church and feel they are not being looked down on.

H.M. Surely, surely.

QR:94 And unfortunately that does happen.

H.M Yes, the other sort of element in worship is thinking about their place in the sacraments. How would you feel about someone who was very confused taking communion?

QR:95 If they had been a church member I see no problem with that.

H.M Right, right.

QR:96 This lady, who joined the church I'm pretty sure she took communion. If she didn't take it, it wasn't because I had said she couldn't take it.

H.M Sure, yes.

QR:97 I just can't remember the details but.

H.M Yes, not a problem.

QR:98 No, no with her its not my job to decide whether she understood anything.

H.M. Right yes, exactly.

QR:99 Give her the opportunity.

H.M. That's right.

QR:100 And in the mercy of God he will deal with her as he sees fit.

H.M. Exactly.

QR:101 And its not going to upset and cause Him trouble if I -

H.M Give her the benefit of the doubt.

QR:102 Yes that's right.

H.M The last issue I will raise, is that the questionnaire had an 87% response rate, have you any ideas why that was so?

QR:103 I wouldn't say from contact with colleagues that they have mentioned it.

H.M Right.

QR:104 I wouldn't say.

H.M Right.

QR:105 It may just be that the way you have presented was fairly good. I seem to remember a very good covering letter from David Lyall and the questionnaire, the questionnaire, itself, was I think relatively quick to do and easy to follow and I suspect that it was the stamped addressed envelope as well.

H.M Sure.

QR:106 I would be inclined to look for.

H.M. The practicalities, yes.

QR:107 That probably isn't what you are wanting to hear.

H.M No that's fine. It was designed to elicit a high response rate.

QR:108 Sure.

H.M. Those are all the main areas that I wanted to cover. Thank you very much indeed for your help.

INTERVIEW WITH ST

Following an explanation of the aims and rationale behind the project, I asked permission to tape the interview. This permission was granted.

H.M. Could we proceed fairly formally? I have a list of questions is that all right with you?

ST:1 Yes that's all right, yes.

H.M. Really the first thing is, what have you found most effective in ministry with people who are moderately to severely confused.

ST:2 I am a regular visitor to a group that meets twice a week on church premises. The organisation itself which was set up involving local churches several years ago, I only moved here two years ago, has always met on two sets of premises, one of which is a hospital site so that has all the aura of professionalism about it. But one part of it, the group, meets two days a week on our church premises. I certainly call once a month and often twice.

H.M. Right.

ST:3 And its largely being a known visitor, that must be the main thing, because my actual involvement with the project, is as Chairman of the management group, that's where most of my time goes so my actual contact with dementia sufferers and users of the project is mainly as a regular visitor.

H.M. A visitor.

ST:4 And after a year you become known.

H.M. And you find that people do recognise you?

ST:5 Yes they do, yes, yes,. And because I also know members of staff and volunteers they jog memories and get into "what about the holiday you're going to have".

H.M. That's one area that came up, I'm sure you don't remember the detail of the questionnaire it was a long time ago, but it was about knowing specifics about the persons life or knowing specifics about the routine of the place where the person is?

ST:6 Yeah

H.M Most people responded and said yes that was helpful. But what I was wondering was, is it practical for folk to know those sort of issues? Obviously that works well in your situation.

ST:7 Well it does. You see its usually the same time of day that I call, so certainly once a month, which is when I more or less guarantee a visit they know that I have been at a previous meeting of a local council of churches and I am calling just before their lunch. And sometimes I arrive just as their lunch is being unloaded from the local canteen, so yes its the habit yes.

H.M. I was amazed and pleased with the response rate, 87% which was terrific. Of those 44% said that they agreed or strongly agreed that pastoral care of elderly confused people was a priority for them. I have questions about that in the practicalities of ministry I am just wondering whether people have time for it to be a priority,

ST:8 Well I am calling in on an operation which is up and running and caring I am not visiting people in their own home.

H.M Right.

ST:9 I'm not one of the volunteers who sit in with people for two hour sessions.

H.M So within your congregation do you have a system of lay visiting would you?

ST:10 Well it isn't only our own congregation we are involved with other churches in this, the majority of our volunteers are non-church people. Its community as much as, in fact its community more than church, and there is no one who is a user on the project who is a church member, they are all people from the local community who have been referred from social work, local GP's or the local hospitals .

H.M And within your local congregation are there any confused elderly people?

ST:11 people confused, right, of that congregation which is a very small congregation possibly two, possibly two.

H.M. Right and in your own experience is it worth spending time pastorally with folk who are confused, I'm searching for good experiences which would indicate yes, maybe it is, or on the other hand experiences which would indicate that time could be better spent.

ST:12 (after a few seconds silence) I think that really it is in response to the level of need rather than signalling out well this is a good group I must be careful to spend a lot of time with them.

H.M Yes.

ST:13 That this is a particular concern. And there again it might be that more time needs to go to the wider family, and to the generation below them rather than with the actual person.

H.M Yes.

ST:14 The problem might very well present itself as what will we do with Mum, what are we going to do with Dad, because the person themselves might not be aware of what is going on. So the priority is more likely to be the family or the next generation or whatever.

H.M That's interesting. That would have been my experience pastorally too. I was stationed to the Belfast Central Mission - probably a similar type of congregation to your own and I found that I would have spent most of my time supporting the family, so I came away wondering is there anything that we can be doing for the individual with Alzheimer's that actually makes a difference. That is really what I am searching for here. If, in the end of the day I can say, "Well it looks as if pastoral visits do make a difference people have been helped, the Holy Spirit has moved in some way that we do not understand " and if it is worth it then these are some things which we can do which will enhance communication. And really this is a search to see do folk have experience or beliefs that make them say " Yes its worth it" or in the main is it very difficult to get through.

ST:15 Yes, I think one of the interesting things is the simple fact that we don't know, and do you persevere or do you give up. Maybe you persevere for a while and ease off for a little, and very often the other problem is when is this person as it were referred to you. I give an example of pastoral visitors in the life of the church who eventually say to the minister that they have been visiting this person for however long and it has reached the stage where they no longer recognise me, and in a sense it is at that stage too late to be asking the minister to go and pay a special visit, you need to recognise that need a jolly sight earlier.

H.M I know what you mean. Have you ever had experience of someone getting Alzheimer's and facing the issues raised by the decline that is inevitable.

ST:16 Yes I can think of two at present. One is a bachelor and it would be friends more than family who are keeping more and more of a part up, for instance at the level of, at the present moment he gives someone a lift to church, that person is now afraid to travel in the car with them.

H.M. And is afraid to tell them?

ST:17 Yes. The other is a husband and wife of many years. She has a family history of dementia. Certainly two older members of her family, probably both sisters have already died with dementia and her husband is now scared stiff about admitting the fact that she clearly has Alzheimer's and is over-protective and not quite ready yet to accept, he knows that this is likely to be the beginning of the end.

H.M. One of the most memorable things from my reading was a case history of a woman who had been a Christian for years and began to get Alzheimer's and interpreted her growing frailty as punishment from God. She withdrew from church life and spiritually became very withdrawn, that got me thinking about the needs of a person facing the disease,

ST:18 It's difficult to know whether she knows.

H.M. The other issues which influence this question of "Is it worth it" was that 53% said that they felt that their visits made a difference to the people with dementia. Would that be your experience?

ST:19 Well I think it is. We go back to this particular couple the support is more for the husband than for the sufferer but the woman, the sufferer herself she delights in company she is bright and alert. The pity is that you go over every conversation three times in every twenty minutes. But it is animated and excited while it lasts.

H.M. So it probably does make a difference.

ST:20 Yes, the problem is that this can give the impression that everything is all right to visitors with the result that the husband feel that he has to battle on alone.

H.M. Yes in conversation about ministry with people in the early stages one minister asked if it would be possible to set up patterns in the early days. Visiting at a particular time, taped Bible readings in the ministers own voice if the person found it helpful so that when the disease progresses the person with Alzheimer's might be able to relate to those established patterns and they might be triggers to memory and meaning, is that a practical idea.

ST:21 I think the routine is valuable, whether taking something with you, whether that association would come, certainly thinking about the group that I visit the work that they are engaged in is supported by the constant reinforcement of the staff, now you can't achieve that in one to one visiting, there is no sort of backup. So maybe its just the feel good factor for the visitor.

H.M It's so hard to get underneath that isn't it.

ST:22 Yes, ticked another one off on the list.

H.M And as you have said it is hard to know what is going on the individuals mind, there might be a spark there.

ST:23 That's right, so again I am back to saying I visit because of the need not because of the need not because of the very particular need, it is because my work is to visit, is to be alongside those in need, rather than to single out a special group or to say I've found a niche.

H.M. So they become part of the routine.

ST:24 Yes.

H.M The other area that I want to explore is about the content of the message that is being communicated. I think of Speech Therapy on one hand with these principles and on the other hand the individual there with their need, and I am just wondering what is the message which we as ministers are needing to communicate to the individual, particularly at the moderate to severe end of the scale?

ST:25 The group where I visit is at the moderate to severe end, my visit reinforces the fact that they are meeting on church premises and secondly that the church is glad that they are there. The individual visits to members of the congregation who are suffering - in each case it is maintaining a long link which they have with the church, there is opportunity to pray with them.

H.M. There is a symbolism in the minister being there?

ST:26 Yes, and leaving behind a card so that somebody else might say " Oh, has [ST] called" and that is a reinforcement , a member of the family or home help or whoever it might be. "Who was this, did they call yesterday, and what were you doing when they called".

H.M The other issue around the message that we are seeking to communicate is, is it possible to assess the needs of the individual and the issues in their relationship with God that they are working through. Have you ever come across a person with dementia who is obviously angry, depressed ?

ST:27 No I don't think so. I suppose that the prayers that I might share follow a pattern, there are certain phrases which I use repeatedly and that may be a reminder that they are not forgotten by God. But that is more at the level of proclamation.

H.M. Maybe proclamation is where its at. Is a ministry of presence valid?

ST:28 Oh I think so. But whether people distinguish who it is in terms of their function, in other words, "Oh its the driver, its the man who brings the dinners, its the man from the church" or whether they just think in terms of its that tall thin lady, its that short fat man we just don't know.

H.M. Which is why I asked the question in the questionnaire about clerical collars. Does it act as a trigger something that folk latch onto. Whether they recognise you as [ST] or whether they see a collar and think church, or God or whatever?

ST:29 Yes, again in the group situation there are people at different stages of dementia, so some are more aware than others and again the staff will say " there's [ST] there's the minister" so again we're back to reinforcement.

H.M. Moving to worship. Are there things which you have found helpful in worship that folk have responded to?

ST:30 I don't think so particularly. When I think of the nursing home, this was part of the routine of their Thursday.

H.M. One important thing from a speech therapy point of view is being understood. That the person with Alzheimer's actually understands what the minister is saying to them.

ST:31 Yes.

H.M. My concern arose after talking to a speech therapist friend, she observed a minister visiting a confused person, with whom she had frequent contact on the ward. This minister came in and had a conversation with this person and left feeling that he had been understood , whereas she felt, knowing the persons level of confusion that he probably hadn't been.

ST:32 Right.

H.M That sort of confusion arises because many confused people hold on to the ability to respond to stereotyped questions like " How are you?" and can give a false impression of their ability. On the questionnaire I asked "Do you think that it is easy to assess a persons level of confusion". About half of those who responded said it was. What I am wondering is, what are the pointers which we are given in conversation which help us decide how confused a person actually is?

ST:33 Well conversations with individuals would often become repetitive, and it is always interesting to see if in the repetition people are telling the same story or if it has become another nephew or another grandchild who has slipped in. So if the characters change. Another one, in a group session I have often sat in, or if they have been out for an outing and between them are telling where they have been and what they have done, in a group setting you can see how others in the group cope with individuals, whether they cut them out or keep the conversation going with them. So yes there are pointers, there are pointers.

H.M. Yes thank you. In the comments section at the end a couple of people said that pastoral care of people with dementia in the later stages, raised for them the question of euthanasia, I am just wondering if that was true for you, and what ethical issues in general are raised for you by this area?

ST:34 I think the big ethical issue is whether another person has taken over the running of another persons life. It something that happens with a lot of elderly people

whether or not they have dementia. It is often seen as an excuse for jumping in and taking over.

H.M. Yes.

ST:35 When is that stage honestly reached? I think ,the euthanasia question, there would need to be more than dementia involved, physical frailty or chronic illness or some other illness alongside.

H.M. My next question is about theological issues. Really it links back into what you were saying earlier- you visit because that is what you are here for, to be alongside?

ST:36 Right.

H.M. I was just wondering about the theological issues that surround pastoral care of elderly confused people, Why, what need is there if the person can't respond or understand?

ST:37 Why bother, well the answer must be because nobody, you can't just let them go.

H.M Right.

ST:38 Well I think that I would go back to saying that it is at the level of need rather than just routine.

H.M. Right, some theological issues which people raised were to do with personhood and worth, would that echo with you?

ST:39 Yes, its certainly eh, its certainly there. Another interesting question related to why we persist in these things is that at some level it is of value to me. Now I can't communicate with this person that it is of value to me, but I must be doing it because it is. I wouldn't just be doing it out of function, there must be something more to it.

H.M. Wwhich is hard to put your finger on?

ST:40 Oh, absolutely.

H.M. But what value is there with someone very confused, and you are getting minimal feedback, and its even a bit embarrassing because you are trying, trying , trying and getting very little back.

ST:41 But that person in their need finds you out. It is very stark you can meet someone and in yourself feel absolutely desolate.

H.M. Yes. Thank you very much for your time and your thoughts, it helps me to put meat on the bones of what I have, in conversation with a lot of colleagues they have said, yes its a very interesting area, I know so and so, but in the end prove it to me,

prove that it is worth it and I'll use all the techniques of the day, that became a big issue in my mind, well is that generally reflected or was it just the people I talked to, and it does raise issues about pastoral care, who are we trying to please, who are we doing this for?

ST:42 I think that sometimes there is a professional danger in going out and seeking a corner of the market, and saying this is mine.

H.M. And I'm good at this.

ST:43 Yes, my particular style of ministry has always been as a generalist rather than any type of a specialist, being alongside and befriending people, whatever the circumstances might be.

H.M. Well if as a generalist someone was to say to you well H.M. has at last got to the end of this, and there is a list of things which people have found helpful. Would you find something like that useful?

ST:44 Oh yes, for that reason I look at a wide variety of things rather than having just a shelf on depression. How many people responded?

H.M. 87% so I was really pleased with that.

ST:45 It may be that we ministers are not as busy as we like to pretend we are.

H.M. They may also be more methodical than they are given credit for being.

ST:46 Yes, it is an interesting response rate.

H.M. One of the things that it raises is why?

ST:47 Well it is something that I am involved in, and therefore I made a response. From time to time I get letters like a minister on sabbatical leave is looking into the redecoration of graveyards, I will let him.

H.M. Right.

ST:48 So how many are you going to interview?

H.M. About twelve, so it helps me to explore wider issues and see if we can apply some of the things which Speech Therapy is saying may be useful.

ST:49 Well what are those things?

H.M. We have said some of them, routine, repetition, being aware of your surroundings. Particular things like trying not to use too many pronouns because the

confused person may forget who the subject is. With regard to worship familiar hymns, short familiar Bible readings issues like that.

ST:50 Right, and I suppose that could apply to a large number of people, ordinary geriatric visiting.

H.M That's right, for research I have to narrow it down but there may well be a broader application. Thank you again for your help and your time.

INTERVIEW WITH UV

H.M. Do you have folk with dementia in your congregation?

UV:1 We do. I find this is true of every congregation we've worked in, I mean I've been in [Church Name] for three years and there are people with dementia here and I found this in each Church. A lot of the house-bound do suffer from dementia. I have about 150 house-bound members in my congregation and quite a number have dementia, but compared with other congregations I've worked in, [Community Name] is more of a community and people will stay in the home. I may have a list of about 20 or so in Nursing Homes, but apart from that, people of around 90 years-old or so have died at home. There's quite a high level of caring in the home here and also stimulation. One very elderly lady with severe dementia said, last week, to me, and the last few months she didn't really know me at all, "Have you stopped smoking, ?" She had moments of lucidity!

H.M. Can you think of things which do trigger? This is one of the areas which I'm trying to get into?

UV:2 The most successful thing is, usually, something secure from away in the past, because dementia is like a sponge when you put your foot on it, it jumps back, there's nothing in recent memory. However, memory in the past, is like someone standing on cement and here you find more firm footprints and firmer memories. The politics of the day - none of that is meaningful. If you go back to childhood and talk about streets which were known to them and things like that, the memory can be triggered, or start singing a song. Occasionally, I go in and recall names of their relatives from the past. The ones which are more confusing, I find, are the ones who sound completely credible and lucid, and sound completely fine, and you realise, from someone else afterwards, all the people who they've been talking about died about 20 years ago.

H.M. Yes - I understand.

UV:3 Deep conversations are difficult, obviously. I think it's a matter of reacting to the moment - to the way their mind is going. Sometimes, there's no conversation can be pursued, really, because there are a lot of distractions - some people try to cover up, at the early stages anyhow, and they will blame other people and say "you know so-and-so has hidden my teeth" or someone has stolen something or this man has come in and everything doesn't seem right. Whereas others seem quite comfortable, as if they are quite happy, they're not being unduly hurt by the situation - it's only the family who are.

H.M. Yes, I know what you mean.

UV:4 I find it's more difficult for families than for the actual person with dementia, especially if the person is fairly young and the husband isn't a husband any longer or

hasn't been for a few years, and the person changes from someone that someone has been depending on, to being someone who is dependent totally. People can't handle that and it's sometimes easier for an outsider to be able to accept them at the level they're at - whereas if you are emotionally involved, it is really difficult.

H.M. Oh yes, it is, indeed it is.

UV:5 I mentioned my own Granny (before going on tape). We have some crazy stories, but the start of it is hard. After some tooth extractions, she just couldn't fit anything in.

H.M. It just totally threw her.

UV:6 Yes, it did. My Granny, I suppose, is the one who is easier to see because I know what she was like before. She would be so funny at times. She's been in three Nursing Homes and also stayed with my Mum for a while at home. The first Nursing Home was just no good at all, she was always trying to get out. Then she stayed with my mother and that was great, because my mother has the patience of Job, but my Mum couldn't go out. Then Mum gave up her work and had to move as well and it was all such an upheaval. So Gran went in to a place in [Town Name] and she was heavily sedated and that is one thing which I'm very much against. I find it happens. The telling sign in a Nursing Home is when they say "Oh, we don't mind people with dementia, we find it very easy to work with" because they sedate them and often they develop Parkinson's - shaking, stamping the foot and they'll say it is Parkinson's Disease, but I find this is secondary, it is a reaction to the drugs, heavy sedation. Then, when they get to the stage that they're not listening to anybody, you feel, in a sense, they've lost their dignity.

H.M. Yes, yes, I understand.

UV:7 What happened then, we did move my Gran and Grandpa (who doesn't suffer from dementia but is quite badly crippled) to another place. My Gran can be as batty as anything at times, but she'll say "I'm so happy" which is fantastic.

H.M. Isn't that great.

UV:8 In this place, they have things which stimulate her, various videos and Scottish Country dance music and things which she has known since childhood. She still lives with my Grandpa and she'll have a laugh "Take my advice" she'll say "and never marry a man!" (laughter), but if you said anything against him, she'd be the first to defend him.

H.M. Right, right.

UV:9 She'll listen, she'll listen. But if people constantly question, it makes folk feel uncomfortable. I'm trying to educate some of the congregation. One of the ladies who died had got terribly confused. Her sister had been confused and eccentric and

I don't know whether or not it was with just having too much, that she developed confusion as well. It was almost exactly the same behaviour, phoning me at 3 o'clock in the morning and seeing jobs in the paper for people and time meant nothing. She was moved into a place but, you know, it was always using money, using money all the time, hundreds of pounds, they would hand their purse over the counter, or give donations to the Church or hand their purse over to the taxi driver. They were both doing this. She actually died before her sister although her sister was the one who had really bad dementia. There's someone in the congregation who had been a life-long friend, who has a handicapped son who is in his fifties now. He's quite severely handicapped, although he can do quite a lot as well and has a great memory for dates and events.

H.M. Yes, yes

UV:10 He'd been up to see this lady, just before she died, and she'd said, after he'd gone out "There was a strange chap in here" and got very indignant and angry that he couldn't remember her son. She couldn't cope with the fact that this person who had known her wasn't recognising her son, she said "How dare you not remember my son and he's been round every week". This is when people start to draw in on themselves because they think, well, you know, I'm being doubted, I feel it can be reaction a lot of the time which can make people draw completely in on themselves.

H.M. Right, so the "acceptance" aspect would be very important.

UV:11 Acceptance is very important, just to accept. You know we've had things with my granny, she used a waste-paper bin instead of going to the toilet in the Nursing Home and we just had a laugh about it. She said "I always have a laugh with [UV]". The whole thing is, she's got this thing about me, she still thinks I'm about 16 and she laughs if we try to tell her I'm in the Ministry. At the same time she always thinks that everything I say is a joke, because she got it into her head "you always get a laugh with [UV]" and that's one of the things which stick with her and you go in and you want to tell her something serious and you say to yourself, right, I suppose I'd better be light-hearted!

H.M. Yes - right (laughter)

UV:12 Better give her a laugh. My brother's in [English City Name] and when he comes back she knows [Brother's Name]. He was away abroad and that confused her, being away threw her because he'd always been in for his lunch every day after school, when he'd been staying here.

H.M. Yes - yes

UV:13 When things are going well and everything's constant, there's continuity, but it's the unknown which knocks completely.

H.M. Right, yes.

UV:14 You know, moving. That sort of thing can be traumatic. I think you had it on your paper - I sometimes think that that is not so affective.

H.M. Do you not?

UV:15 It depends. You see I feel everyone is totally different and you've got to assess and if it's fine, it's fine. I can just give you an example.

H.M. Sure.

UV:16 To go back to the two sisters I was telling you about - one would have driven you batty at one point, you know, to the extent of talking about different things during the Service because she didn't really know where she was. She had always been eccentric, actually, so it was just an extension of the eccentricity sometimes. I took home Communion to her and she wanted Communion, but she was quite confused. You know, going through the sacraments, she was quite deaf as well and she kept saying "Eh?" and I'm quite loud so I would say "Have you got your hearing aid in, Jean?" "Eh?" So we'd look for the hearing aid and get it and, you know, start again.

H.M. Yes - yes (laughter)

UV:17 Then we got to the part with the bread and she was fine. I handed her the bread and said "the body of Christ broken for you", "is it blest?" she shouted "Yes, it's blest [Lady's Name]. Then we had to do the wine after that "I can't take wine for my stomach" I said "That's fine, [Lady's Name], you don't have to have it - it's not alcoholic". She then said, "Well, you'll have to wait a few minutes, I'll have to go in and take some milk first, I want to take the wine". However, if I felt someone was well enough, I would give them Communion but it can be difficult, you've got to judge. I mean, I'm the first one to give Communion to an older person.

H.M. Sure.

UV:18 to someone who misses the sacrament, but when it's at the stage when they're not remembering each bit as you go along, and you feel it's not having the spiritual input - just a reading or something like "the Lord's my shepherd" or even singing might be better. Psalms and things are good for geriatric folk.

H.M. There's one thing which I'm trying to explore and it's so hard to put a finger on it, that is, whether or not when mind and body are gone, if you can get at something of the Spirit

UV:19 That's right

H.M. Would you have experiences at all of folk who are in a very confused state and yet something triggers or you think, you know, there's something going on in relationship with God here?

UV:20 Well, in one of the Churches where I worked before, there was a lady who was quite bad, I mean her husband and she had been separated just through dementia. She kept thinking she'd be able to do everything and hitting with a stick occasionally and things like that. She'd been a lovely person, although I hadn't known her at that stage because I was only there for two years and she and her husband had been separated and sent to different hospitals. When I visited her, she kept telling me that the chap in another Ward was making advances towards her. She was quite deaf and shouting and everything. The thing is you've also got to lose the embarrassment with people like that, when you're visiting, because people would say to make the most of the accusations that nurses are poisoning them and suchlike. Now, families get embarrassed but it doesn't bother me, I'll say "What are they giving you, are they giving you arsenic?" - something to let the Staff know that you're not exactly taking it seriously but you're taking THEM seriously.....

H.M. Right.

UV:21 I mean, the Staff are wise, they know that people make accusations all the time. However, this lady had been so bad, I said to her "You know I think it's very rude of you pulling my hair, because, you know, I've come up just to see you and I was hoping to spend time with you".

H.M. Yes - right.

UV:22 So I went on to say to her "Do you want me to say a wee prayer with you?" She had been quite confused about everything - I find it helpful to wear a Collar, I wear a Collar most of the time.

H.M. That's interesting. Yes

UV:23 I wear a Collar most of the time for my work. I think, even for giving people a boost they think "well, here's my minister". People find it a comfort, sometimes, when they're frightened and things like that, to see a collar can be good. As long as it's not used to pull rank or anything like that.

H.M. Yes, yes.

UV:24 It's just - it is to be helpful.

H.M. Absolutely.

UV:25 I find, when people see the collar, this chap who was confused, I went one time without my collar and he had no idea, but the other time, he would just be looking at the Collar and pointing and it clicked

H.M. Right

UV:26 So this lady, I said a prayer with her. I just went over things which she's been through and things we'd talked about to help her to be able to trust a little bit more. You have got to pray so simply and then, at the end of the prayer, I didn't even look into her face at the time, I was just holding her hand and she was holding my hand so tightly and when I stopped, you know, there were tears on her face

H.M. Yes, yes

UV:27 and you know, obviously something got through - you don't know what, but something that is positive and good

H.M. Yes, exactly

UV:28 You don't know whether she's tuning in or God is communicating in some way, or just giving some peace.

H.M. Yes, yes.

UV:29 My Granny is so simplistic in her faith, you know, she'll start singing a wee song, she loves to sing "Jesus loves me", and when she sings, it's almost in "wee girl" voice. You can start singing things like that with her and "What a friend we have in Jesus" and some of the old Mission hymns

H.M. Right, right.

UV:30 and there's a sort of Scottish and Irish spirituality which comes from the music of the land, a creativity. something of folk culture too, I think a lot of it is identity.

H.M. Right, right.

UV:31 Obviously, it's harder in the spirituality line if someone has no church background at all, because it's very difficult. You can talk about a lot of things, and roots and suchlike, but I think that people's faith, their grounding as a child, is so important if they do become confused, because they can go back to something they've trusted in.

H.M. Yes indeed.

UV:32 I mean there are severe cases when you don't know if you're getting through at all - you don't know - but a lot of people are at the stage when there is still something - you know - it's a see-saw thing, very strange.

H.M. Oh yes.

UV:33 My Session Clerk's wife's mother stayed with them for long enough with dementia. She would talk to [Session Clerk's Wife's Name] as if she were someone

else. She would say "Oh, you're so nice to me, you know my daughter's not" and it was terribly funny. [Session Clerk's Name], my Session Clerk's super and she would tell him to get off the phone! (laughter) - I mean, I was in their house one time, and they were on the phone to someone and she said "You've been on the phone long enough - this isn't your house"!

H.M. You just have to laugh at some things.

UV:34 I know - I think the main worry, sometimes, is the way people are coping, you know families have to go through all the changes involved, about whether it's better to bring someone in, to live with them, or to move the person to a Home. If one is not confused at all and the other one is, it's very, very difficult. Also, once they've dealt with all that, then they've got to work on well, the relationship - the relationship.

H.M. That's right - it changes them utterly, sometimes.

UV:35 I know - yes - I mean - on your form, I think, there was something which made me laugh a bit, about whether you raised your voice to somebody and that made me laugh, because it depends on whether they've deaf or not. (laughter)

H.M. That's right!

UV:36 You repeat yourself as often as you have to. I keep saying it's [UV] you know, the Minister - I've been here before - I've seen your wife, you know you remind them of things. You've got to drive the conversation a lot, even if it takes three or four minutes. Sometimes, they'll be sort of indignant and say "I know you are!" - just checking, just checking! (laughter) But you know you need humour, a lot of humour - but I do think you have to have the patience of Job sometimes. I have seen Ministers going in and saying "I told you last week, when I was up", but you know they can't help being like that - I get confused enough about things myself! That's when people lose their confidence.

H.M. Yes, yes.

UV:37 it's good to take them as far as they can go - but not doing everything. I found that people were spoon-feeding my Granny and things like that, but I mean she could have done it herself - and now she can't, because in one of the places she was, well, it was just convenient - feed them quickly and that will be fine. At one time she was able to feed herself, but there was such a dramatic deterioration after she left my mother's house.

H.M. Right, right.

UV:38 I don't know whether or not I wrote on your form - there was one time my Mother was talking to my Granny, my Granny was chatting away and she said something about calling my Mum "[Relative's Name]", who was a relative who died

years ago, and my Mum said "How many daughters do you have Mum?" - I don't think she even said "Mum", "Well, there's [Pastor's Name], [Pastor's Sister's Name] - oh, how could I think you were [Relative's Name]?" and she had been quite away on a number of other things.

H.M. Interesting

UV:39 You know she feels threatened by television (I maybe wrote that down). But you know, rationalising on the level on which she's probably thinking is important - she's thinking of the immediate - he's watching me, I can't get changed....

H.M. Right.

UV:40 Well, I said "Well, Gran, I'm younger than you, he'll be watching me" and fine, you just address the problems as they come along. If you say "Don't be silly" then that can get aggressive.

H.M. Right, right.

UV:41 The thing about her teeth as well. You know I was just talking recently about the funny things which people with dementia do and the behaviour seems obscure and embarrassing, but if you don't let it be embarrassing, then you are better at dealing with the issue in hand.

H.M. Yes, you're right.

UV:42 You see, that's why families can't cope at all - with someone coming up, who has been a family friend for years and they don't recognise them.

H.M. Right.

UV:43 and they say "surely you know them" which shows they're not really thinking about the person who is confused. Instead of saying "surely you know them" say "Well, you know, [Girl's Name] was at your wedding" or whichever and you did such-and-such together and in the case of my Granny, she would think "Oh, well, I'm not being given a ride" and may say "How-do-you-do?" or something like that, but then occasionally she'll suddenly say "Oh, [Girl's Name]" - because she is feeling more secure - she's not being given a ride.

H.M. Right - and met where she is.

UV:44 That's right, exactly. It's all about where they're at. It's got to be where they're at and what their potential is - not where they are in their regressive sort of state, because you can actually take someone back towards that way, that's my thinking. You have got to stimulate someone as much as you can, you know, for example we ask my Granny a lot of questions, things which won't make her feel uncomfortable - we'll say "How are you feeling?" and things like that and "do you

know what day it is?" and she'll say "No!" and sometimes I'll say "Oh, I don't know what day it is either" - you know, you don't want to come in with the answer all the time - you know I ask as if I don't know the answer sometimes

H.M. Right, right.

UV:45 and it's sometimes a blessing, you know if you have had a severe bereavement in the family, to go and tell my Granny or anyone and they'll be upset, they'll react immediately, on the spot, but ten minutes later they've forgotten about it.

You may have to remind them if they're to be part of the conversation - so to keep them up-to-date there's a conversation going on to keep them from being upset again. I also think they SHOULD be part of whatever is taking place.

H.M. It's very important, yes.

UV:46 Public worship is very difficult because it can be upsetting sometimes. The sermon isn't all that constructive for someone with dementia, but I feel in Nursing Homes a small Service with hymns which people know and just a few words, even just to say "Jesus loves us" and then a short prayer and sometimes to get people to repeat after you

H.M. Oh, that's a good idea

UV:47 "Can you say these words after me" - I do it with primary children - sometimes you've got to use children's tactics and say "Do you want to say the words after me?" and if they get lost, well, it's fine - it's just very short phrases "we thank you that you love us".

H.M. Yes, yes, it's a nice idea.

UV:48 and "you are our Friend" - and this is all not so much in public worship, I'll do this in a Nursing Home - by a bed or something. I'll say "Do you remember hearing stories about Jesus, you know He still loves us" and the face lights up sometimes and this is great.

H.M. Right, yes.

UV:49 Hand contact - touch is very important.

H.M. Yes, you think touch is important.

UV:50 Touch is very important. If someone pulls away, then that's different. But I find, on nearly all my visits, I would take somebody's hand, sometimes at the moment when someone is confused I would take their hand and be quite close to them. I always say a prayer and my idea of a prayer is using what we've spoken about in the conversation, you know such things like - "we thank you for the time we've had together and being able to talk together". Also, reading into the situation of what

they've been saying, I try to give "feed-back" in the prayer but if someone is very confused, I may not give feed-back because that's not always going to be relevant. In that case, I would usually say "Would you like to say it with me? - Thank you for the time we've had together" or perhaps just say one line after me - you go back to the childhood Faith.

H.M. Right, right.

UV:51 I mean it's no great theology, it's loving God and loving everyone, that's the whole thing and accepting people.

H.M. reassuring them.

UV:52 and not condemning.

H.M. Yes, yes.

UV:53 I'm just trying to think of some of the things which I do use. I always give folk a wee kiss on the cheek and a cuddle. People who are older and who have been bereaved, and especially, I think, people who are quite confused, they're not used to physical touch and are unwilling to let go because you feel comfortable to hold on. I feel, sometimes, that people like war widows and folk like that, they've not had, the touch, because people are quite reserved and Staff don't go round hugging folk all the time. But I find this is easier because I'm female.

H.M. That's what I was wondering.

UV:54 I'm not - I mean, I never found there's all that much difference between male and female in the Ministry. From my point of view, I've got friends who are equally sensitive and all the rest of it. There're one or two things which I've been called upon to do, you know when people have lost babies and still-born births and things, when they wouldn't ask a male to go in, but they're quite happy with a female Minister. I've been asked through people whom I've known in other Churches. I think it's easier for a female to get away with giving a hug.

H.M. Yes, yes.

UV:55 because if a man went in, just say it was a married couple, you see I can give both of them a hug but guys would be uncomfortable about hugging another guy - (laughter) - I suppose it's an unfair advantage. It's important to be tactile. My Session Clerk and a number of our Session are very tactile; they will shake hands with men or women, which is really good.

H.M. It really is.

UV:56 [Session Clerk's Name], my Session Clerk is about 65 and he will have no problem in going up and taking someone's hand and saying "You know, I've been

thinking about you". My predecessor became quite confused, he's not confused now, but it was after having acute gangrene. You find that sometimes after operations people have this for a short term, or after strokes, you think it's confusion, but it's not. With him, it was just listening on my part and if there were questions, answering them and reminding him who I was again. I had this sort of thing after being on morphine, when I was very ill one time and when I was asked "Where does it hurt?" - that was when I got glimpses of strange things - and I replied "Behind the radiator" and I was quite conscious of saying that and of people being there but was just very, very confused about things and thinking "Why are these people here?"

H.M. Right - right.

UV:57 I was just very confused about things and I started to think, how much do people with dementia understand and how much of it is a failure to communicate?

H.M. Yes

UV:58 You know, that's one of the things. So, I never like talking; I don't talk about somebody, I think that's so bad. It's very hard, when you're with a family, perhaps when a person is dying and maybe just semi-conscious and they say something like "I don't think he's going to make it". To counteract this, I try to talk directly to the person and say "Well, we'll have a little prayer with you and do a wee reading". This is so important as otherwise people withdraw. I hate when people say something like "You know she's been awfully confused today", it's as if the person is not a person and that is so difficult. It's just a matter of trying to train people away from that but again it is harder for those who are closely involved.

H.M. Right, right.

UV:59 It's so strange because somebody dies and they'll say "Oh, it's been so difficult, because we feel we've lost them a long time ago" and I'll say to them, but you weren't able to grieve then, you had to work through that and in a sense I think it has been easier than they have admitted to themselves.

H.M. Right.

UV:60 It could have been really hard but because they've still been there, they have had to get on with it. People cope with dementia, sometimes, better than they make out. They'll say it's hell and sometimes it is, but they get to the stage when they do start accepting and it sort-of becomes easier.

H.M. Right.

UV:61 It's the transition which is the difficult bit.

H.M. Yes, I know what you mean.

UV:62 It's at the start, when "I can't find such-and-such and I've lost this" and they can't remember where they're supposed to be going

H.M. Yes, yes.

UV:63 I mean, one of my Elders came in yesterday and said he thought one of our members was getting dementia and I said that I thought it was really his arteries, because he has collapsed a few times in his house and in the Church. He has a twisted artery in his neck and has had black-outs for years. My Elder said that he would go out of the room and not remember where he was going, and apparently he had just sat, shaking his head, whilst his wife was telling all of this. But I said, "You know, his wife shouldn't really be saying all of this in front of him, because he will be feeling that he's letting her down".

H.M. Yes.

UV:64 I said that when he went back to do the visit, if he wanted, I would go with him. He said "Oh, I see what you mean. Do you think he'll be able to understand us?" I said "Of course he probably will and even if he doesn't understand everything, there will be parts that he'll understand". His wife had probably said those things out of embarrassment, you know there is apology all the time

H.M. Right.

UV:65 and it is so important to steer away from that.

H.M. It makes it very hard for the person.

UV:66 Yes, it's hard for the person - it's hard for both because I mean, it really is just so hard for both, because one person is not recognising the other, part of them tells them that they're not recognising someone that the other person is with. One gets uncomfortable and the other gets withdrawn.

H.M. Withdrawn, yes.

UV:67 My friend, [Man's Name], who is a Minister, also, is really terrific. He was always great with my Granny. You know we're friends but we've never gone out together. My Granny thinks he's wonderful and she'll even forget who he is sometimes and say "that's a wonderful chap [UV]'s going out with" and [Man's Name] will say "Oh, I see, tell me more about him". (laughter). But, you know, we went away to an optician one time and again, that's confusing for my Granny. You know, it's a strange thing because I think she can see, but she'll pick up a photograph or something and she won't look at it properly and never sees what's in it; and she'll look at me, sometimes, but she's not focusing on ME. But what she will do is - for example, the optician will ask her if she can read such-and-such and she won't reply - just silence. Then I'll say "Gran, tell him what you can see". "Well, I think I can see a wrist and a finger..." and I said "But what's the finger pointing at?" - but obviously

she wasn't concentrating. I said "Gran, we're trying to get you specs - " "Well, these ones I've got on are quite comfortable" (laughter). However, eventually, when people stopped pressurising her, she was able to read off all the letters.

H.M. Really?

UV:68 You know, it was strange. Because she'd been good, we decided to take her out for a fairy-cake and she picked it up and crammed the whole thing into her mouth (laughter). This is all part of another sort of regression - when people have been deprived when they're young - I find this a lot with people who are confused, they will want to sup sugar out of a bowl, they will want to stick their fingers into the middle of a cake - childish things.

H.M. Yes? Right.

UV:69 Also, when something smells nice, they can't ascertain whether it's food or perfume. They want to stick it on their wrists, as if it's perfume. It seems obscure behaviour, but I think you can understand it. Or, if there's a bit of ribbon on a wrapper, they'll pick it up and stick it on their hair.

H.M. Yes, it's logical enough.

UV:70 Yes - you know a child would do that. It's the childish impulses which come out - but with my Granny, I'm not embarrassed at all - it doesn't bother me. She could pick up the whole cake on the table and stick it on her face and I would help her get it in her mouth! People around about are more comfortable, if you're at ease. At my brother's wedding, my Granny was so confused - and with a hat on, she looked so funny! We thought my friend [Man's Name] is the best one to sit beside her, because he'll help her with her food and, whereas some other relatives will want to feed her, [Man's Name] will cut up her food and then hand her fork to her.

H.M. Oh yes.

UV:71 so that she thinks she's doing it herself. He is very good with her, so gentlemanly, and she feels special.

H.M. Exactly.

UV:72 But when you're sitting there and you're the only one who is being spoon-fed.

H.M. Yes, it's demeaning.

UV:73 That's what I feel - she could easily become lazy. You have got to keep someone going and talk about different things, and for Staff - I think it's good for Staff to remind them of what day it is occasionally. I like places where they do this and have a Menu and this sort of thing. If they can read, I feel this is all quite helpful. The awful places are where everyone sits in circles.

H.M. Yes, yes.

UV:74 I mean in the place where my Grandmother is and other places round about here, they have a small room about this size where there are seats all round, but there is a focal point, and they have a video and country dance music or something that they can take part in. I tell you it's so good for my Granny, and she loves it. They have fiddle groups who come in and most of the residents just love it. Music is wonderful. Again, it's all sense, smell, touch.

H.M. It brings in everything.

UV:75 Yes.

H.M. That's been a tremendous help, it really is.

UV:76 I don't know. Most of it to me is just common sense. I haven't done any research into it as such, apart from reading things and I was at a Conference on dementia, a few years ago, at New College. This made me realise that carers need a break and things like that - I also feel that carers need training.

H.M. Absolutely.

UV:77 you know, about keeping somebody's dignity all the time. I like them to have their dignity, you know, and that is spiritual as well. You see, sometimes you feel that, as a Minister, you can't do very much on the spiritual line, but to me, spirituality is just being with someone.

H.M. Right, right.

UV:78 Jesus got alongside people. He wasn't issuing prayers all the time, it was a working conversation in life. It was being there as love, in flesh, and to me that's what the ministry is all about - the acceptance of someone and loving them and doing what would be the best for them.

H.M. Yes, yes

UV:79 No hidden agendas - just accepting them. Every situation is different, you know every person with dementia is different, just as every person is different.

H.M. Exactly.

UV:80 I feel that we can't generalise, although we can generalise on certain things like forgetfulness, you can generalise on symptoms, sometimes, but not on the person. You know, there may be the same symptoms in any of us, but we do show them in a different way. You know, someone can be scared by dementia, someone can be quite undisturbed

H.M. Sure, sure.

UV:81 and quite happy, singing all the time.

H.M. That's right, it's amazing.

UV:82 Also, there's the violent behaviour and obviously you have to react to that as well, rather than saying you can't do that, I've actually taken someone's hands firmly and said "Now, come on, you don't need to do that, I'm just here to talk to you".

H.M. Did that make a difference?

UV:83 Well, she got her walking-stick and was going to hit me with it and I said to her sternly "Do that again and I'll break your walking-stick in half" (laughter), she said "You wouldn't" and I said "I would". The fact that she started talking, it engaged her in something. They want to touch your face sometimes, as well. Also, and I've only had this about two or three times ever, not with males, but with females, wanting to touch your whole body and running their hands down your body and you don't know whether it's a sexual thing or something like that. They'll sometimes take your hand and put it on their breast or something

H.M. Right, right.

UV:84 and that can be uncomfortable and I sometimes don't know exactly how to deal with that.

H.M. Yes, yes.

UV:85 I don't want them to feel uncomfortable about their bodies or anything like that, but I feel that there's something sexual dysfunctioning here. I can understand this being embarrassing for family, and the person, herself, seems to be disturbed by it usually. I just took hold of the person's wrists and hands, rather than reacting badly. I think that when the clothes start to come off a little bit of scolding is good.

H.M. Exactly.

UV:86 There was an old man who used to annoy everyone in the place. He was quite confused but he'd catch you and say things like "Let's see your chest". Probably he had been a bit of a Casanova in his day and it wasn't really out of disrespect for females either. The ladies were all so lady-like and he would do indecent exposure all the time. So what I would do, until he started to behave himself, was to turn his wheel-chair in the opposite direction! I would say "This is not fair, other people don't like it". I found, sometimes, ignoring it as well was quite good, because it was an attention seeker.

H.M. Right, right. What I was hoping to hear, what I need to hear, are the stories and this is terrific.

UV:87 Well, I couldn't get by without humour. You know it's repression as well sometimes and I've had a few discussions about it with colleagues - is the soul awake to anything?

H.M. Yes.

UV:88 and that brings in spirituality. There are certain things and not necessarily things which are "Churchy" which cause emotions and to me, emotions come from the soul.

H.M. Yes, yes.

UV:89 So even if it's not reading about something, but talking about something which has raised an emotion, that, too, is spiritual in a way. But you know you wonder how much - you know somebody moves on - when I have a funeral of someone who has been confused and perhaps they have had difficulties with their confusion and life didn't have the quality which it once had for them, or, there is the other person who has been confused but has seemed very happy with their confusion, so that life had quality

H.M. Absolutely.

UV:90 so there are different things which I bring out - I do very much life-centred funerals - some remain a character to the end.

H.M. (laughter) - yes, yes.

UV:91 So I think it is very, very different. Now my Granny - now my Granny's my best example and my Grandpa's a character as well. He was driving the car when he shouldn't have been on the road. The Doctor said to him "You know, I don't think you should be driving" and my Grandpa would say that he was perfectly fine but he was stiff, you know, his responses wouldn't be so good and the Doctor said "These roads are very difficult now, I find it really bad" and my Grandpa said "That's because you young ones drive too fast" (laughter) but my Grandpa was so good, because there were times when he was accused of everything, of drinking and things like that. My Grandpa would take my Granny up the town to pay the rent, she would go in - and my Grandpa who has had no training in anything from a human relations angle anyway, he would be waiting in the car - and my Granny - he wouldn't see her anywhere and she would have got the bus home.

H.M. Right, right.

UV:92 Then she'd accuse him of drinking and everything and, you know I suppose he was quite annoyed with her, but he would try to say "nothing of the kind", but she would doubt him. But, at the same time I could never be hard on him getting annoyed - and he would sometimes make the soup and my Granny would criticise him because the vegetables were too thick, she liked it a bit thinner. But my Granny

would say "we have the loveliest bit of chicken for tonight [Grandpa's Name]" - and every night it was the same, oat-cakes and cheese! (laughter) - He took her along to a Supermarket, now this is the level of caring, and he would have written a list and she'd go in and give it to the girls there and he would reverse the car so that he could see her and watch her, and then get her back into the car - and if there were problems, he would go and see my Mum. She would often try to go out walking and he would say "Now, you must stay in the house, [Granny's Name]" "No, I have to go out, you cannot keep me here"

H.M. Right, right.

UV:93 but he was just so brilliant about it - especially for a guy that was so Macho and had everything done for him. He really is brilliant, because, he felt in one of the places they were staying in, that she didn't have her dignity - the place where they were sedating her - she had once or twice had incontinence and it was because she had a urinary infection and they never even got the Doctor in. But what they thought was that she shouldn't have a proper nightie, just something down the back, well my Grandpa said "My wife is no being treated like that, she's wearing her nightie". They said he was being aggressive, but I understood and I stuck up for him. "Look, if Granny doesn't want to wear it, she's not wearing it - she wants her nightie, she wants her dignity, she likes her pretty nightie".

H.M. Exactly, yes.

UV:94 she doesn't want to be told she has to wear something, like a hospital gown, just because it's convenient. They say "Well, we've got to look after her" and I thought the whole thing is, do we look after her as an animal or as a person.

H.M. Exactly, that's the key to it all

UV:95 and they're short-staffed - now, she's in a place where she can be so confused, but so happy.

H.M. Right, right.

UV:96 Occasionally, she'll have an outburst. It's run by an ex-social worker and he's just so good because there are guys there as well and most of the guys haven't dementia - some people are just mildly confused, my Gran is probably the most extremely confused there, but they're all so protective of her

H.M. Isn't that lovely.

UV:97 One of the other guys had been a farmer and he loves the Church, I think he was Plymouth Brethren or something, and he always says "Oh, it's [UV], are you going to say a prayer with us?" (laughter) - and he will look after my Granny, and if there's some member of Staff that he's not been happy with, he'll tell us - but, on the whole, the Staff are very good. They'll get cross with Granny if she goes up and

wanders around in front of the television or something like that, but they're really very good. Also, not everyone has the wherewithal to have patience all the time - so, I mean I can understand - but this guy is just so nice that he tells my Mum - you know, he'll say "She's just a lady"! He looks after my Grandmother when my Grandpa's in hospital and he makes sure she's OK. and has sweeties on her table - (laughter)

H.M. Yes, yes

UV:98 which, to me, is what it's all about

H.M. Exactly.

UV:99 when people who are staying there are nice to one another. I've been in so many places where there's no communication between residents or it's been fighting all the time, you know "My chair!", "My cushion!". There was one lady who used to shout all the time and Grandpa used to shout back at her, you know Grandpa's cruel! But he's so witty, he started quite a bit of banter with this old lady - they went through a difficult time, in the Home, because one old lady was quite confused and fell down the lift-shaft and got killed. They were just putting the lift in, one that has seats, and it's just a two-floor building, but they probably thought it would be easier for people, because the stairs are quite narrow. This is the problem with confused people wandering, now they had everything - barriers and everything. However, when the workmen had been there, during the day, she had been talking to them because she discovered they were from the same road in Glasgow, which she had been brought up in, and she had gone to bed about 8 o'clock and about 9 o'clock, some of the residents were still up and heard a tremendous crash. What happened was that she'd crawled under three barriers

H.M. Oh, dear

UV:100 she was looking for the men and they had heard her shouting, calling to the men, and she died in [Man's Name]'s arms, that is, the guy who runs the Home

H.M. Right, right.

UV:101 apparently she said to him "I was looking for the men", sort of apologising to him and my Grandpa said "Do you think she might have meant to do this?" and I said "No, Grandpa, I don't think that at all, it was confusion" and he said "I hope your Grandmother doesn't do anything like that" - and the police came in to see if there had been negligence on [Home Manager's Name]'s part - now, there hadn't been. [Home Manager's Name], who runs the place was in tears. It was just one of those unfortunate accidents.

H.M. Right.

UV:102 But that's the sort of danger which people with dementia are in as well. I mean - cooking - my Granny - the gas, we used to worry thick, you know. I mean, I

know if my Granny fell in the lift-shaft, it would be confusion, it wouldn't be negligence

H.M. That's right.

UV:103 and also, it's the same as walking in front of a car and wandering outside in a nightie.

H.M. That's right - [UV], this has all been tremendous.

UV:104 Sorry, (laughter) you'll have to do a bit of adjustment.

H.M. Thank you so much.