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I SEE YOU

**EXPLORING THE STORIES OF PEOPLE WITHOUT DEMENTIA WHO
HAVE MEANINGFUL CONNECTIONS WITH PEOPLE WITH ADVANCED
DEMENTIA**

FRANCESCA GREENWOOD

**Thesis presented in fulfilment of the requirement of the degree of
Doctor of Philosophy**

THE UNIVERSITY OF EDINBURGH

2020

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree. Except where states otherwise by reference or acknowledgment, the work presented is entirely my own.

Francesca Greenwood

Date.....

Acknowledgements

This thesis is dedicated to my Nonnas. You both loved much and were and will always be loved much.

Firstly, I thank all those who took part in this study and shared their stories with me. It was a privilege to listen to your stories. You taught me so much and I am truly grateful.

I thank my supervisors Professor Heather Wilkinson and Rev. Dr. Harriet Harris for your never-failing support and encouragement to keep going, especially when it got tough. Thanks also to Seamus Prior, a “critical friend” who brought invaluable insight to our annual reviews.

Thanks goes to the Ecred tribe and my friends at the University, especially to Julie Watson, an encouraging and honest voice and an inspiration to follow this line of research.

Special thanks to Bev, Den, Freda, Graham, Lynne, Steve, Lesley, Mark, Rachel, Ellen and Irene, for your continued support, love and friendship.

Thank you to mum and dad, for your love and patience, especially when writing this thesis meant I couldn't see you both for a while. Thanks to my brother and sister for your prayers, your love and your incessant ability to keep me grounded with your humour and wit.

Thank you to the two most precious people to me on this earth, Adam and Aaron. Thank you for who you both are. Love you to the moon and back, plus one.

Most of all I thank my husband Mike. You have believed in me right through this process even when I did not believe in myself. You have listened, encouraged, hugged me and given me a push to keep going. You have been my steadying force and I truly could not have done this without you. *You see me.*

Abstract

Dominant narratives in a hypercognitive Western society invite others to see people with advanced dementia as those whose human identity is disappearing and fading away. Dementia is often presented in catastrophic and terrifying terms and people with advanced dementia may be positioned as a “non-person” (Lesser, 2006, p58) and as “already in the house of the dead” (Post, 1995, p136). This leads to a perception that people with advanced dementia cannot be known or understood as they are no longer seen as an “active agent within their relationships” (Watson, 2016, p0).

People with advanced dementia may begin to feel invisible in a world that seems to value independence, memory, clarity of mind and the economic productivity of a person.

Additionally, people with advanced dementia are often positioned as a burden on their families and on society, and as Mary Warnock said that they are “wasting people’s lives...and wasting the resources of the National Health Service” (Beckford, 2008, para.10).

Narratives like this are not only inaccurate but are dangerous for people with advanced dementia. They dehumanise the person with advanced dementia. This can lead to marginalisation, isolation and poor care. It may even influence the way in which people think about how dementia should be treated, “including medically assisted death” (Johnstone, 2011, p390). People with dementia can be perceived as no longer belonging to society and feel “unworthy of being treated as a human being” (Sabat, 2008, p83).

The main aim of this doctoral research is to explore stories that counter the dominant dehumanising narratives and instead position people with advanced dementia as fully human persons.

This PhD research takes an interdisciplinary approach that has blended sociological and theological concepts. It has applied these to the findings of an empirical study that explores the experience of making meaningful connections with people with advanced dementia.

The research employed a narrative methodology drawing on the work of Arthur Frank's (2010) *Socio-Narratology*.

Seventeen narrative interviews were carried out with a range of people without dementia that had experienced meaningful connections with people with advanced dementia. The interviews explored the experience of meaningful connections with people with advanced dementia.

Participants included family members of people with advanced dementia, care staff who worked in residential care homes for people with advanced dementia, spiritual carers who supported people with advanced dementia, and Elderflowers who are professional arts practitioners who work with people with advanced dementia using clowning techniques.

Findings were discussed within a Christian theological framework of hospitality (Swinton, 2012, Sutherland, 2006) and drew on the writing of Professor of Old Age Psychiatry Julian Hughes' (2014a) aesthetic approach to people with dementia.

The stories revealed in this research and discussed within the above framework trouble and challenge the damaging and dehumanising narratives that position people with advanced dementia as a non-person and burden. The stories in this research provide a counter story that calls others see people with advanced dementia as fully emotional, physical and spiritual human persons who are valued; loved; known; belong and continue to be aware of and experience the world.

Lay Summary

We live in a society where people with advanced dementia are often seen as those whose human identity is disappearing and fading away. People often talk about people with advanced dementia as those who are already dead, no longer there or that they are no longer human. People with advanced dementia might begin to feel invisible in a world where we seem to give more value to people who are fully independent, have good memories, a strong mind and who are economically productive.

Some people think of people with advanced dementia as those who are a burden to their families and to society. In some cases, euthanasia is considered to be a suitable alternative to living with dementia.

These types of narratives about people with dementia are dangerous. They lead to marginalisation, isolation and poor care. They dehumanise people with dementia.

The aim of this doctoral research was to explore stories that would counter these dehumanising narratives, with a specific focus on the humanising stories that are told about people with advanced dementia.

I explored these stories by interviewing people without dementia who make meaningful connections with people with advanced dementia. Those people included family members of people with dementia, spiritual carers, Elderflowers, who are professional arts-based practitioners who use clowning techniques to engage with people with dementia, and care staff. I carried out 17 interviews in total.

When I analysed the stories, I found that they troubled the dehumanising narratives, and narratives that position people with dementia as a burden. Instead they position people with advanced dementia as people who are loved and valued by others, as people who continue to fully belong to society and make an impact, as those who are able to connect and engage with the world and people in the world and who are a whole, physical, emotional and spiritual human person.

These stories provide a counter-narrative to the dehumanising narratives that continue to exist in our society about people with dementia.

Overview of the Thesis.

This is a qualitative study that explores the stories of people without dementia who have meaningful connections with people with advanced dementia. It draws on sociological and theological concepts as it explores those connections.

In chapter one I give a brief introduction to how dementia is framed in Western cultures and the challenge that dominant dehumanising narratives bring to people with advanced dementia. I then tell my story and how I decided on the phenomenon I wanted to investigate. Mason (2002, p7) writes that the qualitative researcher “should seek to understand their role” in the generation of data and knowledge in the research process. Chapter one is an attempt to reflect on and make transparent my influence on the focus of the study which inevitably influences the generation of data and knowledge.

In chapter two I present a review of the academic literature that leads to the rationale behind my research aims and research questions. I draw on a broad base of literature that shows how people with advanced dementia are often dehumanised in Western Society, thought of as a non-person and are vulnerable to isolation and poor care. I review different perspectives of personhood and humanness in Western society. I then consider how the perspectives of personhood that counter the dehumanising narratives about people with dementia have changed the landscape in terms of how people with advanced dementia are noticed as fully human persons. Lastly, I focus on literature that explores the experience that individuals without dementia have in seeing the person with advanced dementia as a fully human person.

Chapter two concludes as I identify the gaps in the research and highlight the need for further research that can contribute to knowledge. I then present my research questions.

In chapter three I set out my ontological and epistemological position. I describe the narrative methodology I employ in detail and explain why I used this methodology in my study. I then detail the method that I used in this

study including recruitment procedures, data collection and method of data analysis. I also discuss the reflexive method I adopted throughout the data collection and analysis process.

In chapter four I present the stories of twelve of the participants who took part in my study.

Chapter five presents the findings that emerged from the analysis of the stories shared in this study. I discuss what the stories make visible in terms of how people without dementia make meaningful connections with people with advanced dementia, and the narrative identity that is made visible for people with advanced dementia.

In chapter six I present my key contribution to knowledge and then discuss the findings of this study within both a sociological and theological framework.

In chapter seven I present the limitations of my study and make recommendations for future studies, policy and practice. I then draw this thesis to a conclusion.

The terms “advanced dementia” and “meaningful connections” appear throughout this thesis, and I provide clarification of how I have used these terms throughout this study.

- **Advanced dementia** - is a term that is sometimes used when a person is in the later stages of dementia. In this study I refer to a person with advanced dementia as a person with dementia who is likely to experience significant deficits in memory, difficulties in communication as their ability to communicate verbally may be minimal, difficulties with everyday activities and likely to be increasingly frail (Alzheimer’s Society 2019, Mitchell, 2015).
- **Meaningful connections** – is used in this study to signify an interaction between the person with and without advanced dementia that has left the person without dementia feeling some, or all of the following ways:

1. Deeply emotionally moved or touched.
2. Feeling that they “know” what the person with advanced dementia was communicating.
3. Able to see the person with advanced dementia differently to how they had seen them before.
4. Able to recognise that they share the same feelings or reactions as a person with advanced dementia – a shared humanity.
5. Noticing that the relationship has moved from one of being the carer to the cared for by the person with advanced dementia, or noticing the relationship has an equal standing.
6. During a meaningful connection the person without dementia encounters the person with advanced dementia, and the person with advanced dementia appears to encounter the person without dementia as they connect with them in a way that appears to be meaningful for them too.

I SEE YOU

I see you in the light in your eyes

I see you in the faintest smile

I see you in the repeating tap of your arm on the chair

I see you

I see you there

I see you in the quietest breath

I see you in the rise and fall of your chest

I see you in the lines on your face, the shape of your jaw

I see you

I see you there

I see you in the softest touch

I see you in the squeeze of my hand

I see you as you notice me there, relaxing your muscles in welcome

I see you

I see you there

I see you as I wonder if this will one day be me

I see you whole, you now, you you

I see you; I see me, I join you and we meet

We see us

We see us there

Francesca Greenwood

October 2019

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Chapter 1 Introduction

Dementia, in Western cultures, is primarily framed as a medical concept, however dementia is a process that has personal, social and relational aspects to it. Dementia is a major cause of both “disability and dependency” among older people throughout the world (World Health Organisation (WHO), 2019, para.3) and as dementia progresses this dependency increases. People with dementia continue to experience the world, and continue to contribute to society despite the many challenges they and their care partners face (Alzheimer’s Disease International (ADI), 2019) both financially and in terms of their physical, mental and social well-being (Alzheimer’s Society, 2014, Kahn et al, 2016, WHO, 2017). Many of these challenges are exacerbated and by the way in which people with dementia are positioned and treated by other people in society.

Whilst there is both a global and national focus on research for a treatment, cure or prevention of dementia (WHO, 2019, Department of Health, 2015, Alzheimer Scotland, 2019) there is currently no known cure. In the last three decades there has been an increase in understanding that attention needs to be paid to the social and psychological aspects of the illness, and on the person with dementia (Hughes, 2014).

From a neurological, clinical perspective, dementia is understood to be an umbrella term that describes a group of symptoms, that can be caused by “any number of diseases” (Post, 1995, p4). It is the product of damages and changes occurring to the brain cells (Swinton, 2012, Macdonald 2018). The symptoms are often associated with a decline in cognitive skills such as memory and thinking. Dementia begins to affect someone’s ability to carry out day to day tasks to the extent where it begins to impact on one’s daily function (ADI, 2019a, Swinton, 2012, Gale et al, 2018, Alladi and Hachinski, 2018).

Dementia has a significant impact on the lives of the people who are currently affected by dementia and those around them, from a personal, social and relational perspective.

A major challenge for people with dementia is that they are often dehumanised in our Western society. A society which places great value on rational thinking, “economic productivity”, “clarity of mind” (Post, 1995, p5) and independence and memory (Swinton, 2012). People with dementia are often denied their human rights (WHO, 2017, Camp, 2019). They can experience social isolation due to the stigma that surrounds dementia (Bartlett et al, 2017) and receive poor care (Camp, 2019, Pachana, 2019). This dehumanisation can become increasingly more apparent for people with advanced dementia.

Aileen Barclay’s article about her “journey into the world of dementia” (Barclay, 2012, p95) with her husband who has Alzheimer’s, describes this dehumanisation. As her husband’s Alzheimer’s progresses and he is now in full-time nursing care, she writes: “He has become a nonhuman person, a stranger, to those who are building their successful happy lives. Few people visit him” (2012, p95).

Camp (2019) presents examples of how people with dementia are dehumanised in his paper that calls for a change in the paradigm of dementia care. Camp (2019, p221) terms this paradigm as one of “learned helplessness while waiting for “the cure””. He uses the example of the story of a conversation he had with his colleague who was at a dinner party and was discussing the dental problems of residents with dementia in a nursing home. Another person at that dinner party replied: “Well, why don’t they just pull all of their teeth before they come into a nursing home?” (2019, p221).

Some people think that dementia represents social and biological death (Beard, 2017) or is the death “that leaves the body behind” (George, 2010, p586). People with advanced dementia may be described as no longer there (Swinton, 2012), an empty shell, or “already in the house of dead” (Post,

1995, p136). These dehumanising narratives can lead to a sense of hopelessness (Beard, 2017, Camp, 2019). This is reflected in a recent study that explored the impact for physicians in the Netherlands who get requests for euthanasia for people with dementia, it was found that:

according to some participants, society considers dementia as a disease with hardly any quality of life, with euthanasia being perceived as a more dignified alternative (Schuurmans et al, 2019, p5).

In this thesis I challenge these dehumanising narratives through the stories of people who make meaningful connections with people with advanced dementia. These stories have the potential to bring a sense of hope to the lives of people with dementia and those who care for them. In doing so a key contribution to knowledge is made as the dominant dehumanising narratives are troubled and others are invited to notice the ongoing “humanness” of the person with advanced dementia.

I now tell my personal story that gives the background to this study before presenting how I came to understand the landscape that led to the aims of this research.

1.1 My Story

1.1.1 Knowing People with Cognitive Impairment and Dementia

My motivation for this study comes largely from my lifelong personal experience of knowing and spending time with people with profound cognitive impairment and dementia.

I grew up with my cousin who has hydrocephalus and severe cognitive impairment. As a child I frequently spent days with him and his friends from his special needs school joining their school outings, loving every minute of it. I also spent many a day in school holidays in the “old people’s home” that my mum used to work in as a hairdresser. I used to love going and spending the day with the “ladies”, (who I now realise all had dementia), walking around

the garden with them, joining them for dinner, and sharing sweeties while my mum worked upstairs doing their hair.

My grandma, who passed away twenty years ago, had dementia. I remember fondly how she would smile and giggle when one of her grandchildren or children entered the room even when her dementia was advanced. If you placed a picture of her brother in her hand, she would take it and kiss it before giving it back to you. I remember the love and care my grandad showed her as her dementia progressed. The tough, traditional Italian husband whom she had cooked and cared for all their married life was now the one who sat by her beside her. He moved his bed into the downstairs living room where grandma now slept so he could stay next to her day and night.

Growing up with my cousin, knowing my grandma with and without her dementia and spending time with people with dementia as a young girl meant that in my mind people with cognitive impairment and dementia were just people who communicated in a different way to me. They were still people who loved much and were deeply loved.

1.1.2 Work with People with Cognitive Impairment and Dementia

Before I started the PhD journey, I had my own small business through which I provided music workshops for, adults with learning disabilities, some of whom had complex and profound disabilities, and for people with dementia in care homes in my local area.

During the workshops for people with dementia we would sing, dance, play percussion instruments and interact with different props. Some people with dementia were able to hold a coherent conversation, remembered who I was and why I was there. Some were physically able to get up and dance. Others had lost the ability to speak in way that was easily understood by others, were frail with limited mobility and their memory function was reduced. Some people with dementia appeared as though they were sleeping or were unresponsive before the workshop. I remember being struck when I first

started doing the workshops at how animated and joyful they became as they heard the music. People with limited mobility began to move their feet or hands in time with the music, and many with limited speech would begin to sing or hum along and join me in a song.

On one occasion, I had sensed by the way that he was trying to make eye contact with me, that a very frail older gentleman in a wheelchair, Tony, wanted to dance with me. I assumed that Tony had limited speech and diminished cognition. Given that Tony was frail I was anxious that if I did try and dance with him, I might not be able to support him and would cause him to fall. Unbeknown to anyone else, I purposely avoided coming too close to Tony so that I wouldn't have to acknowledge that he wanted to dance with me.

Tony made it known to the care staff that he wanted to dance with me. They called me over and as I approached him, Tony looked directly at me and said in no more than a whisper, "*you don't want to dance with me, do you?*" In that moment I realised that Tony appeared more attuned to me than anyone else in that room. Tony knew I was avoiding him. As I stood close to him, and heard him, I knew that dancing with me was important to Tony. I had tried to deny him that opportunity by avoiding him because of my own fears and anxiety.

Moved and somewhat ashamed at my attitude, I decided to face my own fears and I asked the care staff to help us dance. The staff were able to stand behind Tony and support him as he stood up, and we all danced together. Tony and I had tears running down our cheeks in a moment of what I understand to be a true connection. I felt Tony had shown me what it meant to really see and know another human being through what I felt was an almost ineffable connection. In our joint meaningful connection, I was empowered to go beyond my own fears and share a moment of joy that would not have been possible if I had continued to see Tony as a frail old man with dementia whom it was best to avoid because of my own fears.

That moment was a gift to me, and it remains with me. It also gave Tony space to express his wishes and his emotions and be noticed and valued for who he was in the present moment as we both shared the fullness of our humanity; our emotions, our vulnerabilities and frailties, our desire to truly relate to another person beyond fear and anxiety, and our ability to share joy in a precious moment in time.

I have no doubt, through my experience of spending time with people with cognitive impairment and dementia, that cognitive ability does not diminish a person's humanity or ability to contribute to others in the world. Moments like the one with Tony, time with my own grandma with dementia and the "ladies in the old people's home", reinforce my belief that people with dementia continue to be fully human and bring a gift to the world.

1.1.3 The Reactions of Others Towards People with Dementia

I noticed that when I spoke about my work with people with dementia in general conversation people would often react in horror and despair at the thought of ever having dementia. Reactions of fear of losing memories, not knowing anything, losing independence and thoughts that people with dementia no longer contribute to the world were not uncommon. As I spoke of my experiences of interacting with people with more advanced dementia in my music workshops however, I noticed how surprised people often were as my stories appeared to challenge their understanding and perspective of dementia.

Alongside running my own business, I was also doing an undergraduate degree in Psychology. During the degree I had studied a module on dementia that revealed how little time and attention people with advanced dementia are given in some residential care homes. I was becoming increasingly aware of the stigma that surrounded dementia and how people with advanced dementia were sometimes dehumanised and thought of as no longer a person, which in turn could lead to isolation and poor care. I found myself incredibly moved and disturbed by what I was noticing.

Coming to the end of my undergraduate degree I began to think about what my next steps might be in my life path.

Aware of the tension between my own experiences of profound, meaningful encounters with people with dementia and my awareness of the dehumanisation that people with dementia could face, I found myself wanting to tell people about the way in which people with dementia responded to music so that others might see them as the fully experiencing human being that they were.

Adding to this tension was my belief through my Christian faith that all human beings are created by, and in the image of God. I believe that we continue to be held and loved by God, and that it is impossible for any person to ever be less than human regardless of cognitive ability.

Just over 4 years ago, I sat in my local church service and heard the words from Proverbs 31:8 spoken: “Speak up for those who cannot speak for themselves”.

I decided that I wanted to explore how the voice of people with advanced dementia could be heard so that they would be seen by others in society as human beings who continue to be in and experience the world.

I approached my undergraduate tutor and explained what I wanted to do. She encouraged me to explore PhD opportunities that might make this possible.

1.2 Understanding the Landscape and Aims of the Research

As I began my PhD journey, I explored why people with advanced dementia were often spoken or thought of and treated in dehumanising ways. I began to trawl academic literature to gain a deeper understanding of this phenomenon. I discovered the long-standing narrative that positioned people with dementia as having a “death sentence” (Bartlett and O’Connor, 2010, p98) or as being “already in the house of the dead” (Post, 1995, p136).

I found evidence of the high prevalence of stigmatising and dehumanising attitudes toward people with dementia (Bruens, 2013). Dementia was framed as being catastrophic (Johnstone 2011, Peel, 2014, Bartlett and O'Connor, 2010) and meant “losing one’s identity” (Johnstone, 2011, p382). I also came across a paper that investigated the way in which Alzheimer’s disease was possibly used in public policy in Australia in the debate on legalising euthanasia (Johnstone, 2011). The paper found that metaphors around Alzheimer’s disease “mediate public opinion supporting the legalization of euthanasia as an end-of-life ‘solution’ for people with the disease” (2011, p377).

This evidence jarred with my own experience of people with dementia, and with my own sense of what it meant to be a human being. I found it troubling that dehumanising narratives were being used to support euthanasia as a solution for dementia. I wanted to design a study that had the potential to counter these dehumanising narratives.

1.2.1 Thinking About a Research Design

My initial thoughts about the design of my study were that if people saw people with advanced dementia in a situation where they became more animated and communicative then they would have little option but to acknowledge their humanity. I considered carrying out research that explored the impact that sharing in a musical activity with people with advanced dementia might have on the way in which a person without dementia might position a person with advanced dementia in terms of their humanity. My rationale behind this idea was that I had personal experience of noticing how animated people with advanced dementia could become when they heard music. There was an increasing provision in the UK and other Western countries of musical activities for people with dementia in local communities and within institutions (Hara, 2011). The positive impact that music had on people with advanced dementia (Sacks, 2008, Kontos, 2014) was evident in much academic literature.

I felt I had grounds for this type of study both theoretically and practically. When I spoke of my ideas about music with colleagues and supervisors, I was asked why I only wanted to use music in my study. I found myself unable to answer this question.

I wrote in my research diary on 29th September 2016 following a supervision meeting: *“It was also confusing as to why music was important.”*

On 31st October 2016, as I began to think about whether I could answer this question I wrote:

There is something that must happen as we work alongside people with dementia. The focus is on what we can offer the person with dementia, but do we ever stop to consider what they offer us? Do I need to consider reciprocity? Is this where I go here, do I need to look at music as a two-way communicative language that helps us identify with the other person? Is it embodied? Why do we connect through music? Do I need to forget music all together?

On 3rd November 2016 I wrote:

What happens in that moment when we suddenly see someone with dementia as “the same as me”” people are people”. That’s what I want to capture...what is that called? Is it a feeling, a connection ...a something? What does it look like, how can it be articulated – is it a meeting of two souls, a recognition – a touching of something deep inside.

1.2.2 “Locking In” – Discovering John Swinton

As I continued to search the literature, I came across an article by John Swinton (2014): “What the Body Remembers: Theological Reflections on Dementia”.

I found the article to be a powerful reflection of Swinton’s experiences as he kneels before a person with dementia and administers communion. I wondered whether there is a moment when we suddenly see people with dementia from a different perspective and notice them in their full humanity. Soon after I read that article, I attended a lecture by Swinton at the University of Edinburgh. He talked about a moment where you “*lock in*” to the person

with dementia and I knew then that this is the moment I wanted to capture in my research. My research did not need to be limited to music.

A further review of the literature led me to articles and books that spoke of arts-based practitioners who had similar experiences of seeing people with dementia in a new way and “*locking in*” to them or experiencing a meaningful connection with them. These practitioners included musicians (Smilde et al, 2014) and Elder clowns. The Elder clown’s goal is “to make contact with people who are not (any longer) capable of communication in the usual, cognitive manner” (Hendriks, 2017, p208).

My reading about the Elder Clown’s resonated with my thoughts that there is a moment where we see people with dementia in a new way. I was keen to explore their work in more detail.

As I shared my ideas with a colleague, she told me that she had heard of similar experiences of meaningful connections from care staff in care homes. As I began to gather information about different people who appeared to have these moments of “*locking in*” I noticed that whilst they were from very different backgrounds, there was a thread that seemed to resonate between each one. I wanted to know more about what that thread was that seemed to link this phenomenon of “*locking in*”. A phenomenon which I understood to be a moment when a meaningful connection was made between the person with and without advanced dementia.

1.2.3 Developing my Focus and Aim

I decided that my research would focus on hearing the stories of the experiences of people without dementia who had made meaningful connections with people with advanced dementia. I wanted to understand how and why they were able to make these connections, how and why they were able to notice the humanness of the person with advanced dementia, and how they positioned people with advanced dementia in terms of their humanity as they spoke about them.

As my research focus developed, I began a deeper exploration of the work of Swinton's dementia related work. Swinton comes from a strong faith tradition. The way he writes about people with dementia resonates deeply and speaks a truth to my own understanding of humanness and personhood, and with my position that people are created by and held by God.

Swinton is a well-known scholar and theologian who researches dementia and dementia-care interactions. His book "Dementia Living in the Memories of God" (2012, p16/17) offers a "practical theology of dementia" and a "theological redescription" of dementia. Whilst my thesis is not primarily a theological argument, reading the work of Swinton and my own faith has inevitably brought a theological lens to the way in which the study has taken shape and findings have been explained.

My aim in this study was to explore stories of people without dementia that had meaningful connections with people with advanced dementia and explore how we might understand these connections if we thought of human beings as created by and held by God. I would explore how these stories made visible the "humanness" of the person with advanced dementia and use them to counter the dehumanising narratives that are prevalent in Western society about people with advanced dementia.

Chapter 2 “Not all There” or “Humanity Unleashed?”

This chapter explores the literature I reviewed that led to the research aims and questions of this study. The literature I reviewed primarily focused on how people with dementia are dehumanised in our Western culture, and on the challenges that are made to those dehumanising narratives through more life-giving concepts of dementia. Table 1 shows the dichotomy between these narratives that I discuss.

Table 1: The Contrasting Narratives of Dementia

<u>Life-Giving Narrative</u>	<u>Dehumanising Narratives</u>
I believe that as people progress with dementia, their humanity increases. People have to get ready for that humanity to be unleashed (Richard Taylor who had dementia, quoted in Power, 2015, para.17).	At this conference, people with dementia were publicly referred to with disrespectful, offensive, dehumanizing and devaluing language, such as ‘demented’ ‘sufferers’, ‘victims’ and ‘not all there’ (Kate Swaffer, who has young onset dementia, 2014, p711).
Yet, in her silent world Muriel is so content, so lovable, I sometimes pray, “Please, Lord, could you let me keep her a little longer?” If Jesus took her home, how I would miss her gentle, sweet presence. Oh yes, there are times when I get irritated, but not often. It doesn’t make sense. And besides, I love to care for her. She’s my precious (McQuilkin, 1998, p85, who cared for his wife Muriel who had Alzheimer’s Disease).	If you’re demented, you’re wasting people’s lives – your family’s lives – and you’re wasting the resources of the National Health Service (Beckford, 2008, para.10).
In the emotional range, many dementia-impaired people become more openly loving, more accepting of love, and more appreciative of tenderness and care. Emotional capacity becomes more naked in those who no longer have the mind structure to create barriers to hide their feelings. In many ways, the deepest revelation of the Alzheimer journey is that it is a kind of passage from the mind into the heart (Gray-Davidson, 1993, p6)	American views about ageing suggest that seniors (especially those with dementia) are not actors, or agents, in their own right but are a drain on limited societal resources (Beard, 2017, p686).
I think the more important thing just learning that the human experience doesn’t end because someone has an illness, that enriches my life I think (Peter – Elderflower in this study).	This terrible disease has destroyed our aunt. That is why we hardly visit. We would rather remember her as she once was (Stokes, 2008, p78/9 relaying the words of the nieces of a lady with Alzheimer’s who had become quite aggressive having been admitted to hospital).

I have used the phrases “Not all There” and “Humanity Unleashed” as a title to this chapter because they reflect the dichotomy between the two narratives. The phrases are also direct quotes from people who have or had a dementia diagnosis.

The term “Not all There” was used by Swaffer (2014, p711) in her editorial in the *Dementia* journal. Swaffer was diagnosed with younger onset dementia at the age of 49 (Dementia Alliance International (DAI), 2019). Swaffer speaks, advocates and is an author on the experience of living with dementia (Alzheimer’s Society 2017). When using the term “Not all There”, Swaffer was referring to the 2014 ADI conference where people with dementia were referred to in “dehumanizing language”. Swaffer argues that even though people with dementia may have changed “we are all there” (Swaffer 2014, p711).

The term “Humanity Unleashed” was used by the late Dr. Richard Taylor who was diagnosed with dementia at the age of 58. Taylor also became a public advocate for people diagnosed with Alzheimer’s disease.

Dr. Al Power, a contributor to the blog “ChangingAging with Dr. Bill Thomas” which challenges conventional views on aging (ChangingAging, 2019), writes in his blog (Power, 2015) that he asked Taylor: “What is the main point you would like people to know about dementia at this time?” (2015, para.17). Taylor responded talking about “recognizing the “human-ness” in people” before making the statement: “I believe that as people progress with dementia, their humanity increases. People have to get ready for that humanity to be unleashed” (2015, para.17).

As I reflected on Taylor’s use of the word “humanity unleashed”, I imagined that they mean that as dementia progresses, we can learn more about what it means to be human as some of our cognitive abilities are shed and we begin to see the emergence of a new way of showing our humanity.

2.1 Context of the Literature Review

I began my literature review by reading key authors in the field of dementia. These early readings included the work of Kitwood (1990, 1997, 1997a), Sabat (2001), Hughes (2011, 2014), Hughes et al (2006) and Kontos (2005). I later discovered the work of Swinton (2012) as a key academic contributor in the field of dementia and theology.

I received regular email alerts through the “Zetoc” database for updates on new articles in dementia, Alzheimer’s, aging, gerontology and humanity and society. I also used the University of Edinburgh’s Library’s online discovery service “DiscoverEd” which uses a large number of academic databases and resources, and “Google Scholar” to access relevant journal articles and books.

I searched for articles on “DiscoverEd” using keywords which included “dementia”, “advanced dementia” “Alzheimer’s”, “dementia and stigma”, “dementia and connections”, “arts and dementia”, “theology and dementia” “dementia and euthanasia”, “personhood”, “humanness” etc. I also searched for articles and books by key authors by surname using “DiscoverEd”. I searched the title of the article I wanted to view on “Google Scholar” if it wasn’t available on “DiscoverEd”.

I used the bibliographies from these core texts and articles to locate other contributors to the field, and other literature that was relevant to my area of inquiry. I used a facility on “DiscoverEd” where I was able to see where an article had been cited. This helped ensure that I was keeping abreast of current literature, critiques of the literature and how literature had been applied by other researchers. It enabled me to build a picture of the narratives about dementia that exist in the academic field.

I wanted to ensure that I was considering the newest research in an area and ensured that as well as historical literature I searched articles that had been published within more recent years.

Approaching the literature in this way allowed a wide range of literature to be reviewed and I was able to gain a broad understanding of past and current

work within the field. By drawing on bibliographies and where work had been cited, I was also able to gain an understanding of the empirical studies that had been done and discover the gaps in the literature which led to the formation of my own research questions.

2.2 Structure of the Literature Review

Having begun the literature review by detailing the context of the review, I now split the remainder of the review into two parts.

In part one of the review I explore how particular concepts of dementia contribute to or challenge the dehumanisation of people with dementia in more detail. The concepts I have drawn on are those that exist in Western societies. Perceptions of the humanity of people with dementia are closely related to how one understands what it means to be a human being and a person in Western society. I explore the concepts of dementia that emerge within some of the prevalent frameworks within which humanness and personhood is understood.

The prevalent medical concept of dementia within the dominant views of humanness and personhood in Western society is discussed. I argue that a focus *purely* on the medical concept of dementia can become problematic for people with dementia.

I then discuss the impact that the voice of people with dementia themselves has had on changing perceptions of dementia and influencing policy before looking back to earlier concepts of dementia that began to challenge the medical concept. Consideration is given to how these concepts have developed, how they bring a different perspective on how people with dementia continue in their humanity before I introduce a theological concept of dementia, humanness and personhood.

I show that the medical view continues to dominate the way in which dementia is understood, and dehumanising narratives continue to exist, despite the introduction of more life-giving concepts of dementia. Whilst this

is challenging for all people with dementia, I focus on how it becomes particularly difficult for people with advanced dementia who are often unable to counter these narratives using their own voice.

In part two of the review I explore empirical research that offers a counter story to the dehumanising narratives that exist about people with advanced dementia. I explore how this draws attention to the humanness and personhood of people with advanced dementia.

The chapter concludes by identifying the gaps in the research to highlight where further studies in this area could respond to dehumanising narratives about people with advanced dementia and make more visible and the humanness of people with advanced dementia.

I now introduce the concepts of dementia and personhood that I argue have contributed to the dehumanisation of people with dementia.

Part One

2.3 Dehumanising Dementia

In this section I focus on the medicalised, neurocognitive concept of dementia and give a brief history of how dementia became understood as a medical concept.

I argue that a *purely* medical concept of dementia, and I include neurocognitive in this concept, contributes to dehumanising narratives about dementia and people with dementia. I suggest that this is because the medical concept sits within a culture that places a high value on a person's cognitive ability and independence. These attributes have become deeply associated with how personhood and humanness are understood in our society. Any deterioration in these attributes leads to stigmatising attitudes which further dehumanise people with dementia whose cognitive abilities are considered to be impaired.

I show that the pervasiveness of the medical concept of dementia is influenced by Western understandings of personhood and humanness that place cognitive ability as a key condition of personhood. I then discuss how the medicalised focus on cognitive loss contributes to a sense of catastrophe, fear, burden and hopelessness around dementia, often exacerbated by the media. This generates new or feeds into the longstanding dehumanising narratives that position people with dementia as those who are no longer fully human.

As I discuss the medical concept of dementia, I am not suggesting that it is not necessary, rather that when this is the primary way of understanding dementia, it becomes a precarious platform from which to understand and see the person with dementia as a human person.

2.3.1 The Medicalisation of Dementia

Berchtold and Cotman (1998) in their article that traces the evolutionary history of the current concept of dementia and Alzheimer's write that:

The concept of senile dementia has evolved from a rather vague notion that mental decline occurred inevitably in old age, to become defined today by a distinct set of clinical and pathological features with the potential for treatment and prevention within grasp (1998, p173).

They suggest that an etiological basis for dementia was found by the end of the 19th century. Vatanabe et al (2019) who also describe the history of dementia concepts, suggest that in the mid-19th and early 20th centuries the clinical marker of dementia was cognitive disorder, with memory indicated as one of the "main markers of dementia" (2019, p.4). They suggest that from this time, it was cognitive changes that were responsible for a dementia diagnosis, and the behavioural disorders were the byproduct of dementia. This understanding remained until the end of the 20th century (2019).

By 1994 the Diagnostic and Statistical Manual of Mental Disorders (DSM¹)^{4th} edition (DSM-IV) (American Psychiatric Association, 1994, cited in Vatanabe, et al, 2019, p6) defined dementia as:

the development of multiple cognitive deficits (including memory impairment) that are due to the direct physiological effects of a general medical condition, to the remaining consequences of a substance or resulting from multiple etiologies.

DSM-V is the latest edition of the manual, published in 2013, and has replaced the term dementia with “major neurocognitive disorder” (2019, p6). According to Alladi and Hachinski (2018, p265) DSM-V defines major neurocognitive disorder as:

“based on the presence of a substantial impairment in cognitive performance, preferably documented by standardized neuropsychological testing and a functional criterion to reflect a loss of independence in daily living.”

The International Classification of Diseases (ICD²) 10 (2016, para.2) describes dementia as:

a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

2.3.1.1 A Faulty and Deficient Concept or Faulty and Deficient Person?

Psychologist Tom Kitwood, termed the medical concept of dementia as “the standard paradigm” (Kitwood, 2019, p1) within which we understand dementia. He argues that the standard paradigm of dementia is “faulty and

¹ The DSM is the handbook used by health care professionals in the United States and much of the world as the authoritative guide to the diagnosis of mental disorders (American Psychiatric Association, 2019, para.1.).

² The ICD identifies health trends and statistics around the world and is “the international standard for defining and reporting diseases and health conditions” (WHO, 2019a, para.2).

deficient” (Kitwood, 1997, p177), that it leaves the person with dementia as someone who is “unknown and irrelevant” (Kitwood, 1990, p195) and undermines the personhood of the person with dementia (Kitwood, 1997).

Sabat (2001, p10) also a psychologist, uses the term “Classical Science” to explain the medical lens through which Alzheimer’s Disease is approached by many researchers where symptoms can be reduced to “abnormalities in the brain” (2001, p5). Sabat argues that through this reductionist lens the person with the disease is considered in terms of their deficits and declining cognitive capacities as they are “defined principally in terms of his or her catalogued dysfunctions” (Sabat, 2001, p10). The whole dynamic person with dementia is not considered as it focuses on the “functions” of the person rather than how dementia affects them as they live in the world (2001, p10).

Sabat warns that:

Once persons are positioned socially as nothing more than instantiations of a diagnostic category, their essential humanity, including their intellectual and emotional characteristics, needs, and their social personae beyond that of “demented, burdensome patient” become more and more obscured and can ultimately become erased (Sabat, 2008, p84).

I discuss the theories that Kitwood and Sabat proposed in response to this medical concept in more detail later in this thesis. At this point it is important to notice that both Kitwood and Sabat draw attention to the danger that the person with dementia can become unnoticed and regarded as irrelevant when dementia is only understood as a medical concept. The person with dementia is seen as faulty and deficient rather than the fault lying within the standard paradigm.

The continued prevalence of the medical concept of dementia can be better understood by paying attention to the prominent philosophical concepts about personhood and humanness that exist in Western culture.

2.3.2 Personhood and Humanness

Bartlett and O'Connor suggest that the concept of personhood is a "contested concept" (2007, p109) that dates to the pre- and early-Enlightenment period and the philosophies of René Descartes [1596-1650] and John Locke [1632-1704]. It is a concept much debated in philosophy and theology today. I do not enter a detailed discussion or debate about the context within which these philosophies emerged as that lies outside the purpose of this thesis. I give an overview of these early philosophies to show how they continue to influence how personhood and humanness is understood in our current culture and how that understanding might influence the way in which we understand people with dementia.

White (2013, p74) speaking from a theological perspective, gives an overview analysis of existential and relational constructs of personhood in "human social order" in his essay. He suggests that personhood is recognised within two different constructs. Firstly, the case of the existential construct of personhood; personhood is inherent to being human and cannot be lost, regardless of the status of the human being. The second construct is that personhood is a relational construct and a conditional state that is defined by society.

Kitwood (2019) suggests that the term personhood is found in the discourses of transcendence, ethics and social psychology. Within the discourse of transcendence, the being is in itself "sacred, and that life is to be revered" (2019, p7). This view is often seen in theistic religions and their position that people are divinely created. In ethical discourse in Western philosophy, Kitwood suggests that absolute value is given to each person. In social psychology however, personhood is primarily associated with "self-esteem", "the place of an individual in a social group", "performance of given roles" and "integrity, continuity and stability of sense of self" (2019, p7). This resonates with the second construct of personhood that White (2013) suggests; that personhood becomes a "conditional state", and it is others who define those conditions.

It is this relational and conditional construct that I suggest is particularly troubling for people with dementia when they are viewed *purely* through a medical lens. It is this construct that appears to resonate most loudly in the dehumanising narratives of people with dementia.

As I discuss personhood and humanness, I explore the concepts of Descartes and Locke. I later refer to the philosopher Immanuel Kant [1724-1804] and draw on Rhodes' (2007) and Budić's (2017) interpretation of what Kant regards as "person". I argue that these philosophies are visible in the medical concept of dementia and resonate with White's (2013) overview of the relational concept of personhood. I suggest that these relational concepts of personhood lead to the notion that the personhood of the person with dementia can be undermined or parts of their personal identity completely erased when dementia is understood as a *purely* medical concept. I also suggest that conditional concepts of personhood contribute to dehumanising narratives.

I show how a sense of tragedy and catastrophe is heard in these narratives, that can lead to a sense of fear and hopelessness following a dementia diagnosis. I also show how this may invite people to consider medically assisted death as a suitable treatment option

2.3.2.1 Descartes [1596-1650], Locke [1632-1704] and Kant [1724-1805]

The philosophies of Descartes' and Locke have greatly influenced Western understandings of personhood and humanness.

Descartes, in his pursuit of philosophical truth and as a thought experiment, doubted away everything that it was possible to doubt, including the evidence of our senses. He discovered that in doubting everything however he was thinking them, thereby that the one thing that he couldn't doubt was thought, as doubting was a form of thinking (Descartes and Maclean, 2006). This led Descartes to declare that "I am thinking therefore I exist" (2006, p28).

Descartes found himself able to pretend that he had no body, but could not pretend he did not exist, because he was thinking about such things.

In his meditations on first philosophy, Descartes writes:

I am therefore, precisely speaking, only a thinking thing, that is, a mind or a soul, or an intellect or a reason—words the meaning of which was previously unknown to me. I am therefore a true thing, one that truly exists; but what kind of thing? I have said it already: one that thinks (Descartes, 2008 p19/20).

Descartes tried to work out how the thinking thing, the mind, is related to the body as he started to build his understanding of the world step by step in terms of what he could believe in.

He writes that the “I” which he called the “Soul” (2006, p29):

is entirely distinct from the body...and would not stop being everything it is even if the body were not to exist (Descartes and Maclean, 2006, p29).

The Latin for soul is “animus” also translated as “mind” (Gray, 2010, p638).

Descartes’ philosophy was rooted in the concept of dualism within a human being, reinforcing a view that there was a “mind-body” split. Descartes places the image of a person as someone who is a thing that thinks, which he calls “a mind”, and this mind is separate from the body. This suggests that personhood resides in the mind, and humanness, or “man” resides in the body (Tomaselli, 1984, p201); they are two separate substances.

Locke’s concept of personhood “began as a critique of Descartes” (Tomaselli, 1984, p198) understanding of the self. According to historian Tomaselli (1984, p200) however, “Locke contributed to the deepening the gulf” between the mental and physical aspects of a human being.

Locke’s position was that “man” consisted of the body, but in contrast to Descartes, it wasn’t the body or soul that carried personal identity, it was consciousness that did that (Harris, 2016). Locke suggests that a person is:

...a thinking, intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking (Locke 1964, II. XXVII.9 cited in Matthews, 2006, p165).

Locke held that ““Person” is a forensic term” (Essay II xxxvii.26 cited in Harris, 2016, p316) binding the idea of personhood to ideas of both agency and “moral responsibility” (Hughes, 2011, p35). Different models of personhood based on Locke’s criteria are generally designed to assist with “legal and ethical decisions” (Swinton, 2012, p123). Even though Locke’s concept of personhood was developed for forensic purposes it has highly influenced those modern theories of personal identity (Harris, 2016, Swinton, 2012) that place personhood as something separate from the body, (although it is not a substance) reinforcing the dualistic concept of Descartes.

Dualism also resounds in the discussion of the later enlightenment philosopher Kant’s position on personhood, cited in Rhodes (2007).

Rhodes (2007, p47) cites Kant (1785 [1959], 428/46) writing that:

Beings whose existence does not depend on our will but on nature, if they are not rational beings, have only relative worth as means and are therefore called “things”; on the other hand, rational beings are designated as ‘persons’ because their nature indicates that they are ends in themselves...Such a being is thus an object of respect.

Rhodes (2007, p47) suggests that when ‘person’ is used in what he terms “this Kantian self-legislating” sense, that there will be some human beings who are “not yet persons (e.g. children)”, some who will “never be persons (e.g. the profoundly mentally retarded)” some who whilst not presently persons may become so in the future, “(e.g. the unconscious, the mentally ill)” and “humans who were previously persons but who will never have that status again (e.g. the demented)”.

According to Kitwood (Dewing, 2019), however, Kant argues that we are obligated to treat persons with respect, and they have a “unique value, often called dignity” (Dewing, 2019, p21). Budić (2017) takes a Kantian approach as she addresses the philosophical issue of euthanasia for people with dementia. Budić suggests that Kant would consider that people with dementia would not *be* persons because they only have a biological life and

not a moral one, as they are not in possession of “autonomy, rationality and dignity that form the basis of autonomous (moral) life” (2017, p100).

Dignity according to Budić is seen in “our status in the form of autonomous and free beings” (2017, p98).

Descartes, Locke and Kant also suggest that personhood is a conditional rather than an existential concept. From their perspective, the conditions of personhood are cognitive function; the ability to think, reason, understand and, for Locke, to remember. For Kant, according to Rhodes (2007) and Budić (2017) the conditions of personhood are rationality and autonomy. Their philosophies suggest that without these abilities then personhood can be lost.

2.3.2.2 Dualism and the Problem for People with Dementia

The word dementia derives from the Latin word “demens” and suggests “being out of your mind” (Hughes, 2011, p14). According to Descartes, the person resides within the mind, and the mind is the thing that thinks, reasons and understands. In other words, for Descartes, the mind is the place of cognitive function, it is the place of the person, meaning that personhood becomes conditional on cognitive function. Swinton (2012) who questions whether the mind actually exists, (a discussion that lies outside of this thesis) asserts that there is a cultural assumption that the essence of the person resides within the mind. If we buy in to the suggestion that people with dementia lose their minds, we can begin to understand how the emergence of the narrative that dementia is a “kind of living death” (Matthews, 2006, p163/4) where the person is gone but the body remains.

2.3.2.3 Cartesian Dualism in Medical Science

Medical science continues to be influenced by the Cartesian mind-body split, which it takes as it's foundation (Macdonald, 2018, Gendle, 2016, Mehta, 2011).

Gendle (2016, p141) discusses “The Problem of Dualism in Modern Western Medicine”. Gendle suggests that the Cartesian approach to medicine facilitates the “biological reductionism” of the disease, and promotes a “mechanistic approach to patient care” which “discourages humanistic ways of thinking that focus on the whole patient” (2016, p142).

Mehta (2011) discusses Cartesian dualism in the light of medical practices. Mehta writing that Descartes’ mind-body split meant that the body was handed over to medical science for study through “physiology and anatomy”. In doing so this isolated the mind, denying its “significance in individual’s experience of health” (2011, p203).

The position of Gendle (2016) and Metha (2011) reinforce the concerns of Kitwood (1997) and Sabat (2001) about the medicalisation of dementia that I mentioned earlier in this chapter, that personhood becomes undermined and ignored.

Cartesian dualism has been widely debated, and rejected by many philosophers, health practitioners, theologians and scientists, however it is accepted by some and continues to be present in our culture and practices (Mehta, 2011, Kinghorn, 2015, Kitwood, 2019a).

These early dualistic and conditional concepts of personhood have continued to impact the way in which we understand humanness and personhood throughout more recent decades. I show this in the following examples that span the last five decades.

2.3.2.4 Continuing Dualistic and Conditional Concepts of Personhood

Philosopher Daniel Dennett (1978, p267) suggests that whilst “we recognize almost all human beings as persons”, personhood it is not an inherent part of being human. Dennett says that we:

recognize conditions that exempt human beings from personhood, or at least some very important elements of personhood...infant human beings, mentally defective human beings and human beings declared insane by licensed psychiatrists

as those who are “denied personhood” or “crucial elements of personhood” (1978, p267).

Philosopher and ethicist Dan Brock (1988, p73) also suggests that people with dementia can lose their personhood, in his discussion about the justification of health care and expenditure of resources on people whom he refers to as “the severely demented elderly”. He refers to “severely demented patients” as patients who “are plainly still live human beings” (1988, p85) however writes:

The dementia that destroys memory in the severely demented destroys their psychological capacities to forge links across time that establish a sense of personal identity across time and hence they lack personhood (1988, p87).

Brock (1988, p73) argues that the “erosion of memory and other cognitive functions”, the effects of dementia “attack...destroy personal identity and personhood in the patient”.

In more recent decades, Peter Singer, a current influential philosopher and ethicist also separates the biological human, which he refers to as a “member of the species Homo Sapiens”, from the person, with the conditions of personhood being “a rational and self-aware being” (2011, p74/5).

These dualistic concepts of humanness and personhood are not limited to the field of philosophy, however. In 2012 a study by Van Gorp and Vercruyssen, explored dominant media images of dementia in six Belgian newspapers, between 2008-2010, and images of dementia in “movies, documentaries, literature and health communications” (2012, p1274). The findings show that the most dominant way in which dementia is framed suggests that a human being is made up of “a material body and an immaterial spirit or mind” (2012, p276). Van Gorp et al (2012, p389) write that in Western culture, dualism is a “fundamental image of a human being”.

2.3.2.5 Losing Human Dignity and Human Rights

Gerritson et al (2018) argue that whenever personhood is unrecognised there is always a risk that the human dignity of the person with dementia will not be respected. White (2013) also argues, although not exclusively about dementia, that unless the concept of personhood is firmly attached to humanness, then “relativistic application of human rights” (2013, p80) is also a risk.

This is seen in the philosophies of Singer (2011) who claims that being a human being is irrelevant in terms of the human right to life. Singer (2011) discusses the wrongness of killing a human being, in terms of a human being someone who is a member of the species, Homo Sapiens. He argues that it is not the fact that being a human being makes it wrong to kill it, rather it is cognitive capacities such as “rationality, autonomy, and self-awareness” (2011, p160). He goes on to argue that “killing infants who lack these characteristics” cannot be equal to killing “normal human beings or any other self-aware beings” (2011, p160).

I argue that a dualistic understanding of personhood and humanness does risk the human rights of people, as does the understanding that personhood is conditional personhood. These positions can lead to the dehumanisation of people with dementia.

Within the medical concept of dementia cognitive ability and independence are highlighted as being at risk of being lost. These characteristics have become embedded in our culture since the time of Enlightenment philosophers as the things that give a person and human worth, value and identity. They have become the culturally understood conditions of personhood. Stephen Post (1995, p5) terms this culture a “hypercognitive culture”. In this culture if cognitive abilities diminish and autonomy is lost then so is personhood.

2.3.2.6 A Hypercognitive and Independent Culture

Post (1995) explores major ethical issues that relate to dementia and dementia care and suggests that our culture is largely dominated by our expectations of “rationalism and economic productivity” (1995, p5) and it is “clarity of mind and productivity” (1995, p5) that give value and worth to human beings. Swinton (2012, p110) supports Post’s assertion that our culture is marked by “hypercognition” and adds to this our “excessive emphasis on memory”. Kitwood (2019a) and Swinton (2012) draw attention to a person’s autonomy, rationality and individualism as something that is valued in Western culture.

Again, we hear the voice of Descartes, Locke and Kant in these notions that high levels of cognitive function become the mark of a person.

These functions are the very things that a *purely* medical concept of dementia focuses on as the things that dementia will take from a person. This encourages the narrative that the person with dementia becomes understood to be “just a shell of the person” they once were (Kinghorn, 2015, p101).

The medical concept also focuses on abnormalities within the brain and changes in emotional control and social behaviour. This can make people with dementia appear different to those without dementia. It places the person with dementia as the one who is faulty and deficient rather than the fault lying in our understanding of people with dementia.

This creates further problems for the person with dementia as when a member of society is seen to have an attribute that makes them different from others in society, they can easily become stigmatised.

I argue that dehumanising narratives are fuelled by the stigma that is attached to dementia and people with dementia.

2.3.2.7 Stigma - Not Quite Human

Stigmatised persons can rapidly become someone who is thought of and treated as if they are no longer human.

Stigma reduces a person in our minds to one that is “tainted and discounted” (Goffman, 1963, p12). This echoes Kitwood and Sabat’s concerns about people with dementia becoming “obscured”, “erased” (Sabat, 2008, p84) or “irrelevant” (Kitwood, 1990, p195). Dementia is still often seen as a stigmatising condition (Gove et al, 2017, Weisman de Mamani et al, 2017, Kahn, 2016).

2.3.2.8 Stigma Today

The World Alzheimer’s Report 2019 (ADI, 2019b, p17) cite Bryden (2015, p40), a dementia activist writing:

Our lives become limited by the stigma we face in the world around us. It’s like we have a target painted on our foreheads shouting out ‘dementing’ for all the world to see. People become awkward in our presence, are unsure of our behaviour, and our world becomes circumscribed by the stigma of our illness.

Stigma can lead to being “disqualified from full social acceptance” (Goffman, 1963, p9) and can ultimately lead to the stigmatised person being positioned as “not quite human” (Goffman, 1963, p15).

The World Alzheimer’s Report, 2019 suggests that it is the stigma about dementia that prevents people from understanding dementia as a medical condition (ADI, 2019b) causing a barrier that can prevent people seeking diagnosis and support. I believe that the medical concept of dementia is needed, as it is helpful in focusing medical professionals on the pathology of the illness and subsequent treatment. If people understood dementia as a medical condition it may well encourage them to seek diagnosis earlier (Gerritson et al, 2018) or to get some support. A medical understanding of dementia may also bring a degree of “respectability” as it can now be understood as damage to the brain that is not the same as other “psychiatric conditions” (2018, p598). However, my argument is that it is the dominance of this concept that sits within the dualistic and conditional concept of personhood that creates the difficulties for people with dementia. The medical concept alone within this culture risks “reducing the person with

dementia to a damaged brain” (2018, p598) that will gradually deteriorate over time. The person with dementia becomes “unknown and irrelevant” (Kitwood, 1990, p195) as their narrative becomes about what they will lose, what they will behave like or will not be able to do, rather than who they are.

This not only fosters stigmatising and dehumanising narratives but creates a fear in society about dementia and about people with dementia.

2.3.2.9 The Fear of Dementia and Stigma

Currently the fear that one might develop dementia is greater than the fear of developing cancer (Swinton, 2012, Department of Health 2015). People “fear losing their memory” (Swinton, 2012, p188) and they fear the perception that people with dementia lose their “selfhood” (Basting 2003, p88). This fear can further contribute to stigma and dehumanising narratives.

Kitwood (2019a) suggests that people with dementia are often positioned as inhuman by others as a form of defence mechanism due to the anxiety and fear that some people without dementia may feel when they encounter those with dementia. This anxiety may come from a fear of becoming frail and dependent on others, or from a fear of the process of dementia and even death. In order to cope with the anxiety people with dementia are turned into a different species (Kitwood 2019a). Brannelly (2011) suggests that younger and healthier people are often unwilling to empathise with the older person who is incapacitated. They are unable to relate to their weakness and frailty. Dehumanising the person with dementia puts a “protective distance” between them both leading to an “inability to engage” (2011, p663) with them.

Dehumanising narratives within our society reflect these stigmatising attitudes. They often position people with dementia as if they are less than human, a “non-person” (Lesser, 2006, p58).

I now discuss the media as a further powerful influence on these dehumanising narratives.

2.3.2.10 Dehumanising Media Representations of Dementia.

Johnstone (2011) carried out a study that investigated whether Alzheimer's disease was being used in public policy debates on whether euthanasia should be legalised in Australia. She reviewed data collected from media databases as well public opinion polling and legal databases, and home pages of dementia associations, palliative care groups, right to die and right to life groups. She reports metaphors about Alzheimer's that she describes as "military". This included dementia being framed as an enemy that will "attack" "destroy" and "rob" (2011, p384-386) resulting in the essence of the person being lost or destroyed and no longer being the person that they are.

The media presents people with dementia as those who are "victims" (Harvey and Brookes, 2019, p998) who are suffering "a living death" (Hillman and Latimer, 2017, p2), or as those who have lost their minds, dignity and identity (Johnstone, 2011).

Encouragingly, Hillman and Latimer (2017) suggest that TV, film and literature are beginning to challenge the way in which dementia is culturally understood. Dementia is portrayed as "disordering identities and ways of relating to others that transform" (2017, p2) rather than ignoring the person with dementia completely in some instances. They also suggest that some characters are portrayed as those whose being is "embodied, emotional and finally social" (2017, p2). Even with this challenge through the TV, film and literature, however, Schweda (2018) argues that the dominance of the medical concept of dementia in our society might make it difficult for us to assimilate a non-medical understanding of dementia.

Schweda (2018) examines how dementia is dealt with in motion pictures from an ethical perspective. Schweda suggests that because of the way in which dementia is now commonly found in public discourse as an explanation of any strange or irrational behaviours of older people, that we apply this same "medical gaze" (2018, p3) to understand the behaviour of older people in

films. The central meaning of the story goes unnoticed and any irrational behaviour is explained as dementia.

The dominant imagery in films where dementia is specifically represented is one that draws on meteorological phenomenon (2018). For example, the use of “fog” in the film suggests that people with dementia cannot see clearly; “snow” suggests that their reality is covered over by a layer of whiteness, and “twilight” suggests that objects slowly begin to lose their definition before disappearing into darkness (2018, p4). These all are very suggestive of the medical concept of dementia as they focus on changes in behaviour, impairment and not being able to think or see things clearly. They all suggest the person with dementia is fading away when we assume that personhood is rooted in cognition.

Images like this add to the stigmatising and dehumanising narratives about dementia, and they also create a sense of catastrophe and tragedy about dementia.

2.3.2.11 Dementia as Catastrophe, Tragedy and Burden

I referred earlier to the military metaphor that Johnstone (2011) found in her study. Brookes et al (2018) found similar metaphors in their study that examined the way in which the British press reported findings from the 2016 Office of National Statistics report. The report claimed that “dementia is now the leading cause of death in England and Wales” (2018, p371). Dementia was represented as “Our biggest killer”, and the newspapers call on the government and pharmacology to “fight” and “combat” dementia (2018, p380).

Zeilig (2013) refers to emotionally charged metaphors about dementia that are found in the media, films and documentaries and in political speeches. Zeilig highlights catastrophic metaphors such as dementia being a “rising tide”, a “slow-moving tsunami”, and a “demon” (2013, p260). Similarly, Peel (2014) reported that dementia was represented as a ‘tsunami’ and ‘worse than death’ (2014, p885).

These catastrophic and tragic metaphors suggest that our society is going to be overtaken by dementia by “an irrepressible force of nature” (Brookes et al 2018, p372). They suggest that the only way that dementia can be kept under control or beaten is through medical treatment. Brookes et al (2018) quote the Chief Executive of Alzheimer’s Research UK, Hilary Evans, in an article in several newspapers saying that dementia is “caused by diseases that can be fought through research...our greatest medical challenge” (2018, p380).

Brookes et al suggest that the media are “fixated” with portraying dementia through a “techno-scientific and epidemiological lens” (2018, p372), and emphasises prevalence and cause of dementia as well as how medical cures are developing. The militaristic metaphors that are used to frame the response of government and pharmacology to dementia position science to be the savior that people with dementia can depend on. Brookes et al suggest that this “faith in science” (2018, p381) reproduces the medical model of dementia, squeezing out any non-medical or psychosocial approaches.

Once again, we see the person with dementia being disregarded, it is only the body that needs to be treated, and yet there is no treatment or cure.

2.3.2.12 A Burden to Families and Society

The fact that there is not yet a cure for dementia and that people with dementia will become more dependent on others for care, often results in people with dementia being positioned as those who are a burden to family (ADI, 2019b, Beckford, 2008) and a burden to society (ADI, 2019b, Beard, 2017, Beckford, 2008). There is no doubt that the impact of dementia is financially significant, and has a human cost for society, families and individuals (WHO, 2017, Department of Health, 2015). I argue however that when positioned as a burden we are invited to again question the value and worth of the person with dementia.

Beard (2017, p686) states: “American views about ageing suggest that seniors (especially those with dementia) are not actors, or agents, in their own right but are a drain on limited societal resources”.

Baroness Warnock, a previous UK Government adviser and leading moral philosopher in the UK, made the following statement: "If you're demented, you're wasting people's lives – your family's lives – and you're wasting the resources of the National Health Service.” (Beckford, 2008, para.10)

These narratives of burden and waste further dehumanise people with dementia, implying that they have no place in a society that appears to value economic productivity and autonomy (Post, 1995, Swinton, 2012, Kitwood, 2019a).

2.3.3 The Danger of Dehumanising Narratives

The lives of people with dementia are directly affected by the way we perceive and portray dementia (Gerritsen et. al, 2018). Post (1995, p94) writes: “if we think that there can be no quality of life because of cognitive deficits, then we will probably not do the things that can enhance quality.” Reports in the media bring our attention to many instances of abuse towards people with dementia in UK care homes (Hughes, 2013) and people with dementia often receive undignified treatment towards the end of their lives (Alzheimer’s Society, 2019a). People with dementia often experience loss of social networks (Van Gorp and Vercruyssen 2012, McParland 2014, O’Sullivan et al 2014, Watson, 2016,) and “...can experience social death before their physical death” as they are no longer seen to be an “active agent within their relationships” (Watson 2016, p0). People with dementia might begin to feel invisible in social environments as they feel “ignored, unworthy of being treated as a human being” (Sabat, 2008, p83).

It is not surprising that many people fear developing dementia as they grow older (Higgs and Gilleard, 2017, Corner and Bond, 2004, Swinton, 2012). I argue that a purely medical perception of dementia within our current culture

that values cognitive ability and autonomy brings a sense of hopelessness, until such time as a cure can be found.

Beard argues that we must continue to show that dementia does “not destroy either sociality or personhood” (2017, p687). She shows concern that the pessimistic biomedical approach to dementia suggests that the only thing meaningful that can transpire in the final stage of life is “advocating death with dignity and intact personhood” (2017, p686). This suggests that the biomedical pessimism encourages the view that personhood is lost as dementia progresses.

I now discuss euthanasia and dementia as a prevalent topic of conversation that warrants further exploration.

2.3.3.1 Euthanasia – A Solution or a Duty?

Johnstone (2011) in her study referred to above found a specific Alzheimer’s metaphor used in public policy in Australia that positioned people with dementia as non-human “on account of being deprived of the positive human qualities culturally deemed to make them human” (2011, p388). Johnstone’s concern was that some of the metaphors about Alzheimer’s carry the risk of “influencing the way people think and behave about the disease and it’s treatment options – including medically assisted death” (2011, p390). Her findings reported metaphors that were “morally loaded” (2011, p377) and she argues were used to stigmatise Alzheimer’s disease, mediating public opinion to support euthanasia as an “end-of-life ‘solution’” (2011, p377) for people with Alzheimer’s. She refers to a euthanasia metaphor in her findings that functioned as a reassurance to people that symbolized:

ownership and personal control of one’s body...the capacity to make self-determining choices, to protect one’s dignity, and the opportunity to face one’s mortality, uncertainty and helplessness heroically (2011, p385).

Draper et al (2010) inform that there is an increase in the number of people putting in place living wills that state they wish to end their lives if they develop dementia. In countries where euthanasia is not lawful, it is suggested

that people are making “covert arrangements” (2010, p78) for assisted suicide were they to be diagnosed with dementia.

Baroness Warnock’s statement suggests that thinking about euthanasia is an acceptable consideration for people with dementia. She wrote:

Actually, I've just written an article called 'A Duty to Die?' for a Norwegian periodical. I wrote it really suggesting that there's nothing wrong with feeling you ought to do so for the sake of others as well as yourself (Beckford, 2008, para.12).

The question of euthanasia and dementia has not only been raised as an option that can be considered however, but also whether euthanasia becomes a duty.

Budić (2017) addresses the issue of euthanasia in people with dementia. She analyses this through a position that suggests philosopher Kant could argue that people who “suffer from dementia have a duty to die” (2017, p88).

According to Budić (2017) Kant suggests that it is autonomy that gives human nature its dignity, and it is dignity that gives life a value. Budić (2017, p98) writes that “a patient suffering from dementia no longer possesses rationality, honor, dignity, and their life has no absolute value.”

Budić (2017, p112) goes on to say that:

we have no duty towards individuals suffering from dementia, as we do towards other people, since such individuals are no longer regarded as persons.

According to Budić (2017, p113) the duty that we have to act in a fair and righteous way towards patients who are “ailing”; those who have lost “rationality, autonomy, responsibility or dignity” is “a duty to conduct euthanasia over them, and thus act towards ending their biological life.” She goes on to say that regardless of whether people with dementia pose a threat to others around them, they do pose a burden, especially to their families.

I have not conducted a detailed study of Kantian philosophy and have only taken the interpretation of academics who have studied his work. However, by referring to those who draw on his work, I have highlighted that these discussions about the duty of euthanasia and dementia do circulate in our

society. This position reinforces the risks involved when people with dementia are dehumanised and positioned as a waste, burden and of no value.

Arguments like that of Budić (2017) reinforce the concerns expressed by White (2013) that where personhood and humanness are separate that human rights become relative.

2.3.4 A Precarious Platform

I have shown that a *purely* medical concept of dementia within a culture of dualism, conditional personhood and hypercognition becomes a very precarious platform from which to understand and position people with dementia. This platform opens the way for dehumanising narratives about people with dementia. These narratives can inform our understanding of people with dementia as those who are no longer persons and are a burden. In this context, and without a medical cure for dementia, the story of the person with dementia is finalised. People with dementia can be thought of as having no hope, no value and as no longer human. I suggest that this is a gateway for diminished responsibility in the way that people with dementia are cared for and for euthanasia to be considered as one possible solution, and even, by some, as a duty.

I argue that it is essential that we challenge the dehumanising narrative about people with dementia and introduce a narrative that brings life, hope and makes visible the value and the humanity of people with dementia. In order to do this, the way that people with dementia are perceived and thought about needs to change (Wilkinson, 2002). A counter story needs to be told that positions people with dementia as people who are valued and continue to experience and belong to the world.

The next section of this chapter considers and critiques concepts of dementia that have begun to challenge these longstanding dehumanising narratives

and have attempted to offer a counter story that humanises people with dementia.

2.4 Humanising Dementia

Over the last three decades there has been a growing movement in research and policy that attempts to move beyond the medical concept of dementia and notice the whole person with dementia. More research focuses on the personhood of the person with dementia. Informed by the social model of disability (Wilkinson, 2002) a social model of dementia has entered the landscape of dementia care and research. Key to the social model of disability is its definition of disability as “a social creation - a relationship between people with impairment and a disabling society” (Shakespeare, 2016, p197). A social model that informs dementia care and research, focuses on the impact that “policy frameworks”, “cultural processes”, and “environmental and social barriers” (Wilkinson, 2002, p11) have on people with dementia and how they might disable people, rather than focusing on the deficits of people with dementia.

Hughes (2011) suggests that the dominance of the medical concept of dementia may be beginning to weaken. The NICE³-SCIE⁴ 2007 Guideline in England and Wales recognises that a purely clinical perspective of dementia can influence how people with dementia are approached both socially and professionally. It introduces dementia from a clinical perspective as:

a group of usually progressive neurodegenerative brain disorders characterised by intellectual deterioration and more or less gradual erosion of mental and later physical function, leading to disability and death (National Collaborating Centre for Mental Health, 2007, p66)

It also introduces dementia from a social perspective stating that:

³ NICE is the National Institute for Health and Care Excellence that “provides national guidance and advice to improve health and social care” (NICE, 2019).

⁴ SCIE is the Social Care institute for Excellence that co-produces, shares and supports “the use of the best available knowledge and evidence about what works in practice” (SCIE, 2019).

dementia can be viewed as one of the ways in which an individual's personal and social capacities may change for a variety of reasons, and changes in such capacities are only experienced as disabilities when environmental supports (which we all depend upon to varying degrees) are not adaptable to suit them. Moreover, dementia thought of from a clinical perspective (that is, diseases and disability leading to death) may also prefigure our collective social and professional approach to people with dementia as irretrievably ill and fundamentally different from able-bodied healthy young people (National Collaborating Centre for Mental Health, 2007, p66).

The guideline suggests that good practice is that carers need to respect both the clinical and social perspectives of dementia.

People with dementia are becoming more readily recognised as people who continue to experience the world, who have emotional, psychosocial (Kitwood, 1997a) and spiritual needs (Powers and Watson, 2011, Smeaton and Maher, 2016). This shift beyond the medical concept is seen in the wider literature including a call from Alzheimer's Society (2019a, para.1) for "holistic support" that includes "emotional and spiritual support" (2019a, para.6) for people with dementia. WHO (2017, p23) write that palliative care that provides "physical, psychosocial and spiritual support for people with dementia" is a core component of the "continuum of care for people living with dementia".

I suggest that the challenge to the dehumanising narratives of people with dementia has emerged from two key voices. Firstly, through the voice of academic research and more recently through the voice of people with dementia themselves.

I explore this in a way that might seem somewhat back to front, for reasons which I hope will become clear, by discussing the impact that the voice of people with dementia has had on challenging dehumanising narratives about dementia before discussing the voice of academic research.

2.4.1 The Voice of People with Dementia

The *purely* medical concept of dementia undermines the personhood of people with dementia, and according to Kitwood (2019b, p44) “feeds into an extremely negative and deterministic view”. This leads to narratives that are false and that dehumanise people with dementia. When false stories are told about us, we are often able to counter them by telling our own story and correcting the picture (Swinton, 2012). In more recent year’s people living with dementia are beginning to correct this picture.

The increase on the focus of the personhood of people with dementia began in the academic field in the 1990’s. At that time, this would largely have applied to people with more advanced dementia. The process of early diagnosis was not as developed as in more recent years, and early symptoms were not recognised as a concern (Oliver and Guss, 2019). Since then there has been swift developments in the earlier diagnosis of dementia. This along with the increase in focus from the academic field on the personhood of people with dementia has brought the opportunity for people with dementia to begin to make sense of their changing experiences, and to tell their story about dementia. Many people with dementia can voice their experience and the support that they need both in the present and what they would want in the future (Oliver and Guss, 2019). Christine Bryden, Richard Taylor, Kate Swaffer and Wendy Mitchell are all people who among others have written and published books about their experience of dementia. They have offered a counter story reinforcing their ongoing humanity and position in the world.

Not only are many people with dementia more able to tell of their experience they are also more able to actively influence the political field and policies that impact the lives of people with dementia. To give some examples: The Scottish Dementia Working Group (SDWG) is a group run by people with dementia that campaigns nationally to improve services and attitudes towards people with dementia (Alzheimer Scotland 2019a). The Dementia Engagement and Empowerment Project is the UK network of dementia voices that consists of approximately 100 groups of people with dementia

(DEEP, The UK Network of Dementia Voices, 2020). According to Oliver and Guss (2019, p101) activists living with dementia have “helped shape the working programme” of the National Dementia Action Alliance, (NDAA) a group who campaign for change across the health and social care sector of people living with dementia and their carers (NDAA, 2019). They have also contributed to the 3 Nations Dementia Working Group and represented DEEP at the Disability Rights at the UN Committee (Oliver and Guss, 2019). The Dementia Alliance International (DAI) is an organisation made up of people with a diagnosis of dementia that represents people with dementia globally. Established in 2014, it promotes “education and awareness about dementia” (DAI 2019, para.2) with the aim of putting an end to discrimination and stigma, improving the lives of people with dementia and urging government, private sector and medical professionals to “listen to our concerns and take action to address this urgent global crisis” (2019, para.3).

2.4.2 Challenging Dehumanising Language

People with dementia, publicly and academically challenge language and policy that dehumanises and stigmatises people with dementia, including the language that has been used in academic research about dementia (Swaffer, 2016).

Swaffer (2016) calls for researchers and service providers to stop contributing to that stigma, which continues to exist and is “increased by the language used” about people with dementia (Swaffer, 2014, p714). One of Swaffer’s criticisms was of the way in which researchers and presenters at an ADI conference used “dehumanizing and devaluing language” (Swaffer, 2014, p711) positioning people with dementia as “‘demented’ ‘sufferers’, ‘subjects’, ‘victims’ and ‘not all there’”. These words are amongst the list of words that DEEP have called “never be used to describe dementia or people with dementia” as well as the words:

senile or senile dementia, burden e.g. people are a burden or cause burden, plague, epidemic, enemy of humanity, living death e.g. dementia is a living death.

These words send out a message that life with dementia is worthless and people with dementia have “nothing to contribute” (DEEP, 2015, p2).

2.4.3 The Research Participant and The Researcher

Swaffer also challenged the fact that people with dementia themselves were not included in research, the research became about people with dementia “without them” (Swaffer, 2014, p710). Wilkinson (2002) argues that the assumption that people with dementia cannot take part in research because they are unable to express views and experiences reinforces the assumption that they are not capable of doing so, perpetuating excess disability and stigma. There has been a shift change in the last two decades where people with dementia are becoming more involved in research as participants (Clarke et al, 2018). Whilst people with dementia are still often excluded from doing academic research (Mann and Hung, 2018) there is a gradual, albeit slow, shift towards people with dementia now becoming more involved in the research process as co-researchers rather than just being the research participants (Clark et al, 2018, Phillipson et al, 2018).

The voice of people with dementia is offering a strong challenge to the dehumanising narratives that exist in society about dementia. These voices are incredibly effective in changing the perception in society about dementia as they enter the political field, influencing policies and the research landscape. I argue that it is imperative that the voice of people with dementia continue to be heard so that a better understanding of dementia is developed and dehumanising narratives about dementia can continue to be countered.

According to McParland et al (2017) however, the research of the experience of those with dementia is disproportionate in that it potentially excludes the voice of those who are “most frail” (2017, p263) and have a greater extent of cognitive impairment. They suggest that many of the voices of the person with dementia that participate in research, conference presentations and appear in campaigns aimed at changing public understanding of dementia are often of those who are “younger and well educated, usually, and often of

necessity, not living with the most challenging aspects of the condition” (2017, p263). Many can articulate their experience in words and language that the general public will be able to relate to, and they may be less cognitively impaired and not as frail as many other people with dementia.

Not everyone with dementia, particularly those with advanced dementia, has the opportunity or ability to tell their own story in a way that will make a strong enough impact on society that their identity as “valuable and capable human beings” will be sustained (Swinton, 2012, p23) even as their cognitive impairment becomes greater.

2.4.4 The Voice of the Person with Advanced Dementia

For people with advanced dementia it is the voice of others that determines what stories are told about them (Swinton, 2012). These stories could either be damaging to the person with dementia, or could breathe life and vitality into the identity of people with advanced dementia, depending on how they are positioned in terms of their status as a human being and person (Sabat, 2001, White, 2013, Gerritsen, et al 2018).

Stigma and dehumanising narratives continue to circulate in our society about dementia and people with dementia (Swaffer, 2016, Gove et al, 2017, Weisman de Mamani et al, 2017) despite the increasing voice of people with dementia who are effecting social change. I suggest that another voice needs to be heard, and it needs to be the voice of people with advanced dementia.

It is with a focus on people with advanced dementia that I move on to discuss the historical and current academic research that has challenged the dehumanising narratives of dementia that continue to exist. I discuss the effect they have had on how the person with advanced dementia is understood in terms of their ongoing humanity.

2.4.5 Focusing on the Person with Dementia

I base this next section of the review primarily on the work of Tom Kitwood. Kitwood was seminal in his academic work and driven by a moral concern for people with dementia (Dewing, 2008). He challenged the medical concept of dementia by focusing on the person with dementia. As explained earlier, Kitwood's early research would have related to people with more advanced dementia, and the reason that I chose to discuss his work after the discussion of the voice of people with dementia is that it relates more closely to my own research aims.

As I discuss and critique Kitwood's work I introduce the different concepts of dementia that have developed from his early ideas as a response to those critiques. The reason I have chosen to approach this review in this way is because Kitwood consolidated his key theories that had formed much of his writing in his book "Dementia Reconsidered: The Person Comes First" which was published in 1997. This book became a seminal text in the field of dementia and continues to influence the dementia studies landscape today (Brooker, 2019). This book set out Kitwood's concept of personhood and detailed how Kitwood gained insight into the subjective experience of people with dementia. Kitwood died unexpectedly twelve months after the publication of his book (Brooker, 2019) and therefore was unable to respond to and develop his theories based on critiques of his work. Since that time there has been considerable change and development in the landscape of dementia research. Although Kitwood himself has not been able to develop his concepts and theories, Kitwood drew our attention to noticing that people with dementia are persons, and his work has paved the way for other scholars, people with dementia and communities to continue to find ways to ensure that that message continues to be heard. I therefore introduce these different concepts of dementia as responses to the critiques of Kitwood's work.

2.4.6 Tom Kitwood – A Malignant Social Psychology

Kitwood introduced the biopsychosocial concept of dementia, as he considered the relationship between the brain, mind and society. He suggested that it is not just the disease aspect of dementia, but also the social experience of people with dementia that exacerbates neurological decline and gives shape to the way in which the symptoms of dementia emerge (Kitwood, 1997 Swinton, 2012, Bartlett and O'Connor, 2007). Kitwood, shocked by the way in which people with dementia could often be "demeaned and disregarded" (Kitwood, 2019, p3) developed a list of elements, through observation, that he describes as malignant social interactions with people with dementia (Appendix 1). These interactions can be damaging to the person with dementia. Not only do they dehumanise people with dementia but Kitwood argued could also damage nerve tissue. Kitwood suggests that "dementia may be induced in part, by the stresses of life" (2019a, p15).

Steven Sabat develops Kitwood's thinking and explains why the phenomena of a malignant social psychology occurs. I now discuss Sabat's explanation in more detail before returning to further explore the theories of Kitwood.

2.4.7 Steven Sabat – Excess Disability and Social Positioning

Like Kitwood, Sabat challenges the standard paradigm of dementia and regards dementia as a relational social concept as well as neurological (Swinton, 2012). Sabat asks the important questions as to why people with dementia continue to be treated in such malignant ways (Sabat, 2019) suggesting that it is because people with dementia are positioned socially in a malignant way.

The standard paradigm of dementia, with its focus on diagnosis concentrates on the defectology of the person with dementia. It positions the person with dementia as someone who has less functional capacity than their dementia causes. This is described by the phrase "excess disability" (Sabat, 2001, p93).

The standard paradigm of dementia has created a narrative about what people with dementia are able to do, or not do, leading to incorrect and negative

assumptions by those who interact with people with dementia (Sabat, 2001). Once people are positioned in particular ways in society, we can either take up those positions for ourselves, “impose” those positions on others or decide whether to accept or reject them (Sabat, 2019, p60).

For the person with dementia, it is not always easy to reject a social position, especially as the disease advances. Where a person with dementia is positioned in terms of their “dysfunctional attributes” (2019, p60) this positioning becomes malignant in that it can lead to depersonalising treatment. Attributes that are positive and valued are ignored which leads to a deprivation of the basic rights to be treated as a human being (2019).

Sabat (2001) argues that when a person with dementia is subjected to malignant social positioning it reduces the ability that people with dementia have to a good quality of life as it affects how other people see you and care for you (Post, 1995). Malignant social positioning therefore can easily lead to malignant social psychology, even when this is unintentional. Sabat suggests that it is possible to avoid malignant social positioning when the person with dementia is positioned as:

(i) having intact selfhood, (ii) possessing the ability for creative expression and (iii) one whose actions are driven by meaning of situations, thus demonstrating semiotic behaviour (Sabat, 2019, p62)⁵

This becomes problematic for people with dementia amongst narratives that invite others to see dementia as something that will dismantle the self (Davis, 2004).

Sabat explores how people with dementia show an enduring sense of self through his model of selfhood that is made up of Self 1,2, and 3:

⁵ I use the term selfhood to mean the same as the term personhood

Self-1: Is expressed using first person pronouns such as “I”, “Me”, and adjectives such as “My” and “Mine” (Sabat, 2001, p17) and can also be expressed in gestures (2001, p277).

Self-2 Is expressed through physical and mental attributes and “beliefs about those attributes” (Sabat, 2001, p17). Some of these attributes will remain stable, such as eye colour, race, but others will change. For example, a person will not always be a child, at some point they will become an adult; this is a changing attribute. Attributes, such as the ability to quickly complete mathematical calculations, or memory function, mental attitudes such as faith, belief or political positions may also change. People without dementia will find it easier to maintain a positive “self-2” than people with dementia as they may be able to more easily give an explanation as to why some of their attributes appear to have changed.

Self-3 Is expressed in the way in which a person presents themselves to the world, “the displays of one’s personality and character” (Sabat, 2001, p18). There are many ways in which a person can present themselves to the world; a loving parent, a strict teacher, an excellent pianist. “Self-3” relies on the co-operation of other people because it can only be manifested if others recognise you as the person you are presenting. “Self-3” becomes a vulnerable place for a person with dementia because it can be undermined by certain reactions or positioning by others. Sabat argues that a loss of “Self 3” is not always caused by the dementia, but rather because the person does not get the cooperation they need from a person without dementia (2001).

If others were to help the person with dementia build their own valued “social personae” then this would bring the opportunity for social inclusion, the development of relationships and bring “honor” to the person with dementia (Sabat, 2001, p308).

When we begin to notice that the selfhood of the person with dementia is not lost because of the disease, but because of malignant social positioning, and malignant social psychology, we begin to question whether the person with

dementia is in fact “gone”. Rather we notice that selfhood endures but is given little opportunity to manifest to the world. According to Sabat, people without dementia can help to sustain the self in a person with dementia.

Having diverted to discuss how Sabat has developed Kitwood’s theory of a malignant social psychology, and his understanding of an enduring self, I return to discuss how Kitwood’s position on how personhood can be maintained for people with dementia.

2.4.8 Kitwood on Personhood

According to Kitwood, dementia within the medical concept that sits within a culture of intellectualism and individualism means that “the person has almost totally disappeared” (1993, p541).

Kitwood refers to the work of Post (1995) who rejects the attitude that a person is given moral standing and protection because of their rationality and memory. Post argues that these “rationalistic theories” (1995, p4) are both discriminatory and dehumanising to people whom he refers to as “those among us who most need our moral commitment because they are forgetful” (Post, 1995, p4).

Caring for the whole person, according to Post needs to include paying attention to “will, emotion, relationship, and creative expression” (1995, p4). Kitwood suggests people with dementia are often more competent in these characteristics than their carers (Kitwood 2019a). In fact, Kitwood suggests that people with dementia “may have something to teach the rest of mankind” (2019, p5).

For Kitwood, the person might change, but would persist through dementia. It was important that the person with dementia continued to be valued as a person by others throughout the dementia process (Bruens, 2013).

Maintaining personhood for the person with dementia means recognising each individual person with individual needs that need to be met (Bruens, 2013). Kitwood recognised the needs of people with dementia as the same

as those that all other human beings have, and without which “a human being cannot function, even minimally, as a person” (1997a, p19). These needs are” comfort; attachment; inclusion; occupation and identity” and they all join in the “central need for love” (1997a, p19).

Kitwood offers a counter story to the one that argues that personhood lies in rationality, intellect and autonomy, suggesting that personhood can be maintained by other people as they draw near to, notice and care for the person with dementia. He defines personhood as “a standing or status that is bestowed on one human being by another, in the context of relationship and social being” (Kitwood, 1997, p8).

2.4.9 Person-Centred Care

Kitwood’s aim was to introduce a new paradigm of dementia care where the “the person comes first” (2019, p2) and not the disease (Bruens, 2013). He introduced the concept of person-centred care, where care focused on caring for the individual person with dementia in ways that attended to much more than the physical care but on all the needs of the person with dementia including emotional needs.

In contrast to malignant social interactions, Kitwood introduced a provisional list of positive care interactions that enhance the personhood of people with dementia (Appendix 2). The first ten interactions are led by the carer and the person with dementia is being cared for or invited into the social world. The last two interactions are led by the person with dementia and the carer responds (Kitwood, 2019c). This positions the person with dementia as someone who continues to engage with and influence the world.

Kitwood’s focus on the personhood of people with dementia, the damage that could be done through malignant social interactions and the introduction of person-centred care has challenged the “standard paradigm” and expanded the understanding of dementia in society. He has raised awareness of the continuing personhood of the person with dementia and has had a significant theoretical and practical impact and improved care standards for people with

dementia (Hughes, 2011, Bartlett and O'Connor, 2007 Bruens, 2013, Brooker and Snaedal, 2016). Kitwood's work has challenged the narrative that dementia is a "death that leaves the body behind" (George, 2010, p586) and focused attention on the fact that people with dementia continue to experience the world. Kitwood's work reflecting the sentience, relational and agentic abilities of people with dementia has shown that the behaviour of people with advanced dementia has meaning (Brooker and Snaedal, 2016, Hughes, 2014, Sabat, 2001) as opposed to it being regarded as irrational behaviour.

The person-centred care approach to dementia continues to have a significant impact on the world stage of dementia, and in government policies in the UK (ADI, 2017, Department of Health, 2015).

However, Kitwood's work is not without critique.

2.4.10 Critique of Kitwood and Responses

Kitwood's focus on positive care interactions is criticised in that it offers little support to those who are close to the person. It is often seen as being exclusively about people with dementia (Dewing, 2008). The "untrained carer" can become implicated as "being involved in the disabling process" (Davis, 2004, p376) and feelings of guilt that the carer may feel may "compound a bereavement that has not yet come to pass" (2004, p376). Bons-Storm (2016) applies this same critique to Sabat, arguing that both Kitwood and Sabat place the responsibility for the development of the dementia at the partner's feet. She suggests that they deny how much impact the neurological disorder has on the personality of the person with dementia.

Having said that Kitwood does recognise that sustaining positive interactions with people with dementia makes high demands on the caregiver and recognises that at times there can be high levels of distress and anxiety (Kitwood, 2019d). He asserts that if an organisation is truly committed to the personhood of its clients, this same commitment must be applied to its staff (2019d). This is an issue that is at the forefront of much debate and research

in our present culture (ADI, 2019, WHO, 2017, DoH, 2015). Alzheimer's Society, (2014, para.2) state that "carers must be provided with comprehensive support" which includes emotional support. ADI (2017) recognise that need to support and empower people with dementia and their care partners, as do the World Health Organisation (2017).

2.4.10.1 Relational Centred Care

Nolan et al (2002, p203) recognise the transforming effect that person-centred care has had in dementia practice but argue that "it does not fully capture interdependencies and reciprocities that underpin caring relationships", rather it focuses on how one can better care for people with dementia. The concept of Relational-Centred care redresses this focus (Kontos et al, 2017) as it considers the person with dementia within a context of relationships with others (Ryan et al, 2008). Relational-Centred care recognises that dementia impacts not just one life but many lives, as the quality of life for the person with dementia cannot be separate from the life of the caregiver (Post, 2001). Within this concept Nolan et al (2001) developed the "Senses Framework" (Ryan et al, 2008, p.79) that sets out six senses that are understood as prerequisites to forming good relationships in dementia care and delivering that care. The sense of "security", "continuity", "belonging", "purpose", "achievement" and "significance" (Nolan et al, 2001, p.175) relate to the older person, the staff and the family carers. It is suggested relationship centred care can only be delivered when all parties experience the "Senses" (Ryan et al, 2008, p.79).

2.4.10.2 The Problem with Kitwood's Relational Personhood

Whilst all members of the relationship are important in dementia care, Kitwood places personhood directly within relationship. He says little about the person with dementia's standing as a human being outside of a relationship with another. This becomes problematic as in some ways the person with dementia finds themselves somewhat protected by the person without dementia. Given Kitwood's moral concern for others however, it is understandable that this type of protection emerges from his concept of

personhood. His concept however, inadvertently places the focus on the person without dementia as the one who is upholding personhood, the one who in some sense appears to have the power of gifting another with personhood, placing a lower status on the person with dementia (Dewing, 2008).

Where personhood belongs within relationship with another, then personhood can become “a matter of degree dependent on the quality of relationships formed” (Harris, 1998, p229). Impoverished relationships for the person with dementia will therefore result in a diminishment of personhood within Kitwood’s concept. Personhood becomes undermined when the needs, emotions and rights of a person with dementia are ignored or not given validity from another person (Brooker and Snaedal, 2016) as is evident in a malignant social psychology. This reinforces Harris’ (1998) claim that personhood is at risk of being diminished when it is understood to be relational.

2.4.10.3 Missing the Structures of Society

A further critique of Kitwood’s concept of personhood is that it says little about the agency and power that person with dementia has in society (Bartlett and O’Connor, 2007). Bruens (2013) argues that Kitwood’s work did not reach the structures of society. Kitwood’s person-centred care focused on care approaches and settings and the individual with dementia. Introducing relational-centred care may shift the focus from individuality to relationality and interdependence, however both person and relational centred care pays no attention to the relationship that people with dementia might have with the state (Kontos et al, 2017).

2.4.10.4 The Citizenship Concept of Dementia

Bartlett and O’Connor (2007) recognise the limits of Kitwood’s concept of dementia, and argue that the two lenses of personhood and citizenship need to combine so that both the individual person with dementia is recognised in

their own right as both a unique individual and also as someone who has power and agency in society.

The citizenship concept of dementia focuses on how people with dementia can continue to exert power as social actors in society and continue to participate in community. As people with dementia have become instrumental in influencing the political field, they are not just maintaining their personhood but are “repositioning themselves as active citizens rather than as ‘tragic victims of a disease’ (2007, p112). Traditional citizenship, however, focused on how people acquire and participate in the membership of their country or community and involved “civil, political and social rights and responsibilities” (Bartlett and O’Connor, 2010, p31). This view tends to assume that people can claim rights, make judgements and take part in civil responsibilities such as employment and voting. It overlooks those who may be unable to do this (2010).

Social Citizenship

A social-citizenship concept is increasingly called upon to understand the experience of people with dementia as more than the rights and responsibilities that come with being a citizen. Social citizenship is defined as:

a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level (Bartlett and O’Connor, 2010, p37).

It recognises people with dementia as people who have agency, are competent and have rights and a history (2010).

Brannelly (2011) acknowledges that those whose dementia has caused a greater disabling effect on cognitive abilities are often viewed as lacking citizenship. Their citizenship relies on their story or narrative. A story that those with advanced dementia are often unable to voice and is told by others.

The stories that are told are often “narratives of deficit” that do not reflect the agency that people with dementia have to “shape their own world” (Birt et al, 2017, p199).

Brannelly suggests that caregivers who see people with advanced dementia as “socially alive” (2011, p669) can facilitate their citizenship. They use narratives from what they know of the biography of the person with advanced dementia to either try and engage people with dementia in “good care choices” (2011, p669) or if they were unable to contribute to the discussion that they would ask friends or relatives what the person with dementia would want (2011, p669). Brannelly suggests that each care interaction with a person with dementia has the potential to either disempower or for “transformative citizenship” (2011, p670).

Birt et al (2017) acknowledge that some frail and dependent people with dementia may not be able to be “active citizens” who contribute to communities, rather they will be “passive citizens” (2017, p204). They suggest however that they can continue to live as passive citizens if others are able to recognise the different ways in which people with advanced dementia might display their agency. These may often be through embodied action (2017).

The sociological lens of citizenship, whilst it continues to recognise that people with advanced dementia may be dependent on others to meet their care needs shifts the discourse from one of dependence to one of interdependence. It recognises that those who support people with dementia may still gain something from the relationship they have with the person with dementia. Bartlett and O’Connor (2010) ask the question of how the person with dementia continues to contribute as a citizen to society within these relationships and seek to “reposition” the persons with dementia as “active citizens” (2010, p123).

According to Birt et al (2017) social citizenship provides a framework for:

reviewing the role of society and culture in repositioning dementia away from deficit to a discourse of agency and interdependence (2017, p199).

Beard (2017) insists that this framework must be fostered to challenge medical arenas and the mass media.

Social citizenship is a helpful framework within which to understand people with dementia as those who continue to belong and contribute to society and as human persons who have the same rights to all aspects of private and public life.

In understanding people with dementia as active or passive citizens, social citizenship recognises that people with more advanced dementia continue to retain “*embodied agentic actions*” (Birt et al, 2017, p205). Kitwood is criticised for using the term embodiment in a limited way (Dewing, 2019). For Kitwood, embodiment referred to the mental and neurological effects of a condition on the physical body (2019). Since Kitwood’s seminal works there have been many developments in how personhood is understood. A significant development in this area is the focus on the embodied self.

2.4.10.5 The Embodied Self

Pia Kontos carried out an ethnographic study of elderly people with moderate to severe cognitive impairment in an Alzheimer’s support unit (Kontos 2004). Kontos makes the claim that selfhood is “embodied” (2004, p831). She extends this view to suggest that the body itself should be regarded as a fundamental source of selfhood separate from cognitive function (Kontos, 2005).

Seeing a person with dementia through the embodied selfhood lens, contradicts dualistic concepts of personhood. It enables us to step away from a culture that celebrates the “values of the mind” (Van Gorp and Vercruyse, 2012, p1279) and see people with dementia as fully human and fully alive regardless of cognitive ability.

Kontos (2005) argues that the body has its own ability to communicate and act in its environment separate from any cognition. Her theory is based on the philosophies of phenomenologist Merleau-Ponty's pre-reflective and primordial body that "knows" (2005, p560) to perform without any cognitive requirement, and Bourdieu's concept of "habitus" (2005, p559). Habitus illuminates the understanding of sociocultural sources of how the body engages with the world. Merleau-Ponty (1962, p169) cited by Hughes (2013, p356) wrote "the body is a general medium for having a world".

In order to understand people with dementia we need to notice the body rather than just cognitive interactions (Hughes 2013). By considering the way in which the body of a person with dementia is signalling distress, joy, discomfort or pleasure we can develop an understanding of how best to respond personally and socially towards them. This enables us to recognise individual needs and wants when language ability is impaired (Downs, 2013), and allows us to embrace and meet the psychosocial needs of a person with dementia. Good care of the person with dementia relies on understanding embodied reactions (Hughes 2013). Any meaningful connections that we can make with the person with dementia depends on how we interpret "gestures, looks, grimaces, mien, nuanced movements and so forth" (2013, p354).

The Situated Embodied Agent

Julian Hughes expands the embodied selfhood lens with his perspective of a human being as a "situated embodied agent" (SEA) (Hughes, 2011, p42). Not only does he agree that the 'self' resides in the body and knows how to perform, he also reminds us that the person with dementia is situated within and is an agent in the world.

Situated

Any psychological phenomena can only be understood within the situated context within which it is embedded (Hughes 2001). According to Hughes (2001) persons are situated in different cultures, families and historical

contexts that all contribute to the narrative of our lives. As we remember that a person with dementia is acting within a situated context it develops our understanding of the person as we are reminded that their life has a narrative, it has a story. When we begin to understand that narrative, we can begin to understand the actions and communication of the person with dementia. We are reminded that the person with dementia has not just suddenly disappeared but continues to act from a place embedded in their own life narrative.

Agents

According to Hughes (2001) human beings are not passive observers in the world but are active agents, that act with purpose and from a perspective. We can only be an active agent however if we are situated with the world through our bodies. Persons cannot show agency without being embedded in the world or being embodied in the world. This reinforces the view that body is “inextricably involved” (Hughes, 2001, p88) in a person’s psychological state rather than totally separate.

Hughes (2001) and Kontos (2005) bring an important perspective on humanness and personhood, which does not place the responsibility of personhood of a person with dementia on the shoulders of another person. Personhood is embedded in the human body, in the context and situation within which they live and have lived their life, and people are seen as agents in the world.

The embodied selfhood concept of dementia and the SEA view firmly attach personhood to humanness. Together with Hughes’ (2001) view that the person with dementia is also an active agent in the world, this helps to protect the rights of the person with dementia as discussed within the social citizenship framework.

The view of the embodied self is not just limited to the individual person with dementia. The concept of embodied selfhood can be extended to offer an understanding of people not only as selves as individuals but as inter-

embodied and inter-corporeal, and as people who are inter-dependent and intertwined with each other (Watson, 2016) where space is created for other capabilities to emerge in both the person with and without dementia.

2.4.10.6 Inter-embodied self and Intercorporeality

Jenkins (2014) suggests that human selves, rather than individual are “dividual” in that they are “transacted and reproduced across persons” (2014, p126). Jenkins suggests that “self is achieved through dialogical (self-other) interaction, both at the reflexive (discursive) and pre-reflective (embodied) levels” (2014, p126).

Zeiler (2014) explores an interaction between Gladys who has dementia and Naomi Fell who engages in validation therapy with her. She explains that both Gladys and Naomi can do more with the interaction than they could alone because certain capabilities seem only to be there where they acted together:

Naomi sees a tear in Gladys’ eye and responds to this received object by reaching forward, saying that she sees a tear, touching Gladys’ cheeks and wiping away the tear. The tear draws Naomi physically closer to Gladys’ experience of the situation in some way: Gladys straightens her back and starts to beat the arm of the chair rhythmically and faster. In other words, two bodily subjects express themselves through posture, touch, eye contact and movement and by so doing create a shared space of dynamic intercorporeal engagement (2014, p11).

Zeiler suggests that intercorporeal capacities “spring forth through the interaction” (2014, p16). Both participants are already affected by the other in this interaction and therefore what emerges is not a latent capacity but can only be the result of the joint interaction rather from the intention of any individual within that interaction (Zeiler, 2014). Meaning of the interaction develops for both parties in the relationship that can’t be attributed to any one of the participants.

Watson (2016) through her ethnographic study that explored interactions with care staff and residents in a care home for people with dementia supports

this notion of capabilities springing forth in interaction. Watson (2016, p15) writes:

when a resident who rarely speaks is spoken to, has their hand held and is included and as a result they reciprocate with a word of thanks or a smile, something of that person's remaining embodied selfhood and their agency "springs forth in that joint activity".

Often these moments are understood to be instigated by the person without dementia, however, Kontos et al (2017) argue that the person with dementia also has the capacity to initiate an engagement. This capacity is often overlooked in people with dementia.

Watson (2016, p13) refers to a "mutual exchange of feelings between bodies, or intercorporeally" affecting both residents and staff. She shares how this intercorporeality can bring positive effects to the carer when she quotes:

(If) I'm feeling rubbish or whatever...I like to go and sit beside Penny (resident) and...you cuddle in or whatever. That gives something for each of you, she...I think she likes it too because sometimes she puts her hand on yours or she'll play with your hair or...and it's quite nice, I feel quite calm sitting beside her...(Vera, Staff Member, Interview, 26/06/13)

This second story shows how the person with dementia initiated the engagement with the member of care staff:

...and they feel as well, if you are nervous they know that...I walked in one day, I was just walking in and Ingrid said to me 'oh is there anything wrong?' and I thought no, I didn't say anything and what was it, I can't remember what it was, something quite simple but she actually picked up so much and then I think that's quite odd...they are very perceptive and they feel your feelings, you know, again they are very experienced people...(Brenda, Staff Member, Interview, 29/01/13).

Stories like these that show that the concept of an inter-embodied self, position people with dementia as those who are not only in need of receive care but also as those who are able to provide care. This dissolution between the carer and cared for can reconstruct the relationship between the person with dementia and carer from one that is often seen as one-way and instead frame it as a "life-sustaining web" (Jenkins, 2014, p133/4). This places people with

and without dementia on a much more even footing in terms of their humanity. It enables us to notice that we all belong to the same species and human race, and whilst we are all individuals, we are also the same in that we are all interconnected, in relationship with each other and affected by each other.

2.4.11 Living Well or Living with Dementia

Each of the above concepts of dementia enriches our understanding of what it means to be a human being with dementia. They draw attention to the enduring personhood of the person with dementia, and the way in which the quality of life for people with dementia can be supported by those around them. Hearing the voice of people with dementia as they tell their own story, influence policy and challenge stigma has challenged the dehumanising narratives and offers a real sense of hope for people with dementia. The focus on the person with dementia in research has led to a positive or “living well” (Bartlett et al, 2017, McParland et al, 2017) narrative about dementia and people with dementia in policy and academia that challenges the “empty shell” and “living dead” narrative (McParland et al, 2017, p263). Although the public discourse on dementia has not been greatly impacted by this more positive view as discussed earlier in this thesis.

The Department of Health, 2009 National Dementia strategy for England “Living well with dementia” aim was that “all people with dementia and their carers should live well with dementia” (Department of Health, 2009, p7). Swaffer (2014) argues that “people can live well with dementia” and Morgan, in her journal article (2018, p307) writes that “people living with dementia can continue to live well – life does not need to, nor should it, end with a diagnosis”.

The “Living Well” narrative has been the source of some debate, however. Bartlett et al (2017, p177) challenge the understanding of “Living Well with Dementia” arguing that it is “relentlessly positive” and does not offer a realistic understanding of dementia. McParland et al (2017) argue that this discourse can be as equally discriminatory as the tragedy discourse of

dementia as it divides those who feel that they are unable to live well with dementia from those who do.

This is not to deny that people can live well with dementia, rather a purely positive view offers a limited picture of the condition as it is not always easy to live well with dementia and the condition has its limitations (McParland et al, 2017, Bartlett et al, 2017).

Wendy Mitchell who was diagnosed with young onset dementia at the age of 58 wrote in her blog about the comments she shared at a conference about living well:

I have a problem with the phrase 'living well' it was a good idea some years back as there was nothing else but I've since realised from meeting other people that it sets such a high standard that not everyone can reach, so it ends up having a negative instead of positive effect as it makes some feel inadequate. So instead I prefer living as well as you can (Mitchell, 2018, para.13)

Many people with dementia prefer the phrase "living with dementia" rather than "living well" (Oliver and Guss, 2019, p99) as it relieves the pressure of "living well" and offers a more realistic perception of their experience of dementia.

Bartlett et al (2017) argue that people with dementia do suffer although they clearly do not condone the use of the phrase "dementia sufferer" (2017, p177). They suggest that the living well discourse risks denying that people with dementia may suffer (2017). Bartlett et al (2017) argue that we need to recognise suffering so that a person with dementia can be established as legally disabled, and that others can recognise the distress it can cause which calls for social action. Whilst not positioning suffering as something that is good, when suffering is acknowledged as a human reality, a call for a response of "love, compassion and solidarity" is heard (Matthews, 2019, p163).

I suggest that overlooking the potential suffering that a person may endure can also be dehumanising as suffering is part of our humanity

which becomes denied. Matthews (2019, p163), drawing on a theological understanding of suffering writes that:

suffering does not demean the person by somehow making the person less human. Instead suffering is an unavoidable part of the human condition and living well with suffering deepens our being human.

However, acknowledging suffering as a human reality becomes difficult as people are often unable to face their own reality that they may too suffer at some point. They may defend themselves by dehumanising the one who appears to be suffering (Kitwood, 2019a).

2.4.12 What We Know

So far, I have shown that a purely medical concept of dementia can lead to stigma and dehumanising narratives for people with dementia. Being able to hear the voice of people with dementia and the introduction of the focus on personhood within the field of dementia research has led to important new concepts that challenge those narratives and position the person with dementia as a valued and whole person. They have had a significant positive impact on the care of people with dementia, and the influence that people with dementia have in society. However, it has been argued that this shift in focus inadvertently led to an unrealistic “living well” narrative (Bartlett et al, 2017, p177), that people with dementia feel unable to always live up to.

Bartlett et al (2017, p177) suggest that “social death” to “living well” narratives have resulted in an unrealistic presentation of dementia. The social death narrative leaves little space for the person with dementia to be seen as a fully human person who continues to experience the world. Whilst the living well has been very welcome and a strong challenge to the tragedy and catastrophe discourse, there is debate as it is suggested that it does not consider that people with dementia might experience suffering and may not always live well with dementia.

McParland et al (2017) suggest that the dichotomy between the two discourses of “social death” and “living well” needs to be challenged and redressed. Discourse, according to McParland et al (2017, p266) “must acknowledge the limitations associated with this condition, while discovering the remaining pleasures”.

Whilst I suggest that McParland et al’s (2017) use of the word “remaining” in their phrase “remaining pleasures” is not helpful on the basis that it reinforces dementia as an illness that will deprive people of pleasures, I do agree that a more realistic discourse of dementia is necessary. This discourse should include the suffering and the pleasures of dementia, as suffering is a realistic aspect of human life.

Each of the concepts I have discussed focus on a dimension of what it means to be a human being, and views people with dementia through a particular lens. Each perspective enriches our view of what it means to be a human being. The concepts have been a welcome challenge to the medical concept of dementia and bring our attention to the continuing selfhood and humanity of persons with dementia, including people with advanced dementia. There has also been an important shift in care practices with the introduction of Person-Centred-Care (Kitwood, 1997) and Relational-Centred-Care (Watson, 2016, Kontos et al, 2017).

However, the concepts in themselves are narrow in their focus. I suggest that a lens that offers a more nuanced understanding of what it means to be a human person in its entirety will be helpful in bringing a more complete way of understanding what it means to be a person with dementia, and specifically a person with advanced dementia.

It is at this point that I introduce and discuss a theological concept of what it means to be a human being. I explore how this concept might be helpful in understanding the ongoing humanness of the person with advanced dementia.

2.4.13 Persons Created By, and Held By God

Swinton (2012), in his book “Dementia, Living in the Memories of God”, develops a theological perspective on dementia. He writes for Christians and his writing is located within the Christian faith and provides a hopeful re-description of dementia that I believe firmly demonstrates the worth and value of every human life.

Swinton suggests that it is the Christian story “which offers real possibilities in terms of the development of transformative counter stories” (2012, p24) because it radically re-describes the way in which the world is understood and how dementia is understood.

Swinton purposively contributes to “theological anthropology” (2012, p161). He argues that it is only possible to understand the situation of people with dementia and validate their personhood and implement effective care when we recognise and acknowledge the position of human beings before God.

Theology is one way of seeing the world and the people in the world (Sapp, 1998). I have chosen to explore a theological perspective on humanness and personhood, alongside psychological and sociological concepts. Firstly, this fits with my own personal perspective. Secondly, not to develop a theological argument but to discover what we might be able to learn from a theological perspective that might also be appreciated by those of all faiths and none in terms of how we understand people with advanced dementia. As I do this, the concepts I draw on should not be separated from the Christian theological framework, however.

The first helpful concept I draw on is one theological understanding of personhood and humanness as inviolably attached (White, 2013), that “human beings are irrevocably persons” (Swinton, 2012, p159) and that there is “psychophysical unity” (Sapp, 1998, p31), i.e. no separation between body and soul or flesh or spirit.

Swinton (2012, p161) develops a theological perspective of personhood and humanness using a “fivefold exploration” that suggests that the human person is:

- Dependent and contingent
- Embodied
- Relational
- Broken and deeply lost
- Loved and profoundly purposeful

I discuss the theological concepts of personhood and humanness within Swinton’s fivefold exploration and draw on the work of other theologians, some of whom have focused on theology and dementia (Allen and Coleman, 2006, Sapp, 1998, Harris, 1998, Kevern, 2010 and 2012). I focus primarily on the work of Swinton (2012) because he brings together in one whole, many of the previous individual perspectives of dementia and personhood that I have already discussed, in a way that other theologians have not yet done.

Dependent on God

Within the theological concept of human personhood, it is God who creates persons and God’s breath that is said to breathe life into and sustain human persons. This positions human person as dependent on God (Brueggemann, 2009).

For the Christian, it is understood that all human beings are dependent on God and that all that is given to them is a gift from God. Dependency is therefore the true state of what it means to be human, not just when we have dementia. This understanding challenges the quest for autonomy and independence in our hypercognitive culture (Sapp, 1998, Brueggemann, 2009, Swinton, 2012).

According to the Jesuit priest Teilhard de Chardin (1957, p76) dependence is part of belonging to the world into which we were born as human beings. He writes that:

the depth and universality of our dependence on so much altogether outside our control all go to make up the

embracing intimacy of our communion with the world to which we belong.

Embodied Personhood

Drawing on the Old Testament, Brueggemann (2009, p60) writes that the human person is “formed of earth and is breathed upon by God in order to become a “living being”.

The living being, for which the Hebrew word is “nephesh” (2009, p60) is often understood to mean the soul, which has led to a perception that it is something separate from the body. However, “nephesh” is actually more like “life-force, life principle or simply vitality” (Sapp,1998, p31). When this life force departs from an individual, they no longer exist (Sapp, 1998, Swinton, 2012). It is this very life force that creates the living being (Swinton, 2012) and therefore a dualistic notion between body and soul is rendered irrelevant. According to Sapp (1998, p31) both body and soul or flesh and spirit were seen by the early Hebrews as “interdependent elements that are both necessary for a human being to exist”. Human beings don’t just have a body, the person “is a body” (Sapp, 1998, p31).

The body becomes an important place for a theological understanding of the human person as it is the centre of God’s activity within us, and “where God meets and sustains us” (Swinton, 2012, p170). It is the place where we experience the world (Swinton, 2012).

Relational

A key concept in Christian theology is that human persons are relational, (Knabb et al, 2012, Allen and Coleman, 2006, Harris, 2016). Within the Christian belief, God creates each human being as an outpouring of His love and offers each human being the gift of relationship with Him. This gift of relationship, according to Swinton (2012, p179) is “an inalienable source of human identity”. The human being will therefore be in relationship with God regardless of cognitive ability.

As we look to the book of Genesis in the Holy Bible, we see that God first created a man, and then extended the gift of relationship to one that was not limited to a relationship with God, but one that also included relationships with other human beings. God saw that “It is not good that man should be alone” and created “a helper comparable to him” (Genesis 2:18) when he created Eve. For the Christian, human beings were created out of love, in relationship with God and for relationship with God and other human beings.

As we explore the relational concept of human beings, it is helpful to consider the Christian Doctrine of the Trinity, that God is both One and Three: one God; three divine persons, God the Father, God the Son, and God the Holy Spirit.

Understanding the concept of the Trinity is complex and difficult to illustrate, (McGrath, 1987) and certainly outside the remit of this thesis. However, for the purposes of this study I draw on a helpful explanation by Allen and Coleman (2006, p213):

The Trinity is a doctrine about the identity of God, but by implication is also about the identity of the human person.

Because the aim of human life in Christian understanding is to share in God’s life, this means sharing in the life of the Trinity. Just as God is not an isolated person but is considered always in relationship, Father to Son, to Spirit, so a human person is never considered in isolation from the rest of humanity.

For the Christian, the Trinitarian image of God, whose whole being is in “perfect relationship” (2006, p215) is a model for their lives.

The central notion of the trinity is that there is “perichoresis”, which translated from the Greek word means “mutual indwelling” or “coinherence” (2006, p215) of the three persons, Father, Son and Spirit. Perichoresis could be thought of as a “round dance” where “in the Trinity each person contains the other two and moves within them in an unceasing movement of mutual love” (2006, p215). Swinton, (2012, p158) describes this as the three persons of the Trinity “inextricably interlinked in an eternal community of loving relationship” (2012, p158). Each person in the Trinity is distinct and in

complete unity with the other, (2012). Swinton writes that through their “mutual relationships of love, identity is bestowed upon one by and through the other” (2012, p158).

The relational nature of God means that human beings are also inherently relational as those who are created in His image (Swinton, 2012, p158). As persons come together in community “they discover and develop their capacities and come to recognize themselves and be recognized as part of one extended human family” (2012, p159). It is in the coming together that the identity of each person can be held. This becomes increasingly important for the person with dementia who may find it more difficult to hold their own identity as they often find themselves dehumanised and socially isolated. Kevern, argues that just as infants are recognised by others before they recognise themselves, so as dementia progresses:

the responsibility again shifts back from the individual to the community; simply recognising the social contribution of someone with dementia can help to maintain their recognisability as an individual person (Kevern, 2012, p49).

As we begin to understand the human being as inherently relational, we move our concern away from independence and autonomy and redirect our gaze to relationship and communion with others (Kevern, 2010) and for the Christian, with God.

Kevern (2010a) however, warns that this approach may place too much emphasis on relationships. It may shift the discourse from one that suggests personhood is lost when awareness ceases, to one where we say that “a person ceases to be human when they are isolated from others” (2010a, p413). Kevern argues that at some point people with dementia “will probably end their physical life unable to maintain any recognizable form of relationality” (2010a, p413).

Taking the analogy of the Trinity to view humans in the same way to its extreme would therefore mean that God’s involvement with the person with dementia would also cease at some point (2010a). Swinton is clear that

human beings are “held and known by God in God’s memory” (2012, p212) and whilst Kevern (2010a) suggests that God is never absent from any sort of human suffering, he suggests that we need to consider the possibility that Christ experienced dementia when he was crucified in the sense that he lost awareness of himself and his motivation. When we understand that Jesus suffered, then according to Kevern “Jesus turned out to be more human than expected” (2010a, p416). Newell (2007) makes a similar claim as he speaks of a mental disability or “madness” (2007, p337) and discusses a new way of understanding the dynamic between the human and the divine. In understanding Christ as the “disabled Christ” (2007, p333) whose “resistance to models of exclusion, to the denial of human flourishing has left him disabled...divinely weak”, Christ was also “not disempowered” and his humanity remains “gracefully strong”.

If we consider human beings to be created in the image of God, and if Jesus experienced dementia, then this places dementia as a wholly humanising experience.

It is important to be reminded that "relational ties are not constitutive of personhood; they are...an outworking of that which is already present" (Swinton 2012, p158). Even if a human being were unable to maintain a recognisable relationality, as Kevern warns, from a theological perspective, they will always be in relationship with God as He continues to sustain and hold us.

It is at this point that I move on to the next part of Swinton’s (2012) exploration, that human persons are broken and deeply lost.

Broken and Deeply Lost

Whilst Kevern writes that thinking about whether Jesus had full self-awareness as he died has its difficulties, a discussion that lies outside of the scope of this study, he writes that “The identity of Christ is not negated by his dementing, but reasserted” (2010, p417).

Developing dementia makes us more visibly human as “another of the possibilities intrinsic in the human condition is made visible for us” (2010a, p417) in that we see the weakness and contingencies that are part of the human condition.

Harry Lesser (2006, p59) writes that our empirical experience is:

“that we are born, we undergo constant change mentally and physically, and we die. That is to say, our identity has to be the identity of an impermanent and changing being, relating in all kinds of ways to other beings, especially other persons and remaining the same through these changes because of the special links to its own past and future. So I suggest that both philosophical and psychological personal identity have to include ‘boundedness’ (like it or not, we are all subject in the end to birth, development, decline, and death), connections to both the past and future, and being involved in all kinds of relationships with other people”.

Swinton (2012) draws on the story of creation in the book of Genesis to help us understand the place of dementia within God’s creation. Swinton explains that as those created by God, human beings are “loved by God “beyond measure” (2012, p182), and those whom God sees as “very good” (Gen. 1:31). However, the first man Adam, sought “self-sovereignty, and God-like freedom and knowledge” (2012, p183). In doing so he pushed aside the both God’s love and the recognition that as humans we are contingent on God.

Swinton writes that human beings continue:

to alienate themselves from their one source of life and love, to reject the sustaining love of God. It is in rejecting the recognition of the absolute necessity of human obedience, dependency, and contingency that human beings find God’s loving embrace toward them loosened – not because God loves them less, but because their desire to be loved becomes distracted by their sinful desire to be free (2012, p183).

This is recognised as the “fallen nature of the world” (2012, p183).

There are different interpretations of the Fall. Swinton draws on an interpretation that places all human beings as always mortal beings, and always dependent on their “life-giving, nephesh filled relationship with God” (2012, p183). Human beings might have had eternal life, but only by the

God's sustaining breath. Mortality is now encountered as a reality rather than a potentiality because humanity chose to turn from their "eternal sustenance" (2012, p183). Whilst this may seem tragic, Swinton argues that it can help develop "a positive understanding of dementia and how dementia "sits" within God's creation" (2012, p183). If being human means being mortal, then for the person with dementia humanness is not diminished, rather it is part of what it means to be a human being living in a broken creation (2012) "but in the process of being redeemed" (2012, p183/4).

Swinton suggests that "nothing exists apart from God's desire for it to exist" (2012, p184), which includes dementia. Dementia does not exist through a punishment or a work of evil, rather Swinton describes it as "a mystery which is firmly rooted in God's creative and redemptive actions in and for the world" (2012, p184). Even though we may not understand this, and it may cause distress and anger, according to Swinton dementia still has meaning, people with dementia are meaningful and loveable (2012). He goes on to write that whilst it may be difficult and complicated to practice that love, that human beings are "both wanted and loved irrespective of their physical or psychological condition" (2012, p.185). Their identity is held by God who continues to sustain them and continues to "offer the gift of life and relationship to all humanity" (2012, p185).

However, the theologies that position God as the one who gives dementia, including when this is a mystery are disturbing to some (Bons-Storm, 2016).

Bons-Storm (2016, p6) argues that:

partners of dementia patients cannot do otherwise than be convinced that dementia is evil. It causes destruction, not only in the minds and personalities of dementia patients, but also in their families. Dementia is evil in a concrete sense, in its particularity of causing suffering in concrete persons. Before we think about God as creator of dementia – and the rest is mystery- we have to take this suffering seriously.

Bons-Storm suggests that evil begins with "the articulation of suffering" (Bons-Storm, 2016, p6). God did not create evil, rather he is acting in the world to fight against that evil. According to Bons-Storm (2016) if we think

about dementia as evil, then “God is battling against dementia” (2016, p6) and all of the difficulties it brings, and human beings are invited to join God in that work.

I argue that however we understand the creation story in Genesis, and why dementia exists, it is a fact that human beings are mortal, and any understanding will always necessarily mean that all humans are subject to decay and deterioration. The lifecycle will include a period of “slowing, decline and dying” (Post 1995, p3).

Kelly (2012, p92) writes that “to be human is to be vulnerable; it is to know the experience of having cracks, being open and fear breaking completely”. Titchen and McCormack (2008) refer to the strength and fragility that allow us to flourish in our humanity. I argue that we need to understand that human beings are a mix of strength and fragility, vulnerability and brokenness. In acknowledging the brokenness and strength that exists in each one of us, we can notice out differences and similarities. We need to see that in some sense all human beings are broken and lost, and that is part of the wholeness of being human.

Loved and profoundly purposeful

Within a theological context, Swinton tells us that all human beings are “wanted and loved irrespective of their physical or psychological condition” (2012, p185). They are assured by the God who created them that they are always valued, and their identity will always be held by Him. They are also assured of God’s continued relationship with Him. It is not others that bestow a value on people with dementia, it is a value bestowed on them by God.

People with dementia continue to be wanted and loved, from a theological perspective by God, but also often by those who are close to them. Evidence of this is seen in the stories that are shared by those who are close to them. An example is seen in the story of Robertson McQuilkin (1998) who cared for

his wife Muriel who had Alzheimer's disease. McQuilkin writes: "Loving Muriel isn't hard: she's so loveable" (1998, p58).

The purposefulness of people with dementia is made visible as Swinton remembers that the embrace of a person with dementia whom he is giving the Sacrament of Communion to "contains and reveals Jesus" (Swinton, 2014, p168). As he administers the sacraments to the person with dementia, he writes:

suddenly I discover that I am encountering God. The power of Jesus's words, "When you do this to the least of them, you do it to me" seems to surge between us – though precisely which one of us "is the least of them" is not at all clear.

Using Swinton's fivefold exploration to understand what it means to be a human person offers a holistic perspective of personhood and humanness. It includes dependency, embodiment, relationality, brokenness or suffering and love and value.

By understanding human persons including those with dementia within this framework that includes brokenness, leaves room for the more challenging aspects of dementia to be explored both from the perspective of the person with dementia and those who care for them. Through the theological lens, personhood and human identity can never be removed or lost for the person with advanced dementia. Nor can any human being ever lose their intrinsic worth and value. They were created by love and for love and are sustained in their humanity by the God that created them.

Summary of Part One of the Literature Review

Having undertaken an extensive literature review, I have shown that despite new insights into personhood, and a shift in care practices to person-centred or relation-centred care, people with dementia are still subject to poor care (Hughes, 2013, Alzheimer's Society, 2019a), loss of social network, (Watson, 2016), stigma, (ADI, 2019b) and dehumanisation (Budić, 2017, Beard, 2017). I have shown that some people with dementia can campaign, speak and advocate and challenge these dehumanising narratives, however the voice of

the person with advanced dementia remains unheard. Swinton (2012) argues that we need to have a counter story for people with advanced dementia, and that this counter story is heard through the stories of other people. It is to this counter story that I now turn in the second part of this chapter.

Part Two

2.5 Searching for the Counter Story

According to Gerritsen et al (2018, p596/7) people develop their understanding of dementia through “the meanings and explanations they give to their personal observations, knowledge, beliefs, expectations and experiences, and through direct and indirect interaction with other people”.

Brannelly (2011) advises that those who work with older people with dementia often sustain their humanness and avoid “dehumanizing practices” (2011, p664). A study that explored whether personal experience of dementia changes attitudes (Cheston et al, 2018, p2) suggested that “increased contact with people with dementia leads to more person-centred attitudes, and by inference, less stigmatising views”. However, the study did not define whether the contact included people in the more advanced stages of dementia. Bogden and Taylor (1989) write that nondisabled people who care for those with severe disabilities value and love them as human beings.

I now move away from the broad theoretical perspectives on personhood and humanness and explore the empirical evidence in an attempt to uncover a counter story that gives voice and an identity to people with advanced dementia as whole and valued human beings.

2.5.1 Meeting Someone Just Like Me

Brannelly (2011), Cheston et al (2018) and Bogden and Taylor (1989) bring a counter story that when someone without a disability or dementia has close contact with people with dementia or a disability that they are less likely to

stigmatise the person. Bogdan and Taylor (1989) demonstrate how nondisabled people who are involved in caring relationships with those who are severely disabled recognise persons with severe disability as “someone like me”, having the same qualities that define them as a human being and are “accepted by the nondisabled people as valued and loved human beings” (1989, p135).

It is as if in these moments of connection, the person with the disability and the person without share a “mutual recognition” (Swinton, 2012, p157) something that makes them essentially the same and equal as human beings.

Whilst the link between dementia and disability may not always seem an obvious one (Matthews, 2019), there are similarities in the way in which both people with advanced dementia and people with severe disabilities can be subject to the same dehumanising attitudes and perceptions of those in the more advanced stages of dementia. This link is seen in the comments of Singer (2011) and Baroness Warnock (Beckford, 2008).

I discussed earlier that it can be difficult to recognise our sameness in a person who no longer has the same cognitive ability and is totally dependent on others. It appears however that when someone is able to push beyond any protective distance and find ways to be spend time with people they can often engage and see something that is “quintessential to the person” (Hughes, 2014a, p1409). In that space meaningful connections are often made as they recognise their shared humanity with the person.

2.5.2 Becoming Estranged

Whilst I have made the comparison in the previous section between caring for people with disabilities and people with dementia, it must be noted that the behaviour and characteristics of many people with disabilities may not

radically change over their life span. Dementia is an illness that is progressive, and people with dementia will change not only in their cognitive abilities, but their expressions of self will also change (Swinton, 2012). This makes it more of a challenge therefore for the carer to maintain the sense that the person with dementia is still someone like me, because the person will often seem different to the person they were previously, or indeed from moment to moment.

Sikes and Hall (2016) explored the experiences of nineteen, 8-31-year olds who had a parent with dementia. One participant (2016, p11) whose father had dementia said:

I felt a bit of a disconnect with who that person was in the hospital and when I went to visit him because I cared about him and he was my dad but there was definitely, that that's not who I know...it was almost like talking to a stranger really (Harriet, 24).

People with dementia themselves often find it difficult to have a sense of who they are (Mitchell, 2018a, Davis, 1989). Swinton (2012) refers to an autobiography by Tomas DeBaggio who wrote "Losing My Mind: An intimate Look at Life with Alzheimer's". Swinton (2012, p259) writes that "De Baggio finds himself a stranger to both himself and the world". He says that "to be an afflicted stranger is to be someone whom others do not and really cannot understand" (2012, p268).

The process of becoming a stranger is a long process and a painful one (2012, p264), and the affliction of dementia:

can so overwhelm the person that he/she loses sight of who she is...For the person with dementia, this relates to feeling that somehow their true selves are fading away – even though this is not the case"

According to Swinton, "The affliction of dementia makes strangers of ourselves and the ones we love" (2012, p267).

Seeing people with dementia as strangers can create "distance and safety" (Swinton, 2012, p269). However, Swinton argues that if we see people with dementia as strangers then we can also engage in the practice of welcoming

and embracing strangers, in terms of showing them hospitality in the way that it is set out in the Christian faith.

Embracing and welcoming the stranger is to “become a neighbour to someone in need, to the point of accepting responsibility for his life” (Sutherland, 2006, p.xiv). In doing this they no longer stay as strangers, rather the stranger become a “household member” and room is made for their unique presence (Reynolds, 2006, p191).

Hospitality to the Stranger

For the Christian to offer hospitality is an obligation (Nouwen, 1975). God calls the Christian to practice hospitality by standing with the stranger and joining them in the difficulties they face (Frambach, 2011). Theologian Sutherland, writes that Christian hospitality is:

the intentional, responsible and caring act of welcoming or visiting, in either public or private places those who are strangers, enemies, or distressed, without regard for reciprocation (2006, p.xiii).

Offering hospitality means that we “visit” the other person, not only in that we are physically with them but that we actually “see, notice, or observe” (Swinton, 2012, p280) them. This means that we learn to “come close, take time and listen carefully” (2012, p280).

Hospitality is based on a “desire to create communities...that are based upon love” (Boys and Alexander, 2012, p65), where people are willing to “open their lives to one another” (Braganza, 2018, p35). It is more than an act of offering food and shelter, but also an offering of love and friendship (Jones, 1992).

Loving someone according to Pieper (2012) means that we find them “good”. Loving someone means that we turn to them and say, “It’s good that you exist; it’s good that you are in the world!” (2012, p164). According to Swinton (2012, p229) love also means that we need to be “present” for one another.

Therefore to offer the hospitality of the Christian faith to a person with advanced dementia means that we visit them in the present moment and as we do so offer our love and friendship as a way of saying that we are glad that they are in the world, just as they are.

Theologian and Catholic Priest Henri Nouwen suggests that it is possible for people to “offer an open and hospitable space where strangers can cast off their strangeness and become fellow human beings” (1975, p43).

Taking time to visit and really notice and see the person with dementia helps us to notice that they are still and always will be ‘someone like me’, a fellow human being, even though they are constantly changing.

2.5.3 Seeing with New Eyes

Swinton (2012, p157) writes of the “mutual recognition” that binds all of the members of human community together. Hughes (2014a, p1409) writes that it may be possible to see “something quintessential to the person” if we approach people with dementia “without theory” or “symbolic language”.

Determeyer and Kutac (2018, p1681) write that when we touch another person in a way that conveys caring, that it is possible to notice that “something ineffable is also present within the physical body – a thing that could be called the soul”. They write: “In the space where flesh meets, two humans encounter each other’s personhood” (2018, p1688).

This suggests that there is a moment of encounter when we can meet and recognise our fellow human being and connect with them.

Whether meaningful connections are made through touch or other means, there are many examples where people without dementia have been able to see the person with dementia with new eyes, as they attempt to step beyond their own fears, invite the person with dementia into their world and enter into the world of the person with dementia and really look and notice them.

In the following sections, I give empirical examples of the different ways in which these meaningful connections are made that have led to an encounter with the person with dementia which brought a new way of seeing them in their ongoing humanity. I draw on examples of encounters through music, through the Sacrament of Communion, through theatre clowning techniques and encounters through the body in everyday interactions.

It could appear that a person administering holy communion, elder-clowns, and professional musicians have very little in common, and linking them together could almost feel irreverent. However, I can't help but notice the key similarities that we can discover when we compare the experiences of those who find themselves relating to and connecting with people with dementia in different situations and for different reasons. As I read about the work of elder clowns, the experiences of the musicians and those of a minister in relation to people with dementia, there are moments where the person with dementia is seen in a new light.

2.5.3.1 Connections Through Music

Oliver Sacks, (2008, p385) writes:

I have seen deeply demented patients weep or shiver as they listen to music they have never heard before, and I think that they can experience the entire range of feelings the rest of us can, and that dementia, at least at these times, is no bar to emotional depth. Once one has seen such responses, one knows that there is still a self to be called upon, even if music, and only music, can do the calling.

Through the medium of music Sacks can notice the wholeness of the person with dementia and their enduring emotional connections to the world and enduring self.

Smilde et al (2014) write about an interactive creative music workshop project that took place in a care home for people with dementia over a period of eight weeks. The project is mainly concerned with the identity of the person with dementia with "finding, or rather "re-finding" the person behind the dementia" (2014, p4). The book uses the stories of those who have

worked closely together, “three musicians, eight women living with dementia, five caregivers, a staff development practitioner, a project coordinator and three scientific observers” (2014, iv), to explore the interaction of music and dementia.

During the sixth session of this project an incident with one of the residents “Rosamund” occurs which is described as a “big learning moment for the musicians” (2014, p72). I suggest this is a moment where they see the person with dementia through new eyes, not as someone masked behind dementia, but as someone who was whole whilst living with dementia.

The following is the account of one of the musicians, Fiona as she describes the incident:

“At the beginning of the session Rosamund was unable to get out of her wheelchair into her armchair and so the staff had to wheel a “hoist” into the centre of the circle and very publicly use it to transfer her into her armchair. Rosamund was actually fine throughout this process and seemed very calm. Anneliese and myself played gently in the background just to try and create a calm atmosphere and also to take the focus off of her.

However, in the debrief there was a general feeling that this had been distressing to see and seemed a very public, maybe de-humanising thing to have happened to Rosamund before the session. During this part of the conversation I was really struck by Brian’s insightful comment.” (Brian was the care staff development practitioner). “He simply said ‘I hear what you’re saying but I think it’s important to remember that this is a very real part of every day for the residents. We often have to use the hoist and many other similar procedures that are difficult to see and experience for the residents. But this is the reality...This is their reality’. I was really struck by what he said and realised how important it is that a Music For Life session operates out of this sense of reality...“I think the amazing thing about music is that you can be ‘held’ in the moment, or taken to a new place. You can provide a safe place in music that accepts each person as they are in that moment, or you can help to transfer them out of their current emotional/mental state to a different place, even for a moment. I was really pleased that Anneliese and I had played during this procedure; I think the music helped to ‘hold’ this difficult moment and also made the incident simply a part of the session as a whole” (2014, p72-73).

As I read the reflection it seems as if this incident gave Fiona a new perspective of Rosamund. Whilst it made her uncomfortable, and perhaps vulnerable, by seeing the reality of Rosamund's experience with dementia Fiona was able to connect with her in a new way.

2.5.3.2 Connecting Through the Sacrament of Communion

I wrote earlier of Swinton encountering God in the lady with dementia to whom he was administering communion (2014). Swinton talks about how the change in the position of his body so that he can serve the sacrament to the person with dementia allows him to see the world from a different perspective. He can see the person with dementia from a different light and be "deeply moved" by this new perspective that "takes the precognitive seriously as a mode of knowing and learning" (2014, p169). Swinton suggests that he needs to let go of his preformed theories, "theories that make sense, and indeed may be useful "up there", mean nothing in this place" (2014, p168).

Swinton suggests that in order to see the full person with dementia, he needs to "be formed in a quite particular way to achieve this task of proper looking" (2014, p170). In this place, he noticed that not only was he the giver of ministry in that moment but also received ministry from the lady with dementia.

Farmer (2007) offers a reflection of seeing the person with dementia in a new way as he describes "something extraordinary" (2007, p383) happening as the Minister for Congregational Care began the ritual of the sacrament of Communion for a lady with Alzheimer's who appeared mostly incoherent. Farmer talks of her changing facial expressions as the liturgy was read:

after finishing the Supper, I saw new life in many places...I saw new life in the joy of a woman who, if only for one brief moment, had a renewed expression of youth and true love on her face (2007, p384).

Farmer explains this encounter as "The Holy Spirit resurrected us all into a renewed loving relationship with God and with one another" (2007, p384).

In the encounters through music and Holy Communion there is a sense of tuning into the person with dementia and noticing them with new eyes as fully human beings. This sense of seeing with new eyes is continued as I explore the work of Elder-Clowns.

Encounters Through Clowning

Elder-clowns use an “arts-based approach to person-centred care” for people with dementia (Kontos et al, 2015, p1). They use techniques such as “improvisation, humour and empathy, as well as song, dance, and music” (2015, p1). Elder-clowning has developed as other more creative approaches aimed at supporting the identity and quality of life of vulnerable adults have been introduced (Hendriks, 2017).

Hendriks, in his paper on elder clowning talks explicitly about tuning in to a person with dementia, where the clown can notice how the experiences of the person with dementia impact his own body as the clown is “moved, touched and stirred to specific reactions” (2012, p461) Hendriks (2017) researches the miMakkus⁶ method of clowning which is for people living with advanced dementia. The word miMakkus, means “my pal” (2017, p208), and it is a method of clowning specifically for people in the later stages of dementia that was developed in the Netherlands. The specific goal of the miMakkus clown is “to make contact with people who are not (any longer) capable of communication in the usual, cognitive manner” (Hendriks, 2017, p208). Fundamental to clowning is that the clown can “achieve a state known as ‘presence’” (Kontos et al, 2015, p4). To be present needs personal judgement to be suspended, which resonates with Swinton’s experience of letting go of his preformed theories.

As Hendricks (2012) explores how the miMakker clown attempts to reach the person with dementia, we notice this same lack of cognitive assumptions and a sense of curiosity as he explains how he learned that “a clown has to be

⁶ “miMakkus is a special method of clowning for people living with an advanced stage of dementia” (Hendriks, 2017, p207).

completely attuned to the other” (2012, p467). Hendricks describes tuning in as “a form of inquisitive awareness of the unknown way in which that person may experience things” (2012, p467). The miMakker looks “with new eyes to people and things around them (2017, p207) focuses on the present and looks using their whole body. The miMakker in “acquiring a sensitive body”, helps the clown attune to the other person and fine tune as they:

search for each other’s wavelength, wherever that may be” – “not by observing the person from a distance but by trying to “go along” in his emotion, physical presence, sphere of attention, and experience (2017, p213).

The miMakker, according to Hendrik, taps into the latent ability of people with advanced dementia through “sensorial conversation” (2017, p215). They notice how people with advanced dementia still have the capacity to have an impact on other people, and that they are able to “be captured and moved by the world and others” (2017, p215) as they seek to look at people with dementia with “fresh eyes” (2017, p216). Kontos et al in their mixed methods evaluation of an elder-clowning programme in a dementia unit, identified that even persons with advanced dementia were able to “initiate affective, creative and playful engagement using verbal and non-verbal communication” (Kontos et al, 2017, p60).

Just as music and the administering of the sacrament of Communion make way for the fullness of the person with advanced dementia to be presented, so does the work of the Elder-Clown.

2.5.3.3 Connections Through the Body in Everyday Interactions

Meaningful connections are often experienced through noticing the non-verbal languages of the person with advanced dementia.

Family members in a study by Quinn et al (2014, p264) identified a “twinkle” or “spark” in the eyes of the person with advanced dementia. This signified that they had made a connection with their loved one. Noticing a person with advanced dementia as being capable of communicating through the body,

was a theme that ran through the above study, and is echoed in McCleary et al (2018).

A study by Nicholls et al (2013) that explored touch in people with advanced dementia in relation to mental health showed that through their interactions of touch the carers were often reminded of the humanness of the person with advanced dementia. One carer, through her interaction as she massaged a resident's hand and to her "I love you", was powerfully moved when the resident "grabbed my hands and she put them close to her heart" (2013, p575). The carer, according to the author was reminded that "this person was able to be connected with in a very real and physical way" (2013, p576)

A participant in the study by McCleary et al (2018, p5) said "touch can sometimes be that final way of connecting when the words don't make sense anymore".

2.5.3.4 Correcting the Picture

It is within this person-to-person encounter, where people make meaningful connections that the human identity of the person with dementia is made visible. These stories that establish connection help others to have faith that the mind of the person with dementia is not gone, and to "give them the benefit of the doubt" (Swinton, 2012, p284) that they continue to experience and give meaning to the world. It is in the stories of these meaningful encounters that the person with advanced dementia is seen as a human person. Without these meaningful connections it is difficult to notice the person with dementia. The stories of people without dementia who do make these connections bring a narrative of "human identity" to the person with advanced dementia. Their stories go some way towards correcting the picture for people with advanced dementia and give them a voice.

2.5.4 The Foundations of Care

Hughes (2013, p356) points out "the foundations of care rest in the shared connection that establish human meaning". He suggests that the potential

that we have to feel the meaning of those with severe dementia comes from “our standing as human beings in the world” (Hughes, 2013, p356).

However, we can only do this when we recognise people as humans, just like me and therefore relate to them as someone like me.

I suggest that it is the stories of those people who make these shared meaningful connections that will provide a counter story that have the power to trouble the existing narrative and shift the way in which we might think about people with advanced dementia from a discourse of deficit and dehumanisation to one of fullness in humanity.

2.6 What the Literature Tells us and Where are the Gaps

In this chapter I have shown how that people with advance dementia are still positioned as less than human in our society and that dementia is still one of the most feared conditions in Western cultures (Birt et al, 2017). This is despite significant challenges from a multitude of voices.

I have shown that empirical evidence from studies that explore the meaningful connections that people with and without dementia experience through the arts, in spiritual rituals and through embodied encounters and familial knowing develop the narrative identity of people with advanced dementia and position them as fully human persons. These studies provide evidence that often the person with dementia is noticed as someone who continues to impact the world and others and flourish in their humanity.

However, much of the literature that explores connections with people with dementia focuses on how those connections are made in a particular role and context, i.e. as a musician, family member or care staff, Elder clown or Minister. The focus of the literature is often on how the connection is made in terms of noticing the impact that that activity has on the person with advanced dementia.

Additionally individual explanations are given as to why the connections can be made; these may be music (Sacks, 2008, p372, Smilde et al, 2014); the

presence of the Holy Spirit (Farmer, 2014); attunement (Hendriks, 2016); embodiment and body work (Kontos, 2005, Watson, 2016, Quinn, et al, 2014, Hendriks, 2016); familial knowing (Quinn et al, 2014).

There is a paucity of literature that steps back from the individual ways of making and understanding meaningful connection and takes a broader view of why and how these connections might come about, and discusses what this makes visible about the human identity of people with advanced dementia.

I suggest this gap in the literature could be filled by exploring stories from a broader range of people without dementia who experience meaningful connections with people with advanced dementia. People who engage with those with dementia for a variety of reasons and through a variety of methods. This should include those whose purpose is to engage with a person with dementia, such as musicians, Elder clowns, spiritual carers and care staff, many of whom will be specifically trained in how to make connections. It should also include those where dementia has entered their lives through a family member and therefore had no choice in whether to take part in the relationship with a person with dementia.

In exploring a broader range of stories I can examine both the detail of how and why meaningful connections are made and any overarching themes that appear to facilitate these connections. A broader range of stories could offer a deeper understanding of the overarching ways in which people with advanced dementia are positioned as human persons as people talk of meaningful connections and offer an opportunity to explore the narrative human identity about people with dementia that those stories might bring forth.

Much of the empirical research in exploring personhood and dementia has been grounded in popular sociological frameworks, such as embodiment, person-centred care or citizenship, and little has used a theological perspective of humanness and personhood. Whilst this is not a primarily

theological study, my understanding of personhood is rooted in a theological perspective. This is influenced by, but not limited to, Swinton's "fivefold exploration" of humanness (2012, p161). Swinton suggests that the human person is:

- "Dependent and contingent"
- "Embodied"
- "Relational"
- "Broken and deeply lost"
- "Loved and profoundly purposeful"

In understanding all human beings to be created by and sustained by God, my own position throughout this study is that human beings are:

- "Irrevocably persons" (Swinton, 2012, p159).
- Dependent on God's life-giving breath, and that dependency on so much else and on so many others is a natural part of being human.
- Have "psychophysical unity" (Sapp, 1998, p31) – human beings are embodied.
- Always in relationship with God, and with a craving for relationship with other human beings (Swinton, 2012). I understand that whilst personhood is not relational, we are able to better flourish in our humanity when we are in relationship with others
- Broken and lost. Swinton (2012) frames the sense of brokenness in loss within the biblical interpretation of the Fall. For the purposes of my study, however, I consider that human beings are broken and lost in the sense that we are all subject to weakness, vulnerability, decay and decline (Lesser, 2006, , Post, 1995). We all experience a sense of brokenness throughout our lives, and we often feel lost as we experience times of change and of not knowing what to do for the best. Brokenness and lostness do not diminish our humanity, they are part of the human experience.

- Loved by God and have a purpose in life. Whilst not all human persons are shown love by other human beings, I argue that when we are shown human love, any weakness, brokenness or lostness that we experience, or any suffering that we endure can be supported and held (Romesin and Verden-Zöller, 2008).

Taking this position throughout my study allows for a multi-layered perspective of the human person and sits within my own ontological position that personhood and humanness can never be separated.

I suggest that rooting my understanding of humanness and personhood in a multi-layered, theological perspective and drawing on sociological and theological understandings of dementia, my study will offer an opportunity for perspectives for making meaningful connections with people with advanced dementia to be explored, challenged and developed as we find ways to learn from different disciplines. The findings of this study can be shared amongst the community and society with the intention that they will create a visible narrative that positions people with advanced dementia as fully human, valued and loved that can be seen, known and understood.

Frank, (2010) suggests that it is stories that contain the power to change perceptions and shift horizons of understanding. It is at this point that I move on to the next chapter of this thesis and discuss the narrative methodology within which the following research questions that guided my study were explored.

2.7 Research Questions

I developed the following research questions which guided the direction of my study:

1. How do people without dementia have meaningful connections with people in the later stages of dementia?
2. What are the common characteristics of people without dementia that make these meaningful connections?

3. How do people without dementia who experience these connections talk about the person with advanced dementia in terms of their humanness and personhood?
4. How do people with advanced dementia continue to make an impact on the world and those around them?

Chapter 3 **Methodology and Methods**

3.1 Introduction

In this chapter I present the narrative methodology I used to conduct my study.

My research uses a methodology of narrative inquiry grounded in Arthur Frank's (2010) theory of "socio-narratology" to explore the experience of the meaningful connections that people without dementia make with those in the advanced stages of dementia.

The chapter begins by discussing my ontological and epistemological position that human beings are both relational and interconnected, and that human beings live storied lives that shape our identity and position in the world.

I discuss how stories influence our ideas about ourselves and others, and how they can act to dehumanise individuals, or act as a counter story that gives people an on-going human identity and a narrative to live and be seen by.

The chapter then gives a thorough explanation of my decision-making processes as I developed the methodology.

It makes clear why I chose to use a narrative approach to answer my research questions that was highly reflexive and focused on the stories of people without dementia who had made meaningful connections with those living in the more advanced stages of dementia.

I then discuss the specific methods employed to conduct the research within this study. I firstly explain the theoretical underpinnings of my method of data collection before detailing how I collected the data including the ethical procedures I followed during this process.

Secondly, I explain the theoretical principles underpinning my method of data analysis before presenting my specific method of data collection.

There is no simple definition of the word narrative that covers all the different ways in which it may be used but it is often used in the same way as the word story (Riessman, 2008). For the purposes of this study the word narrative and story are interchangeable.

The narrative inquiry involves engaging with participants through the telling of and listening to stories; my own stories, participant stories, stories that exist in society and examining the stories that the participants and I co-create about meaningful connections with people with advanced dementia in the context of the research interview. These stories are interpreted using dialogical narrative analysis. Drawing on Frank's concept that stories "become true" as they are told (2010, p41), that they are performative rather than mimetic, the analysis focuses on how the stories have capacity to make visible the whole person with advanced dementia.

The research design was developed to pay close attention to the co-creation of stories that emerged in the interviews in context of the research questions and through the dialogic interactions between participant and researcher. Attention is given to the dialogic interaction between the researcher and participant on the basis that meanings are influenced in the dynamics of the dialogues and relationship between them both (Russell and Kelly, 2002) and it is not possible to separate the influence of the researcher on the generation of data (Mason, 2002). Reflexivity was a key feature of the research design.

3.2 Ontology and Epistemology

Emerging from my Christian world view that human beings are created and held by God, my personal ontological position is that as human beings we share a form of life that is bound by relationality, and wholly dependent on God. My position is that we all belong to one extended human family" (Swinton, 2012, p159), the human race,

and that personhood and humanness are inseparable.

Human beings are understood as those who are breathed upon by God in order to become a “living being” (Brueggemann, 2009, p60) and therefore all carry something of God in within them. I take this ontology as the wider position for the overall study. There was no assumption during the data collection process that this would also be the position of the participants.

Whilst my ontological position is grounded within a Christian worldview, this study is not primarily a theological study, rather it draws on theological concepts that may be appreciated and applied to those of all faiths and none, and blends them with other philosophical, sociological and narrative positions.

Secondly, my ontological position is such that human beings live storied lives with the ability to tell stories and understand them (Frank, 2010, p13, Swinton, 2012, Clandinin, 2006). Those stories help shape our human identity and the identity of other people, locate our position in the world, and can take us backwards in time or project us towards the future with hopefulness or despair (Swinton, 2012, Okri, 2014, Frank 2010). It is also possible to create a new story, that can change the way we and others position ourselves or others socially.

Whilst my position is that we do live storied lives, there is an assumption that “human beings are naturally narrative” (Woods, 2013, p73) that Woods, (2013) argues goes unexamined. There is an assumption that narrative or story co-exists with a person’s “subjective humanity, their psychological health and indeed their very humanity” (2013, p73).

Strawson (2017, p123) rejects the claim that “everyone stories themselves” arguing that some people “aren’t Narrative at all” (2017, p107) and that his story is not his identity. He claims that:

I certainly have a past, a history; even if you like, a life story. But I’m blowed if I constituted my identity, or if my identity is my life story (2017, p111).

Phelan (2005, p209) is persuaded by Strawson's arguments against narrativity, and suggests that a narrative identity thesis, "overlooks the diversity" as it is based on the understanding that "one size fits all (2005, p210). However, he does claim that he has a "strong narrative identity" (2005, p209) but "whatever narrative I construct is only one of many possible narratives" (2005, p209). Whilst he regards his life in different stories, he argues that these different stories do not become one master story. Phelan warns that when narrative makes imperialistic claims and becomes a phenomenon there is a danger that the claims can become unsustainable and may become "harmful to our field" (2005, p210).

Caine et. al (2013, p576) suggest that "story is how people make sense of their existence". My first epistemological position is that stories can make knowable, or provide deeper understanding, of how people experience the world and what those experiences mean. However, I also remain sensitive to the claim that every individual living and telling a story is different, and that seeing lives through story and narrative should not make an imperialistic claim that all people would understand their identity as their life story, nor that a narrative identity becomes a master story. Rather, stories are one way through which we can view and understand the world, people and their experiences, and once people have heard these stories, they can do with them what they will. The focus on stories and narrative in this study is not so that the narrative identity that people claim for themselves and others become a master story, but rather that narratives and stories have the power to give shape to identity and influence how people are positioned, cared for and valued as human beings. The very dialogic and relational nature of human beings in the co-creation of stories and their meaning means that they go far from offering a master story, rather they offer story that is not finalised and with which a person can "continue to form themselves, as they continue to become who they may yet be" (Frank. 2005, p967). This approach importantly allows for the understanding of the human identity of the person with advanced dementia to continue to be animated, reanimated and be

more deeply understood as people listen to, create and absorb and act on these stories.

My second epistemic position is that due to “our standing as human beings in the world” (Hughes, 2013, p356) people have the potential to gain a sense of what another person is experiencing. I believe that we can gain this sense through developing an “aesthetic sense of things” (Hughes, 2013, p355), rather than relying on approaches that require purely cognitive abilities such as the use of verbal language to understand each other. Whilst each person’s experience will be subjective, and it is impossible to conceive of the “specific subjective character” (Nagel, 1974, p493) of that experience, it is possible to gain an understanding and give meaning to the experience of another because we are “sufficiently similar” (Nagel, 1974, p442) in our shared humanity. In other words, it is possible to gain a sense of another person’s experience, both from a researcher/participant perspective, and in understanding the experience of a person with advanced dementia. The meaning that is attributed to that experience, however, will also be subjective and not finalised as people form meanings in relationship to others and the world that they inhabit. Clandinin and Connelly (2000) cited in Clandinin (2006, p46) write that:

People are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, and always in a social context.

Meanings are formed in relation with other people, cultures, environments and can develop and change as we move through life and the world.

3.3 Deciding on a Research Methodology

Before deciding on a narrative methodology, I explored the different research paradigms within which this study could have been conducted.

Phenomenology

I considered taking a phenomenological approach in this study with a view to understanding whether there might be a “universal essence” (Cresswell, 2007, p58) to each meaningful connection. Phenomenology attempts to offer a description of experience, rather than an explanation or analysis before we begin to reflect. In my research it was important that I explored how that experience was given meaning in terms of understanding the person with advanced dementia as a human being in order to notice how it might challenge some of the long standing dehumanising narratives about people with dementia.

Phenomenology is also concerned that the philosopher “should bracket out preconceptions in his or her grasp of that world” (Bryman, 2012, p30). My research is a deeply relational and dialogic study, and close attention to the researcher’s influence is important. Taking a phenomenological approach would not sufficiently attend to the relational nature of the stories that emerged within the research.

Grounded Theory

A grounded theory approach to the research would attempt to describe the steps of the research process (Charmaz, 2006) and build a theory about how meaningful connections with people with advanced dementia are made. However participant accounts are fragmented into “thematic categories” (Riessman and Quinney, 2005, p395) during the analysis process of grounded theory. The purpose of this study is to tell a story that would make the humanity of people with advanced dementia visible and therefore narratable. Frank, (2010, p75) acknowledges that where life is not “fully narratable” it is “vulnerable to devaluation”. The fragmentation of stories in a grounded theory approach would not offer enough scope for this human narrative about the lives of people with advanced dementia to flourish in its fullness.

Narrative

Riessman argues that narratives are used to make meaning of experience as people link their “experience of the world and our efforts to describe that experience or make meaning of it”, as they are a “universal human form for reconstructing and interpreting the past” (1989, p744). Anderson and Kirkpatrick (2016) suggest that there is often a moral to stories that are told that “provides value or meaning to the events that have been described” (2016, p632).

Rather than considering an event in isolation from other events or fragmenting a story a narrative account links events with the context and different characters that were present forming a story. In doing this the plot of the story becomes visible and is given “meaning and coherence” (Anderson and Kirkpatrick, 2016, p632).

The literature suggests that it is the experience of connection that facilitates a person’s ability to recognise humanness in another (Brannelly, 2011, Cheston et al, 2018, Bogden and Taylor, 1989). Using a narrative methodology would therefore not only show how meaningful connections were made, but pay attention to the context of those connections, and the characteristics of those that made those connections, including the values of the storyteller and the moral basis for telling that story.

I suggest that this would give a much richer understanding of how people with and without dementia form meaningful connections, and how people without dementia recognise the humanness in people with advanced dementia.

It is important to hear the stories of people who make meaningful connections with people with advanced dementia as stories influence our ideas, they can become our companions, “create the terms of what we consider good or bad” and teach us “what to hope for and what to fear” (Frank, 2010, p144). Stories can give us a new way of thinking about ourselves and others. They can affect the way we understand and treat other people. Stories can also affect how we view ourselves and they form part of

our identity as they give us “a sense of who we are” (Swinton, 2012, p22). When a new story or narrative enters our world, it can trouble our existing way of thinking and being. We can then decide whether to accept the new story and replace our old ways of being. Stories can enable us and others “to be” (Frank, 2010, p43).

Therefore, narrative inquiry is the overarching methodology of this study that focuses on the stories of the participant’s and how their stories make visible and narratable the humanness of people with advanced dementia. I now explain this in more detail.

3.4 Narrative Inquiry as Methodology

Narrative inquiry positions people as living storied lives both as individuals and socially (Clandinin, 2006). Stories are “lived and told” and a “fundamental unit that accounts for human experience” (Pinnegar and Daynes, 2007, p4). Within a narrative inquiry, narrative is not only the method of the research, but becomes the phenomena that is being researched (Caine et al, 2013). Therefore, the narratives that emerge from the interview are analysed using a narrative method of analysis, but attention is also given to how the whole narrative came into being throughout the research. The narrative is seen as the lived experience, “unfolding” in different contexts and place, and “co-composed in relation” (Caine et al, 2013, p575), and the co-created stories that emerge from within its particular context are used as the data to be examined.

The people and the stories always remain visible in narrative inquiry with a focus on the interactive relationship between the researcher and the participant on the understanding that what we know is rooted in a “particular context” (Pinnegar and Daynes, 2007, p7).

Narrative inquiry as a methodology means that bringing forward the experience, or story of the meaningful connection, and seeking to understand that experience comes from within the inquiry itself (Caine et. al, 2013, p576).

Within the narrative inquiry, the research questions themselves emerge from the researcher's relationship with their own story and experience. In this study, it is my own experience of making meaningful connections with people with advanced dementia, the dehumanising lay perceptions of people with advanced dementia that I personally encountered and the academic literature that reinforced these dehumanising narratives and stories. This created a tension within me prompting my research inquiry about whether the narratives of others who made meaningful connections might go some way toward countering these dehumanising narratives.

A narrative inquiry methodology keeps my focus on the understanding that the research questions are intrinsically linked to my own story, which is linked to the wider social and cultural stories that exist. It also keeps the focus on remembering that participant stories will be inevitably influenced by the stories I have told them and their own reasons for taking part in the research based on their own experiences, stories, social and cultural location. I also pay attention to the fact that participants tell and live the stories they share with me within the bounds of the relationship that we had developed and this is influenced by us both.

As Pinnegar and Daynes (2007, p5) state: "in essence, narrative inquiry involves the reconstruction of a person's experience in relationship both to the other and to a social milieu".

Whilst narrative inquiry is the overarching methodology, I specifically adopt some of the concepts of Socio-Narratology in my methodology.

Socio-Narratology moves beyond understanding stories as a way of accounting or understanding our experience, rather it seeks to understand "what the story does" (2010, p13).

3.5 Socio-Narratology

Riessman (2008, p105) tells us that "stories are social artefacts" that tell us about people, groups, society and culture. Stories can do more than just

inform about other people and make life visible, however. In socio-narratology, stories are “actors” that don’t just tell us of the mimetic experience of the storyteller, but they are performative in that they act in the world and do things (2010, p13).

A key principle of socio-narratology is that stories and humans “work together, in symbiotic dependency” (2010, p15). Stories need humans so that they can be told, and humans need to have stories so that they can represent their experiences that do not yet have a narrative form (Frank, 2012, p36). Stories are symbiotic in that they are “made up of signs” (Frank, 2010, p43) that will convey meaning to others, and help us to make sense of things in the world.

Stories are a mixture of different types of characters, “motivations, forms of action, symbols and tropes” (2010, p90) and then they are recycled as the present story is told and then made public for use in the future by others (2010, p90).

In socio-narratology stories are understood to act in the world as they are the resources that we use to understand other stories, and construct our own stories, Frank argues that stories “conduct” (2010, p14) people to act in a certain way although people are not always aware that a story is acting in them.

Stories make life social as they connect people into “collectivities” and “coordinate actions among people who share the expectation that life will unfold according to certain plots” (2010, p14).

Socio-narratology focuses on the capacities that stories have and describes stories as “material semiotic companions” (2010, p42) that have the capacity to “allow us humans to be” (2010, p44).

3.5.1 Material Semiotic Companions

Within socio-narratology, stories and humans interact with each other, the story influences the person and the person influenced the story, and these

stories can become materialised in society. Stories and humans have a symbiotic relationship and stories become “material semiotic companions” (2010, p42).

“Material semiotic companions” is a phrase developed by Frank (2010) as he combined two phrases from John Law and Donna Haraway.

Arguing that the statement from Law (2000, cited in Frank, 2010, p42/3) “seems crucial to the objectives of socio-narratology” Frank quotes Law at length:

Donna Haraway and Sharen Traweek teach us that when we tell stories these are performative. This is because they also make a difference, or at any rate might make a difference, or hope to make a difference. Applied to technoscience, the argument goes further: in fact, it is quite radical. It is that there is no important difference between stories and materials. Or, to put it a little differently: stories, effective stories, perform themselves into the material world – yes, in the form of social relations, but also in the form of machines, architectural arrangements, bodies, and all the rest. This means that one way of imagining the world is that it is a set of (pretty disorderly) stories that intersect and interfere with one another. It also means that these are, however, not simply narrations in the standard linguistic sense of the term (Law, 2000, p2).

Stories are “made up of signs” (Frank, 2010, p43) that convey meaning to others and they ‘do things’ as they become materialised in society and culture as we use our bodies to act in a particular way that is influenced by these stories as we absorb and then reflect on them.

“Material-semiotic” stories also become “human companions” (2010, p43). Frank takes the idea of “companions” from Donna Haraway’s writing on “companion species” writing that Haraway’s ideas are that “companion species shape each other in their progressive evolution”, and that “good companions take care of each other” in that they shape each other and “enables the other to be” (2010, p43). Therefore stories “allows us humans to be”, (Frank, 2010, p44).

Socio-narratology aims to study “the work that stories do as material semiotic companions” (2010, p71).

Making lives narratable

Within socio-narratology, one of the key capacities that stories have is that they can give a life that is sometimes invisible a narrative. Stories “can make lives vivid and morally recognisable” (Frank, 2010, p75).

Understanding stories in this way is particularly important for people with advanced dementia whose lives are often invisible and can easily become morally unrecognisable (Budić, 2017, Singer, 2011, Rhodes, 2007).

Shape fears and desires

“Stories shape people’s fears and desires” (Frank, 2010, p81). They can present a clear image of what is feared and suggest what is desired (2010).

Understanding the fears as people tell a story about meaningful connections with people with dementia will help understand what drives the person telling the story to continue to make those connections. Given the capacity that stories have to act on the world, those that hear these stories may be able to identify with those fears and notice how they can be managed in a way that brings life to the person with advanced dementia.

Stories that teach good and bad

Stories can also “teach people who they are” (Frank, 2010, p49). Socio-narratology studies how people can “figure out who they are” and how stories “connect and disconnect” people, and how they “inspire people toward the good...and...make life dangerous” (2010, p71).

Dehumanising stories make life dangerous for people with dementia as they diminish their moral worth, value and position in society, often exacerbating stigma and distance between people with and without advanced dementia.

People with advanced dementia to a large extent rely on the stories of others to counter dehumanising narratives about them (Swinton, 2012). I suggest

that when we understand stories to be “material semiotic companions” (Frank, 2010, p42) then hearing stories about making connections with people with advanced dementia can influence people “toward the good”, (Frank, 2010, p71) and make a difference in the way that those without dementia notice the humanity that they share with people with dementia and have the capacity to influence the way in which people think about and care for people with advanced dementia.

For people with dementia therefore, if stories become material-semiotic companions, they necessarily will affect the way that others care for and treat them. If stories of good care are told, then those that hear them can absorb that story as their companion and into their own way of being and learn how to offer that good care to others. In offering that good care, they allow the person with advanced dementia to be the fully valued human person that they are. This allows new stories of good care to be generated as others might see and hear about these ways of caring and be compelled to do the same. The story remains alive and unfinished, an important aspect of socio-narratology.

Unfinished stories

Within socio-narratology stories are to be dialogic “no voice is ever singular- every voice contains multiple other voices – and that in the telling of stories no speaker should ever be finalized” (2010, p16).

Stories live and are kept alive as people can continue to talk about them, use them to draw meaning from and to grow through them.

The story that is told within that specific context and time will be added to many other stories for people to do what they will with. The one who chooses to listen and respond can grow and change as they hear and respond to the story.

That story becomes part of the polyphony of other stories that will continue to be heard, interpreted and embodied by all who choose to listen and respond

to it. Stories are recycled as they are told and then set free for others to use (2010).

It is important not to finalise stories that are told about the experience of making meaningful connections with people with dementia, as the person who experiences the connection along with the person with dementia “retain the right to change” (2010, p98). Both the person with and without dementia may find other ways to make connections, and there maybe times of no connection. Not finalising the stories enables both to continue to flourish in their humanity even if different ways of being with each other are experienced.

Socio-narratology focuses on the performative capacities of stories and using some of its concepts as a methodological framework within which to frame this study enables us to understand the capacity that stories have to make the lives of people with advanced dementia narratable, and their full humanity visible.

In addition, by approaching the stories that emerge from my study as having the capacity to ‘do something’, they can offer a counter story that positions people with advanced dementia as valued, loved and continuing in their humanity. These stories can importantly call others to take up the identity of someone who can make meaningful connection with people in the advanced stages of dementia and interpolate them to be those that see the humanity of people with advanced dementia.

The stories can be added as another voice that helps to breathe life on the humanity of people with advanced dementia, and taken up as companions by others in our society, helping to shape ideas, thoughts and actions so that people with advanced dementia can be noticed, better cared for and understood.

If stories shape people and people shape stories, then necessarily the stories that I carried into this research and the stories that are told and heard within

this study shaped and reshaped both the participants and me as the researcher as we told, listened to and co-created the stories.

I now discuss how I paid close attention to how my own past stories, together with those that I heard during the research process reshaped my thinking throughout the research process by adopting a reflexive approach as a methodology.

3.6 Reflexivity as Methodology

The way in which the research was presented to participants from the outset, the research questions that were asked and my relationship with the participants would all influence how they described their experience of meaningful connection and how they created meaning from those experiences. My own values, bias, world view and personal experiences influenced not only the relationship that I had with the participants but the way in which I developed the research strategy.

Reflexivity wove through the development of the research questions, research strategy and framework, methods of data collection and analysis and interpretation of the data. It continued throughout the writing period of the research process.

Bryman (2012, p715) describes reflexivity as the way in which social researchers reflect about “the implications for the knowledge of the social world they generate of their methods, values, biases, decisions and mere presence in the very situations they investigate.”

Mason (2002, p7) states that the qualitative researcher “should seek to understand their role” in the generation of data and knowledge in the research process. This involves asking oneself critical questions about their own actions and role in the research process, subjecting these “to the same critical scrutiny as the rest of their ‘data’” (Mason, 2002, p7).

In using narrative inquiry as a methodology, there is an inherent recognition that both the participant and researcher will “learn and change” as they encounter each other through the study (Pinnegar and Daynes, 2007, p9). Adopting a reflexive methodology, therefore, allows me to acknowledge my own influence and that of my participants throughout the study as I am able to ask those critical and sometimes difficult questions of myself.

A research diary was maintained throughout the period of the study that contained my own reflections and thoughts, and these were often discussed and shared with my supervisors for further reflection and processing.

Adopting a reflexive methodology enables me to present a thesis that is coherent, transparent, and robust enabling its audience to understand how the knowledge in this study was produced (Watt, 2007) and also to fully engage with its meaning and impact.

3.7 Methods

The following section discusses how I arrived at my chosen methods of data collection and the type of participants I sought to recruit for the study. I then discuss the ethical considerations, procedures and approval of the study before describing how I recruited participants and collected the data.

3.7.1 Deciding on a Method of Data Collection

Key to my ontological and epistemological positions and the research aims, was that the data collected were the stories of people without dementia who made meaningful connections with people with advanced dementia.

The experiences of the participant had the potential to offer an alternative story to others who had only experienced dehumanising narratives about people with dementia, and influence the way in which people with dementia were positioned and treated by others as personal narratives can “encourage others to act” (Riessman, 2008, p8).

I considered conducting focus groups and individual interviews as a method of data collection in this study. I finally decided on individual interviews using a technique that was a blend of semi-structured and narrative interviews styles. I now discuss the reasons I did not use focus groups and why I chose individual interviews.

Focus Groups

A focus group can focus on eliciting as much as possible about a participants experience and how they feel about that experience (Morgan and Krueger, 1993), and with an “open and permissive” atmosphere participants can feel free to share their experiences with each other (1993, p7). Storied experiences of meaningful connection may have been generated within a focus group setting.

Focus groups can offer a freedom of discussion and opinions that some participants may not feel they have in an interview situation. Sometimes in an

interview situation the participant may feel they have to give the 'right' answer in a one to one interview situation, however in a focus group the participant may feel more freedom to change their mind as they listen and are prompted by other participants experiences and understandings (Bryman, 2012).

Often a focus group can produce a more realistic account of what a participant thinks on a topic than in a one to one interview. Apart from feeling that they must give the right answer in an interview situation, the participant is "rarely challenged" by the interviewee (2012, p503). However, in a focus group as other members of the groups challenge and respond to each other's differing views they may change their understanding or view of an experience that they have had (2012). Whilst this may be a reason to conduct focus groups, it can also be a disadvantage as a dominant group experience may well suppress the voice of a participant who has had a different experience (2012).

I decided not to use focus groups as I felt that the stories that were ultimately shared would be influenced by the other participants' experience and this might detract from the individual experience of connection from each participant. Given my ethical focus on the autonomy of the participant to freely share their experience in this study, it was important that each participant felt that they had control over situation of being interviewed and the opportunity to share a full and fair representation of their experience (Mason, 2002). A focus group would not have offered the space to hear a fuller story about the experience of each individual participant.

I was also mindful that sharing stories of meaningful connection with people with advanced dementia had the potential of triggering emotional upset. Expecting participants to share potentially moving or upsetting accounts with others in a focus group may have added to any distress or unwillingness to share their story. I therefore decided that data collection would be focused on the stories of the individual participant shared in a face to face interview rather than stories shared within a group setting. From an ethical perspective

this would not only offer the participant a more private space to share their stories but also offer them the freedom to control what they shared rather than be overwhelmed by stronger voices in a focus group setting.

3.7.2 Interviews as A Method of Data Collection

Within qualitative research the focus is on understanding the social world through an “examination of the interpretation of that world by its participant” (Bryman, 2012, p380). There are different styles of interview that may be used to provide the rich data that qualitative research seeks (2012), and my study sought rich data about experiences of meaningful connections with people with advanced dementia.

Generally, interviews are either unstructured or semi-structured interviews, sometimes referred to as “in-depth or qualitative interviews” (2012, p471).

Unstructured interviews

In an unstructured interview the interviewer may ask an opening question and the participant then has the freedom in how they wish to respond while the interviewer remains a listener (Brinkmann, 2014) and responds when they hear a point which they feel is worth exploring further (Bryman, 2012). Unstructured interviews are useful if a researcher has a general “notion of wanting to do research on a topic” (2012, p472), however in my study I had a clear focus on what I wanted to investigate and therefore decided that the interviews would be weighted more to a semi-structured style.

Semi-structured interviews

A semi-structured interview offers a similar amount of leeway as an unstructured interview to the participant in terms of how they reply to the questions, however the interviewer retains more control of the direction that the interview follows. A pre-prepared interview guide can keep the research focused on the questions that are to be asked in each interview (Bryman, 2012) but offer the participant the flexibility to respond in the way that best suits them.

I chose to use a loosely semi-structured interview approach during my data collection in that I had prepared an interview guide that I would refer to in all interviews (appendix 3), but not stick to rigidly. This allowed me to ask similar questions about the participant's experience of meaningful connection with people with advanced dementia in each interview and keep the conversation focused on the issues that were important to the experience of meaningful connections (Brinkmann, 2014). In not being overly rigid with the use of the interview guide, I was able to adapt my questions with each individual participant. A purely semi-structured interview would not necessarily provide the rich stories of connection that this study demanded.

Stories, or narratives is "one thing happens in consequence of another" (Frank, 2010, p25) they are about sequences that are contingent (Riessman, 2008) on something else and it was important that I blend a semi-structured approach with a narrative style of interviewing that would encourage participant stories to be told.

Narrative Interviews

Narrative interviews are a way of "collecting people's stories" (Anderson and Kirkpatrick 2016, p631) and keep the person telling the story "at the heart of the study process" (2016, p63).

Narrative interviews allow us to collect people's stories or experience as the researcher asks questions that will open a topic for discussion and then allow the participant to respond in a way that means something to them (Riessman, 2008). The narrative interview involves the use of "narrative-inducing questions" (Gunaratnam, 2009, p49) that encourages participants to tell their story. They are more of a conversation between the participant and researcher but allow more space for detailed accounts to be shared than in an everyday conversation (Riessman, 2008) as the researcher allows the participant to control the pace and to some extent the direction of the interview (2008).

In my study it was important that the participant chose what stories to share and how much of their story they shared as the priority needed to be the story teller's perspective rather than my own agenda (Anderson and Kirkpatrick, 2016). It was also important that the autonomy of the participant to choose what to share was always respected.

I chose to blend a narrative and loosely semi-structured framework to the interview which would allow rich and detailed stories of meaningful connections to be shared whilst ensuring that the interview remained on topic and relevant to the research questions.

3.7.3 Deciding on a Participant Type

Participants were selected through purposive sampling that was strategic to the goals and objectives of the research (Bryman, 2012, Palys 2008).

Participants were selected based on their professional or familial contact with people with more advanced dementia either in the present or in the past, with further criterion sampling (Palys 2008) that selected individuals who had experienced meaningful encounters or connections with people in the later stages of dementia.

Participants were invited from five groups of people across Central Scotland where data collection took place. The groups were:

1. Musicians who had worked with people with advanced dementia in a professional capacity.
2. Family Members who had or previously had a close family member with advanced dementia with whom they had regular contact.
3. Elderflowers – a group of specially trained performers who use a style of clowning technique to creatively engage people living with dementia. They use their personalities, bespoke communication techniques, intriguing themes, musical arrangements and gentle movements to engage with people with dementia.
4. Spiritual carers who offer spiritual support to people with advanced dementia.

5. Residential care home staff who cared for people with advanced dementia.

The decision to invite participants from these different groups was based on the evidence detailed in the literature review that people within these groups are often able to experience meaningful connections and see the full humanity of the person with dementia (Smilde et al, 2018, Swinton, 2014, Hendriks, 2012, Watson, 2016, and Quinn et al, 2014).

Recruiting participants from different groups of people meant that the experience of meaningful connection with people with advanced dementia could be explored through the stories of people who had five quite distinct reasons for their contact with people with advanced dementia. Musicians and Elderflowers would use their professional skills and arts based techniques as they purposefully sought out these connections in their work, care staff made these connections in their everyday work with people with advanced dementia, spiritual carers in the spiritual support of people with advanced dementia, and family members as they would visit and care for their loved ones with advanced dementia.

Gathering data from a variety of sources would also allow for a triangulation of data sources. This leads to a study that is credible and robust as the findings from each group of data sources are cross checked with each other to look for the qualities that those without dementia bring to engaging meaningfully with people with advanced dementia overall. Limiting the investigation to just one group of people, may develop a deep understanding of how one particular skill can be developed to help facilitate a meaningful connection, however this would not be as transferrable to different contexts or situations as with an investigation like this one that studies a range of data sources from different groups of people.

Having decided on a method of data collection, and the type of participant that would be invited to take part in my study, I prepared my application for ethical approval for the study.

3.7.4 Ethical Considerations, Procedures and Approval

In preparing my study for ethical approval, I paid attention to the overarching ethical principles of participant autonomy, fully informed consent, minimising any potential harm to participants and respecting the participants privacy (Yuko and Fisher, 2015, Traianou, 2014, Bryman, 2012 and Orb et al, 2001). Additionally, I needed to consider the potential harm and privacy of the people with advanced dementia that the participants would talk about in sharing their stories. The person that is spoken about will not have given consent to the research. Participants were likely to give rich descriptions of a person with advanced dementia which had the potential of that person being recognised by those reading the research findings.

I also explored whether any care home organisations had any specific ethical requirements when research was carried out within their care home and with their care staff.

3.7.4.1 Participant Autonomy and Fully Informed Consent

In any research study it is important that the participant's autonomy is respected (Traianou, 2014). Central to respecting the autonomy of the participant in this study is that they were able to give informed consent to take part.

Participants in this study had to be over 18 years old with no upper age limit and had to be English speakers so that any experience spoken of during interviews or wish to withdraw or stop the interview would not be misunderstood or mistranslated through an interpreter.

It was important that participants were able to clearly understand the information sheets and consent forms that were written in English so that those who took part were fully informed about the study and able to make autonomous decisions about whether to take part.

I developed information sheets and consent forms (Appendices 4-8) that were sent to potential participants who had expressed an interest in taking part in the study. I then gave the participants one week, unless otherwise agreed, to read the information sheet and consent forms before following up with a phone call to discuss any questions they might have and whether they wanted to take part. If they said that they did, I asked for the consent forms to be signed and sent back to me, or to be brought along to the interview. Most participants brought them to the interview, but for those who forgot to do so I gave them another copy at the interview.

At the interview I asked if they had any more questions about the information sheet, and we went through the consent form together. If the participant had not already signed the form, they signed it before the interview began. I signed the form in front of the participant.

Participants have the right to freely choose whether to take part in the study and the right to withdraw from the study at any time “without penalty” (Orb et al, 2015, p95). The information sheet and consent forms clearly stated that the participant was free to withdraw from the process at any time.

At the beginning of the interview I checked that they had read and understood the information sheet, asked if they had any more questions, explained their right to withdraw adding the proviso that they were able to withdraw until the interview had been transcribed or written up. I checked that they were clear that I might take a Christian perspective to the research and asked if they were happy that the interview would be recorded before we started the interview.

3.7.4.2 Minimising Potential Harm and Respecting Privacy

In any research study the researcher has a duty to maximise benefits and minimise harm (Yuko and Fisher, 2015). Whilst risk of harm or burden to the participants in this study was unlikely, it is often difficult to completely avoid any harm completely in research (Traianou, 2012). In my study the main for

potential for harm was that in discussing meaningful connections with people with advanced dementia during the interview participants may become emotionally distressed as dementia is a sensitive topic. Stress and emotional distress are considered a source of harm to participants (Bryman, 2012, Traianou, 2012). In order to minimise this threat, I explained to the participants before I began recording the interview that if they found themselves become emotional, distressed or upset, or that they no longer wanted to continue for any other reason that they could ask me to stop the interview at any point. If any participant did show any signs of upset, I asked if they wanted to continue with the interview or if I should stop the recording. Several participants did become tearful and where I was aware that they might not have emotional support through the organisation they worked for I asked if they wanted me to pass on details of organisations who they might be able to use for support such as Alzheimer Scotland or the University of Edinburgh Chaplaincy service. Participants who did get upset were all happy for me to keep recording and to use that information in my research. Although on one occasion I made the decision to stop recording when one participant became particularly emotional and we began recording again when she felt she was able to and wanted to continue. No participant said they felt they needed me to pass on information about organisations that could support them further.

In maintaining the principle of minimising harm to participants, there is a moral obligation on the research to understand that there could be consequences if participant identities were revealed (Orb et al, 2001). The use of pseudonyms to anonymise data (Orb et al, 2011, Traianou, 2014) is recommended. Although, Mason (2002, p80) argues that it is often the case that the interviewee can be recognised even if you have not named them because of the “full, rich and personal nature of the data generated from qualitative interviews”. In this study, whilst data linking that might uncover participant identity is possible, I suggest that the risk was generally minimal. All participants names were anonymised, and a pseudonym used.

Elderflowers

There was an increased potential for the identity of the Elderflowers to be revealed because they are unique to an organisation in Scotland who are the only organisation in Scotland that have Elder Clowns. I had gained permission to use the term Elderflower when referring to the participant's work in my research findings from the organisation. I also anonymised the name of the Elderflower, however once I began transcribing the interviews, I noticed that each Elderflower has very unique characteristics and skills. It therefore might have been possible for others reading the research to identify which Elderflower character they are.

I spoke to each Elderflower on the phone and explained what I had noticed and asked if they were still happy for me to use their interview data in my research. If they were happy to do so I requested that they read new information sheets (appendix 9) and sign new consent forms (appendix 10) that stated that I would anonymise their Elderflower name and real name, but those reading the research might be able to identify which Elderflower character they are. Each Elderflower participant was happy to do this, and I received new consent forms from each one of them.

Care Staff

The care staff that took part in study may have also been identifiable to others in the care home should they notice that they were attending an interview with me on care home premises. I stated in the information letters to care staff that whilst other people may know the care homes that I have contacted for people to take part in my research that I would not name the care home in my findings. I stated that the participant could choose where the interview took place if they did not want other people in the care home to notice that they were taking part in the research. All of the care staff that took part in this study did so following a presentation from me at the staff meetings, and all were happy for the interviews to take place on care home premises even though others might know they were taking part.

Both the care home and staff were anonymised in transcripts and any consequent publications.

3.7.4.3 Protecting the Identity of and Minimising Harm to People with Advanced Dementia

I needed to consider the privacy of the people with advanced dementia that the participants would talk about in sharing their stories. The person that is spoken about will not have given consent to the research. Participants were likely to give rich descriptions of a person with advanced dementia which had the potential of that person being recognised by those reading the research findings. In order to protect their identity, I agreed with participants before we began the interview that we would use a pseudonym instead of their real name or refer to them as the lady or gentleman with dementia. Where participants inadvertently gave the person with dementia's real name, this was not recorded in the written transcript, rather was changed to the appropriate pronoun or a pseudonym used.

There were certain stories that I did not feel I should share in my thesis when I reflected on them to protect any potential misrepresentation of the person with advanced dementia. I felt it would be too difficult to reflect the spirit and context within which the story was shared within the limits of the thesis. To include these stories within the confines of the thesis would have created an ethical tension that I did not feel was justifiable or necessary. Mason (2002, p183) writes that "it is important to focus your mind on whether a...segment of data is actually integral to, or constitutive of, your argument". The stories that I felt might create an ethical tension were not integral to the arguments I developed in this study. I therefore decided that they did not need to be, nor should they be included in the body of the thesis.

3.7.4.4 Ethical Requirements of Care Homes

I contacted the head office of the care home organisation to check whether they had any specific ethical requirements that would need to be met before conducting interviews. One care home wanted to see my University ethics

application approval, and another was happy for me to speak with the care home manager. Several care homes head offices did not reply to my phone calls. This included two care homes where the managers had already agreed to be a gatekeeper. For one of these care homes I had already sent out the invitation letters and two members of staff had expressed an interest however I felt it was unethical to recruit participants from the care homes where I had no reply from their head office, including the two people who had already expressed an interest. On reflection, it would have been prudent to wait for confirmation from the head office before sending the invitation letters to the care home manager who had agreed to be gatekeepers.

3.7.4.5 Data Management, Data Protection and Confidentiality

In order to protect the privacy of the participants is a need not only to anonymise them, but to maintain confidential records of participant identity or data that could potentially identify the participant (Bryman, 2012).

Personal data such as participants names, address, telephone numbers and signatures were stored manually either in a locked draw at my home or in a locker at the University. The consent forms state that personal details will not be revealed to people outside the project.

Emails that participants sent to me were printed off and deleted from my University email account and the printed versions stored manually as above.

The audio recordings were recorded on a device supplied by the University and downloaded to my Edinburgh University M drive as soon as possible after the interview. Until that time the device was either kept on my person or in a locked drawer at home or in a locker at the University. This recording was downloaded either at the University on one of the University computers, or from my home laptop. I accessed the University M drive computer network through the Virtual Private Network (VPN) required through the University when working on my laptop. This is a secure connection and access to the VPN was password protected on my laptop, and an additional password was

required to access the University network also. The audio recording was also copied on to an encrypted, password protected USB. The recording on the audio device was then deleted from the device.

There were occasions where I made an audio recording of my reflections of the interview immediately after the interview. The same procedure was followed as above.

I was the only person transcribing the voice recordings and the only person with access to the participant's personal data during the study therefore minimising the risk of compromising the confidentiality of the participants.

I transcribed the audio recordings on my home lap top computer, and anonymised transcriptions were saved in the University of Edinburgh M drive via my VPN connection, on my home password protected laptop and, on a password protected, encrypted USB.

Early in the recruitment process I made hand-written and typed notes about different organisations and care homes that I might try and contact to generate participants. I made notes of discussions I had had with people in these organisations and these notes were either stored in a locked drawer in my home or in my university locker.

I also included some details of these organisations in some writing that I had shared with my supervisors before I had recruited participants. This writing is stored on my M Drive on the University network drive and does not contain information about participants, rather it contains details of potential gatekeepers. My copies of this writing will be destroyed at the end of the study.

A data management plan was put in place at the point of my ethics application (appendix 11).

Although my ethics application and data management plan stated that my home laptop would be encrypted, I later discovered that this was not

possible. Following a discussion with the University's Data Safe Haven Manager we agreed that I would delete any data sensitive files from my laptop as soon as they had been moved to my M Drive and delete them from the recycling bin also. My latest ethics approval reflects this.

The ethics application and data management plan also stated that the encrypted USB would be in a locked drawer at my home or in my locker at the University. However, there were occasions when the USB was in an unlocked drawer at my home, but no-one had access to the password and therefore data remained secure.

I deleted all sensitive data from my laptop's hard drive by doing a complete reset on the laptop as advised by the Deputy Chief Security Office once I no longer used that laptop and began using an encrypted new laptop.

Personal data will be stored until the data analysis is complete and any summary report of findings have been given to participants should they want them. Audio recordings were deleted from my M Drive upon completion of my first draft of my thesis and the encrypted USB once the research findings had been written up.

All anonymised data will be held in the University of Edinburgh data store during the research period, on my home lap top or on an encrypted password protected USB and then will be placed in the University of Edinburgh data vault for a period of 10 years with an embargo not to share any of the data at any time during the future. Data held on the USB will be deleted once the research has ended. The UK Research Integrity Office Code of Practice for Research suggests that data is held for at least 3 years to validate research findings, however the University of Edinburgh School of Health in Social Science suggest at least 10 years.

3.7.4.6 Ethical Approval

Level 2 Ethical approval for this study was granted by the CPASS Research Ethics Committee in the School of Health in Social Science, University of Edinburgh in April 2017.

Having gained ethical approval, I began the process of participant recruitment.

3.7.5 Participant Recruitment

Participants were recruited for this study in several different ways; through gatekeepers, snowballing and following a presentation of my research aims at a care home. I now explain how I recruited participants from each of the participant groups in more detail.

3.7.5.1 Musicians

I contacted an organisation that employed musicians to work with people with advanced dementia, and they were keen to act as gatekeepers to invite musicians to take part in the study. However, despite several attempts at sending the invitations to prospective participants by the organisation no musicians expressed an interest in taking part. I decided not to pursue this group of people as participants for the study for two reasons. Firstly, I discovered that the work of the Elder clowns often involved music and therefore felt that I would have a rich source of data to draw on by reducing the study to include four rather than five groups of people. Secondly, to spend more time on recruiting would have taken the time study period beyond what was possible within the boundaries of the PhD process.

3.7.5.2 Elder Clowns

There is only one organisation in Scotland, that employs practitioners who use clowning to engage with people with dementia.

I approached the director of the charity who employs elder clown practitioners, known as Elderflower's, who engage with people with dementia and asked if they would act as gatekeeper for potential participants.

The director emailed the Elderflowers with details of the research asking for those interested in my research to email me directly, specifically asking that they do not include telephone numbers or addresses on the email. Five Elderflowers showed interested in the research. I then emailed those who had shown an interest and we arranged a time when they could phone me at which point, I was able to obtain their contact information to send the information sheets to.

I was able to recruit five Elderflowers who participated in the research.

3.7.5.3 Care Staff and Family Members

I approached several care homes either via email, by telephone or in person and where possible spoke to the care home managers about my research. I asked if they would agree to act as gatekeepers for potential participants that were either family members of someone with advanced dementia or care staff. If they agreed I sent a covering letter to the care home, (appendix 12) and asked if they would hand out invitation letters, (appendices 13 and 14) that invited care staff or family members to contact me if they wanted to know more about my research.

Five care home managers agreed to act as gatekeepers. However, when I contacted the head office of those care homes to check for any additional ethical requirements two failed to return my calls and I could therefore not pursue research participants within these two care homes.

Presentations for Care Staff

No care staff expressed an interest in taking part in the study following the invitation letters from the gatekeeper at the care homes. It was suggested that sending out invitation letters to staff to attend would not prove successful, as staff were generally very busy. I suggested that I attend staff meetings to explain my research and I could ask staff to contact me if they were interested to which they agreed. Four members of care staff expressed an interest in taking part in the study after a presentation.

One member of care staff withdrew her interest at a follow up phone call and three were recruited as participants.

Family Members

One of the care staff who had attended a presentation suggested to a family member that they might like to take part in the study and introduced them to me personally. This family member expressed an interest in participating in the study and was later recruited.

Two family members responded to the invitations sent out by the care home managers acting as gatekeepers in care homes and were later recruited as participants.

A further two family members were recruited through snowballing.

3.7.5.4 Spiritual Carers

I approached an organisation that promote the spiritual care of those with dementia and asked if their director would act as gatekeeper and send out letters to ministers/faith leaders who they felt might be suitable participants to take part in my research.

The organisation spoke to several individuals and three of them expressed an interest in the study and asked for their contact details to be passed to me. I contacted them directly by email and arranged for them to phone me so that we could discuss the research further. All three of these spiritual carers were later recruited as participants.

Another spiritual carer expressed interest in my study and was later recruited via snowballing.

I also attempted to contact faith leaders from a variety of faith communities via phone calls and emails however was unsuccessful in recruiting spiritual carers from non-Christian faiths.

3.7.5.5 Gathering the Participant Sample

Once those who were interested in my research had made contact with me via email, we arranged for them to phone me and we had a discussion over the phone about my research in more detail. The invitations sent to the gatekeepers and the care home presentation explained that I was interested in exploring the connections or encounters from a Christian perspective, and this was discussed again when the participants contacted me via telephone.

All the participants who had expressed an interest in taking part in the study did so except one of the care homes staff who withdrew her interest. For the participants that were still interested in taking part in the research, they passed on their address and phone number to me over the phone at which point this was written on contact form and filed away securely in a locked cabinet either at my home or at the University.

I then sent the participants an information letter and a consent form specific for their participant group. I explained that I would follow up with a phone call in one week at which point I asked if they had any further questions and if they were happy to go ahead with an interview. If they were, we agreed a time and place for the interview to take place.

Seventeen participants were recruited for the study as follows:

<u>Group</u>	<u>Gender and Number</u>	<u>Method of Recruitment</u>
Family Members	Male x 2	Snowballing
	Female x 1	Snowballing
	Female x 2	Gatekeeper

Elderflowers	Male x 2 Female x 3	Gatekeeper Gatekeeper
Spiritual Carers	Female x 2 Female x 1 Male x 1	Snowballing Gatekeeper Gatekeeper
Care Staff	Male x 1 Female x 2	Presentation Presentation

3.7.6 The Interviews

Interviews took place between May 2017 – January 2018 in various locations across central Scotland that were agreed with participants, including at the University of Edinburgh, in participant homes, or in a private room at a care home. Where interviews were held in participant homes, I advised my supervisor of the time of the interview and we arranged a phone call once the interview was over to ensure that I minimised any danger to myself.

Participants took part in only one interview and the interviews lasted between 53 minutes and 1 hour 45 minutes.

To carry out a good qualitative interview is a complex process that requires planning and the use of both “intellectual and social skills” (Mason, 2002, p67). Mason (1996, p45), describes the social task of the interview as orchestrating “an interaction which moves easily and painlessly between topics and questions.”

Carrying out good narrative interviews requires the additional skill of encouraging the participant to tell of their experience in narrative ways (Riessman, 1993).

I ensured that the interviews I carried out were of high quality and encouraged story telling in several different ways which I now explain.

3.7.6.1 Developing a Semi-Structured, Narrative Interview Guide

Whilst it is important to be flexible and adapt questions specifically for each participant through the interview, and to “think on my feet” (Mason, 2002, p67) to ensure that the interview generated data that was relevant to the research, a set of open-ended guided questions and prompts were developed and referred to in each research interview (appendix 3).

Open-ended questions are a key way to conduct a narrative interview (Anderson and Kirkpatrick, 2016) and were based on the research questions which enabled the interview to be kept on topic and move between questions, whilst giving the participants the freedom to talk at length about their experiences. The questions were designed to produce data based on the participants experiences, and the prompts that I used would encourage the data to be as narratives as they encouraged the participant to think reflexively about how those experiences came about.

As the participants told their stories I used affirming non-verbal and verbal signals such as a nod of the head or saying “yeah”, “right” to encourage the participants to tell me more about experience (Anderson and Kirkpatrick 2016).

In the interviews I would sometimes specifically say that I wanted to know the participants story. For example, in my interview with a participant, Dorothy, I said:

“So I think I did explain a little bit about what I was interested in. It’s just your story really and your experience, of those really special moments, making those meaningful encounters.”

Often participants would acknowledge that they had told me a story in the interview. For example, a participant, Margaret, talking about her mother said:

“so that’s the story, and she was a public speaker, she was a teacher, she loved words.”

The questions in the guide were not adhered to rigidly however, as in narrative interviewing it is important for the participant to be in control of the stories they were sharing and to be able to follow their flow of conversation (Anderson and Kirkpatrick, 2016).

The guide was a useful reminder of the topics which needed to be covered in all the interviews, and it was used at the end of the interview as a check that all areas of interest had been covered.

3.7.6.2 Establishing Rapport and Listening Well

A good narrative interview needs to be able to establish “rapport and trust early on in the interview” (Anderson and Kirkpatrick, 2016, p632). DiCicco-Bloom and Crabtree (2006) suggest that a positive relationship needs to be quickly developed when doing in-depth interviews to elicit the richness and detail that the study demands. Building rapport allows a more natural dialogical interaction to develop through the interview, and a trust develops so that participants feel more comfortable in sharing their experiences. Participant experiences were the crux of the research, the participants were the experts in generating knowledge in this study, and the data they provided needed to be in a relaxed and open environment that would allow them to feel comfortable and their voice to be heard.

Rapport was also important so that the interview process could be a positive experience for the participants.

I began the process of building rapport during the pre-interview phone call which gave me the opportunity let participants know how grateful I was for their participation and that I valued their contribution. It was also a time to

give reassurances that their data would be respected and treated appropriately. Rapport building continued in the informal conversational style of the interview, where the tone was relaxed, and I also reiterated my gratitude for their participation and reassurance that their data would be treated appropriately.

Some participants clearly stated that the interview had been a positive experience for them as is seen in the following excerpt from a transcript from a family member:

F: Yeah... thank you. That's erm, that's, yeah that's been super, thank you for your time

P: (laughs)

F: and thank you for sharing that.

P: [ahh no!] It's actually been quite cathartic for me to kn'd'f

*F:
[ahh]*

P: off load a lot a lot ### stuff"

A necessary skill for conducting a good narrative interview is that the researcher can listen well to the participant. Listening well involves allowing the participant to tell their story uninterrupted and making a "mental note" of something that the researcher may wish to explore further later (Anderson and Kirkpatrick, 2016, p632).

I actively listened to participants tell their stories, avoiding interruptions and the following excerpt from the transcript of the interview with Leah, a member of care staff shows how I went back to something that she had said earlier as I wanted to explore it in more detail without interrupting her original story:

"You were talking earlier about knowing there's a spirit and a soul...it was when you were saying that about attending to that bit"

When I asked for clarification on a point that participant had mentioned I used the participants words and often drew on something that they had said

previously. This reinforced to the participant that they were being listened to and ensured trust and rapport continued to develop throughout the interview process.

3.7.6.3 Participant – Researcher Interaction and Co-creation of Meaning

Salmon and Riessman (2013, p199) argues that “all narratives are, in a fundamental sense, co-constructed.” She argues that whether there is a physical audience present when the story is told or not, the intended audience will “exert a crucial influence on what can and cannot be said, how things should be expressed, what can be taken for granted, what needs explaining and so on” (2013, p199).

Mason (2002, p93) tells us that qualitative interviewing “tends to be seen as involving the construction or reconstruction of knowledge”. Necessarily in an interview there is an “interactional exchange of dialogue” (Mason, 2002, p62). The data and knowledge that is produced is constructed within that dialogical interaction between the interviewee and researcher as they both shape “the communication process” through listening and responding to each other (Harvey, 2015, p25). From this perspective it is difficult and somewhat unethical to “separate the interview from the social interaction in which it was produced” (Mason, 2002 p65) or to leave the researcher’s voice out of the data.

This process of dialogue and interaction, construction and reconstruction of knowledge in my study began before my narrative interviews took place. Participants had received the information sheet and a follow up phone call in which I shared some of my own story, the reasons why I was doing the research and why I felt it was important, and my perspective on the human identity of people with advanced dementia. The phone call allowed participants to ask questions where we established the meaning of the research in more detail.

This was imperative to my research aims and objectives as sharing this information before the interview meant that participants were clear about the aims of the research. The data that would meet those aims and answer the research questions needed to be based on their specific experiences of meaningful connections with people with advanced dementia. Burgess (1984, p84) refers to interviews as “conversations with a purpose” and having the dialogic interaction with participants before the interview meant that participants in my study had time to start thinking about these experiences before the interview, and that the interviews would be purposeful and relevant. Necessarily therefore the stories that were told in the interviews were co-created by the participant and myself, and it was important to notice this as it would influence the type of analysis that I would apply to the data produced in the narrative interviews.

3.7.6.4 Ending the Interview

As the interviews came to an end, I asked if there was anything further that the participants wished to add. Occasionally this resulted in another story that had come to mind about connection, or something about their life experiences. Other participants were happy that they had covered everything.

I thanked each participant for their time and contribution, advising them that they could withdraw from the study up until the time I had written up the transcripts. No participant withdrew from the study.

All participants were offered the opportunity to be sent details of the findings from the research and all participants said that they would like to receive these details.

I advised each participant that I would contact them once findings had been written up and arrange to send them a copy.

3.7.6.5 Post Interview Reflection

After the interview I immediately wrote or recorded a personal reflection of the interview. This reflection allowed me to recall and remember more accurately the nuances of the interview when I transcribed the interview and began my analysis of the data.

Some of the interviews were quite moving and emotional. Reflecting on them immediately after allowed me to process that emotion and have a record of that so that I could discuss it with my supervisors if I felt I needed to.

The following is an excerpt from my reflection on an interview with a family member followed by a note from my reflexive journal about when I discussed this in supervision:

I asked if she thought these moments meant something to her dad – did he know? And as I said it I felt awful – what right did I have to even put a doubt in her mind? Did I overstep the mark? But she seemed happy to answer, and I could feel myself wanting to convince her that he did know.”

Note from supervision December 2017:

We spoke about how I feel guilty when asking family members about whether the meaningful connections might have meant something to the person with dementia. I acknowledged that the guilt might come from how I felt I was viewed by my family - that because I deal with the reality of a situation, I felt others saw me as quite harsh sometimes. This I think is something that I need to keep reflecting on and writing about to process it and understand it.

Heather asked if I was coping with the emotional interviews and over all I think I am – I acknowledged that I find writing a really useful tool to process my emotions.

I also listened to the recordings several times immediately after the interview making notes where I needed to of anything that particularly stood out to me whilst I listened.

3.7.6.6 Participant Verification of Transcript

During the interview I asked each participant if they wanted to see a copy of the interview transcript before I began the data analysis. Only two participants wanted to have a copy, which were duly posted to them by registered post. Both participants wanted to have a copy of the transcript for their own personal memories rather than for verification purposes. Both said that they were happy for me to start the analysis before I had sent them copies of the transcript.

I decided not to ask participants to check copies of the transcript or the later condensed narratives that I produced to verify the data as the stories generated in the interview were within the context of that interview. To send the transcripts back for participants to check would mean that the context would change if any changes were made to the transcript and would not be a true reflection of the data that was produced in the interview. Pinnegar and Daynes (2007, p11) acknowledge that “human interactions are seldom static” and that “findings from one setting cannot be effectively decontextualized”.

3.7.6.7 What Was Included as Data?

The transcription of the interview was included as data in my project, and my initial stage of data analysis was based on that transcription. I transcribed the interview verbatim which enabled me to retain a sense of the whole interview and how things were said. Before I transcribed the interviews, I re-read my reflections and observations which helped me interpret the data from the transcript within the context of the interview and analyse the data with my own reflections in mind.

Having collected the data for this study and decided what would be included as data, I reflected on my influence in the interview process and on the stories that were shared. I kept detailed notes in my research diary that enabled this reflection. Before I discuss the process of analysis I applied to the data in this study, I take some time to discuss how and why I applied reflexivity as a method in my study.

3.8 Reflexivity as Method

Keeping a reflexive journal was a key part of my method during the research process. My reflexive journal was a record of my own “active reflexivity” (Mason, 2002, p7) as it recorded my own values, bias, and interests (Bryman, 2012, Hammersley and Atkinson, 2007). It made clear where I was positioned in terms of my “socio-historic” location and I was then able to notice how that implicated the research process and the generation of knowledge and data throughout the processes (Mason, 2002).

The reasons I kept the journal were five-fold:

1. As a researcher it is vital that I understand the knowledge that the research produces and how that knowledge came about.

Watt (2007, p84) suggests that researchers “may be able to better determine what they know and how they think they came to know it” by keeping a journal.

The research I carried out was in no doubt a relational endeavour and a dialogic interaction between the participant and myself as the researcher. According to Russell and Bohan (1999, p404) that relationship forms “part of the context that frames the research process”.

Each one of us had an “active part in speech communication” (Harvey, 2015, p24) resulting in a co-construction of meaning that emerged from a dialogic interaction between us. In addition to the dialogue, each one of us brought our own perspective and experiences into the process (Russell and Kelly, 2000). Whilst I was able to explore the perspectives and experiences of the participants in the interview and use that knowledge to make interpretations about the data, it was important that I paid attention to my own perspectives and experiences and the influence they had on the data that was generated. It was also important that I noticed how the interaction between the participant and myself influence the generation of data.

It was in my reflexive journal that I was able to ask myself critical questions about why specific data was generated and notice what was not generated. It also gave me the opportunity to notice whether there was an imbalance of power between myself and the participant during the research process, and it was important that I took the time to reflect on that and notice whether that might have affected the data that was generated (Yardley, 2000).

The following excerpt from my diary shows how I reflected on whether participants might be expecting me to want to hear a particular type of experience:

7th January 2018

I phoned a member of care staff who had initially expressed an interest in taking part before Christmas. When I spoke to her today she said that she wasn't having much joy with the person she wanted to talk to me about so wanted to cancel and not take part any longer. I explained that I was interested in the good and the bad, but it was clear that she wasn't wanting to take part any longer. This, together with the interview with the member of care staff last week (an interview where I felt they might be holding things back and only telling me the good stuff) has left me wondering whether I am actually getting a picture of the whole reality of the ability to make connections. Do people think I am only looking for the good? Are they just reluctant to tell me what it's really like? Is there suspicion about what I might do with that information? Can I realistically leave out care staff experiences and still be true to this?

I think that the answer to that is yes as I am only telling the stories that other people have told me – but it is important to acknowledge that there will be a very different side to this also.

2. The research process changed me.

My values, bias and interests changed throughout the research process and therefore my “socio-cultural” position changed, and my reflexive journal kept track of those changes.

The following entry shows how important it was to me to find an objective truth in the early stages of my research because of how I understood my own

Christian faith at that time. Later entries show how the relevance of objectivity becomes less important;

26th January 2017

I am beginning to feel quite clear about my research design and how I will go about collecting data and am about to start my ethics application. I am however not sure on my overarching philosophy. My gut that it needs to be based in phenomenology, however on reading the background to phenomenology it seems that much of it points to relativism and no real objective truth. There is much discussion about it leading to an atheistic position, although having looked up phenomenology on Wikipedia it appears that Hegel grounds it in the Divine. I am getting really confused with this and perhaps over complicating things. I just want a framework that stays true to the Gospel message and to Christ.

18th August 2017

I need to think about whether the participant's interpretation of what the PWD mean to them is subjective or objective. I am thinking it must be subjective that actually there might not be an objective truth about this – but in some ways that is irrelevant if it allows us to connect with PWD and to no longer see them as not fully human. So, there might be more to this subjective understanding that I need to explore. Maybe I need to push more on this point – about what it means to the participant – the “how do you know” question.

1st October 2017

I am doing narrative analysis I think but am concerned that it seems rooted in Social Constructionism. I ask if this is really a problem however as Cresswell (2007, p20 - 21) says that “In this worldview individuals seek understanding of the world in which they live and work. They develop subjective meanings of their experiences – meanings directed toward certain objects or things. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow the meanings into a few categories or ideas.” “The goal of the research, then, is to rely as much as possible on the participants' views of the situation. Often these subjective meanings are negotiated socially and historically.” “formed through interaction with others (hence social constructivism) and through historical and cultural norms that operate in individuals' lives”

I guess it is true however that experiences will be subjective and depend on interaction, context and historical context but I don't

think that that is a wrong thing as maybe it is this ability to construct this meaning that might lead to an ultimate truth.

3. The research journal provided a transparency to my study.

My research journal became an interactive source of discussion that I could have with my supervisors as we discussed my reflections at my supervisory meetings. Through those discussions I was able to notice how my own bias was clouding my vision of the data. Reflecting in my journal allowed me to sit back and notice how the data “wants to talk” to me (Russell and Kelly, 2002, p10) rather than draw a conclusion about what I thought the data was saying.

The following excerpt from my journal reflects the bias I have towards wanting a definitive answer

27th June 2017

After supervision yesterday I am again realising that I am bringing my own expectations into this research. I said that what I was thinking was that people with dementia can bring out the fruit of the spirit in others – gentleness, patience etc. Heather again mentioned that I was almost waiting to see if these things were there and I realised that I need to let the data speak for itself. I know that I need to do this – to hold it and let it speak for itself, but also there is a tension as I am taking a particular perspective in terms of personhood. What I think I have to do is try and let this go a bit and just trust and abide in it all and let it happen. Maybe I need to read some stuff on reflexivity and letting things go as a researcher.

4. The reflexive journal added coherence to my study.

The journal recorded how my methods developed and were used throughout my study.

The following excerpt was written once I had decided to take a narrative approach to the data analysis which reinforced my focus on the interactive influence on data generation, which ultimately led my method of analysis.

8th March 2018

I notice that Riessman (1993, p26) talks about the narrative method employed by Ginsburg (1989a, 1989b) who did life story work and she says that her style of presentation of the talk into text “determine how readers are to understand” the participant experience. This has left me wondering then if I can also decide on how I will represent my talk in text so that I present it in the way I want it to be read and understood? Is that what I am supposed to do or let it speak for itself and find a way from that?

5. The reflexive journal added ethical rigour to the study.

The participants in this study had given freely of their time and shared their personal experiences and stories. These stories were important, and their voice was important to the furthering of knowledge about how we might be able to connect with people in the later stages of dementia. Taking the stance of a reflexive researcher recognised that their stories were co-created within a context at a particular time and location and included other voices and influences. It was important that transparency and recognition is given to the multiplicity of voices that will have been part of the final story that emerged from their participant in the research.

3.9 Data Analysis

Understanding stories as having the capacity to become “material semiotic companions” (Frank, 2010, p42), and the potential that stories have to call those who hear them to act in the world meant that I needed a method of analysis that would highlight what the stories in this study made visible about the humanness of people with advanced dementia. Stories like this within a socio-narratology framework have the potential to influence the way in which people with advanced dementia are understood as whole human beings.

Dialogical Narrative Analysis (DNA) examines the participant’s stories and it looks at what the story does “for and to people” (Caddick et al, 2015, p290). In practice, based on the understanding that there is a mutual dependence on the content and effect of a story DNA considers “the mirroring between what is told in the story – the story’s content - and what happens as a result of telling that story – it’s effects” (Frank, 2010, p71/72)

The aim of DNA is to ask the stories questions “and then let those who do analyses decide which of these questions are most useful to emphasize” (Frank, 2010, p74).

I decided to use a method of data analysis based on DNA as a way of exploring the stories that were told by participants in this study as I could focus on the capacities that the stories had to trouble and counter dehumanising narratives about dementia.

The analysis I conducted included several different steps. I began with the initial transcription of the interviews, then drilled down deeper to identify individual stories that emerged from within the transcripts and understand the capacities those individual stories had to make visible the humanity of people with advanced dementia. I then wrote a condensed narrative that captured the overall essence of the stories within the context of the transcript that focused on the capacities that the stories had to answer the research questions.

Before I describe how I analysed the data through these different stages I explain the underlying principles that I ascribed to the stories that were used for DNA in my study.

3.9.1 Co-Created and Unfinalised Stories

As already discussed in the methods sections of this study the stories that were produced in the interviews in my study were co-created, not only between myself and the participant but by the narrative resources that the participant and myself had available to create that story. Frank writes that “in storytelling, perception and memory are always filtered through narrative resources, shifting and expanding those resources” (2010, p90).

When we hear a story, it becomes dependent on an interpretation of it, but this interpretation is a constant “work in progress” (2010, p87) because of the multitude of perspectives within which meaning can be formed.

When analysing stories, the stories are again dependent on the interpretation of the analyst. Rather than causing a problem however, dialogical narrative analysis works on the basis that the analysis will get a sense of what the story is about, not only using an element of intuition, but also by using a systematic process that helps us arrive at that intuitive moment (2010, p87). I show how I did this when I describe my process of data analysis.

When using DNA, the purpose is not to assume that the stories have a mimetic function. The analyst's interpretation is not about verifying the truth of the story, rather stories are understood as pointing towards the truth by focusing on the performative capacity of the story and the truth that is enacted in that performance (2010, p89). For example, if we tell a story about a football match where the whole stadium was on 'tenterhooks', it doesn't necessarily mean that every single person in that stadium was feeling tense, but there was an atmosphere of tension within the stadium. This story performs that feeling of tension so that the listener can get a sense of what it was like to be there.

As an analyst arrives at their interpretation of the stories in DNA it is important to remember that "no-one's meaning is final and no one meaning is final" (2010, p99). The dialogue created between the participant and analyst does not end with the analyst's interpretation, rather the final voice of the research is co-created by both the participant and analyst as it comes from speaking with the participant and not about them (2010, p100).

As a researcher, there is a duty that the participant is clearly seen as one who is involved in that final voice of the research and that nothing is said about them that they could not have said about themselves. It is important that the participant is not presented as saying what they cannot say about themselves, rather it is "that they are not yet located to say those things" (2010, p102).

The researcher has no interpretative authority of the stories that the participants tell (2010, p100) but adds to the stories in a way that the

participants could not do so themselves in isolation. The researcher has the potential to link the participants stories to other stories which “expands the dialogue” (2010, p102) as it creates a new connection that the participant may be able to use as a resource for themselves. The dialogical researcher can keep the stories unfinalised as they can offer the opportunity to show what else the story is connected to (2010, p102).

The researcher can do so because the individual stories are situated amongst other similar stories and in doing so it shows how they are connected to each other and become a collective voice.

Using this method of analysis in my study can therefore create a collective voice which gives weight to what becomes narratable about people with advanced dementia and those who make meaningful connections with them.

The analysis of these stories then becomes another voice that is added to many other voices (2010) that will connect the stories to many other people and situations in many other ways, leaving the stories of people with dementia able to continue to flourish and breath as they have the opportunity to be taken up as material semiotic companions by those that hear them.

3.9.2 Notice the differences between the storyteller and analyst

The stories that were shared with me in the interviews were co-created within my overarching story set out in the information sheet that I sent to participants that states:

“What it’s like to live with dementia is not always well understood.”

“Sometimes people with dementia are thought of as “Non-persons” especially when they no longer communicate with words.”

“People with dementia can become socially isolated because people find it difficult to relate to them.”

The information sheet states that I experienced meaningful encounters with people with advanced dementia and want to hear about the meaningful encounters that the participants have had too. This automatically creates a similarity, or some shared understanding between the participants and me

about the experience of these encounters. A follow up phone call before the interview or the initial discussion in the interview clarified that we had that shared understanding. Added to my own experiences were the stories and accounts of meaningful encounters and connection that I had read about in academic literature (Swinton 2014, Zeiler 2014, Smilde et al 2014). These narratives expanded my own inner library of stories which meant that there was a greater chance that I would recognise and understand the experiences that participants shared with me.

As I interpret the stories, I adopt the principle that understanding stories “is enabled and also limited by understandings that have already been set in place by knowing previous understandings that have already been set in place by knowing previous stories” (Frank, 2010, p94).

Frank suggests that we need sufficient similarity in our horizons, or the “background against which anything is known” (2010, p196) so that we can understand each other, but that we need difference in our horizons so that there can be a dialogue and our initial understandings can shift “in response to the story and the storyteller” (Frank, 2010, p94).

As my research takes an approach that seeks to understand the capacity that stories have to act in the world and with people, it is important that I allowed the stories to act with me also. I needed to allow my initial understandings to shift as I heard new stories from the participants, and not be fixed within my own horizons and experiences. To interpret the data in this way means that we see the “shifting of horizons based on an ethical will to understand what is not immediately accessible to the self but matters crucially to the other” (2010, p95).

I therefore ensured that throughout the analysis I was mindful that the participant in this study is the expert and they have something of value to offer as I learn from them.

This is made clear in the introduction sheet and in the interviews as I stress my interest in their experience. I am clear that my understanding of

meaningful connection is limited to my own experience and was mindful of this throughout the study to ensure that I was able to hear their story that went beyond my own horizons of understanding.

Adopting this stance through the analysis supports the reflective methodology of my study, and I continually reflect on the differences between the participant and me. Below is an excerpt from my research diary which shows how I reflect and notice the differences between us:

“Time and time again I notice in interviews that I am looking for the participant to say a certain thing to almost tie them down. For example I interviewed a spiritual carer who was talking about the connection he makes whilst anointing a person with oil and I kept asking him what he thought that was. In my mind I was waiting for him to say “the Holy Spirit, but he didn’t. I noticed that I use the sales techniques I was trained in at the bank to bring out a certain response to then offer the benefit of a product – strange how I can’t just sit back and trust the data – but hopefully noticing this will allow me to do so as I transcribe and analyse.”

Noticing the differences gives the utmost respect to the storyteller as it regards what the storyteller says as of utmost importance. It shows that the listener is prepared to look beyond what they initially hear to what the story is saying and doing.

Having explained the underlying principles applied to the stories I now detail the steps of data analysis that I took.

3.9.3 Transcribing

I interviewed seventeen participants in my study but only sixteen interviews were transcribed. One of the interviews referred to a person with advanced dementia who had a separate medical diagnosis that manifested similar symptoms as dementia. Throughout the interview it was not clear whether the participant was referring to behaviours that were due to the dementia or the other illness and therefore it was not appropriate to include this interview in the data analysis.

I transcribed all sixteen interviews verbatim. Transcribing helped me reconnect with each individual participant and become more familiar with the data (Bazeley and Jackson, 2013). It also helped me notice things that I hadn't noticed in the interview.

In doing my own transcribing I was also able to notice how some participant experiences resonated with other participants and begin to form some sense of the differences and similarities in the stories that emerged within the interview context. The following excerpt from my field notes shows this:

15th August 2017

Am transcribing this interview and what I am noticing is the reference to the senses again. He makes reference to the physical, to the touch, to what she sees, to the sound of sentences being short so they are a noise that can be understood. I also notice that he refers to the interactions as "a craft" and it made me think whether the link here could be with the elder clowns – that they are trained to do what they do, do we need to train ourselves in order to communicate with people with advanced dementia?

The references again here are also to do with "being with" someone. These could begin to be some of my initial codes that I could build on.

Millet (1971) cited in Riessman (1993) discussing her own research reveals that she was disappointed with the results of her transcription. She noticed that when the words that were said were written on paper, they didn't reflect the "eloquence of what was said" (Millet, 1971, p31 cited in Riessman, 1993, p12) nor did it reveal the delivery style of the participant and in her case the "tang" (Millet, 1971, p31 cited in Riessman, 1993, p12) of her participants voice.

I noticed the same phenomenon as I transcribed my interviews. I found it difficult to reflect sufficiently the emotion that came through the interview and the aesthetic sense of what is being said about those deep moments of connection and encounter. The emotion in the interviews was often reflected in tone of voice, speed of speech, use of pauses and laughter, 'erms' and 'mm's' and sometimes tears which did not translate well on paper. It was important that I was able to maintain a sense of the emotion during the

interviews as it reflected the relationship between the participant and me and influenced the co-creation of the story and the meanings that developed within the interview.

I developed a system of transcribing the interviews verbatim that incorporated as much of the emotion and nuances of speech as possible when a text is transcribed into written form. The transcripts indicated clearly who was speaking; and 'F' for me and a 'P' for the participant. They also indicated when either the participant or I laughed or cried. I included all of the erm's and mm's, 'yeah's etc in the initial transcripts as these often showed a shared understanding of what was being said or encouraged the participant to continue with their story.

Pauses were indicated as '..' for a short pause and '...' for a longer pause, although the length of the pause was not included. Where the listener or teller spoke over the other person, the words are indicated in [], (appendix 15).

The decision to include my voice, emotions, my responses and encouragements in the initial transcription, and transcribe the interviews verbatim allowed me to keep a focus on the dialogical interactive nature of the story and convey some of the emotional depth of the interview. To remove my voice and the emotion from the transcripts would miss much of the context of the responses and the collaborative meaning making that shaped the stories.

Although the transcription of the interviews was verbatim, there were times when I would refer back to the audio recording as I went through the data analysis process to ensure that I was able to situate the analysis within the correct context.

3.9.4 Reading the Data and Rough Coding with NVIVO

All sixteen transcripts were read literally, interpretively and reflexively throughout the analysis process. I used literal readings of the transcript to

familiarise myself with the stories that were being told, the “sequence of interaction” between myself and the participant and the way in which the dialogue was structured (Mason, 2002, p149). Through an interpretive reading of the data I began to think about what the data might mean, (Mason, 2002) and I made notes about any “significant remarks or observations” (Bryman, 2012, p576).

The following is an excerpt of my notes from an interview with an Elderflower that shows my interpretive thought processes:

“He talks very much about not knowing whether he has made a connection or not, but that he feels like he has. I notice that he also talks about not knowing for sure when there is no physical response as with people in the less advanced stages of dementia. So am struck again with the physical reactions being linked with the connection. I think we connect when it's not just physical, but I understand that he says he can't know for sure. Maybe as human beings we rely on words or a physical response to know how someone else is feeling, but this makes it very difficult to understand another person and relate to them if they do not have capacity for this type of response.

I also note he says that you're never sure if you're annoying someone, and again I notice that even if you are you are still making a connection aren't you?”

I also conducted reflexive readings of the transcripts which located my position and influence on the data as I reflected on my role in the “generation and interpretation of data” (Mason, 2002, p149). The reflexive reading captured the dialogic interaction and relationship between the participant, me as researcher and the context and ensured that this was conveyed in the stories that were chosen for deeper analysis.

The following excerpt is a comment I made during the data analysis of a transcript of a family member:

“There is a fear in some of the stories that the person with advanced dementia will be ignored and not noticed, this comes from me and the participant at times, and it animates the desire to talk and hear about the different ways of connecting and how the pwad is communicating”.

Data analysis is a somewhat messy and iterative process. In order to get a sense of what the initial messy data was saying and to manage it in a more structured format, I initially used a Computer Assisted Qualitative Data Analysis (CAQDAS) program, NVivo.

NVivo can help to organise the “messy records” that are often the result of doing qualitative research and can also help to keep track of ideas and thoughts of the researcher (Bazeley and Jackson, 2013, p3).

I used NVivo as a place to organise transcripts into the different groups of participants I interviewed and to undertake a broad rough coding of the data. This gave me a sense of the performative capacities of the data.

The following initial key capacities emerged through the literal and interpretive readings of the transcripts organised and coded using NVivo.

- Context of involvement with PWD
- Attitudes and beliefs about people with dementia
 - Noticing the humanity of people with dementia – including the impact they have in the world and on other people
- Connecting
 - Noticing the person with dementia/doing the hard work/being flexible/noticing body language and physical reactions
 - Connecting through the senses/activities/the past or familiar/guesting and hosting (entering into the world of the person with dementia)/being vulnerable/knowing the person with dementia/Being present/time
 - Not making connection
 - Knowing you have made a connection
- Dementia
 - Communicating with people with dementia
 - Previous understanding of dementia
 - Supporting people with dementia
 - What participant brings to person with dementia

Once these key capacities had been established, NVivo was no longer used for further data analysis.

I then went on to identify the stories that reflected these key capacities that were contained within each transcript. These stories would become the units of analysis for the DNA.

3.9.5 Seeing the Stories

My purpose at this stage was to seek out the individual stories within the transcript that would become a unit for the next stage of the interpretative process.

The stories that were chosen for DNA related to one of the following:

- The context of the participant's involvement with people with advanced dementia.
- The meaningful connections that were made or not made with people with advanced dementia.
- The positioning of person with advanced dementia as a human being.
- The characteristics of the participant as someone who made meaningful connections.

I did this by working through transcripts one by one, methodically working through one transcript from each group of participants at a time and identified individual stories within the overall narrative to be used as units for analysis and interpretation. (I now refer to these units of analysis as the stories). The stories were then rewritten in a form that left out the repeated words, the "umms and ahhs" and overlapping speech as it made it easier to make sense of and work with. I had a copy of the original transcript to hand to ensure that the same meaning in the rewritten unit of analysis was maintained.

Continuing with my reflexive reading of the individual stories, where my voice had clearly influenced the creation of the stories, I included that in the rewritten unit of analysis.

An example of this is seen in a rewritten story from an interview with an Elderflower:

F: So what impact do you think you have as an Elderflower on the life of people with dementia?

P: I hope just to bring a sense of vitality, of real presence and participation in something interesting, something fun, to introduce a sense of fun and enjoyment, and that work of being engaged by something and not hopefully needed again, I think it works best when we get someone singing, if they participate in singing, or if they start singing or dancing with use, that's giving us something and we're enjoying that. So they've given us enjoyment, and that I think is an even really more fulfilling thing for the elder ladies and gentlemen when they have the sense that they've given us something.

So I think it's bringing in that moments of real engagement

F: So would you say it's 2 way?

P: Yeah absolutely

F: It's just hearing from them isn't it?

P: Yes definitely, two-way engagement is the best."

Focus was maintained on the fact that the story itself was the phenomenon to be analysed.

As I looked for the individual stories within the transcripts, I bracketed out the context in which the story is told so attention could be paid to what is said in the story (Frank, 2010, p105). Individual stories were often large chunks of text that were individually analysed and interpreted and then reassembled to represent the whole story within the overall interview narrative. The individual analysis of each story from the individual transcript would later be combined to produce an overall dialogical narrative analysis for the whole narrative within the transcript.

The minimum number of stories in any one transcript was six and the maximum was sixteen.

3.9.6 Applying Dialogical Narrative Analysis (DNA)

In using DNA, the interpretation of the data is about entering “into dialogue with the story, translating it and discovering unnoticed aspects” (Frank, 2010, p105).

The interpretation becomes about retelling the story in a different form so that new connections can be created rather than commenting on the story (2010).

DNA offers the analyst the freedom to decide on which analytical questions to ask the data, which meant that I was able to develop a process of analysis that ensured that I maintained my reflective approach to this study, noticing my own influence on the data that was produced and allowing myself to be surprised by the data. An example of how I was surprised by the data is seen in the following excerpt from my research diary:

9th October 2018

Participant talks about how now that he has stepped back from the hands-on caring role he had, he is able to notice how his mother-in-law builds relationships with others and finds ways to interact. This struck me as it made me wonder if sometimes people are just too close to the situation to notice the agency of the pwd.

What’s surprising in the interview is that he suggests that his mother-in-law can control her relationships and the care that she gets and justifies this because he can now see it from a different perspective.

Using DNA meant that I could focus on the analytical questions that would best meet the needs of the research aims. I could understand how the stories about meaningful connections across the different participant groups could be connected to provide a deeper understanding of how people who make meaningful connections with people with advanced dementia continue to recognise them as fully human persons.

I developed a proforma DNA structure that I used for each individual story (see Appendix 16 as an example of a completed DNA form). I followed this structure for each individual story from each of the transcripts I analysed.

Before I began to ask the stories specific questions, I translated each story into images to try and “see” the story rather than reading and listening to it

(2010, p106). This allowed me to get a sense of how I was beginning to understand the story and gain a sense of what the stories might be saying.

Frank (2010) suggests analysts should try to picture the scenes from the story in their minds eye and then ask the question of “how the story positions you to see” (2010, p106).

I drew a sketch of each story I had selected to analyse within the interview and then laid them out on the floor in order to visualise the whole story.

I then rearranged these images as I developed to clearer sense of what the stories were doing within the overall narrative. Visualising the stories helped me reorder the stories into a logical coherent order that reflected the whole narrative, (Appendix 17).

I then asked each individual story the following analytical questions. As I detail these questions, I explain why I chose to focus on these questions.

1. What does the story make narratable?

By making something or someone narratable then that thing or person becomes visible. This is vitally important when we are talking about a person with advanced dementia who is often positioned as “not all there”, (Swaffer, 2014, p174) as a less narratable life can easily become devalued (Frank, 2010). I asked the stories this question as it can help make visible the counter stories that speak back to the dehumanisation of people with advanced dementia. It can highlight the humanising narrative that those caught up in the tragedy and loss of personhood narrative may not be able to see.

As I analysed the stories I held my position that human beings are created and held by God, which meant that the personhood and humanness of the person with advanced dementia was always never in question throughout the analysis. The purpose of the analysis was not to prove a person’s humanity, rather to notice what the stories made narratable about the ongoing

humanness of people with advanced dementia so that the stories might challenge dehumanising narratives.

2. How do the stories deal with trouble?

“Stories have the capacity to deal with human troubles, but also to make TROUBLE for humans”, Frank (2010, p28). For the purposes of my research, “trouble” is the dehumanising narratives and positioning that exist in society about people with advanced dementia where they often experience social isolation and appear invisible. In focusing on how the story deals with this trouble I focused on the way in which connections were made practically, what the participant did in a practical sense to show care and attention to the person with dementia and how they talked about them as a human being.

3. What is the force of fear in the story, and what animates desire?

“Stories shape people’s fears and desires” (Frank, 2010, p81). They can present a clear image of what is feared and “suggest appropriate and inappropriate objects of desire” (2010, p81). Fear and desire interact with each other in stories and in the analysis, I asked how the stories express fear and desire and how they perform it.

Understanding the force of fear and desire in the stories shared in this study shed light on why the participants continue to try and make meaningful connections with people with advanced dementia. It was able to show something of what it is that keeps them motivated to continue in that engagement. Asking this question has the potential to help us notice the values of those who make those connections in terms of how they understand people with advanced dementia as human beings.

4. How are the characters in the story positioned and what role do they play in the story? How do they deal with the trouble?

Characters in a story are those that make the effort to “come to terms with whatever the trouble is” (2010, p29). The story can tell us how the characters are successful or fail in this endeavour, and why they do what

they do. As others hear the story, they can reflect on the characters in the story and understand what their own experiences might be like if they took on those characteristics. Socio-narratology seeks to understand “how stories work to make characters available as generalizable resources” (2010, p30) so that those who hear the story might relate that to their own character. Hearing the stories of those who make meaningful connections with people with advanced dementia can therefore compel and show others how they might be able to do the same.

The characters in the stories are not just those who make the connections however, they are also people with advanced dementia. I pay attention to how the story positions people with advanced dementia and their role in making meaningful connection with the participants as this makes visible to the listener the influence that people in the advanced stages of dementia have on the world and people around them.

I look at the character of the participant and the character with which the person with advanced dementia is cast by the participant. This is important because noticing how the participant positions the person with advanced dementia can give insight into their reasons behind why they make connections. Asking the data this question has the potential to highlight how much control, influence and agency the person with advanced dementia has over their connections and interactions which potentially adds to the narratability of who they are as human beings.

Human character can also be expressed in relation to non-human objects and I notice how participants use non-human objects to make connections and bring life to people with dementia. This makes the findings practical to those who seek to understand the different ways they might be able to make meaningful connections.

I seek to understand how the characters in the story come to terms with the trouble – that people with advanced dementia are dehumanised, marginalised and socially isolated, seen as non-communicative and non-

persons as this can give practical insight into how the dehumanising narrative can be troubled by those who make meaningful connections.

5. What is the inherent morality in the story?

Stories can teach us the things that we think of as good or bad. People can “respond to trouble” because “stories have taught them how” (2010, p36).

I explore the inherent morality in the stories in my study as it brings a sense of how people with dementia can be treated humanely and well which those that hear the stories can take up and act on.

6. How does the story give the participant and people with dementia life and identity, move through plots and the characters perform to the listener?

Given that the stories are themselves the phenomenon under investigation, and the focus is on the dialogical interaction between the participant, research, and social context, I analysed how the story “breathes life” onto the identity of the participant as someone who has had meaningful connections with people in the advanced stages of dementia and importantly on the humanness of the person with advanced dementia.

This life-giving capacity of the stories does not come about in one single action, nor is it formed separately from the relationship between the participant, researcher and environment. I explored how these identities are fluidly formed as the stories change plots and the participants perform for the listener.

I did this by interpreting the stories in three different ways:

1. How is the story symbiotic?

Stories always work with other things. They come to life as they are told, and in the telling people can also come to life as they are given a narrative (2010). Frank (2010, p38) suggests that “the stories are somehow already there, waiting to be told”.

In my analysis I ask the stories how they bring identity to the characters in the story, notice which stories were waiting to be told and seek how the stories about objects and places bring life to the characters.

2. How does the story shape-shift?

When a story is told and interpreted by different people it takes on a different shape in that there is a sameness at the heart of the story and yet it can be applied to different circumstances. I asked the stories how the plot and characters change to fit different circumstances, and what is it that persists in those stories.

An example of this is seen in the following excerpt from a complete DNA form for one of the stories from a family member:

“Shape Shifting – How does the story change plots and characters to fit many different circumstances which lets people see themselves in the character in the plot? How are the characters fluid and what is it that persists through the stories?”

We see the pwad character change through his journey with dementia, and the participant is consistently re-arranging his care as his care needs change. It shows her adapting to his changing needs, and the story about church and how she asks questions about why he might not want to go reflect her ability to try and understand what is happening for him. Her care for him persists through the story as does her belief that he still needs and deserves interaction with others.”

Asking this question uncovers how the person without dementia learns to adapt to the changing person with dementia and suggests an underlying sense of care that continues throughout these changes.

3. How is the story performative?

Stories are understood to be told to “meet the needs of the performance” (2010, p40) and those needs are the anticipated response from the listener.

In my analysis I ask the stories what they are doing in terms of the anticipated needs of the listener, how this is being done and importantly what appears to be hidden and what is being shown.

The following excerpt is from a complete DNA form for a participant who was telling a story about how a person with dementia seems to “come back” towards the end of their life:

“But it seems to be sort of towards the end that the glimpses of the person you knew best” (excerpt from participant story).

As I analysed this story in terms of its performative capacity, I wrote:

“I notice that I am challenged listening to this as I want to keep asking why we need glimpses of the old person, but the story is highlighting that the person is still there – the old person. It doesn’t speak of when that “old person” isn’t glimpsed, I wonder what impact this has?”

Asking this question helped me retain a sense of the performative capacity of the story and how they can pull the listener, who in this instance was me into noticing the things that happen in the story, but also to wonder what else might be going on keeping the story alive and unfinished – waiting for more detail to be added.

3.9.7 Exploring the Capacity of the Overall Story

Having completed an individual DNA for each story within the transcript, I then pulled the individual stories from each transcript together to form an overall story for each transcript that set the stories within the context of the overall narrative. I completed a summary of all the individual DNA forms and then detailed the capacities of the overall story (see Appendix 18) keeping this focused on how the stories were able to answer the research questions.

Once I had completed the above steps for all of the transcripts included in the DNA process, I went through each of the detailed capacities of the overall stories for group of participants and noted down the common themes that emerged across each of the groups (See appendix 19 as an example).

I completed this final stage of the DNA by focusing on eight different capacities that the overall stories had to “perform” and show those who were hearing the stories the humanness of the person with advanced dementia.

The first capacity was what stories made narratable about people with advanced dementia and those who made meaningful connections with them. The remaining seven other capacities were the dialogical components of the story that brought forth the narrative about people with and without advanced dementia who made those connections.

The final eight capacities of the stories that emerged from the analysis were:

1. What the story makes narratable
2. The force of fear that drives the story
3. The inherent morality in the story
4. The character of the participants
5. The character of the person with advanced dementia
6. How the participant makes connections with the person with advanced dementia (also known as how the participant deals with the “trouble” – trouble being that people with advanced dementia are often seen as “not there anymore” or ignored or marginalised”).
7. How the person with advanced dementia is “still there” (also known as how the person with advanced dementia deals with “trouble”
 - 7.1 How the person with advanced dementia shows loss or vulnerability
8. How the overall story deals with trouble.

Appendix 20 gives a full explanation of why I chose these capacities.

3.9.8 Data Saturation

Whilst sixteen transcripts were included in the rough coding process using NVIVO, only twelve transcripts were further analysed using DNA as follows:

Table 3: Participant Transcripts Analysed Using DNA

<u>Participant Group</u>	<u>Pseudonym</u>
Family Members	Charlie Margaret Dorothy
Elderflowers	Peter Sabrina Jacob
Spiritual Carers	Tamsin Rachel Simon
Care Staff	Paul Leah Polly

I decided to conduct DNA on one transcript from each group of participants at a time to maintain a balanced view of the different contexts within which meaningful connections were made. For the family members and care staff I chose the transcripts in order of the interviews that I conducted. For the Elderflowers I analysed the transcript from the first interview I conducted with an Elderflower, then purposely chose to analyse the transcript from the fourth and fifth interviews I conducted with Elderflowers. I did this because one of the interviews felt particularly different to the other interviews. One participant was very clear that he wasn't sure if he was making connections with people with advanced dementia or not, but this did not change the sense of humanness that his stories brought to people with dementia. The other Elderflower transcript I chose to further analyse had two stories that stood out for me in terms of the subtleties and complexities that are involved in making meaningful connections. For the spiritual carers, three of the spiritual carers were Ministers or Priests and responsible for their whole parish, and one supported people with dementia as an elder in the church. I chose to further analyse the transcripts of three who had full responsibility for their parish as their stories included much of what the participant who the elder spoke of in terms of how they make connection, but were set within the context of their

wider responsibilities. This allowed an analysis not only of their experiences that were similar to the elder, but also how they positioned people with advanced dementia as part of their whole parish.

I had only managed to recruit three members of care staff as participants. Once I had completed dialogical narrative analysis on three transcripts from each of the four groups, I had an even distribution of stories from each group of participants.

I re-read and reflected over the transcripts of the remaining family member, spiritual carer and Elderflower interviews and decided that the data had been saturated in the first twelve transcripts I had analysed. Many of the experiences that were spoken of in these remaining transcripts mirrored those in the first twelve that had been analysed.

One of the transcripts that was not further analysed was a family member who spoke mostly of communicating through facial expression. This was covered in detail in most of the other transcripts. One transcript was from a spiritual carer who spoke of communicating through props and objects, and again this was covered in most of the other transcripts.

The last two transcripts were of Elderflowers. I read over these two transcripts again in detail and compared them to the three other Elderflower interviews I had analysed at length and felt that they would not add anything new to the data. I was concerned that adding an additional two interviews from Elderflowers would change the balance of the analysis across the four groups.

The following excerpt from my research diary shows how I came to the decision about which transcripts to leave out of the DNA process:

5th February 2019

I decided to leave out participant x as it generally talks about communicating through facial expressions etc which is covered in many of the other transcripts. I also decided to leave out participant x as it is generally about using props and objects to

communicate again this is covered in a lot of the other interviews I have analysed.

I am struggling with leaving out the other 2 Elderflower interviews I haven't analysed, however. One really focuses on love, the feeling that exists in the atmosphere, the fact that her body goes first, and the other interview talks about connecting through touch, having a 360-degree awareness noticing small movements etc. I'm not sure if they would add to the data, I have already analysed so I need to have a read through the analysis of the other interviews and decide if I can leave them out. However, if I include them, I will then have more Elderflower interviews than the others so I'm not sure if that would give the analysis a different focus?

3.9.9 Transparency, Coherence and Quality of Data Analysis

Each stage of the analysis was discussed in detail with supervisors at monthly supervisory meetings. Both supervisors received and commented on a sample of verbatim transcripts, samples of the dialogical narrative analysis forms I had completed, samples of condensed narratives and detailed writing of my interpretation of the capacity of the stories.

Involving my supervisors in the process of data analysis meant that the quality of the analysis could be monitored as they were able to see how I had identified the individual stories to be analysed, how these related to the whole narrative, and how they were later translated into a condensed narrative for further interpretation. This gave a robustness to research findings and along with my reflexive stance, helped minimise my own bias.

3.10 Conclusion of Methodology and Methods

I have given a detailed explanation of the methodology and methods of my study in the chapter. It explains why I chose a narrative methodology and conducted narrative interviews to collect data from four different participant groups. I have also discussed my reflexive methodology and methods and why and how I applied Dialogical Narrative Analysis to the data I collected.

I now present the twelve stories that formed the basis of the DNA.

Chapter 4 **The Stories**

4.1 Introduction

This chapter contains the co-created stories that emerged from the twelve transcripts that I analysed using DNA.

I present the overall story from each transcript, setting them out by each group of participants starting with family members, then Elderflowers, spiritual carers and finally care staff.

I present the stories using large sections of the transcript but leave out parts of the conversation that do not add to the overall meaning of the section I present. In this way the section of the transcript I use appears as one section of talk and allows the meaning to flow more naturally for the reader. This also helps the reader gain a thorough sense of how the stories emerged and a sense of both my own voice and the participant's voice in the co-creation of those stories.

I have given each of the participants story a title based on a phrase that the participant used during the interview that struck me as being important to the way in which they were able to make meaningful connections with people with advanced dementia, or felt important as to how they positioned the person with advanced dementia as a human being.

4.1.1 The Family Member's Stories

Charlie – Developing a Craft

Charlie along with his wife, has cared for his mother-in-law who has had dementia for the last 10 years and more advanced dementia for the last 3 years. They cared for her in her own home until she moved into a care home where she has been living for 6 months.

Charlie and his wife are committed to the care of his mother-in-law. Charlie says of his wife:

“it’s her mother we’re talking about and she’s completely and utterly committed to her welfare.”

He describes the caring relationship as a triad that includes himself, his wife and his mother-in-law, each of whom he tells me *“have had to work so intensively together.”* Charlie sees his mother-in-law as instrumental in that caring triad.

Charlie describes his mother-in-law as someone who is:

“compassionate, highly respected and loved by everybody.”

“She’s a human being and she’s my mother-in-law, and she’s lovely.”

And by virtue of being who she is in terms of her compassion determines that she is always at the centre of the decision-making process:

“whenever we do things, I mean we talk about, or have talked about what should we be doing, what should we not be doing, the bench-mark is what would she do in this situation? What would she want in this situation?”

Charlie also tells me that it seems as if:

“you need to have some form of reassurance from a third party” that “you’re actually creating a well-cared for individual.”

He says:

“every now and again it’s just nice to hear that to say yeah we will continue doing what we’re doing.”

Charlie said he has worn “*many hats*” throughout the relationship he has had with his mother-in-law over the years he has known her (prior to and during her dementia), and:

“that created that stronger bond. Knowing how much I meant to her then fed back bits of responsibility, but you also feed off that and then you take it seriously and then this isn’t just a mother-in-law this is someone that is very close to me.”

When I asked Charlie what he felt he brought to his mother-in-law’s life now he replied

“security and stability... when I am there she appears to feel very safe and contented and reassured by my presence.”

Charlie tells me that “*simply being there*” is clearly important to his mother-in-law, “*holding her hand*”, “*chatting and pointing*”, “*interacting with objects*”. When I ask Charlie how he knows this is important to her he talks of the “*micro-expressions*” and “*small behaviours*” she displays. Charlie tells me he knows she’s pleased to see him when she’s in a more lucid state because she recognises him and their history, and she wants to hold his hand and kiss him, to engage with him in a verbal and physical way. She uses what Charlie refers to as “*normal soundbites*”; “*I love you*”, “*You are wonderful*”.

Previously Charlie would have had “*high speed, quite flippant communication*” with “*lots of laughs, lots of jokes, lots of messing about*” with his mother-in-law. As Charlie’s mother-in-law became less able to understand simple sentences he found it hard to accept that his role was now to listen, acknowledge and give the impression that he understood what she meant and to pretend to agree, as he tried to predict what the right response would be.

I asked Charlie if he saw this as a shift in his relationship with his mother-in-law and he told me that:

“it’s a shift in tactic in order to maintain the same relationship. So, you know you have to approach it from a slightly different direction in order to get to the same place. The relationship doesn’t change ... but you gotta find a different way of getting to that same place.”

Charlie has developed a craft in knowing how to respond to and reassure his mother-in-law. It involves using smoothing language to placate her and attends to the rhythm of the phrases he might use to speak to her, using recognisable and familiar sounds. This is reinforced through his facial expressions and physical contact with her.

Charlie tells me that:

“Cos you want to be agreeing with her and supporting her you don’t want to be contradicting what she’s saying giving her the reassurance that her assessment of things was correct. So, we tended to start responding in a very neutral way of simply saying “ooo really?” “mmm” or introduce some sort of smoothing language just to say, “oh well I’m sure it’s ok.” It’s a qualifier to say even if you have just said something that, or your thinking something that concerns you then you’re not giving a direct response. You’re just saying well whatever it is I’m sure it’s ok. So, it’s placating sort of, soothing phrases that’s a short enough phrase for her to be able to understand. Y’know four words and there’s a rhythm there’s a reinforced rhythm to it in that it becomes one recognisable sound “I’m sure it’s ok”. It’s (makes the sound of a run on a trumpet) it’s a noise which is which is familiar. You can take lots of complex structure and syntax and what have you and you back that up with facial expressions and physical contact.”

Charlie tells me that when his mother-in-law was living at home and needed more personal hygiene care she could get quite angry and shout and it was difficult to know whether to persist with the care. There were times when she did not want to leave her chair so that they could help her get into bed.

Charlie questioned what his mother-in-law was trying to communicate when she was shouting, asking himself:

“have I crossed the line with her, am I pushing this too far, have I caused her pain?”

Charlie said that he found this the hardest time and hard to cope with. When both he and his wife carried out this task together, he found it easier for his own:

“peace of mind and my emotional state.”

Charlie and his wife discovered that by carrying out the bedtime routine in stages, the act of leaving her chair to go to bed became disassociated with getting changed ready for bed for his mother-in-law.

When I asked Charlie if he could recall a specific one-to-one encounter with his mother-in-law that wasn't through words, he talks about the ability that he and his wife have to:

“get her from a very dark place to a very light place” where she might by showing “micro-symptoms of being uncomfortable.”

These signs are a language that he and his wife have learnt over the last 10 years, signs that are cryptic and are not always easy to understand, but signs or “*micro cues*” that they have become attuned to and are then able to say “*Yeah we know what the issue is here.*”

When I ask Charlie how other people might be able to have meaningful encounters with somebody in the later stages of dementia where language is lost, he says:

“relax and just roll with it...don't force anything...go with their direction of travel...there's no magic bullet...the more you understand the individual and the closer you get, the more you'll be able to do the right thing.”

Charlie tells me that people with dementia seem to lose the ability to rationalise and externalise other people's moods and behaviours.” *Body language*,” *facial expression*” and *“speed of movement”* all have an impact on them. He says:

“slow down, smile, be gentle...take it easy...become uber relaxed...and the effect is instantaneous.”

I ask Charlie about the impact his mother-in-law has made on his life specifically in the later stages of her illness. Charlie tells me that the experience has been “*incredibly hard work*” but that it's been “*very fulfilling*” “*given his life considerable meaning*,” providing the opportunity to be “*altruistic*” and “*invest unconditionally in someone else's care.*”

Charlie had no preconceptions of dementia but his experience with his mother-in-law has made him more aware of other people, that:

“we have a different pair of glasses on and see the world in an altered state.”

Charlie gives an example of how he and his wife have become more understanding and patient when they encounter people, perhaps in a queue at a supermarket, that would have previously frustrated them. He says that:

“you know what?” And more likely to think about helping if help is required.”

Charlie tells me that he has been so influenced and impacted by his experience with his mother-in-law that he wants to be able to share the experience:

“for the sake of other people. For the sake of the world and society at large.”

Dorothy – Eskimo Kisses

Dorothy's father has dementia and has been in the same care home for the last 8 years. Dorothy tells me that her grandmother had dementia and her dad was adamant he never wanted to come into care. Dorothy wanted to make sure the care home she chose was the right place for her dad when he needed to come into care.

Dorothy shares a story of a previous care home that her father was in where he was asked to be removed:

"And then they had an incident with my dad and basically, I was asked to remove him, because he wandered into a lady's bedroom, and tried to get in beside her. But he always had my mum, y'know, by this point they had been over 50 years married so you're like "come on here" it wasn't handled very well let's say."

Dorothy visits her father with her mother regularly and she enjoys the moments that she has on her own with him. Dorothy is angry that people have disappeared out of his life. He was an active member of his bowling club and once he spent more time in his own house as his dementia progressed, she said people would come to visit in the early days but then *"they pulled away"*. She also tells me that *"other family members never came near either."*

Dorothy is an only child and adopted and tells me that she is *"always a daddy's girl"* and always *"felt I had that special bond."*

Dorothy shares this very moving story about her adoption:

*"When I grew up, I always knew I was adopted and I always said to my mum, "mum why did we never adopt anyone else?" "Y'know why did you never?" Because I knew the background of me, that my mum and dad, their first choice was to be a boy, and then they got a phone call about myself, and I was about 13th on the list for I think it was either 12th or 13th. We'll say 12, I won't say the unlucky number 13. And because of my natural mother's health, everybody had rejected me. And my father didn't. My father, my mother and father, as soon as my mum and dad went up and saw me, dad said **"yeah, she's coming home with us."** And I always felt I had that special bond. And my mum had got a phone call to say that*

there was a boy child, to adopt and my mum was saying “I think we should get her, a sibling “ ahh well they probably didn’t use those words, but a brother and my father went “no, I’ve got everything I want”. And he never gave up on me so why should I give up on him? And I put him through hell, as a teenager can I say...My dad never gave up on me, so I’m not gonna give up on him.”

Dorothy’s dad no longer uses words apart from the odd word, but she says that he smiles a lot. She also tells me that *“anything that is near his mouth he thinks he’s to eat”,* and we laugh as I comment *“including you!”*

Dorothy tells me that her dad loves music and the sensory room and reacts to it. She tells me that:

“you can see the body moving, the old, the shoulders going ready to give it a wee bit of laldy....he loves when he has his own time where they go into the sensory room where there is music there as well...and he loves that interaction.... and he seems to enjoy the movement of lights. And anytime that there is something on, like singers or anything like that you can certainly see that he reacts to something. I’ve got music on my phone of songs that he used to sing... And again, it’s as if there’s this light up moment.”

She also tells me that he’s an avid football fan and the care home have taken him to matches a few times. The staff said to Dorothy that they can see how he enjoys every moment of it.

Dorothy tells me that on her parents wedding anniversary the care home arranged for entertainment by a man who was also a football fan. Her dad was *“deciding to eat the tablecloth!”* but when the entertainer started singing some of his team’s football songs that her dad stopped eating the tablecloth. Dorothy tells me that *“it was as if there was that recognition.”*

Dorothy tells me that when she touches her dad’s cheek, nose, back of his hand that she gets a definite reaction. He smiles and looks at her.

She says he is still *“doing the movements he has always done”.*

Dorothy says:

“there’s still lots of him there, there is, as I said there is plenty of moments when we’re sitting, if it’s just him and ...that, you can still feel that bond.”

I ask Dorothy to describe what happens in that moment and she shares this moving narrative:

P: It’s like I want to climb up on his knee again. That’s the comfort feeling that you get. That’s the only way I can describe it, that when he’s doing it and he’s holding your hand and...

F: [it’s] making me cry

P: [yeah] and I’m maybe going up to his face and I just want to curl up and snuggle in, because that bond is still there. So I hold on to that.

F: [mm] [yeah] do you think your dad’s feeling it?

P: I would hope he is. ‘Cos I have seen me sitting next to him maybe putting my head on his shoulders, and he rubs my hand. Or, he puts his head on my head, that kinda idea. It’s as if I... am I saying, am I looking into what I want it to look into? I do not know. Or is it, he’s just, it’s just an automatic reaction he’s doing? I’m not sure. But I think I want to believe that that is, my dad still knows that’s me.”

Because Dorothy’s dad wants to eat everything that goes near his mouth, she now goes right up to his face and they rub noses, as Dorothy calls them “Eskimo kisses” and her dad gives her “*the biggest smile.*” Eskimo kisses were something that came from Dorothy’s childhood and she says that she often tries to connect with her dad with:

“the memories that I have of a child growing up.”

Dorothy shares a story of how if she goes to visit her dad and she has a dress on he often pulls down at it. We have the following conversation:

“F: What, like it’s too short or something?”

P: Yes! That I shouldn’t be showing off my legs.

F: And he does that now?

P: He does, still does that now.

F: Isn’t that remarkable?

P: I forgot about that. 'Cos I don't wear a dress all that often. Had the dress on today and he pulled the dress. Wasn't my jacket. He's probably saying it's too short! (laughs).

Dorothy tells me that in the past he would have given her a look and told her to go and get changed.

Dorothy tells me that she feels as if her dad still seems to sense her mood, he knows her. She notices how he smiles; he squeezes her hand, and she talks about how he seems to notice when she isn't in a good place. When I ask how she knows that he has sensed her mood she tells me that:

"he squeezes the hand and he just looks at me through...it looks as if concern, as if my dad used to go "you'll be alright.". And that what's his usual saying and that was the same look he would give me. Except not words but the hand movement was there."

She tells me that it's as if her dad still knows that he's her dad and knows his role, that he always had an intuition of knowing something wasn't right.

Dorothy says that she used to sit on his knee and:

"I hung on to every word he would ever say, and I think I still hang onto that, and I think that I give that off to him, that you are special to me, and vice versa back. I think he still recognised that's what I mean, you're still my dad. And I will always give the respect that he needs, and I have to, and I think that's where, when you were saying those moments are there between us."

Dorothy describes her dad as being in a body that he doesn't want to be in, only an existence.

She tells me her dad was the male role model of the household, and that she still respects her father and that *"I want that back."* She talks about wanting him to *"give her into trouble"* (a Scottish phrase for getting told off) or remind her *"not to open my mouth before I thought it through"*.

Dorothy describes dementia as losing everything, the physical appearance of losing weight, the interaction of having a full conversation and that things are now on her shoulders, she is now the parent. We talk about a medical decision she needs to make for him she tells me that:

“I want his quality of life now, what he has left to be the best it can, but I don’t want him going through distress. And that’s where I’m saying at times, I want him back. “Dad, am I making the right decision here?””

I ask Dorothy if there are any positives that her dad still brings her, and she tells me that although it is a difficult illness there is a lot of positives:

“[the] head on the shoulders, the he’s reacting back in his way. There is a bit of him, still, and I believe there is still a lot that they can give out. Might not be in the way we want it to be, but they do. And if it’s just hearing a laughter if you’re speaking, they are communicating through a voice of laughter, and my dad laughs a lot now, he’s so different from the period of where that that point where he was frustrated and angry, we talk about moments, dad loved to laugh. So, you’re still getting that, and that’s where I’m holding on to it, and I think he gives that back. He gives that reaction back, it doesn’t matter if it’s just a sound we’re making to him, he is reacting to our voices. He’s reacting to our touch, so there is definitely something.”

“Football, he’s reacting to that, so there is someone still in there and I mean, you still sit and go “oh dad if you could only tell me what was going on in your head” “try and get me, let me be in your head to try and see where you, what your world is. What is your world? What is it you are seeing with us? Is it that when we’re there there’s a recognition, but when we go away it goes out as quick as?” I would love to know so that when I am with him that reaction, that talking, and I want to keep on talking for him to be part of this world.”

As we talk about the narratives of “empty shell” she tells me:

“There is that person still there... Might not be... what we would hope it would be, but they are still there.”

Dorothy tells me that you need to hear the good things too:

“You want to hear the laughter, you want to hear that time they’ve lifted a pint of milk and put it in the oven turned the oven on, have a joke, but yes, it is frustrating but have the fun about it too.”

Margaret – Love in her eyes

Margaret's mother had dementia for 17 years and is no longer living.

Margaret's mother lived at home with her father for the first 13 years of her dementia and then was in a care home for 4 years. Margaret supported her father in her mother's care eventually having to give up work so that she could give them both the proper support:

"or I was going to crack up trying to juggle everything."

She tells me that her father:

"refused to let mum go into care at a point where she possibly really should have done."

Her mother was by now incontinent and swallowing pills was a problem for her. After 13 years her mother broke her hip and just before then Margaret broke her own wrist when looking after her, so she and her husband had to persuade her dad to let her go into a care facility.

Margaret tells me that there is *"nothing nice"* about dementia and that when others tell her that a loved one has dementia her heart:

"just seizes with what it means for them."

She tells me it was hard to watch her mother go through dementia. She had been a *"public speaker, a teacher, she loved words"*, and for the last 5 or 6 years of her life *"there was very little verbal communication"*.

She tells me that people shy away from dementia because they can't cope with it, that nobody from her church other than the minister came to visit her.

Margaret tells me that as a family you need to *"make the best of it"* and they tried to *"get the best possible scenario"* for her mother at every stage of the dementia.

When I ask Margaret if she had any perception of what dementia might be before her experience with her mother, she told me she didn't. I ask whether

her understanding of dementia changed as the illness progressed and Margaret replies saying:

"Yeah it made me realise how horrific it was. Really. I think probably, the final stage is difficult, but the middle stage, I mean sometimes you actually felt you were going mad... I just didn't know how to deal with it. You know we would get phone calls from my dad asking me to speak to her and she was hysterical, because she didn't know who this man was trying to get into bed with her. She was hitting him. I could hear her hitting my dad with her stick. I mean it was heart-breaking to watch. And to watch how frightened I used to bath her once a week because water hurt mum. Her nerve endings were such that a shower hitting her she couldn't cope with. So I used to dread that afternoon because it was so difficult trying to get clothes off, trying to get her into the bath with the aid of a bath seat. It was terrifying for her."

Margaret talks about developing strategies as she cared for her mother. She tells me that she used distraction, changing the subject or introducing something different that can change the mood.

Margaret shares a story about needing to walk out of the room and come back in again when her mum refused to get out of the seat and would be angry and frustrated:

"I would walk out the room, and I would come back in with a smile on my face and she would say "Ahh thank goodness it's you!" And it had been me. You know? But you just develop strategies."

When her mother went into hospital or respite Margaret had prepared a sheet for the staff letting them know how to deal with possible confrontational situations. I say to Margaret that I hear her telling me that she is doing something active when she talks about looking for strategies and she replies:

"P: all the time yeah and changing all the time as her condition changed

F: yeah so you found yourself just having to go with

*P: [yeah] [yeah yeah]
Yeah and like you would put out you know clothing was, getting an outfit out, dad wasn't terribly good at that so I just used to have various complete outfits in the wardrobe so that you know, care homes, carers when they came in could just choose one and put it on, but before that I mean, mum's clothing wasn't particularly*

clean all the time but you just have to lower your standards, so that, you just have to make life as easy as possible"

By the time her mother went into the care home Margaret tells me that her mother had a lack of verbal communication and was quite docile:

"She was almost in a stupefied state by that point really."

She tells me that the staff at the care home would rest her mother the day before she visited in the hope that she would get more of connection with her as she was then often a bit more responsive. The care home suggested Margaret arrive in time to feed her mum and she said that was nice:

"she always opened her mouth for food even if her eyes were shut, it was strange. So, it did feel like I was doing something."

Margaret says that it was so hard to get a connection and she was so pleased to get a response. She was disappointed if she didn't get a response by the end of visit, and that happened frequently.

She talks about taste being a trigger for a response and tells me of a time when her mother bit into a meringue and Margaret could tell by the expression on her mother's face that she remembered the taste. Her mother used to make meringues and Margaret said to her *"they're not as good as yours mum, are they?"* at which point her mother gave her a verbal response.

Margaret explains that the meringue took her mother somewhere, that it wasn't a connection with Margaret at that moment, but Margaret said that it was something about the meringue then the connection was there between them, the meringue was the trigger.

Margaret tells me that touch was another thing, that her mum would squeeze her hand. She would also turn her head towards a familiar voice, and latterly Margaret discovered that they were able to listen to music together. Her mum would occasionally move to the music and *"try to sing along as well."*

I ask Margaret whether she felt in those moments there were moments of connection and she told me there definitely were. I then ask what that was like for her and Margaret tells me:

“it was just a wonderful feeling to think that you had reached her.”

She then proceeds to tell me about a time when her mother’s medication was removed because they thought she was going to die. During that time *“she came back.”* Margaret tells me that she said her name and the place where her family live, she says:

“So, I have the belief that these memories are just locked. And that they are still there and one day somebody will work out a way how to unlock them.”

She tells me that her mother could have a real blank look and it was a bonus when she got her *“on an alert day.”*

Margaret tells me of another time when her mother’s speech had gone, and they went to a park. Her mother stopped and looked at her and said, *“we must thank God for this wonderful view.”* She also tells me of the time her father was dying, and they were all sat at his bed. Her mother held her father’s hand and when someone put their arm around her mother and asked how she was she replied, *“what am I going to do now?”* Margaret tells me that they were speechless, and goes on to say to me that:

“So that’s why it’s really important that you, no matter how far advanced the illness is that you do give credit for what is being heard and experienced although the face and the eyes can be blank.”

Margaret tells me of another story when she heard a social worker being told by one of the care home staff that her mother had *“absolutely no communication at all, none whatsoever.”* Margaret challenged this saying that her mother communicates with her eyes. Margaret knew from her mother’s eyes whether she recognised you or not, and that *“you could tell because you could see love in her eyes.”* She tells me that her eyes told if she was in pain, if she was happy.

I asked if anyone else could see that and she said her children could, her husband and her father. She went on to say that her father:

“saw in mum the girl he married throughout the entire illness and spoke about that wee smile she had. You know he just never failed to see her as the person he married. So, you just couldn't destroy that love she had for people and that her family had for her, you know so that couldn't be destroyed by the illness, that's one thing.”

I ask Margaret why she thinks that the carer couldn't see that her mother communicated with her eyes. Margaret told me that she doesn't think she has the same insight and skills, skills that Margaret describes as empathy. She said that the carer was in a busy job so wouldn't always have time for difficult patients:

“but if you love someone you have that empathy, you know, and maybe it's different as a family member to a carer.”

I ask Margaret if she feels she was able to connect even if there was no physical response and she tells me:

“No, that was hard. I mean I hoped because she could hear, and I knew she could hear, because she would jump at a loud noise, I'd hoped because of that that something went through. And I think it probably did, but I had no sign that I was connecting with her on many, many visits.”

She reiterates that there is often no sign of connection, that you just couldn't tell, but that she had to go and see her and spend time with her.

“I just loved her so much. We had a close relationship...she was a super mum...you just can't forget that...I just think to abandon someone in a care home is just not Christian either. It's not where I come from.”

I ask Margaret how she knows if her mum felt good, and she tells me that her face relaxes, and she talks about a calmness coming over people with dementia. She also tells me how she knew if her mum had a sore throat because she used to do the same thing as she used to do before she had dementia.

Margaret tells me that if she had dementia, she doesn't think she would want medication, she says she thinks she would want to:

“go as quickly as possible...you really just need to go as quickly as possible.”

Margaret reiterates however that she is saying that because of her experience, whereas one of mother's grandchildren says that they enjoyed every minute they'd spent with their grandparents. Margaret acknowledges that her mother would never had known her great grandchild who loved her if she had gone earlier and that there are mixed emotions. She found it tragic for her mother that she had to experience dementia, however.

4.1.2 The Elderflower Stories

Peter – Doing our Best in a World We Don't Really Understand

Peter is an Elderflower and has one to one contact with people with dementia in different care homes.

He tells me that Elderflowers use the principles of theatre clowning to engage people with dementia, and that the purpose of the Elderflower is to:

“engage the personality of the person in front of us...Our area of expertise is being playful with people, using a sense of humour and meeting the person in the present moment.”

Peter tells me that there is a misconception about clowns and that they are not trying to be funny, they:

“are not stupid, they're trying to do their best, in a world they don't understand. Which if you think about it, is, very much the situation of a person with dementia who's trying to negotiate or do their best in a world that may have become less understandable to them.”

I ask Peter what impact he thinks he has as an Elderflower on the life of people with dementia, and he says that he hopes that he brings:

“vitality”, “presence”, “participation in something interesting”, “introduce a sense of fun and enjoyment”, “being engaged by something” “needed again”, “moments of real engagement.”

When I ask how he engages the person with dementia, he tells me that he sees engaging with a person as a:

“very human activity...we all look for engagement. We inherently look for connection with other people...so it's just the same skills of being human.”

He goes on to say that as a performer and as a clown:

“we have to look at what those human things are that we do and just make sure that we brought them to a different level of awareness I think.... So, an Elderflower engagement as a theatre clown, it's first just being present, with someone.”

I ask Peter what being present means, and he tells me that it's about having no agenda, not needing or wanting anything:

"I'm happy just to sit there with the person."

Peter tells me that:

"theatre clowning very much exists in the present moment. It's not often about big elaborate fictions, it's about dealing very much in the present moment."

Later in the interview he says that:

"you know presence of taking time to be with someone, and again without any kind of agenda is a different sense of being with someone. It's more like sitting with someone you know on a bench on a nice day and you're just sitting there together enjoying the moment."

Peter explains that it is up to the person with dementia whether they want to engage with the Elderflowers or not and he respects their right not to engage.

Some people might offer a verbal response as to whether they want a visit, however for those who are non-verbal he says:

"there are still cues, to be present with someone and see if, we look at, we watch, we look at their face, we look at their eyes, we look at their body language, might be very subtle body language...I mean this is where you have to judge as a human being. If it seems like our presence is disturbing them, then maybe they don't want a visit. But if they seem that, if there's a reaction, certainly smiling is always a good indication, or a little light in the eyes or sometimes they'll, I've found elderly people with dementia very much enjoy touch and so often they'll respond. So that for me would be a yes."

If a person does want to be engaged then they:

"take a few moments to be, simply present. and then might just see, let there be a breath there, there's no sense that "I've come to do something with you."

He talks about "opening the door of engagement". I explain that I'd really like to understand those encounters with no words.

He tells me that he might just sit in silence for a few minutes and just be with someone. Just being present with no agenda can sometimes be a whole visit for Peter, that:

“it's a real luxury for us to come in without having to do anything, and to be able to you know the staff often don't have that time to sit there without an agenda.”

Touch is often a way to connect, people with dementia might reach out and hold your hand. Music and singing and conversation are often used. They often look for humour which according to Peter, is a way that humans connect and:

“laughing with someone is such a wonderful experience.”

For someone who is non-verbal, maybe in their bed, eyes closed but not asleep Peter will try music:

“Maybe a gentle song and, look for a response. And they might open their eyes, they might smile, they might just move their head, so we know they're listening, we know they're present or they are reacting to what's happening. And then again, you sort of judge if it's a response that's not saying no. It's not causing them disturbance then you try to go further with that.”

If the music doesn't work that they will stop and look for another way in.

Peter shares a story about a lady who was not responsive, lying in bed. The Elderflowers knew that she liked music and they sat with her and began to play a melody. As she started vocalising Peter tells me:

“we had to really in that moment judge, 'cos her vocalisation was pretty hard, we had to decide was this a distressing cry out or was this participating in the music? And we thought that it was participating in the music so we did keep going which was I think very nice and so we had this really lovely you about 15 minute engagement with her where she had been before alone in her room and not engaging in anything, she engaged with us vocally and it wasn't tuneful but it was a an engagement , it was a communication.

So again, when people talk about communication it depends on what you, we're a very verbal society but there's many other ways of communicating.”

I asked Peter what he looked for to decide whether she was distressed or not and he tells me, *“grimacing in the face”, “anxiety lines around their eyes”, “scrunching up their face”*. He tells me she wasn't showing any anxiety tension and that they look for tension in the body and particularly the face.

Peter tells of a dichotomy of experience that sometimes involves not connecting with people with advanced dementia or feeling like there is no connection, and yet of other times when he visits a non-verbal person gives no verbal response but:

“you feel like they're present, and you feel like they're enjoying your presence.”

I ask how he knows that they're present, and we have the following conversation as we both try to make sense of this:

“P: I don't think that's anything special. I think that we as human beings have that sense with each other. And it's something I doubt anyone can put into words.

F: yeah 'Cos I've worked with people with dementia as well with music so I

P: [yes] music so wonderful.

F: [understand]. And I think that's what again brought me into this, because I'm like how does this happen?

P: Yeah, I don't know

F: [I don't know] and I want to understand other people's experience of this.

P: Well usually it's with someone like that, with someone who, I'm remembering at the moment, was someone who was not very responsive and we played a song for her, and you feel like again, and I don't know why, but you feel like the person's enjoying the song. It's not any real visible response, but again maybe if you look at it, I'm sure that there probably is, you know, there are probably a lot of subtle cues that our nervous system picks up on that we may or may not know consciously. Again, I would guess that it has to do with tension in the face around the eyes, around the mouth, I don't know. But things that we're not conscious of. Probably that we get the feeling that someone is present. And then I remember that sometimes I'm sitting and playing a song with someone that their just not ...

F: [uh hu] it's not happening

P: [It's] not making any kind of a difference for them. But so, I wouldn't just stop

F: [yeah]

P: I'd probably finish the song and then move on. But

F: [right] [And] would you, I mean is there anything different in those moments? Like that's going on do you think.

P: I don't know (laughs)

F: [ok] yeah.

P: I don't know

F: Yeah, interesting, it's really interesting.”

I ask Peter what advice he would give to someone if they asked how they could have a one to one encounter with someone with dementia. He tells me that it would be more difficult for a family member because they are their parent. He suggests that they need to “make a switch in their brain” and:

“simply think of this person in front of you as a person that you're meeting for the very first time, and you look for their personality, what their interests in the present moment are, and not mind that they don't have any history that you might have, you can find a huge amount of ways to play with them and be present in the moment without your own emotional baggage. Because they don't, they may have lost a lot of that baggage too. So, if you can, I would say be open to meeting the person, in the present moment. And try to think of them, try to look and see this person as if you're meeting them for the first time.”

I ask Peter whether his perception of what dementia would be like has changed since he has been working with people with dementia and he shares that it has:

“expanded my definition of what meaningful communication can be or is. And I think it was something I had always instinctually felt but that's probably the most thing that I have learned. That you can have a something very small like sitting with someone, or holding their hand, but holding their hand in a in a mindful way, to use that use that very over used word. But developing that, being really present with someone so that they know that you're there with them and for them. With them really. And then even, might be, squeezing their hands back and forth. I squeeze their hand, they might squeeze my hand back, and then we can have a playful, or we might create a little rhythm of squeezing hands. And that's a communication.”

I ask Peter:

“if you stepped out of “the clown”, has this work with people with dementia made an impact on you personally, do you think? Has it changed the way you feel about, or understand people with dementia?”

Peter tells me that he feels he interacts and understands people with dementia more and has realised that:

“someone with dementia still has a personality, and that sense of personality can still communicate and still has a sense of humour and can still add something to my life. So, I can still gain something, inside, or they might make me laugh. I mean that's the best part; they share a sense of humour that makes me laugh. So yeah sure, I think the more important thing just learning that the human experience doesn't end because someone has an illness, that enriches my life I think.”

Sabrina – A Whole Beautiful Person

Sabrina started working with people with dementia as a care assistant to help her get through drama school. She tells me that she was glad to discover Elderflowering as she had always enjoyed working with other people but found the care home setting to be “*quite restrictive*” and had little capacity to change things. She talks about the rules and the lack of time she had to really connect with people and offer care in a compassionate way in the care home and the fact that:

“you’re having to rush people, and I just didn’t like the whole system really.”

Sabrina describes to me the work of an Elderflower and explains that they might have a theme, song or problem for the day that carries them through, but that they approach each person with dementia without a plan and no preconceived idea of what might happen. They approach with:

“an openness, a sense of playfulness and curiosity and slight sense of mischief but with a lot of love. Love is a big part of it.”

The person with dementia is in control of the interaction, something that Sabrina imagines is different to most of their other relationships where they:

“are often being told what to do and following other people’s direction, or instruction or routine or demands.”

The Elderflowers use a “*musical wash*”, a song that they play as they move around the care home to offer the people in the home the opportunity to notice that something has arrived:

“a lot of people are not fully open looking at the space or have got sight problems so a lot of people are closed, looking down, and so it helps I think for them to sense us from a distance and that become familiar with our sound and then when we approach that it’s not a huge shock, that we’ve kind of gently enter their space using our, using the musical wash.”

The Elderflowers might use their theme of the day to try and connect with the people with dementia. However, if the person with dementia is engaged in something else, perhaps with an object, the Elderflower might use that to try

and engage, or they might respond to something that the person with dementia says that might not appear relevant:

“but that that’s our way in. So, we don’t fight against whatever might be coming from them. We offer something but if something comes from them, then we go with that.”

I ask Sabrina if she could describe what she meant when she said that they bring a lot of love in and she goes on to tell me:

“the connection between the two Elderflowers the love is very important first of all, because we’re coming in together. And although there may be bits of a dilemma or a conflict or disagreement or competition between us, there is so much love and connection, like we’re just so in awe of each other... And then obviously the love that we offer and have for the person that we’re visiting, it’s just we’re giving them our full attention, we’re looking at them as a whole, a whole beautiful person with everything that they have had in their life before and whatever they have with them on that day. We need them and we love them, and everything that they have to offer is a beautiful gift and we are so grateful for them. For that moment with them. It’s a pleasure and an honour to be with them in that moment and just a delight to be with them and to have that time with them and we just see all the beauty in that person.”

I ask Sabrina if she sees that beauty as a clown and how it would impact her if she were to remove her red nose. She explains that putting the nose on means a sense of not judging and not being judged, that it is a sense of fun, joy and playfulness and a freedom from social rules. Being an Elderflower, she can be curious, hopeful, and have joy in the little things. When she is not an Elderflower she tends to be preoccupied with bigger problems. Sabrina tells me that being an Elderflower:

“allows me to connect with that person because in that state I can’t change their situation, I have no power and I’m ok with that. But all I can do is connect with them and have fun. And it is actually very freeing to be able to do that.”

Sabrina tells me of a story where she had changed out of her Elderflower costume and she noticed a lady she had been working with trying to open the doors and getting distressed. Sabrina said that she felt helpless:

“that you wanna do something but you can’t do anything.”

As an Elderflower:

“You’re coming in as a playful human being whose just as confused as they are, in a in a way and, but a kind of sense of lightness that it’s difficult to have when you’re just yourself.”

I ask Sabrina if doing the work of an Elderflower has changed her understanding of what dementia is and what it might be like for someone who has dementia. She tells me that she has learned to go along with the person with dementia rather than work in conflict with them. Not to try and get them to do something that they don’t want to do:

“if they’re saying that they are a child and they’re on their way to school, then that’s fine, and they are.”

She tells me that her deep belief about people and humanity are the same as they were previously. She says:

“that’s probably why I left being a care assistant is that I found it so hard to see people being treated in a way that I thought was not a good way to treat somebody. Old people being shouted out or being treated roughly, being rushed.”

I say to Sabrina that I hear that that situation made her want to do something to be able to offer more, and she tells me that:

“I think at the time I wanted to change the system. I wanted to I thought right, the way to do this is to become a social worker and actually be able to change things like care plans, change things like the sort of rules or structures of a care, the way that a care home is run or resources or things like that, but I actually, even if I had become a social worker I don’t know if I would have been able to change significant enough things to make that sort of a difference. So, I think I am actually probably able to make a bigger difference by doing this kind of work.”

When I ask Sabrina whether there is any particular time when she remembered making a deep connection with someone who no longer used words to communicate, she told me a story of a lady who she thought was blind, closed off, physically curled around and appeared distressed and in pain. Sabrina perceived a deep sense of grief as she noticed the ladies body language and the sound her voice made:

“She couldn’t be comforted. But because I saw what I thought I could see, my approach was to come up to her, and we had some kind of soft toy, and I put it on her so she could feel the weight of it on her leg, and she was kind of sensing it, and touching it and she was still kind of wailing, but I continued. What I was doing wasn’t making it any worse so I just kind of continued and I kind of moved it kind of closer into her chest, and I kind of gave it weight through my weight and she kind of held it really tightly, and I kind of tried to give it a sense of life by a sense of kind of breath, and so from my point of view I was kind of creating a sense of cradling a baby, and it seemed to settle her and she was holding it closer to her and I was kind of creating this kind of sense of kind of movement or breath with it and I was breathing with it to and I was trying to join her in her breath. She wouldn’t have been able to hear my breath, but I was, for me I was connecting with her through the breath as well. And she was sobbing for a while and she just gradually calmed down and gradually fell asleep. And that was the visit

F: wow

P: And so, I stayed with, obviously for a bit and then just moved our stuff away and left her soundly asleep. And she remained asleep for the rest of our visit. I feel that was a really deep level of connection for me although she may have not known that I, the Elderflower was there, but I think it was kind of an instinct, really that maybe this is something that she needed, and I might have been completely wrong, but I felt like there was a connection there.”

Sabrina tells me that Elderflowers work a lot with breath, and it helps to settle and create a connection, as do rhythms. She describes the repetitive rhythms that some people in the advanced stages of dementia might display, hitting something, getting:

“locked into a sort of pattern where they’re making some kind of sound, with an arm or a hand on a sofa or something like that.”

Sabrina tells me that these rhythms often appear involuntary.

For an Elderflower that is a way in to connect musically, they find the person with dementia’s rhythm, expand it and make it more musical.

I ask what happens to that involuntary movement and Sabrina tells me that it often changes and develops. She says that the person making the movement notices that:

“you’ve come to them and their rhythm, I think. And then you can see that connection there. I suppose it’s a sense of valuing what they’re offering, what they’re offering is this rhythm, and for most people in the care home setting that might be a really irritating thing, but for us, it’s a gift and for us it’s an opportunity for connection and fun and music and creativity, and you do see like a shift in people, but that that has been recognised, and that has been, we’ve joined them in that.”

When I ask what that shift looks like Sabrina tells me that people who are often closed over, perhaps looking at their own lap *“open up like a flower, gradually.”*

She tells me that Elderflowers have a lot of colour in what they wear, including their shoes so when someone is looking down, they would hear their musical wash and banter and then colour would *“enter their circle of vision around their feet.”*

Sabrina goes on to tell me that they then work with sound, rhythm, comment on what the person with dementia might be wearing, use their name, hold their hand very gently and gradually enter their space and awareness. They do this with gentleness so as not to cause alarm to a person who has been closed up for a period of time. Sabrina then tells me this story:

“somebody probably by that growing awareness whether it be visually or from the sound and feeling a sense of connection I think from us because we’re joining them in their rhythm or you know their...whatever it is that they might be offering, and you do see people start to open up. So they’ll go from this hunched over position and they’ll start to look up and I think it could often be aided by the colour of our costumes, cos they want to see more and we do things with scarves and stuff like that to try and get people to look up- more upwards. So where we have the colour down there we’ll try and draw that attention upwards, and we’ll try and get eye contact, and we’ll try and expand their field of vision so we might have made a connection here, and it might be appropriate just to stay there but we might also try to move it outwards so that they can kind of open up to a bigger space so that their awareness, it becomes bigger, they start to engage a bit more with their environment. So, where there might be one Elderflower having a connection here, another Elderflower might be on the other side of the room polishing the mirror with a brightly coloured scarf and kind of “oh hello!” and this Elderflower refers to

that Elderflower and it kind of opens. It goes from this very small kind of awareness in this almost tiny little bubble to kind of opening up like a flower and then trying to engage with the wider environment.”

I ask Sabrina whether she thinks the involuntary movements she talked about shift and stay involuntary as they make that connection and she tells me that she isn't sure if it is totally involuntary, but something that people appear stuck in. She tells me that if the person making the movement makes it stronger, the Elderflower will go louder, and they begin to follow, like a dance:

“We join them in their rhythm, we develop the rhythm, there's a bit of back and forth, we're following their lead. We might... throw in something to change it and develop it and they may take that or not. We're kind of embellishing what they have and allowing it to develop it, and they may take that or not...it's almost like there are different lines of music going on...and they've got one rhythm and we're adding to it with another rhythm.”

Sabrina describes an example of how the person with advanced dementia might be making a sound and how the Elderflower develops that sound to give it meaning:

“P: even if somebody can verbalise, it takes them quite a while to process so what we might do is just do one word and have that one word. So, if I'm trying to do something and I fail, then it might be a “ahh, again” and then try it and then they might just be able to engage with the one word.

F: Right, just that word “again”

P: Yeah yeah but it might be that they are making a sound, and we use that sound and that sound develops a meaning.

F: [right]. Who does it develop the meaning for? For both of you or?

P: [Well] we try, yeah we try to find a some kind of connection where the sound may mean something it might be quite abstract and surreal, it could be just a sound that I'm putting in my scarf or my object or whatever it is up high like this and then “eewwwww!” it's down there and then another sound means “make it go up,” For example, if they're making a sound then it may be that their sound causes us to do something, and they see that their sound has that effect on us, and then we do it again and we do that. They maybe already making that sound and we - we

create this kind of idea that when they make that sound, we do this, there's a kind of cause and effect so they realise that they can make us do that by making that sound. And so sometimes it might be that the sound gets more repetitive or bigger and then or smaller and then we might then adapt to how we react to that sound because we are, that sound has this effect on us. And so, it's quite an abstract thing."

I ask if Sabrina thinks that the person with dementia realises that they're sound is having an effect and she tells me:

"P: Sometimes I think yes and sometimes not. I think sometimes it's difficult to know whether they realise that they're sound is having that effect. Sometimes it very clearly is, you can see that twinkle in the eye, that they've gone "Aww I did that!" and

F: [Right,] so you notice something in their eyes ?

P: [Yeah] You notice something in the eyes or just a change in the breath or a change in their the way they do that sound and you can very clearly see that they have recognised, them doing that sound has had this effect, and they're enjoying it and they're gonna play with that and do it more or whatever. Other times it's not clear whether they are aware that their sound is having that effect. It's just difficult to say for sure whether they know that or not. But it just allows us to have some kind of dance, some kind of rhythm, some kind of musical connection and movement and sometimes it is very very clear that they know and other times it's just difficult to say for sure, but we might just go with that because we think we've found something that we think could be a connection and sometimes you just can't know for sure."

When I ask Sabrina what advice she would give someone who wanted to make meaningful connections with someone who had no verbal communication she says:

"don't rush. Give time because, I think our brains, we work at a such a fast pace compared to a lot of people with dementia and if you're patient and if you wait and if you give time for someone to respond you might be really surprised. So it might feel really awkward, there might be some, what feels like some really uncomfortable silences and you feel you have to fill that gap but I would say just wait and see, because that person might be processing something, or they might be about to offer something whether it be verbal or non-verbal, and if you rush, you're kind of interrupting them. So, I would say it might feel really uncomfortable for you to have the bit of silence for a while, but just wait and see

before you offer the next thing, because people need more time. And I would say just really look at the whole person, because you might think that they're not doing anything, then you might realise that they're tapping their foot, but you hadn't noticed that, and that might be something, a way that you can connect with them".

She also tells me that music is very powerful.

Jacob – Imperceptible Change

Jacob hadn't worked with or had any experience of people with dementia before becoming an Elderflower. He tells me he has always been "*quite terrified of it*" that it is a horrific disease and:

"there's something very scary about the idea of losing oneself."

Yet despite feeling terrified of dementia, Jacob tells me that his role is to engage with people with dementia. He tells me that for the Elderflower rather than seeing themselves as helping people with dementia, the person with dementia is helping them. As an Elderflower Jacob gets to know the people with dementia and builds up friendships with them.

He tells me about one of the tools that Elderflowers use to create connection and engagement:

"as a clown you, usually there's a problem to be solved and the clown is not necessarily capable of solving it alone. Something that might be quite straight forward, in life, suddenly isn't and I think it's quite empowering for people to be able to help someone else and that's one of the things I think you lose when you go into care and when you, certainly in the later stages of dementia, you don't ever have, you don't really have much of an opportunity to be useful, to help people so I think it's quite empowering for use if we're doing that I think."

Jacob also tells me that as an Elderflower he engages people's imagination, lift spirits and allows people to play. That the work they do is about:

"making connections and giving that human connection that they don't often get."

He goes on to say that:

"having someone being able to spend, sort of 20 minutes, half an hour of unfettered personal attention, if someone wants it, is a nice experience and should hopefully, make a difference in terms of mood and spirit, I think."

Jacob tells me that it is very difficult to know if you have made a connection with someone who has very little response. He tells me:

“it’s hard to decide, if sometimes you would go on your own feeling, you think there’s no way of actually proving that you have connected. I would feel that I’ve connected with someone, but it’s just difficult to prove that if there’s no response, ‘cos sometimes there is almost no response, and so you’re looking for almost imperceptible sort of changes in their eyes, or the atmosphere in the room or, which really could be manufactured in your own mind I suppose so, in that sense it is hard to tell I think.”

I tell Jacob that I am interested in the imperceptible change and that I think I’m understanding what he means by that from my own experience. I say that I am not sure I could put that into words either. Jacob agrees that it is difficult to put into words and that the imperceptible could be in our own mind, because it’s difficult to describe. He goes on to say that:

“it also might not be there, it’s difficult to know sometimes if what you’re doing is making a difference if you are really connecting or if you’re not magicking it up, but if you’re so wanting to connect, and you want that , that it is a figment of your own imagination.”

Jacob says that if there’s no physical or verbal response then he’s not sure if he has made a connection, but would feel like he has:

“P: “It’s difficult to be a 100% sure that what you’re doing is annoying potentially or, I’ve been quite negative here, but you do there are many, many times where you do feel like you’ve made a connection, but I think what I’m saying is I don’t necessarily know if that’s a true connection. And I couldn’t ever say it was 100% true, but I feel like there is a, I would feel that I’d made a connection.

F: [yeah] but inside you?

P: [inside] yeah, yeah, in the sense that it’s quite an emotional experience... But I also think the intensity of that, the intensity of eye contact or touch or and the time, because everything can take a long, long time with people in the advanced stages of dementia. And it’s all about giving a lot of space to potentially see a response. Doing something, offering something, a hand or a squeeze or, that eye contact or just being there with them and being able to wait and see if a response comes, and a lot of time it might feel like doing nothing, but it isn’t the case, you’ll be you’re actively there and trying to give space for a response.”

Jacob tells me that music is a powerful way of connecting. He tells me that music is personal both to the person with dementia and to him, so it creates an emotional response which:

“could feel like a connection but might not be y’ know?”

I check with Jacob that he is saying to me that he is making connections, *“whether they’re real or not, but you’re feeling that they’re real”* and he tells me that they feel real and he just must trust that.

Jacob fears that someone who can’t respond might not want him with them.

We share this dialogue:

“F: How do you know if they didn’t want to engage or connect?”

P: That’s the thing. So sometimes it will be very clear, like “no thank you not today”, or give you a clear sort of signal or, sometimes you don’t know, so it can be a sort of awkward position of imposing yourself sometimes, you can feel a little bit like that. So, it really is in those moments important to be truthful. It’s always been a worry of mine that if someone who can’t respond, if you’re there, hoping to connect, you could be, in their head it could be like “this is awful I totally don’t want this person in my room or here with me or”, that’s possible and that would play in the back of your mind I think. So sometimes it become a sort of making sure you’re not offensive in anyway, like annoying or offensive in that in that respect, that you’re not, you’re not intruding or what you’re doing is not intrusive, I guess.

F: So how do you know it?

P: Well, you don’t! You don’t. So, you just have to trust that what you’re doing is not, which is about taking the time and looking for responses. But even then, there can be no response still.”

I ask:

“F: [ok yeah.] Have there been times when you’ve known it’s been absolutely not wanted?”

P: [oh there’s lots of times and it’s not ...it’s you know] ..that’s quite a big part of the work, is if people say no, accepting it, and not pushing it, and not because so, people don’t get to say no to things a lot in in this units, everything is this and this now, and we go “ok that’s fine, you don’t want a visit, that’s totally ok.”

I ask Jacob if he can tell me about a specific connection he has had, and he shares a story of a connection he had with a gentleman who was unable to

verbalise, was difficult to understand, and goes on to say more about the connections he has:

P: "I sat next to him and we shared a sort of a close joke. He really enjoyed having, we were singing but he really enjoyed a close singing very cl- to his ear, very close"

F: So, you were physically close?

P: [Yeah] physically close and he was smiling and laughing at that and also I think there was something about that, just physical closeness, but that took a while to build up to that that trust if you like, there's lots of moments where, if we're singing a particular song, there's a particular song that I sing, which seems to have I think it's quite a personal song, and I think if you sing it for someone, just for them it can be quite special moments there. And funny, there's a huge amount of eye contact, which people don't tend to do so much, or avoid eye contact but with ladies and gentlemen with dementia, I don't know if it's true of ladies and gentlemen with dementia but being in that moment and not being afraid of eye contact, and singing directly with someone, quite a powerful thing. And a song just for them. And there's been lots of moments, like songs for people, or people then giving something back to you, singing to you, like a sharing of songs is very, really beautiful, there's lots and lots of moments."

When I ask Jacob about people who don't give much response, who are maybe confined to their beds, he tells me that what they do is more of a "passive thing." He shares the following:

P: "You're offering something and waiting for a response."

F: [ok] So what would you offer in that, at that time, like

P: a hand, a song, a story, just conversation, a hello, my presence there,

F: What, what is your presence?

P: Well in terms of being there next t to the person breathing and so they can feel you in the room with them, I suppose and again, you don't know, but you hope they can experience that."

I ask Jacob if he brings his same "presence" into the room of those people who are more or less responsive and he tells me that it is the same thing, but on a smaller level.

We have the following dialogue:

P: So, you bring yourself in and, there's things you can potentially use in the room, clothes that a lady or gentleman might be wearing, or how they're breathing, their rhythm or settling into their breathing rhythm. Trying to join them where they are, which is easier I suppose when you have a bit of verbalisation or they're physically able to move. Then you can be informed by what they're giving you, but also you can be informed by if someone has little response, you can be informed by that, it's just on a more low key level I would say, yeah.

F: OK, so what would you look for to inform you?

P: Yeah, if there's breathing, breathing's very important erm I think, eye contact, eventually,

F: [breathing] [mm]

P: you might, a lot of the, we do physical contact where we try to, not place a hand on a hand, but offer a hand underneath, so you're not, that's not restricting anyone and it can, if they can move their hand then they can move it away. There's a different and it's quiet, and making solid offers, so if you're going to touch, not like a gen- but like a something that is, you know that people can feel and it's there. It's also hard with dementia, it could be sore to have that, d' you know so it's

F: [yeah] [yeah] [I know yeah]

P: also going

F: Yeah Yeah

P: [But]

F: But this idea of offering the hand underneath, you know that to me is just showing that you're

P: [mm mm]

F: constantly just reaffirming that they have a choice, to to engage in this or not, yeah. It's really"

I ask Jacob whether taking the red nose off would change things and he tells me that he thinks it would change the "spirit of play". The nose is a symbol of play that signifies that something out of the ordinary is happening. He thinks there would be less imaginative play without the nose.

4.1.3 The Spiritual Carer Stories

Tamsin – Heart-breaking and Beautiful

Tamsin is a Christian minister who said that she did not have dementia on her radar when she first came into ministry. It was after having a discussion with a care home manager about starting a small service in a care home for people with dementia that Tamsin began to think about how much could be done for people. The manager saw Tamsin as someone who was inspirational. Tamsin tells me that she sent her an email that said:

“Tamsin, it was so wonderful to spend time with you, you’re inspirational. You’re this, you’re that, your care for these people”

Tamsin says to me:

“I don’t know why God just meant that person to write to me, that I was meant to meet with her. And then we met again, and I thought, yeah there is so much we can do for elderly people.”

She began to research ways to reach people with dementia.

Tamsin supports people with dementia in various ways including pastoral visits. She carries out a worship service for people with dementia in a secure part of a care home where people with advanced dementia live. Tamsin asked for permission to do that service when she realised that the people there weren’t receiving any form of service. She tells me that you must “*find different ways of worshipping*” in a care home because not everybody in that care home is able to access what people would say in a standard service.

Tamsin shares that the church needs to “*be better at not losing*” people with dementia.

She also talks about making the sacrament of communion still accessible to people with advanced dementia and shares a story about a lady who has, what Tamsin describes as, “*severe advanced dementia*”. This lady sleeps most of the day but offers brief moments of awareness. Tamsin noticed no-

one was going to visit this lady, so she and another person visit and offer an “advanced dementia communion” service.

Tamsin tells me:

“And the more I see how, no matter how lost in her advanced stage dementia she is, she knows exactly what’s happening. It’s very precious.”

I ask Tamsin how she knows that the lady is aware of what is happening, and she describes what happens in that communion service:

“So, when I go in and say “hello it’s Tamsin, one of the Ministers” I don’t know if that word Tamsin, that word Minister, if it means anything. So, what I do is I tell her what I am doing. I tell her that I’ve brought the communion cup, and then I hand it to her without any wine in it. And I let her feel the shape of it because the chalice is very particular, and I always choose a ceramic one, because it’s cold.

And so, it’s got a Celtic Cross on it, so you can feel you can feel the shape of it. And I put her hands on it. That’s not immediate, because the first thing I do, she’s got a beaker and I give her a drink of juice so that her mouth isn’t dry and, we talk about the weather, and I talk about church and I mention key words while I talk to her. And then I say that I brought communion to share with her. I’ve brought the church to her and we’re going to talk about God and share God’s love with her, and then I let her hold the cup and then I put it down and then I have the wine, port and I let her smell it.

And then I pour it near her ear, and then I let her hear glug, glug, glug. And then I say “that’s the communion cup now on the table. And it’s not the table of the home you’re in now it’s the Lord’s table”, you know as many little bits, but I don’t do a lot of talking.

And at this point she could have appeared to have fallen back to sleep or not with me at all, but I keep talking. And I make sure I say key things. And then I’ll say: “and I’ve brought the bread” and I let her feel the bread, ‘cos I always buy a round loaf and I always buy a floury one ‘cos I think there’s something about texture and flour. And then I put that on the table and I really appreciate the fact I go with someone else, so when I think she’s not involved in anything that’s happening I’ll speak to the other person because I believe she can hear.

And then I will say “we are now going to share communion, something you’ve done many times, something very precious to you. May the grace of our Lord Jesus Christ be with you...” And

then I will take the cup and I'll say "it's not the table of your care home, it's the table of the Lord. And it's made ready for you because God wants to meet you here." And then I'll give her the cup to hold again. And I mean, it changes each time I do it because it depends if I get a moment of awareness, but what is lovely is that when I say, "Jesus sat around the table", when I unpack it like this, it's almost as if she's switched off. But the moment I say: "and it was with friends around a table". And at that point, I put the bread into her hands and then I put my hands on top of hers. And then together I pull the bread apart and I say: "Jesus took bread, and having blessed it, broke it." And I tear, and I move her hands, "and said do this and remember Me". And I know, because I can feel, that in that moment she knows exactly what is happening. Because her, whole being and her breathing is much calmer, and I think that's the work, I think the whole thing is a calming thing for her. And, her eyes might be shut but if they are there's a recognition of how she's more alert in her body. And especially when I break the bread, she'll open her eyes."

Tamsin also tells me that she says the Lord's prayer and the lady will mouth the words but doesn't get to the end. I ask if she moves her mouth other than that or if she speaks, and Tamsin tells me that she has lost the power of speech, but that she does try to mouth the words of the Lord's prayer *"and it is lovely."*

Tamsin finds this experience beautiful but sad. Tamsin comes away drained. Although she says:

"It's so Spirit filled, the room, you walk in and it's an empty room with a lady in it and a radio. And when we leave, it's Spirit filled. And you can feel that. And there's a calmness about her. I think she's calmer and I'm more emotionally drained. (laughing) you know there's a real change, but she is certainly calmer"

I ask Tamsin why she feels emotionally drained and she tells me:

"I look on and I think God forbid I end my days like that. That every time I with people in that condition my heart goes out to them, goes out to their family, and I think of my own children, and me being in that position, and maybe nobody caring for me as I care for (this lady) and it fills me with angst. And I look at the care home and I listen; I look at the music they put on and I think "What would it take for you to put on classic FM?"

So, I get frustrated, I get cross and I get sad for her and sad for all the people like that. I worry about myself ever ending up like that. I give thanks that my parents are still they are well, live at home

and independent. It's a whole range of emotion. And I often wonder, you know? I believe in God's timing and God's plan but theologically I begin to ask myself, "God, what's Your plan in this?" The plan is that I become the Minister that God wants me to be by being with her. But I'm only there for communion, I can't visit her every day. What life is it? And I ask all these questions, so I think it's draining on all those levels before I start the communion and then when I do communion it fills my heart with joy. But it breaks it at the same time. So, all in all it's a very draining, it's beautiful and it's wonderful and I feel so, my call so fulfilled and it's just exceptionally beautiful, but it is heart-breaking. It is heart-breaking."

Tamsin believes that people with advanced dementia can be reached and:

"it's up to us to find ways of reaching them."

When I ask Tamsin what advice she would give to others about how to engage with people with advanced dementia she says:

"do unto others as you would like done unto yourself".

She says to speak and read slowly, hold their hand, be kind, patient and use the different senses. *"Learn to be with the person."*

"To be kind and to be loving but to be very patient and to think always of all the different senses you know. The touch, even taking a hand cream and just you know letting them smell the hand cream and just making up a story, "I bought this the other day", even if it's not true and "it's lovely" and massaging their hand or...different readings and it'll be the 23rd Psalm or the John many mansions texts or Ecclesiastes, y'know famous biblical texts and just to read it more slowly."

She also talks about using music and saying the Lord's prayer more slowly.

Tamsin says: *"you have to genuinely care"* and that *"these people mustn't be given up on."*

Prior to working with people with dementia, Tamsin didn't know anything about dementia and tells me it was never a plan.

She says she had:

"this real need, that came from my heart, not from my head, but from my heart that I needed to do something about this. And I had all these plans but God called me here and as soon as I came here I knew, that one of the things I would do, would be to set up

good ministerial practice, for people with dementia so that, when they are no longer coming to church, we wouldn't lose them. That they wouldn't lose the opportunity to worship."

Tamsin says what she does *"fills her heart with joy but it breaks at the same time"*. Her call is fulfilled and exceptionally beautiful, but heart-breaking.

Tamsin tells me that people with dementia make her ministry more fulfilled and blessed, that the people with dementia energise her and minister to her, because it's:

"the two pieces of the God jigsaw coming together."

Rachel – Finding The Keys

Rachel is a Christian minister who noticed several years ago that there were some people in her congregation who seemed to be struggling with memory difficulties. She had noticed a “*huge decline*” in one member of her congregation and found herself thinking “*oh my word this is just awful*” and wondered how she could help.

She tells me she found herself feeling inadequate. Eventually, Rachel tells me, that visiting this lady in her home became difficult because:

“her language skills deteriorated, challenging to visit. Every time that I went in, she would get upset, folk from the church went in she got upset, so you were trying to balance with did you go and upset her? Or did you not go? You didn’t not want to care but, at the same time clearly the church evoked a lot of memories and she was recalling stuff that she was then thinking “I can’t do that anymore.” I can’t explain it, and she just cried! When you went in and you sat down, and she would start crying and folk who went to visit her would say to me “I don’t want to go back to visit her ‘cos I just keep upsetting her.” I just used to think this is just awful so anything, I just thought anything that we could do that’s gonna help a few people on this journey has to be something that you know it’s really worth-while,”

Rachel noticed just how many people had been touched by dementia. She tells me that it had been at the “*back of her mind*” to do something to support people with memory difficulties. Following a conversation with someone from a dementia charity, she set up a type of dementia café that people could pop in to for support if they wanted.

The support group became bigger, and Rachel tells me that

“I’ve realised God’s got a ministry for us to do in that respect.”

Rachel talks about the impact that using Playlists⁷ for Life has had on her work with people with dementia and in her personal ministry. She tells that in the past she would have wondered what to talk about,

“and that was always a really hard visit to do because, it’s a huge challenge, ‘cos within 5 minutes you’re thinking well “what else do I do really?” or “what do I say?”. And, if it’s a nursing home it’s often not a conducive environment either even to having a prayer with them or even if you do you might not remember it, or they interrupt it. So now what I do is I tend to sing.”

Now she sings at most of her visits.

She tells me this story about her visit to one gentleman:

“But if I go to visit him now, I put on some of the war songs, and that’s what we sing. And then we sing one or two songs. And I take my I-pad, and last time I went to visit him he was agitated. He didn’t want to sit down... So, but I managed to get it settled down. And I sat down on the floor beside him and I put on the I-pad and said, “c’mon we’ll sing, we’ll sing one of the songs you like.” So, we usually start with that. And he joins in, and he sits down, and he calms down, and one of the other wee residents on the other side started joining in as well. So, we ended up having a wee sing song. And we sang some hymns. And that’s church for him. Now weather he really recognises that I’m her minister now anymore, I don’t know. But it doesn’t matter. What matters is that he enjoys it. Yeah

*F: [mm] [Well what do you]
[yeah] What do you think you’re bringing?*

P: I bring the fact that God loves and cares for these people. And just by what I do that’s what, I mean it’s not, I don’t need to say that hopefully, but when I when I go in I very deliberately always wear my clerical collar so that even if they don’t remember necessarily my name or who I am or whatever, it doesn’t matter. I’ll always say, that “Remember I’m Rachel and I’m Rachel from xxx Church and I’m the minister”, and sometimes there’s a wee spark there, maybe about something and I’ll say “oh we’ve been singing this in church today” “remember you used to go to Sunday school” or “we sang Jesus love Me” and, this resident has the most amazing voice. And I didn’t know he came to church every week...And I have never ever heard him singing, but he sings beautifully. He has the most beautiful voice and he loves to sing.

⁷ Playlist for Life is a selection of songs or pieces of music that “make up the soundtrack of your life”. Songs that bring you back to another time or place or remind you of a person, (Playlist for Life, 2019)

And I think by me going in there, that's part of my ministry, that's what I'm called to do, called to be there with people. Music has shown me just what a powerful tool it is to connect with people again. So, it doesn't need to be, I don't need to go and read them a bit out the bible or whatever, I just need to go and sing with them, and let them be them. And, sometimes yeah, music's gonna have an upsetting effect for people because it brings back difficult memories maybe for them. But so far, the stuff that I have done has been really positive. And I think that's just a really important part of ministry. And in fact, it's helped me, the music has helped me, because it's helped me have a much deeper interaction with people than I would have been able to have if I didn't sing with them."

When I ask Rachel what that deeper interaction is, she tells me that the music "allows you to communicate", it brings memories to the surface:

"So we can talk about person's family maybe, or what they like to do, or the times that they had in the church and things that help them to realise that they're still part, they're still a human being and that there's something within them that allows them to communicate with you, and with me in that situation. And something that allows me to communicate with them."

Rachel shares a story of a lady who "was very, very, advanced in her dementia", who had no verbal communication. Rachel said when she sang some of the songs she would have sung in Sunday school:

"there was physical communication that said to me she knew what I was singing for her. It was because there was a wee flicker or recognition and the eyes just seemed to have a little sharpness in, 'cos they were completely vague, but you could see in her face "ahh! There's something I remember". And it was a positive memory. The songs I sang were I knew ones that they had sung so I knew so I had to have the key. I had that key because I had known what they had sung and tried that then and clearly, she wasn't able to sing but she knew, I'm quite convinced she knew that's what we're singing about. The music connected her. It was me trying to think how am I gonna make that connection? Sometimes that's really hard work, that's the difficult bit, that's the challenging detective bit. The detective work before hand is the difficult bit, trying to find those wee keys that might just open. And it makes a difference."

I ask Rachel what she would say to someone who said to her that people with dementia aren't there anymore and she tells me that music is:

“one of the things that can create the fireworks in the brain when other bits all seem to have shut down.... it’s about finding that key that’s important.”

She goes on to say that *“we’ve got to try hard to find the keys to enable that communication”*. Communication she tells me is:

“about holding the persons hand, or it’s about a wee bit of massage, or it’s about somebody stroking their hair, or it’s about listening to a piece of music, or it’s finding that piece of music, that suddenly there’s just a wee glimmer in there that says, somethings happening in there.”

She tells me of a man with dementia who she goes to visit in a care home. I ask Rachel if this man was a member of her church congregation and she said he wasn’t. That she knew him through the support group, but that she *“cares for them as I would do anyone else in my congregation”*.

I suggest that it’s a kind of pastoral care, and Rachel agrees. We have the following conversation:

“P: and that’s now happening probably with more of the group that, I find myself trying to offer pastoral care to them so they’re not involved in the church, they don’t have church connection particularly here, they don’t even necessarily stay in this area, but I still have that pastoral connection with them.

F: [mm] [Can I ask] why you do that Rachel?

P: I do that because that’s me. Because I believe that that God wants us to care for these people. And I believe that it doesn’t matter that they can’t really communicate with us, the ones that struggle to communicate, because God still knows what they’re really like even if we don’t understand that. And these people desperately need somebody to be there for them and to listen to them.”

Rachel tells me that people are still people and:

“even if we can’t communicate with them God still can. So, we’ve got to make an effort.”

Simon – The Gifts of Time That Make Your Heart Sing

Simon is a priest in the Christian faith. He is involved in a community group for people living with mild to moderate dementia, as well as his work as a Priest that involves visiting people with dementia, supporting people with dementia in congregations and catering for their spiritual needs.

Simon tells me that he always had an interest in dementia because his Grandma had dementia and he nursed her. He tells me he has never been afraid of dementia, and that he is naturally inclined to include people.

When I ask Simon why he does all the things he does with people with dementia he replies:

“I suppose I don’t see it as any particular special bit of my ministry, it’s just ministry to God’s people. I’m charged by my Bishop to have care, cure of the souls, for use of a better term, in that bit of the diocese, in that bit of God’s kingdom, so I would not naturally seek to exclude but to include is my natural inclination. So, everybody is worthy of my attention. Nobody more so than others, because someone has dementia doesn’t mean they’re any less important in the eyes of God or any less important in my ministry, so I don’t see it as anything particularly special, I see it as part of my job as a Priest. It’s what you do.”

Simon tells me that:

“I learnt very early on in ministry that it was pointless using any form of words or music that was contemporary, because that had gone from people’s memory, but if you actually used the prayer book and the older hymns, folk would kick in and start to sing, start to respond.”

He tells me that he tries to keep worship uncomplicated for people with dementia, focusing on the “*familiar bits*”, the bits that people will have joined in with in the past rather than just listened to. He tells me he has also noticed that for those with a greater degree of dementia that singing is easier than talking.

Simon shares different stories as we talk.

He tells me of a lady who was non-verbal that he used to visit and as soon as he started reading the old prayer book service she would respond. She made the sign of the cross. the Lord's prayer and other familiar prayers. She then began to talk about her past:

"there was about a 15-minute repeated story we'd have it a couple of times while I was there. And then it would lead her to talking about the paintings and the photographs and who they were and how that related to her faith and her church then she gets tired and so I would leave. But the family would "we do not know how you manage to get her to talk, because she doesn't talk to anybody." And I said: "it's not me, it's the familiarity of something which goes back to her (age) 2 or 3?"

Simon goes on to tell me that he sensed she was going to die when she stopped making the sign of the cross and no longer engaged. I ask Simon how he feels he met her spiritual needs in the last week, and he replies:

"I think actually by being there and hopefully by continuing to do something which was familiar, that she had always grown up with and the physical touch. I'd hold her hand, that we'd always done. I engaged with that conversation that we'd had about the family and about the life in the church and, "oh of course I remember you telling me...", I did use the oil to anoint her. All the things that she was familiar with. And the only thing I got was a smile, at the end, and that was after the sign of the cross on her forehead. So that physical contact, again with something familiar that she had grown up with, that sort of did give a response. So it's interesting sort of when the words go, sometimes the physical actions, or the manual actions that people will see, still initiate a response and the anointing of the oil, was, is I've often found that actually the anointing, with the oil, whether that's for healing or in the last rites, there is a response. There is something with that physical connection."

I ask Simon what he would say to someone if they said that people with dementia weren't there anymore and he proceeds to tell me about a conversation with a lady with dementia who was now in a nursing home. She used to make cakes for the church:

P: "yes, I remember your cakes. They were wonderful! So tasty, just lovely" "Ahh you remember me as a baker?"

F: Right my goodness

P: [I said "yes I do] your cakes were wonderful" "oh that's lovely" then gone again. But it was her gift and it had been part of her faith and her ministry that I knew, and that would be our little bit of conversation. That might be a conversation starter".

I ask Simon if there have been times when he hasn't been able to connect, and whilst he says that there were times when there wasn't much there that he never gives up. He tells me:

"and even if there is still no response you might just hold their hand for a wee while and say: "well God loves you; I'll keep you in my prayers, pray for me". And you might get a smile. But it depends 'cos dementia is such a strange, there's so many forms and such a strange thing that sort of the next time you go you might get far more response. It's often I think towards the end where responses get more limited.

F: as they're moving towards dying?

P: yes, going towards like that end time, and you think, "well perhaps I won't see that person next time". Had that once, I remember someone, thinking "oh well they were a bit, wasn't quite" the next time I saw them they were a bit more like they were the time after that, no it wasn't so good and then I thought oh I think actually this is gonna be all coming and going. And then it was, the end. But actually, sort of just acknowledging that, that's ok, keep them in my daily prayers, and always asking them to pray as well. Because I we don't know

F: [yes yeah] [right that's interesting] [no]

P: what people do or what people are aware of, and people with faith are always asked to pray for others. So why do we stop asking people with dementia to pray for others? Just familiar, it's respectful saying "you're prayers are as valid now as they have ever been" so "please pray for me, please pray for so and so, please pray for" and in the services we, we pray for their intentions, for their family, whatever, or their friends err there may be a specific person so that you think that, well there may be no response but actually these are the people that they would pray for, and probably, they may still be praying for, they may not just be able to articulate that? I can't, I don't think we can assume that prayer is lost. And, actually, prayer is many things, and for many that may just be, they may just that touch that they give you, in thanks, maybe their prayer for you. To reassure you that they're still praying.

F: Yes yeah

P: We don't know

F: No, we don't

P: [But] we have to be respectful."

I say to Simon that I am interested in the impact that people with dementia have had on others because of my own experience of feeling ministered to and lifted up by people with dementia, and I ask him of his experience of that.

Simon tells me that he has at times felt quite down and found himself leaving a visit with someone with dementia "*feeling loved*", and glad that he went:

"I really needed that, I needed someone to say thank you" and that genuine, that sort of as I say the uncluttered approach of the child, I that the uncluttered approach that someone with dementia can have which is completely honest? That honesty is there."

Simon goes on to say:

"P: it's knowing that people still have things to offer, that their hand held means as much now as it did before.

F: Yeah, when they're holding your hand you mean."

Simon talks about moments of lucidity where "*you get those little bits back*". He acknowledges how difficult they are because they are temporary, but that they are a gift.

"P: And it's almost they're giving you a bit of themselves again, just to assure you that actually they're still there. That's very, very beautiful and special.

F: [yeah yeah] [yeah] What does it mean to you that?

P: It's actually just knowing that actually we present so many different faces that actually the face that dementia may make us present at that time does not mean that actually the person that we knew differently, isn't still there, that they are still there. And sometimes to see that old familiar is lovely. When it happened to my granny, this is my lovely granny that I've known and adored and spent so much time with, my granny's still there. And that's lovely. Made me feel absolutely wonderful, my granny was, and she knew who I was. I wasn't my dad (laughs) I was her grandson. It was that, those were the gifts of time, that makes your heart sing.

I think when I see couples where one has dementia, those little bits of reminding them why they fell in love with each other. And

actually you see so much love between couples often when one has dementia and where they do come or there's a smile or a hand held or a word that's suddenly you see the depth of their relationship, and there may be times when you want to shout at them (laughs) it's your partner, it's whatever, driving you mad or whatever, or you don't, or you're not seeing anything, but suddenly that little bit reminds you, they're there. They're there. And sometimes towards the end you get a bit more of that coming back and it's almost that opportunity to say goodbye, to the person you really knew. The person you knew really well. 'Cos often the personality can develop I think in some stages of dementia, you almost don't know them. You have to get to know them again. But knowing that the person you do know is there, and occasionally you get to see, helps you then cope with the with the person that presents. So, you haven't lost anything you've actually just suddenly got this new person to deal with as well. I used to think that with my granny, "oh yeah granny's still there but I don't quite understand because she actually got quite violent at times" the violent personality, but actually no, my granny's still there she's actually not gone."

4.1.4 The Care Staff Stories

Paul – Part of Their Family

Prior to working as a carer for people with dementia, Paul had not worked in a care setting. His grandparents had dementia and Paul says that he understood what dementia was like so thought he would try out a care job.

Once he started work in the care home, he says that it was different to being with your Gran, as he is now with 40 other people with advanced dementia:

“at some points you gotta take a deep breath and stand back and think. All living in one house together, so that’s the main difference between before and now.”

As we talk about how the job is different, he tells me that he has had to learn a lot and:

“just even experience from working with other staff and things, there’s been a full new learning curve. I didn’t really know anything before to be honest, I didn’t even know there was different types of dementia before. So, is quite good training wise learning all about dementia you can, how the best way to like calm people and things and all that sort of thing.”

We talk about a specific relationship he has developed with a gentleman for whom he is the key worker:

“so, this gentleman everyone was quite afraid of him, his bark’s louder than his bite. But he’s quite a strong man, he used to be a bricklayer. And he would be going along the corridors he’d be trying to rip handrails off, he would probably succeed, if he thought anything was squint, he would be trying to fix it.

F: So physically strong as well yeah

*P: [yeah physically quite strong yeah]
And didn’t take much to personal care and things like that. But, soon became a thing where, I didn’t realise this at first, but he thought I was maybe his apprentice. So, we had this kind of relationship going from the words he would say, he would say maybe “right come on then, come on! Get on with the job!” But it’s as if we were, so even if it’s like putting trousers on, he would, maybe class that as a job, that we were working on. So that*

helped things a lot from his perspective because we got on quite well together and we were able to do things at a reasonable, sort of high-quality level rather than just, 'cos a lot of people were quite afraid of him. So, just even changing trousers was a massive job, but to, to think I actually was his apprentice, and this was part of his job, that made things quite a lot easier. So, he obviously had an apprentice at one point in his life, or a few, and maybe I just reminded him of someone...so yeah, it was quite a very nice relationship. And then through that I got to know what his favourite song was, well maybe not his favourite song, but a tune that he recognised. So that came on one day and he was up, and he was dancing about, so that immediately sort of lifted his mood and lifted his spirit, if he was maybe distressed about something that would generally bring him out of it and things. Even now I think if you play it, he still kind of recognises it, but has deteriorated a bit since then.

So, from there, maybe going out and things challenge just because, if he generally grabs something, he finds it difficult to let go, because, well, I don't know. He's maybe not familiar. There could be a hundred reasons. But he likes to grab, and his children were saying when he was living in the house with them, he liked a hand massage, so, I thought we would take it a step further and see how he would relax with a head massage and things, and we tried it and he's totally relaxed out, it was amazing, so between that, the music and the relationship we had going, we're getting on great. So then, that all helps hospital visits and things, it's the best way to relax him.

When he's lying in bed at night when he can see you in full view, because his head quite bent forward now, sometimes get that smile and a wee sort of nod of appreciation, like just at the end of the day. That's what I feel and it's just that smile and look you get, you think, about as if he knows me. So that's quite nice."

Paul tells me that he can get the sense of whether the gentleman likes something or not because when he asks him, the gentleman might then laugh, or shout or roar as if he's at a sports match.

Paul goes on to tell me that when he is giving this gentleman a shower, he gets the sense that the gentleman thinks he is in a sports changing room:

"I don't know maybe back then they used to annoy each other in the changing rooms, I don't know like soaking, some of the boys behaviour in the changing rooms, 'cos some of the things he says when, I'm maybe helping him, he does make you think yeah that sounds like you've maybe had this sort of scenario in a changing

room before. I don't know you just get feelings like that then, and some of the things that he says...

F: and do you join in with that?

P: I try to just to keep it going 'cos it seems to be working,

F: yeah so do you feel you're connecting with him at that time then

P: [yeah oh yeah] It's just these wee things like that you would never be able to get taught in a class, or a training course, until, you're in the scenario and you see it all developing where you realise that, this could work. So even though the training you do get is good, it's not, like actual experience."

Paul discovered that it was better to support this gentleman on a one to one basis. He tells me:

"because he's looking down and he's seeing all these feet, I thought, if that's me I'd hate that, but then he's got a fascination with shoes, huh!"

Paul shares that he made a memory box for this gentleman who could be quite angry. The box consisted of:

"everything that was important to him back in in the day when he didn't have dementia."

Paul included items from his hobbies and photographs of his family. He tells me that it gives visitors the opportunity to look in the box:

"and to see the person for who they really are, rather than the person who we deal with on a day to day basis who's maybe angry and maybe hitting things. I suppose it's quite nice for the family as well, 'cos the family do know how difficult it is and they're very appreciative, they do appreciate it quite a lot, and there's been a few times when the family's been here when we've had to go and intervene because he's maybe been, he doesn't really know so I think, that's quite, that's quite sad to see because I think they get a fright as well. 'Cos they'd maybe never seen him like that. But then immediately all the calming techniques that we've discovered, that changes the whole scene and scenario almost immediately."

I ask Paul about the impact that people with dementia have had on him as a person and he shares that:

"P: I suppose you do think about them, you do, sometimes worry about them like, 'cos there's if they're not well. Like if you're out in shops and things or you see something and you think "ahh, that would do for", give that a wee go or something you know?" But you almost feel part of their family. Because the families take you on board quite the thing as well as if "oh we better ask Paul." So, you almost know their family better than they do now. I think that touches you quite a bit.

F: So, you're thinking about them when you're not here?

P: [Ahh yeah you often, you] often wonder what they're up to or how they're, yeah. So, if you think of, being here it's quite a long day, and when you're not here you think "I wonder what they're actually up to? I wonder what's stimulating them right now?"

Paul continues to tell me that he also hopes that they've:

"not done anything bad. You don't know what you're gonna go back to then."

He shares, and I sense almost hesitantly:

"P: "like not mentioning anything too bad and gross and disgusting but you do see a lot of bad things, I think that probably impacts you the most 'cos it kinda scar on your brain.

F: [when when] you see

P: Yeah when you see really, really, bad nasty, nasty things,

F: [yeah] 'cos that's the reality of it as well isn't it? It's like, yeah"

Paul shares some of the difficult situations he faces as a care worker and when I ask him how that makes him feel we have the following dialogue:

"P: Well basically at the time it makes you feel sick and things, but after you think, we often wonder if they ever, if they get a little. I suppose the times that I've really saw the residents have, they've always ended up in tears y'know like, so they've obviously had a moment where they've maybe realised. I don't know, they obviously realised what's happened or what they've done or what they've eat or. Where they just break down and you. There's nothing you can do except like comfort them. But, maybe sorted them and things, you've got them all fresh and things. And there's not a tablet in the world that would make them not do that. There's not, you can only just watch them. And observe them and make sure, but you couldn't do that 24/7. It's just things like that. 'Cos in the back of your mind you're always almost analysing how could of

that have been different? How could you have avoided that or something. Or to make them safer, but you couldn't really, you couldn't really unless you, one to one time with them all the time.

F: And how do you comfort them after that then?

P: A cuddle really, I mean that sweeties and chocolate work wonders with a lot of people but it's a cuddle. I suppose after 10 minutes or so they're maybe forgotten about it and they're back to their routine, they're walking about or whatever they're doing, so yes, I suppose, it doesn't last too long. I suppose it's good that they've maybe forgot you don't know for sure if they've forgot about it but obviously it's still impacted on your mind.

F: Yeah. Has it made you sort of think about your own humanity?

P: [yeah] absolutely you think "what on earth like", you couldn't imagine yourself doing it, but you never know what the future holds."

Paul tells me that:

"P: I suppose at the end of the day, when you like step back from it all, it's a good day isn't it? 'Cos everyone's happy, everyone's safe and although everyone's got bad moments during the day everyone's still safe and well. So you could either look at it "oh it's been a terrible day, oh he hit me" and all that, which is sometimes you do have days like that where you feel you just don't want to be here, like y'know why am I here? why am I putting up with all this? but I think you've really got to look at the day as if, it's been a good day.

F: So, what is it that makes you come back then after these really bad days?

P: Suppose you have to. I know that sounds daft but, when you do come back after a, maybe you've had a bad day and you've maybe had day or two off in between and you think, "Oh I need to go back here", but when you do come back, between all the staff, between the residents as well, they do perk you up a wee bit. It's probably a mixture between staff and residents, who make the mood that wee bit better and you think "ahh today was actually quite good."

I ask Paul what he might say to someone who says that people with dementia are just a living shell or not there anymore.

He explains:

"I wouldn't say they're a shell, but they're the same person they're just at a different time in life I think, from what they look to be. So

maybe somebody is in their early 80's but then they're living their life as if they're in their 50's, when they're working."

I ask Paul what advice he would give to someone who wanted to know how to make a connection with someone in the advanced stages of dementia and he tells me that "*music is the best thing*", or:

"even just say hello. 'Cos a lot of time, saying hello, that's almost the very start of someone want to, so I think even just a look and a smile and hello that's maybe as much as, as that. 'Cos as soon as you say hello to someone it's like you're meeting someone aren't you? So you almost get that thing from the person that you're wanting to engage with and then that hopefully starts the ball rolling."

Leah – Just a Look

Leah had been a baker before coming into work with people with dementia. She wanted a change of career and felt that she had a lot to offer to family members of those in care because she had experienced the loss of a family member to a serious illness. She tells me she loves what she does as a carer and enjoys trying to make a small difference to people's lives.

Leah tells me that her work is totally different to what she imagined it would be:

"P: I actually thought it was going to be working with old people that probably didn't communicate much, probably didn't walk about much and probably just frail elderly people. And I had no idea that it's full of characters and full of life. And, totally different to what I imagined it to be. Definitely. But, it's very challenging but it is rewarding. I think sometimes we all have to take a step back because, when you do something for a living when it's your job full time, sometimes it can be, mundane's not the right word, but it just becomes part of your job. And then there's other times that you take that step back and you go "oh alright ok". These are human people. They are humans, just like us and sometimes I think 'cos you get so used to it, I think that's what it is sometimes so yeah, it is it's

F: [uh hu yeah] [yeah like it's routine isn't it]

P: just routine and you get used to all the different characters and individuals in here and you get to know them, so sometimes it can be like, once I've got to know you, you just you don't think about it anymore, I suppose is the right word I'm looking for. You don't really think of them as somebody with dementia, although you know they have, you don't sort of think about it, it's just natural process if that makes sense?"

I ask Leah if her understanding of dementia has changed over the time she has been working with people with dementia and she tells me that:

"The biggest change I would say is that they are very much still here. Maybe not all the time, but I think sometimes people think folk with dementia that they don't have any abilities left or any skills or anything to offer and the sad thing is that they do. There there's a lot still there."

I ask Leah if she has any examples of people “offering things” and she shares a story of a lady who has never verbalised in the 18 months that she had been working with her:

“P: And I remember one day she’d had a bath and I’d dried her hair and as I walked away, all I could hear was “thank you”. And I actually had to look around to think “oh I did hear somebody speak”, and she was sitting and all I can remember was she actually was sitting there and she had this smile and this beam and I’m thinking “it can’t be you because you never communicated”, but when I said to her “was that you?” the head nodded and I think I thought “wow!” and because she didn’t communicate so much, I actually think that you didn’t actually speak to her probably as much because you think “well she’s, there’s, she’s not gonna speak back”. So sometimes I think for me it taught me that just because they can’t communicate doesn’t mean that they’re not listening or they’re not really understanding what’s going on so. And then that actually happened 3 or 4 times with myself with that particular lady. I remember once giving her a cup of tea and it was it was always as I walked away, she would say “thank you” ...

F: [And] what did that do to you? ‘Cos it looks like it really meant something (laughs)

P: Yeah. It did! I think it’s just that you actually realise that they were there, and I think for me, it’s not that you feel special, but I think you feel, there’s been a connection made. I think over that time, she’s obviously got to know me, and she has obviously, she’s tried and for her, to never communicate to actually say that is quite something. And I think near the end I think she did say a few words to other people. But that was it. It’s something I think that was one of the times where it really sort of stopped me in my tracks and made me go “oh right ok, she is still in there”, it’s just they lose the ability to actually speak. So that’s I think one of my favourite, when I look back I think oh that’s one of the things I’ll never forget. I’ll never forget that day. Oh the feeling that I got or looking back and I think it was her face it was just radiant, smiling and, obviously thanking me for drying her hair so. (laughs)

F: What was that feeling you got like?

P: [so she enjoyed] It was lovely, it was nice, it was really nice, ‘cos you actually felt that you’d done something. That person had obviously appreciated her bath, she’d obviously appreciated getting her hair done. I did it was lovely, it was a nice, I’ll never forget that moment.”

I ask Leah what she brings to people with dementia and she tells me that she hopes she brings:

“something good for them, some sort of reasoning, some peace.”

Leah tells me it can sometimes be hard to bond with new residents and it can be a surprise sometimes when some whom you weren't expecting to bond with *“turn out to be your bestest friend.”*

I ask Leah if it just takes a while and she tells me:

“yeah it does, it's like everything. It's just getting to know them and know them as a person. 'Cos we've all we've all got different characters, haven't we?”

She goes on to tell me that in a care home so many characters come together, and that it's about getting to know them.

Leah goes on to tell me about what she calls the *“negative effect”* of dementia, she says:

“the aggression and not really knowing, and I think that's probably more the harder one.”

I ask Leah if she is still able to connect with people who are aggressive. She tells me that sometimes you might need to get the key workers involved and you need to get to know them as an individual. This leads to Leah telling me about a resident who has a daughter with severe autism and how she connects with the resident:

“Well she's not a girl anymore she's a woman... she is in a care home, but this resident still believes that her daughter is still a small girl and at home and she needs her mum and she's got to get home. So when she sometimes starts to get, distressed and showing signs of “I need to get home because my daughter needs me” sometimes it is just a case of sitting her down somewhere and saying “now remember, she's in a home, she's being looked after, and sometimes it comes back, and she'll remember and then there's other times when the connections gone. But the sad thing for that lady that I was talking about, is her daughter always comes in and visits her maybe 2, 3 times a year, but the last time she came in she didn't actually recognise her daughter. And her daughter was really upset because she was obviously calling mummy and (the resident) didn't actually remember her. But, a

while ago, this particular resident started to talk about her again. And there's no reason for that because she actually stopped talking about her, forgot about her, nobody knows why, and then it's back again. So, it's, the brains a...

F: [right] Yeah, it's funny isn't it?

P: It's a strange thing, yeah so

F: [yeah yeah]. [Is she in] the later stages of dementia would you say, is she more advanced?

P: [she is yeah yeah] Yeah she is

F: Would she communicate?

P: Oh she can communicate very well (laughs). Yeah, she can but it all gets muddle up and mixed up

F: [Yeah yeah]

P: and sometimes she's trying to tell you a story, but the words aren't coming out the way they are supposed to, it can be a bit more muddled up.

F: How do you connect with that story, how do you (get a) sense of what she's saying if it's muddled?

P: I think cos I key work this lady I genuinely start to know. If she's getting a bit anxious should I say. I usually start to notice that she usually starts to walk about the home a bit more. And usually that's a sign that she's starting to look for her. She's just getting a bit more anxious. So, when I see her like that, that is when I will actually take her to a quiet area, and I'll say: "are you ok?" And she'll start to say, "my lassie" or "my girl" and that's when it's "right ok" and we'll go through the story. As I say sometimes she can sort of connect the dots, shall we say and then there's other times when she's like adamant like "no she needs me and I need to get home". But if you were to say to her your girl, she's not a small child, no, 'cos in her reality at that moment, she's gotta get home for her daughter.

F: [So you] really notice how she's feeling by what her physical movements then? Her walking around and

P: [yeah] [Y' sort of you start to get] observant with folks body language and just the way they are because when this particular resident is happy and content she usually just sits quietly. But when she's starting to get a bit "ok" like, (laughs) you can see the agitation starting and just the walking. The pacing. And she's looking for something, but she doesn't know what. And

even now she'll say things like "I'm looking for my mum." Yeah so generally if somebody says that I'll usually just say "I've not seen her, but if I see her I'll let you know", because I think to actually turn round and say to these people "sorry but your mum's been dead 20/30 years" isn't gonna be a good thing for them."

Leah tells me of how frustrated she can be at times because she would like to spend more time with the residents in the care home:

"P: I think sometimes when care homes particularly, there's never enough staff, there's never enough time, we can't always meet all their needs. And sometimes I think if we were in the ideal world where all the staff were in place all the time and there was no pressures of anything else it would be lovely just to be able to, rather than just meeting their basic needs sometimes it would be lovely to just spend more time with them, and offer them a bit more. Because sometimes it's like you can see somebody upset, but you've got somebody else that's come to you that's needing the toilet and somebody else is waiting for you and just sometimes juggling everything. And I think it's just the, the system of communal living basically isn't it? it just would be nice to spend a bit more time with them. 'Cos I do honestly believe if we could spend a bit more quality time with people I think, a lot of situations I think could be handled, better, if that makes sense, for them. I think that's where I get frustrated anyway, 'cos there's times I think, see if we just had" (laughs). This could be done, and that could be done."

I ask Leah about meaningful moments she has had with those who have maybe lost mobility and speech and spend more time in their bed, and we have the following dialogue:

"sometimes it can just be a look it can just be somebody's looked at you and you've looked at them. See to be honest, most of the time it catches you by surprise, because there are times when you can do so much talking so much trying to connect with them, and you never connect. And I've always found that most of the time when they're gonna connect with you is when you're not expecting it. And I don't know why, but most of my, would say even like end of life there's been folk that have opened their eyes and it's just been a look, but you know, they know that you're there and you know that. You think I don't know, if you're thinking the same thing. I can't really explain it. It catches you by surprise. And you can have as much training and I don't know, this is the right way to do things and this is what happens, but I would say most of those moments when you've made the connection for me personally has

actually been, it's being taken off guard, I've not really been expecting it. So, it's a

F: [right. Do you] know what you've been doing at that time?

P: Not really, it can even be just be simple things like you're actually just giving somebody a drink in bed or you've just been assisting to feed them, and it can be something just, they just touch your face, they just hold your hands. But there's never, if you were wanting it to happen, it probably wouldn't happen. It's probably just one of those, for me it's just it's always took you by surprise yeah. And it's not

F: [yeah] [surprise] [yeah and this is] people later on, almost

P: Yeah, I would say later on, I say, I think, when we're going over to your bed care people, like the ladies and gentlemen that are more in bed that are palliative yeah. Yeah, they can, but sometimes it can just be a smile. You just look at them and they look at you and smile. There's always a lovely peace. There always is a very sort of still and a peaceful time. I know it's hard to describe actually

F: [sometimes] I think you can't put it into words.

P: [you can't it's] like trying to put it [that's what I'm

P: into words its

F: trying to get to] the bottom of! It's

P: I know, sorry trying to get those things into wo- and you're like that "oh I can't describe it"

F: [No, not a-] [No] and maybe you just can't. But-

P: [I] don't think you can it's

F: [yeah] Is it like, more like a feeling? Do you think or?

P: It is, it's just something that comes over you. You could have somebody who you've been dealing with, say they've been going down, downhill, later stages of obviously their illness and you can be dealing with them all the time, but there's nothing. And then there's times where like I was saying, it's like you can just be doing something, like brushing their hair in bed, doing a bit of mouth care, doing a hand massage and they squeeze your hand or, and

it's not a real reason why they decided to do it then. I don't know, it just catches you.

F: What does that tell you about the person with dementia?

P: Oh they're definitely, definitely connecting with you then. I think that's part of the, you can tell. For them to actually touch your face or to hold your hand or, they're definitely saying. What they're saying whether it's a, a "thank you, I know you're there" or you don't really know but yeah it's.

F: [Yeah that's] that real encounter isn't it, of just, yeah yeah."

Leah goes on to tell me that:

"there's an intimacy moment, where you know and they know, and sometimes it's not even a conversation, it's just a look, but it's a moment."

I ask Leah if there is anyone with advanced dementia who has made an impact on her life and she tells me about two ladies. When I ask how they changed her she replies:

"I think it's 'cos you actually start to see that there is actually a spirit and a soul that's within, and although they can't, they don't know there's something wrong with them, I don't know if that's the right word or the wrong word, they just can't get it out anymore. And I think you start to see what's within, what's in there. It's there, and I think that's probably what they've done. It's more that I was like ok this isn't just, it's not just working with people with dementia, it's working with people who have got a soul, who still need to be loved, who still need to feel important and worthy and all those things. So, I think that's probably how it changes you that way. Which can be hard as well when you've got a character on your hands (laughs), you're like that "Oh!" "Ahh Give me strength!" (laughs). And it can be, y'know? So

F: [yeah] [How] do you handle that though when it is somebody who's, I take it you mean someone of a more difficult character?

P: Yeah a difficult character, it can be yeah, 'cos sometimes you have to go "oh right Ok they do have dementia, and this is why they're like that." And sometimes you have to actually step back and remind yourself that. They've actually, they've been young, they've been married, they've had children, they've brought families into this world and they wouldn't been here. The only reason they're here is because they can't cope on the outside anymore. So sometimes it's good just to take a step back and to

say to somebody else, "look, I'm really struggling here, do you think you could take them for 20 minutes or something."

I ask Leah about how she cares for the spirit and the soul of the person with dementia and she tells me that:

"There's a person that lives within isn't there that you that you start to see. I think it's just connecting with them. I think it's just that way where you're trying to let them know that you see them. You know that they're there and even if they can't or they can't be bothered, you still know that they're there."

I ask Leah how she would respond to someone who said that people with dementia are a living shell and she tells me that she has seen people who are "demented" and "don't get any peace." She describes this as though the brain doesn't switch off and she thinks this is the "worst kind." But she tells me that for a lot of people with dementia they "still live out a very good quality of life."

When I ask Leah what she might say to someone who wanted to make a connection with someone in the later stages of dementia, she acknowledges it might be harder for a loved one, but that she believes that people are always connecting in some way. Even if it is that they are closing their eyes as a way to say that they don't want to look. She says:

"But I would just be with them. I think sometimes it's just to be able to sit with somebody but not to be uncomfortable with silence, which I think (laughs) we're all guilty of. Sometimes you can be in a room with somebody and you're absolutely saying nothing. Obviously where they are at that moment at that time, that's what they need and I think you'll find then that when you're not looking or expecting them to, I think that's when they're probably more at ease and maybe they will say something. They will touch your face, open their eyes, smile

F: [yeah] [Oh] that's really lovely, just be with them

P:[yeah] just be with them, hold hands. Put music on as well 'cos music is really good. Just all those, relaxing.

Polly – I See Your Spirit Within

Polly's father had dementia and she looked after him until he had to go into care. It was his dementia that led her into her work as a carer in a care home.

Polly shares with me that she is a born again Christian and that she loves and lives for the Lord and that's a huge part of her job in the care home.

Before she started work at the care home Polly had no experience of working with dementia and tells me that *"it was totally alien to me."*

She tells me, however, that:

"P: For me coming in here, it's amazing because I know how it feels to be a family member, and having my dad, had to go into care so I know exactly how that feels. And it's just awful. It's the worst thing ever. So when people come in here I can actually, I feel really comfortable, as in I don't shy away because I really do know what it feels like to, and the different feelings and the different things that you go through as a family member, and having to do that, and I find that's a huge thing as well. But in here I find it's good for me because I see it from a carers point of view, but I also see it from a family members point of view. I find again that that's a huge thing as well. And again, I've got a great connection with family members because, you do feel, when they're crying, you're crying with them. Because you just know how hard it is. And all these feelings of guilt and all these feelings, of different things that you go through and it's really dreadful. And it's really awful."

Polly tells me that dementia is far harder than cancer because:

"it can go on, and you lose this person. You're watching them fading away. You're watching them losing all their inhibitions, you're on this emotional roller coaster. 'Cos sometimes, you can go in and it's a good visit and other times you can go in and, oh you're coming away and you're so upset so it's very, very difficult."

Polly has learned a lot about dementia since she has been in the care home, she has had good training and is always keen to go on as many training courses as she can.

Polly tells me about her work with Namaste. (Namaste is an approach to dementia care for people who find it difficult to participate in traditional care activities (McNiel and Westphal, 2018) and sessions might include massage,

“*personal care...multisensory simulation activities*” (2018, p38) and reminiscence). Polly hadn’t heard of Namaste until she went on a course and heard a lady speak about it. She explains that Namaste, roughly translated means:

“I see your spirit within” ... what that’s saying is...” even though you’re like that, I still see you.” And that’s how I love Namaste. Because you are honouring that person, and saying, “I still see you in there.” And for me that’s what Namaste is.”

She tells me that when she went on the course and heard the lady speak about Namaste:

“See from the minute she came in and started speaking’ about it, I couldn’t stop crying. I was like “I really need to do this.” D’y’know how you just think...this is why I’m here?”

F: [Wow!] [right] [yeah]

P: *This is why I’m on this course. I thought I really need to bring this to the care home. So, oh! It was absolutely amazing Frankie, I’m not joking. And so you got the training on it. Like we got learnt to hand massage, then and see the washing the feet for me is huge. A lot of folk probably think it’s very strange. But I think washing somebody’s feet is the most amazing thing that you can do for somebody. I honestly do, I think it is so beautiful.”*

I ask Polly why she thinks washing the feet is so beautiful and she explains that as a Christian:

“I just think that is what we should be doing. I honestly do. I just think that is exactly what we should be doing. And it’s amazing like the results from just see washing somebody’s feet.”

She explains:

“so, you can bring people in and I’ve taken in, especially the gentlemen who hate personal care and you would get a slap and you would get punched and whatever. And there’s certain things like, some of them even giving them a wet shave. That just wouldn’t happen. Even the electric razor’s a bit mm. But when I bring them into the Namaste room, and it’s just amazing.”

In the Namaste room she will put on soft music, the sensory machine with the bubble tube is there, she uses different aromatherapy smells, the lights are dimmed and there are projections on the wall. She describes it as “*the most*

amazing relaxed atmosphere ever.” Polly tells people how pleased she is to see them and gets to know what they like and don’t like.

She tells me that some people with dementia who walk around a lot and don’t usually sit for any length of time will sit and relax. She explains that men who can be aggressive at times will:

“allow you to wash their feet. They will allow you to give them a wet shave. That would never happen on a normal basis.”

Polly tells me that most people who go into the Namaste room are unable to participate in other activities and a lot of them can’t speak. She tells me that she brings in people who are agitated and tries to spend time with them:

“Relaxation with a lot of them it’s a one to one, because other people would distract. So, there isn’t always a lot of people anyway, because you want it to be quiet. You want it to be quality time. You don’t want to be just spending that short time, so you want it to be, have plenty time that you can actually spend.”

Polly tells me that people become calm in their mood and a lot fall asleep.

For someone at the end stage of life, Polly takes the sensory machine into their room, and creates the same atmosphere as in the Namaste room. She talks about a massage technique that she uses for people who don’t like to be touched and we have the following conversation:

“So, they use a blanket. And oh it’s amazing I’ve had it done. And so, if they’re lying down, which is a good one to do if they are in their room. So, you put the blanket over the top of them. And what you do is you start up, up at the top and then you start off here y’know, and then just gently, just stroke

F: with the, like over the top of the blanket?

P: [over the top of the] blanket yeah. So, you’re not actually losing connection with them and then you’ll go down to the h- and then down to their legs and down to their feet. And it really is lovely. It really is. It’s so comforting and it’s really, really nice.

F: [What] happens to the person with dementia? Like do they change?

P: [Y] can feel, it’s very spiritual. You can feel a peace. You can see, I mean a lot of times you’ll see that they’ll

maybe be stressed to start with. And then you see that changing you can see their face changing, you can see their body changing, relaxing. And again you have this lovely music and if it is someone who has been a church goer, I'll put on hymns and I'll sing knowing that, if they do like that, and then we've got a resident here who likes classical music, so I have bought a classical music cd, but the you know the calm music. So, what you try and do is find out what that individual person likes. It's very individual."

She might try reading poetry, and:

"just really finding what they... 'cos you know by their facial expressions."

Polly tells me that she likes to invite family members into the Namaste room:

"because that is a lovely time for them to be spending with their, it is really nice because they're seeing them different. There's a lady, she was quite agitated and loud and noisy and her husband's in most days. And they come into the Namaste room, and he was so touched seeing her calm and he could see what it was doing to her and the effects. And that was lovely.

F: *[That's] really nice isn't it?"*

As we talk about making connections Polly tells me that:

"you get to know them actually better than what their family get to know them, at the stage they're at. And it's the same if you see somebody and you think "oh, there's something wrong" and you need to get the doctor and then the doctor will come in and say "well I can't really see anything." You're like "no there is something wrong." 'Cos we actually know better than the doctors. And I'm not meaning to be rude when I'm saying that, but you actually do know them so well, that when something happens, and they're a bit off, y' think, "no there's something going on here."

F: *[yeah yeah] So what kind of things do you see then?*

P: *See like infection or something you can see it'll just be the way that they act, they're knocked off, and they'll do things that are out of character, y' just know right away, y'know that that's something not right at all. So it's good because we can kinda spot that.*

F: *[yeah] It's even with those later on in their illness? Yeah*

P: *[Yes yeah] , definitely. Yes, you can tell, you can, and you get to learn, you get to know when they can't speak, it's all like body language and facial expression y'know so you're always looking for that. Y'know to see if they're indicating pain or,*

things like that. And you know, because obviously, like on a normal basis when they're ok, but the minute y'know something's different you think "mm" there's something not right here.

F: Have you got an example of that? Where you've really noticed something change in someone?

P: Well even like, see if they're in bed?

F: Yeah

P: So, if they're in bed normally it would, there would definitely be 2 carers who would need to be giving them personal care and everything, and, so even like if they're moving them, like rolling them, if they'll maybe be moaning or groaning or you'll see their face, their face will change, so you're always, you're always looking' for that, that's a big thing."

Polly tells me that there are times when she needs to be the voice of those who can't speak for themselves and that sometimes with doctors you have to fight for the person with dementia.

Polly explains dementia is like a big umbrella and that everybody within that umbrella is different. She tells me that you learn through experience about the different behaviours and that people need to be aware that there is so much underneath the umbrella.

I say to Polly that I hear that she is saying that people are individuals:

"P: [very, very, very individual] they really are that's one of the nice things that I feel that you can bring. That they are individual, and you can cater to their individual needs. There's a lot of people like quiet, so you wouldn't put them in a lounge where there's lots of noise, you would make sure they were in a quiet lounge. It's learning and finding out what they like. And making sure that that is actually what is happening.

F: Yeah, and how do you learn what they like or?

P: [Just] through getting to know them. It's just well it really is quite, it is quite actually normal because you form a relationship with people. And there are people in here who, I mean there's one lady in here, I just love her so much. She's just absolutely amazing... But I am one of the few people that can go in and get her up, get her out of bed. So, it's about forming, and I'm not like that with everybody. It's still how human nature, some people like you and some people don't. And it might even be, I might remind them of somebody. In their past. But they can't tell me that, but my

face reminds them so they're not going to really like me. And that's just normal. But there's other people where I know I can go, and I have that connection with them. So, it's just about again finding out saying to somebody, if there was somebody that I couldn't work with I would say to somebody I knew who could. I'd say "would you mind in going?" Y'know don't you going in, because that's only going to cause them to be upset and get them all wound up. And it's no through anything that you've done, it's just through, obviously it's I think I remind them of somebody. And that's not a nice reminder for them, and they associate you with whoever that person is. Is that not just human nature?

F: [Yeah] I think so. I think it is, we connect with different people don't we?"

Polly goes on to tell me that, because in the care home people need a high level of support, that you build a "deep relationship" with people and learn "all different ways of approaching people." She tells me that the body language of the carer is important and how you come across to others through your body. She tells me that if you go up to someone with the wrong approach and they are "wound up" that they are "just going to lash out", whereas:

"if you go up to them and you're calm and you're smiling and your body language is relaxed, that makes a difference."

She tells me that that can make the difference between:

"them just going up through the roof and you being able to diffuse the situation."

I ask Polly what the job means to her and she tells me that it means everything. She says:

"coming in here and being able to make a difference to these residents in here. I know that I come in here, and I do my best. And I do, to help and to try and make their quality of life better, and to make their day better, and I go home knowing that I've done that, and that's just, that's everything for me. 'Cos it's not a job. You have to have a passion for this type of work. And to come in and do what you do. Y'know 'cos sometimes I honestly, I go out that door and I think "I can't believe all that's just happened. Because it can be so hectic and so much can happen and there's sometimes, I'll go out and I'll think "oh did all that really happen?" So, you can't do a job like that and not love it."

I ask Polly what kind of things might happen and she talks about people who are aggressive, or someone may have had an accident and also how hard it

is when someone comes to the end of their life because of the relationships she has formed with them:

“But you do get attached you do form relationships you do love people. ‘Cos they’re part of your family! So y’know, when it does come to the end of their life it’s very upsetting.”

She tells me that she misses people who have passed away and that that is the hardest part of the job.

Polly shares that it’s a privilege to be part of someone’s life:

“it’s such a privilege, y’know, erm to get to know the people in here, to get to be part of their life. It really is it’s a huge privilege to be able to do that. And that does a lot for me, I do genuinely feel very privileged that even the fact that you’re doing all this for them and they allow that.”

I ask Polly what people with dementia are giving her and she doesn’t hesitate to tell me:

“Oh joy, joy, and that’s the absolute truth.”

Polly tells me that people with dementia are “*still that person*”, even at the last stages, because “*you can sense that*”.

4.2 Conclusion

In this chapter I have presented three overall stories for each group of participants.

Having presented the stories I discuss in the following chapter what the stories reveal about why and how people without dementia make meaningful connections with people with advanced dementia. I also discuss what the stories of connection make visible about the human qualities of people with advanced dementia.

Chapter 5 I See You

5.1 Introduction

In this chapter I discuss what the stories say in response to my research questions. In doing this I show how the stories hold a narrative that troubles and counters the existing prevalent dehumanising narratives and narratives of burden about persons with advanced dementia.

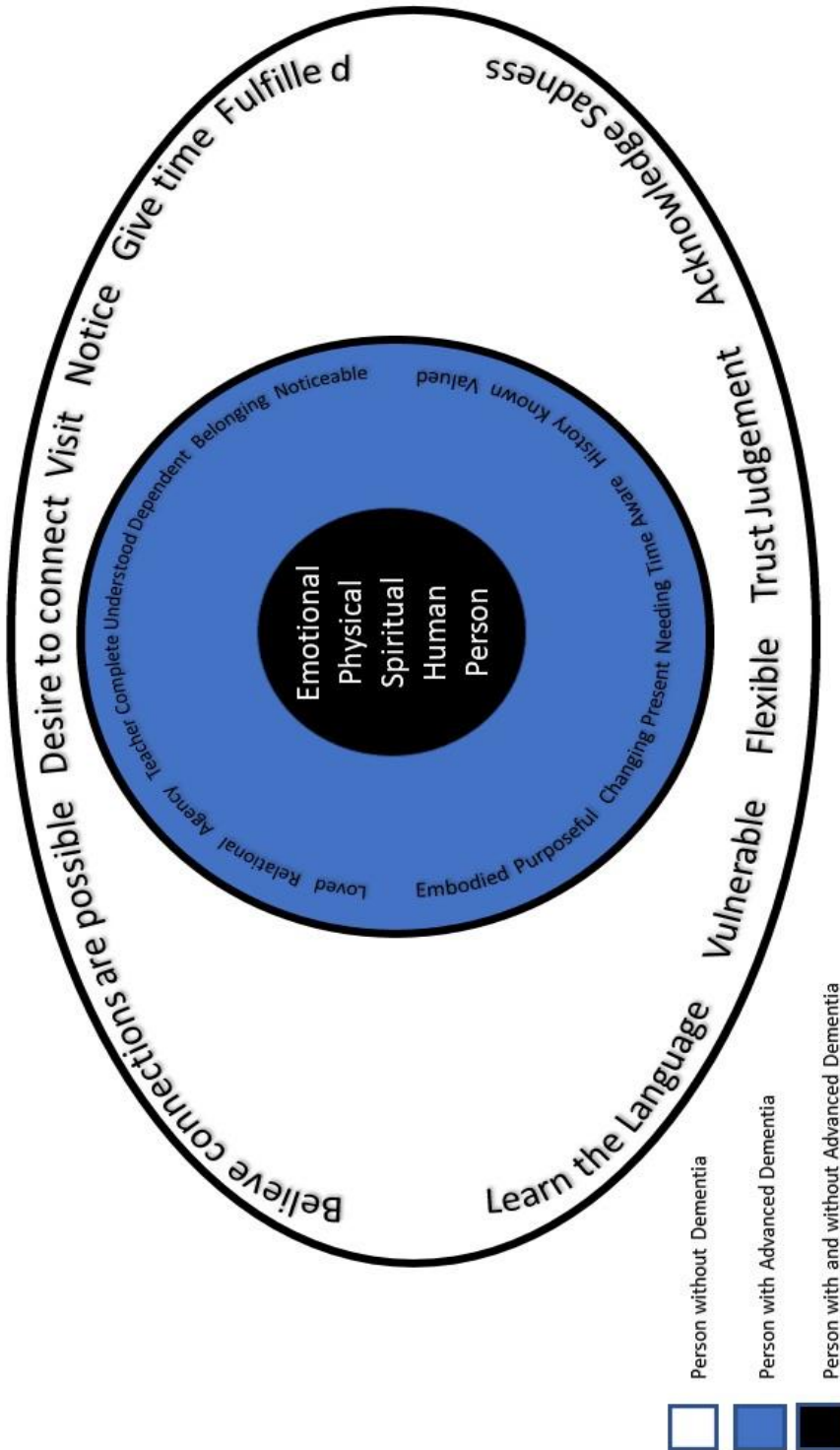
The stories show the different practical ways and the tools that people without dementia might use to help make meaningful connections. This includes using music, humour, play, interacting with objects and using both verbal and body language, and using the five senses; hearing, touch, sight, smell and taste.

Significantly, my analysis of the stories suggests that certain approaches and attitudes of the person without dementia towards people with advanced dementia are instrumental in facilitating meaningful connections. As these approaches and attitudes were explored, a narrative identity for people with advanced dementia was made visible. This narrative identity positioned people with advanced dementia as someone who is “still there” and an emotional, physical and spiritual human person, who continues to experience and contribute to the world.

Diagram 1 on page 234 gives an overview of both the approaches and attitudes of the people without dementia in making connections, and the narrative identity that emerged for the person with advanced dementia.

The diagram is based on the findings of my study. It is important that it is not seen as a finalised version and that it remains unfinished. It can then be continually developed as other people experience different meaningful connections in various ways, and different qualities of “humanness” are made visible in their stories about these connections.

Diagram 1: Approaches and Attitudes of Person without Dementia and Visible Human Identity of Person with Advanced Dementia



The diagram should also not be used to suggest that persons with dementia need to show any, or all, of the qualities described in the diagram to be understood as a human person. My position throughout this thesis is that human personhood cannot diminish or cease to exist whilst the person is still alive.

I structure this chapter by presenting, in different sections, what the stories reveal about the different approaches and attitudes of the person without dementia as they talk about making meaningful connections. At the end of each section I draw attention to the narrative identity of persons with advanced dementia that is made visible by marking this with the “eye” icon:



I discuss the findings across all four participant groups, comparing the similarities and differences across each group.

5.2 The Driving Force

As I conducted the data analysis, two significant motivations emerged that those without dementia appear to be driven by as they seek to make meaningful connections.

These driving forces were the belief that connections with people with advanced dementia are possible and a desire to make that connection. I now discuss these in more detail.

5.2.1 Believing Connections are Possible

Throughout the stories there are clear moments of connection. There are also moments where there is uncertainty about whether a connection has been made. The stories suggest that the participants believe that meaningful connections with people with advanced dementia are possible even in the uncertainty.

The stories of the family members show these two narratives. Charlie talks of “knowing” his mother-in-law is pleased to see him. She shows that she wants

to engage physically as she holds his hand, and verbally when she tells him she loves him. Uncertainty is seen as Charlie talks of wondering whether he had pushed things too far when he wasn't sure what his mother-in-law was trying to communicate when she was shouting at him.

Similarly, Dorothy's speaks of her dad's capacity to sense her mood and her capacity to feel the bond between them. She also talks of not knowing, at times, what is happening for her dad in his "world". Margaret's story speaks of moments of knowing that connections are made, especially as her mother would unexpectedly speak a coherent sentence that was relevant to the context and situation. She also shares about times of no sign of connection. Margaret is clear however that the person with advanced dementia may still be hearing and experiencing what is happening in the present moment, even when there is no sign of connection.

Charlie, Dorothy and Margaret are persistent in their attempts to make connections despite uncertainty about connection. This suggests that they believe that connections are possible.

Like the family members, the stories of the Elderflowers oscillate between knowing that connections are being made and not knowing. Jacob tells us that he doesn't always know 100% if he has made a connection but can sometimes feel as if a connection is made. He says that he must trust his feeling of connection. Peter echoes this capacity to feel as if the person with advanced dementia is enjoying their presence. Their stories contain examples of how the person with dementia responds to their presence and interactions. When the person with advanced dementia appears not to respond however the Elderflower's suggest that this is a choice that the person with dementia is making not to engage. The person with advanced dementia at times also instigates the connection perhaps by reaching out and touching the Elderflower.

Leah, a member of care staff believes that people are always connecting in some way. Leah understands that if a person with advanced dementia closes

their eyes when you are with them, it is their way of saying that they don't want to look, rather than they cannot connect.

Both spiritual carers, Tamsin and Rachel, are explicit in their belief that connections can be made. They place the responsibility of making those connections on the person without dementia, suggesting that there are ways to reach and enable communication with people with advanced dementia.

As I noticed that those who make connections with people with advanced dementia believe that connections are possible, I understood the narrative identity of persons with advanced dementia as:

 **Relational**

Able to relate to other people and their environment.

Having capacity to connect with other people in meaningful ways, even when they offer no outward sign of connection.

 **Having Agency**

Able to choose not to connect with other people.

5.2.2 The Desire to Make Connections

The stories suggest that those who make meaningful connections with persons with advanced dementia have a strong desire to do so. I identified two specific impetuses for this:

1. A commitment to good care for people with advanced dementia.
2. A desire to form or maintain relationships with people with advanced dementia.

In identifying these impetuses, I suggest that they derive from a love that those without dementia have for those with advanced dementia. Whilst love is too complex an emotion to have just one definition, I draw on Pieper's (1997) definition. Pieper writes that loving someone means finding them

“good”. “It is a way of turning to him or it and saying, “It’s good that you exist; it’s good that you are in this world!”” (Pieper, 1997, p164).

The stories suggest that the person without dementia is concerned that people with advanced dementia will not be cared for well, and relationships will not be maintained if they are not noticed or ignored by those around them. They suggest that the person without dementia sees the person with advanced dementia as someone who is “good”, who deserves to be well cared for, deserves to be in the world and is someone who they want to continue to relate with.

5.2.2.1 Commitment to Good Care

Running through stories across all four participant groups is the sense of commitment and responsibility to ensure good care for persons with advanced dementia.

The stories of the family members show this as they talk about what their loved one meant and continues to mean to them. It is seen in the actions they take to care for their loved ones.

Charlie talks about the strong bond that he has developed with his mother-in-law. Knowing he means a lot to her has fed into his sense of responsibility towards her. Dorothy shares the story of her adoption. She shares how her dad never gave up on her and how she has no intention to give up on him. Margaret shares how much her mother meant to her. The stories of all three family members link their commitment to care to their past and present relationships with their loved ones. Their stories are replete with examples of doing the very best they can for their loved one throughout their dementia journey. An example of this is how they cared for them whilst they were at home and continue to do so once they moved to residential care.

The Elderflower stories express their commitment and sense of responsibility to care for people with advanced dementia as they talk about the purpose of an Elderflower. They talk about using their skills and expertise in clowning

techniques to try and create engagement in the present moment. The Elderflower stories show that they are committed to and feel a responsibility to care for the whole physical, emotional and spiritual person with advanced dementia. They show this in the way they talk about the lack of choice and human connection that people with advanced dementia might experience when they are living in a care home. The Elderflowers offer choice to people with advanced dementia, indicating a care for the person's human rights. They use their skills not only to promote engagement but to bring comfort in times of distress. Sabrina's story about bringing comfort to the lady who was deeply distressed is a beautiful illustration of the emotional care that the Elderflowers offer. It shows her commitment to care for the whole person with advanced dementia.

The spiritual carers show this same sense of commitment and responsibility to care. This is made visible as they talk about their purpose in their role as a Minister and their God given calling. Tamsin talks of caring for people with dementia as being "*What God called me to do*". Rachel refers to her realisation that "*God's got a ministry for us to do*" with people with dementia. Simon talks of it being "*part of my job as a Priest*".

The care staff express their sense of responsibility and commitment to care throughout their stories. This becomes particularly evident in the dialogue about seeing people with advanced dementia in a distressed state. Paul's story about seeing "*really bad, nasty, nasty things*" brings out his sense of responsibility. He talks about residents having moments of realising what they have done and how upset they can become. His sense of responsibility is visible as he questions what he might have been able to do differently to avoid that situation.

Paul, Leah and Polly share stories about their different calming techniques and how they use their skills to care for the person with advanced dementia when they are in an agitated or distressed state. They also talk of how they achieve the different practical and physical tasks that need to be done to care well for the person with advanced dementia. Their stories show that they are

committed to and feel a responsibility for the physical, emotional and spiritual care of people with advanced dementia.

Within some of the stories in this study, the person without dementia is purposeful in making sure that other people are aware of the care needs of the person with advanced dementia. Margaret prepares information for the hospital and care home that will help them know her mother's needs when she is in their care. She purposefully lets the care staff know that her mother communicates through her eyes when they suggest that her mother offers no sign of communication. Carer, Polly, shares how she must be the voice of people with advanced dementia and speak for them when they are in pain or unwell, and the doctor appears unable to notice this. Paul's story of the memory box that he created for the gentleman goes beyond a sense of responsibility to care for the gentleman's physical needs. He also shows concern for the way in which others will see the gentleman if all they know of him is his sometimes aggressive behaviour that he sometimes expresses in the care home. Paul is keen to ensure that the gentleman will be understood in his fullness as a person by others. Paul shows a care for the whole person with advanced dementia, including caring for their persona and relationships with others.

As the stories make visible the commitment to good care a narrative identity is created that positions persons with advanced dementia as:

 ***A Physical, Emotional and Spiritual Human Being***

Persons who need more than good physical care, but also need to be well supported emotionally and spiritually.

 ***Dependent***

Persons who are dependent on those without dementia for that support, and as those whom others want to care for.

 ***Loved and Valued***

Persons who are deeply cared for, loved and valued by others.

5.2.2.2 Building New or Maintaining Existing Relationships

The second impetus I identified was a commitment to either form new or maintain existing relationships with the person with advanced dementia.

The commitment to longer term relationships is seen mostly in the stories of the family members, spiritual carers and care staff. It is not as visible in the stories of the Elderflowers. The Elderflower stories are focused on their work with people with advanced dementia in the present moment and little space was given in the interview to the longer-term relationships they may have with the people that they work with.

There is a strong sense that meaningful connections are important to the family members because of the fear of losing their relationships with their loved one. An example of this is when Dorothy talks of wanting her dad to be part of this world. I understand this to indicate that the fear that the relationship might be lost influences her desire to keep making meaningful connections.

Each family member shows their desire to maintain relationships as they tell stories of the relationship they had with their loved one before they developed dementia. They talk of the different ways they have needed to find to communicate and connect. Their stories are infused with a desire to continue to do so. Charlie speaks of shifting tactics to maintain the same relationship. Dorothy speaks of never giving up on her dad. Margaret speaks of just having to go and visit her mother because she loved her so much.

The sense of fear that relationships with people with advanced dementia might be lost is not just limited to family members. The spiritual carer's stories carry a theme that the relationship between the person with advanced dementia and the church needs to be maintained. Where the person with dementia is unable to attend the church, Tamsin, Rachel and Simon are all active in visiting and spending time with them. The spiritual carers all create

activities that maintain links between the church body and the person with advanced dementia. Tamsin talks about “*not losing*” people with dementia from the church. The commitment that she and Simon have in developing worship services that are accessible to people with advanced dementia show how important the maintenance of this relationship is for them so that they can continue to provide emotional and spiritual care for people with advanced dementia. Rachel shows a similar commitment to maintain relationships as she tells of how she has found a new way to maintain those relationships through music.

The care staff talk of a key worker that is allocated to a resident with advanced dementia. The key worker spends more time with the resident and can get to know them better, building a closer relationship. Paul’s story about the gentleman for whom he is the key worker shows his commitment to finding different ways to develop and maintain his relationship with him so that he can give him the proper care. In building a relationship with the gentleman Paul is able to better carry out the practical care tasks, such as getting him dressed, and finds ways to calm the gentleman and bring him joy through music and massage. Weaving through Polly’s story is her focus on relationships as being key to being able to offer high levels of support.

In hearing the stories that focus on building and maintaining relationships the narrative identity brought forth for people with advanced dementia is that they:

 **Belong**

Continue to belong and be important to their families and community.

 **Loved and Valued**

They are loved and valued by those who seek to form or maintain relationships with them.

Having discussed the two motivating reasons behind the desire to make meaningful connections in this study, I now demonstrate what the stories

show about how those without dementia who make those connections attempt to do so.

5.3 Visit

Noticeable in my study is that people without dementia who make meaningful connections are purposeful about taking the time to visit the person with advanced dementia. I use the word “visit” in two ways. Firstly, I mean that the person without dementia physically goes to the place where the person with dementia lives. Secondly, I mean that they also “visit” the person with advanced dementia in the world that they seem to be experiencing in the present moment and attempt to meet in that space. I will call this the “experiential location”.

In visiting the “experiential location” of the person with advanced dementia, the person without dementia firstly acknowledges that the person with advanced dementia is experiencing that place and the world in a particular way in that present moment. Their experience might be different to the way in which the person without dementia is experiencing the world in that moment. The stories show that the person without dementia attempts to enter the experience of the person with advanced dementia. They do not attempt to force the person with advanced dementia to recognise the world in the same way that they do.

Peter the Elderflower talks of being present with the person with advanced dementia when he visits them. Being present for the Elderflowers is having no expectation that there will be a response or joint connection, rather it is about the Elderflower joining the person with dementia through noticing what the person with advanced dementia is offering. An offering might be as subtle as the rhythm of their breathing or just the fact that they are physically there. Peter shares that a whole visit might just be about being present with no agenda. Spiritual carer, Tamsin suggests that we need to “*learn to be with the person*”. Carer, Leah’s story reinforces the sense of being present with

no expectation when she advises that we should “*just be with them*” and be comfortable with the silence.

The stories show however, that it is not always possible to have no agenda when visiting a person with advanced dementia. Often the visit is for a specific purpose such as offering physical, emotional or spiritual care. There is therefore an underlying sense of expectation or at least hope of a meaningful connection at some level so that the task or interaction can happen. The stories suggest, that even when there is an agenda, the person without dementia often has no expectation of *how* connections will be made. They remain open to the possibility of connection and try and find a way to connect. As Peter comments, it’s about “*opening the door of engagement*”.

Charlie tells us that in order to make meaningful connections you need to “*go in their (the person with advanced dementia) direction of travel*”. Elderflower Sabrina talks about learning to go along with the person with dementia rather than working in conflict with them. Paul a member of care staff explains that some people with advanced dementia might be experiencing their life as if they were much younger. Paul’s story about how he took on the role of the apprentice to the gentleman he cared for once he realised that that was how the gentleman saw him illustrates how he goes along with the person with dementia and they both meet within that experience.

The stories of visiting the person with advanced dementia both in their physical and experiential location bring forth a narrative identity that the person with advanced dementia is:



Loved and Valued

Someone whom people want to spend time, reinforcing the love and value that people have for them.



Present in the World

Experiencing the world in some way in each moment which positions them as people who are fully present in the world.

5.4 Getting Noticed and Noticing

Throughout each of the stories across the participant groups, the findings reveal that persons with and without dementia share meaningful connections as they “notice” each other.

As the person without dementia visits the person with advanced dementia, they often take the time to let the person with dementia know that they are with them. They attempt to get themselves noticed. The person without dementia also pays attention to and notices the person with advanced dementia and as they do so they try and find ways to connect.

5.4.1 Getting Noticed

The stories show the different ways in which the person without dementia attempts to let the person with advanced dementia know that they are with them. The way that they do this often depends on what they notice about the person with advanced dementia and their assessment of how they might best engage with them.

Charlie shares how he holds his mother’s-in-law hand, chats and interacts with her. Dorothy lets her dad know she is there through her tone of voice, through touch and using familiar movements. Margaret makes a point of going to feed her mum in the care home. Margaret’s story of how agitated and angry her mother was with her as she tried to get her out of her chair, shows how she was able to shift her mother’s attention away from her frustration. Margaret did this by walking out of the room and coming back in again so her mother could notice her come in.

The Elderflowers let their presence be noticed in a variety of ways depending on the situation. Sabrina talks of the Elderflowers gently entering the space of people with advanced dementia. This is often achieved through playing music as they enter that space and through wearing vibrant clothing and shoes so that the colour might draw attention. Jacob talks about offering something to the person with advanced dementia; a hand or song or

conversation. He even just offers his presence in the hope that they can feel him with them. Connecting through breathing is often a way to connect for the Elderflowers. Jacob shares how he might settle into the breathing rhythm of the person with dementia and Sabrina shares her story of how she connected with the very distressed lady through the breath. The Elderflowers might show their presence by joining the person with advanced dementia in a rhythm they might be tapping out on a chair or by responding to something the person with dementia might say.

Tamsin's story of the communion service shows how she helps the lady with severe dementia notice what is happening and that she is being invited into Holy Communion. She lets the lady touch the cold chalice, touch the bread and smell the wine as she shares the experience with her. Simon's story shows how he talks to the people he visits even if there is no physical response. He uses physical touch as he holds the person's hands or anoints them with oil. Tamsin and Rachel talk of wearing a clerical collar so that people might notice them as they visit people with advanced dementia in the care home.

Polly uses aromatherapy oils to create a nice sense of smell for people with advanced dementia as she offers Namaste care. She has learned massage techniques, uses music and other forms of sensory stimulation to let her presence be known so that she can connect with people with advanced dementia. Paul talks of just saying hello to someone or making eye contact and smiling, as a way of letting people know that you want to connect with them.

As the stories of getting noticed are heard, a narrative identity is made visible that positions the person with advanced dementia as:



Loved and Valued

Someone who others want to spend time with and to engage with.



Present and Aware of the World

Someone who can notice changes in their environment.

Someone who can notice the clothing someone may be wearing, the sound of music, voice or someone's touch or facial expressions, and respond to them.



Someone who continues to be important to and belong to a wider community in that the person without dementia wants them to continue to experience the world together.

5.4.2 Noticing

Across the participant groups, the stories reflect that people with advanced dementia are noticed as those who are physical, emotional and spiritual human persons. I identified three significant ways in which people with advanced dementia were noticed as I analysed the stories:

- Changing – But “Still There”
- Someone Like Me
- Embodied Communicators

5.4.2.1 Changing - But “Still There”

Throughout the stories there is an understanding that the person with advanced dementia has changed in the way in which they behave and communicate. Alongside that understanding runs the narrative that the person is “still there”, or still the same person that they used to be.

Charlie, Margaret and Dorothy all talk of how their loved ones used to be. Charlie talks about the high-speed communications, laughs and jokes he had with his mother-in-law. Dorothy talks of her dad telling her off for speaking before she thought it through. Margaret speaks of how her mother was a public speaker and how she loved words. Dorothy also talks of how her dad still does the movements he used to and still reacts to football. She says that

the person is still there even though they might not be what we would have hoped. Margaret talks of how her mother reacts when she has a sore throat in the same way she used to before she had dementia. Margaret believes that her mother's memories are still within her and just need to be unlocked.

The spiritual carer Rachel tells of the lady in her congregation who began to change as her dementia progressed. Rachel also makes references to people with advanced dementia remembering songs and hymns from their past as they join in and sing along to them. This suggests that the person with dementia is still the same person that they were, albeit there have been changes. Spiritual carer Simon explains that there is a changing personality in dementia, and you must get to know the person again. He acknowledges that whilst you haven't lost the person, that you have a "*new person to deal with as well*".

Paul's story about the gentleman he cares for shows how much of the gentleman's current behaviour and understanding of the world appears to relate to his previous profession. Paul understands people with advanced dementia as still the same person, but that they experience life as if it was sometime in the past. Leah talks of a person that lives within, a person who has a soul, who needs to be loved and to feel important. Polly's story shows how she still regards the person with dementia as still there as a person even though they might be different. She suggests that when you try to find out about them that you may bring part of that person back.

Peter, acknowledging that it is difficult for family members, advises that each time you meet a person with advanced dementia you should imagine that it is the first time you are meeting them. He suggests that you notice and see them as they are in the present moment.

The stories of noticing that persons with advanced dementia have changed, but are "still there", brings them a narrative identity that shows that they are:



Continuing in their humanness as the dementia progresses.

5.4.2.2 Someone Like Me

Noticeable in some of the stories is the sense that people without dementia recognise the shared humanity between themselves and persons with advanced dementia.

They show this in two different ways:

- Imagining self in the same situation.
- Recognising dementia as a human experience.

5.4.2.2.1 Imagine Self in Same Situation.

Imagining themselves as having dementia caused angst for some of the participants in my study. Margaret is clear that if she had dementia that she would want to “*go as quickly as possible*”. Jacob admits he is terrified of dementia and it is scary to imagine losing oneself. Spiritual Carer Tamsin imagines herself having dementia with no-one who cares for her, she worries about “*ending up like that*”, asking what type of a life it is. She admits that it “*fills her with angst*”.

Being able to imagine having dementia however, often helped the person without dementia to better support the person with dementia.

People with dementia often sit looking towards the floor. As Paul imagines what it might be like to have dementia, he imagines what it might be like seeing lots of pairs of feet in front of you if several different people have come to care for you at one time. Paul acknowledges that this would cause him worry. In imagining what this might feel like, Paul discovered that supporting the gentleman on a one-to-one basis worked better suggesting that only seeing one pair of feet causes less concern for the gentleman. Polly is mindful that people with advanced dementia are just like those without dementia in that they respond better to some people than others. In recognising this Polly can know whether particular residents would respond

better to her or another colleague in certain situations and know who would be best able to support the resident in different situations.

5.4.2.2.2 Recognise Dementia as a Human Experience

The Elderflower, Peter recognises the ongoing personality in the person with advanced dementia and that human experience continues even though someone has an illness. Jacob acknowledges that his work is to give a “*human connection*” to people with dementia.

As the stories reveal the shared humanity in people with and without dementia, a narrative identity is made visible that reflects that persons with advanced dementia are:



Understood

Someone whose behaviours and reactions make sense and seem rational to those around them.



Like Me

Someone who is still human, who relates better to some people more than others, and who has the same fears as people without dementia.

5.4.2.3 Embodied Communicators

The stories suggest that people with advanced dementia often express themselves through vocalisations. These vocalisations may take time for the person without dementia to understand, or they might be more easily understood. For example, Margaret’s mother exclaimed “*thank God for this wonderful view*”. More commonly however, the stories suggest the person with advanced dementia expresses themselves through their body language. This meaning of the body language can be obvious at times but can involve very subtle movements and changes. This includes subtle changes in the face, the eyes, in body movements and in the breathing. It requires the

person without dementia to pay attention to, notice and give meaning to these subtleties.

Charlie's story reveals how he senses his mother's-in-law mood and behaviour by noticing her "*micro-symptoms of being uncomfortable*". Charlie has learned what the micro-cues mean because of the time he has spent caring for her over the years. He can meet her where she is and help shift her experience from being in a dark place to a light place. As Charlie tells the story of shifting his mothers-in-law mood, it becomes visible that not only does Charlie notice her, but that she also is aware of his presence as she responds to his offering of support. On other occasions Charlie understands that his mother-in-law is letting him know that she is present with him as she holds his hand and wants to kiss him.

Dorothy, like Charlie, understands the way her dad communicates with her as she notices how he looks at her in the same way he used to before he had dementia when she is feeling low. Dorothy's story suggests that her dad is letting her know that he is present with her in that moment and fully aware of how she is feeling. Her dad finds a way through his body language to meet Dorothy and communicate his feeling to her.

Margaret notices how her mother communicates through her eyes and Margaret can tell if she is in pain or happy. She suggests that her mother's carer couldn't notice this indicating that this may have been because she was busy and didn't have time to look.

The stories of Charlie, Dorothy and Margaret suggest that they were able to give meaning to the body language with which their loved ones communicate because of their historical relationship with them.

The Elderflower stories suggest that they are very purposeful in their attempts to notice how the person with advanced dementia is communicating and in giving meaning to that communication they can meet them in the present moment. Peter shares how he understands that a person with advanced dementia is happy for him to spend time with them by paying

attention to their body language. He looks for a smile, a movement of the head or notices whether they open their eyes. He also shares how he might judge if someone is distressed by looking for grimacing in the face, anxiety lines around the eyes and tension in the face. These stories suggest that people with advanced dementia can connect through the subtlest forms of body language with those who visit them.

The spiritual carers also notice and understand what the person with advanced dementia might be experiencing as they notice subtle changes in their body language or vocalisations. Rachel shares how she notices a “*wee glimmer*” that tells her that the person is experiencing something. Tamsin shares how she knows that the lady with severe dementia understands as she takes part in the Sacrament of Communion because of the change in her breathing and an alertness in her body.

The care worker stories show a similar picture. Polly shares how she notices facial expression, body language and groaning if a person with advanced dementia is experiencing pain or is unwell. Leah experiences a meaningful moment just in the way that someone with dementia has looked at her. Paul shares of how the gentleman that he supports smiles and nods at him suggesting that he is letting Paul know that he is there with him and recognises who Paul is.

The stories that show persons with advanced dementia as embodied communicators bring forth a narrative identity that positions them as:



Embodied and Able to Communicate with Others

Someone who communicates and relates to others through their body in a way that others often understand.



Noticeable and Aware of Others

Someone who is both noticed by others and notices other people around them.

 **Having Agency**

In some instances, the stories suggest that the person with dementia themselves instigates the connection through their body language. This reinforces the narrative that people with advanced dementia continue to show agency.

5.4.3 Learning the Language

Not only do the stories show that persons with advanced dementia are understood to be embodied communicators, they suggest that those without dementia learn and use this same embodied language and use it to make meaningful connections. These connections are sometimes made through the five different senses of the body; touch, taste, smell, hearing and sight.

Charlie recognises that his own body language, touch, facial expressions and speed of movement can all affect meaningful connections with people with advanced dementia. His story makes visible that rhythm and sounds can also help meaningful connections be created. Charlie talks about using soothing language to placate his mother in law and is attentive to the rhythm of the phrases he might use so that she might recognise that rhythm and sound even if she is unable to recognise the words he uses.

Dorothy uses her own body language to greet her father, letting him know that she is there with him as she gives him “Eskimo kisses” and he smiles as he joins her in that joint meaningful connection.

The spiritual carers also both notice the impact of their own body language and voice on the person with advanced dementia and how touch and smell can instigate meaningful connections.

Polly shares how her own body language and facial expression can determine whether she is able to diffuse a difficult situation with a person with advanced dementia.

As I hear the stories of those without dementia learning and using the same language as persons with dementia, the following narrative identity for persons with advanced dementia becomes visible:

 **Valued**

Someone who is important enough for others to want to learn to connect and communicate with.

 **Teacher**

Someone who can teach others the language of the body.

5.4.4 Giving Time and Space

The stories of getting noticed and being noticed show that those without dementia recognise that people with advanced dementia need time to process what might be happening in that moment. They show how they offer the time and space that the person with advanced dementia needs to connect where possible.

Charlie advises that slowing down, being gentle and relaxing are important if you wish to create a meaningful connection with a person with advanced dementia. Jacob reinforces this need to slow down, saying that things take a long time with people with dementia and you need to give space for a response. Sabrina shares of how difficult it was to make meaningful connections with people when she worked as a care assistant as people were always being rushed. She advises to give people time and not to rush. Similarly, Tamsin talks of being patient, speaking more slowly. Leah speaks of needing more time to spend with people with advanced dementia so that she can properly attend to all their needs.

The findings suggest that the process of noticing and connecting with each other does not always happen quickly. It can take time as the person without dementia looks for cues of communication, and for the person with advanced

dementia to notice the person who is with them and process what they may be communicating to them.

The stories of giving time and space to persons with advanced dementia create a narrative identity that shows them as:

 **Needing Time and Space**

Someone who needs time and space to process their environment and what others might be communicating to them.

 **Valued**

Someone who deserves to be given the time and space they need to be able to connect with others.

Someone with whom others want to connect with.

 **Present in the World and Able to Connect**

Someone who notices others and can make sense of what others are communicating.

5.5 Vulnerable and Dependent

Across each of the participant groups the stories reflect a sense of vulnerability in those without dementia as they seek to make meaningful connections. Vulnerability is expressed in the way the participants talk of “not knowing” what to do for the best for the person with advanced dementia. The stories show the person without dementia questioning whether they are understanding the needs of the person with advanced dementia, and whether they are doing the right thing.

As this sense of “not knowing” weaves through the stories, I noticed that accompanying this was the need for the person without dementia to be supported in their actions and decisions.

Charlie's story about his mother-in-law shouting and not wanting to leave her chair so he could get her into bed makes this visible. Even though Charlie says that this was the hardest time for him, his story continues to show how he and his wife began to carry out this task together to make it easier for his "*peace of mind and emotional state.*" The story suggests that he is dependent on his wife to support him. In working together, they can develop strategies that they need to implement to continue caring well for his mother-in-law. Charlie's story also shows that he needs the reassurance from a third party that he is caring well.

Dorothy's story shows her sense of uncertainty as she shares how she wants her dad back and how she wants to ask him if she is doing the right thing. Margaret's tells how she feels like she was going mad and "*just didn't know how to deal with it*" when her mum was in the middle stage of dementia.

The Elderflowers characters appear to be purposeful in their "*not knowing*" in order to enable a connection. Their stories suggest that "*not knowing*" is seen as a real strength. In not knowing what to do the Elderflowers are able to step back and wait to see what the person with advanced dementia is offering them in terms of an opportunity to engage. They can then follow the person with dementia's lead. Having said that, some of the Elderflower stories suggest that the "*not knowing*" is not an easy place to be. Jacob worries that his presence is not wanted by a person with advanced dementia and that he will not notice that. Sabrina shares how helpless she felt when she was out of costume and saw the distressed lady with dementia that she was unable to comfort. I understand this to indicate that the Elderflower costume offers a sense of support and protection against any vulnerability that might be experienced.

Tamsin's story about writing the liturgy for the communion service for people with advanced dementia shows that she does worry that she is getting it wrong. She finds support from her understanding of her faith that God will give His blessing. Rachel's story suggests "*not knowing*" when she talks of the member of her congregation in whom she had noticed had a "*huge*

decline.” Rachel asks herself what she can do about it and says that she found herself feeling inadequate.

The stories of the care staff also show that they do not always know what to do for the best. As the care staff share their stories of residents “*breaking down*”, being distressed and agitated, their dialogue reflects how difficult it is feeling like you don’t know what you can do to help. This is exacerbated as the care staff can feel at times that they don’t have the time to spend with the residents that they would like to have to be able to support them better. Their stories reflect their need for support from each other and the residents that they care for. Sometimes the care staff recognise that a different member of care staff might be better suited to support the person with dementia in that moment and they ask their colleagues to step in.

The person without dementia often draws on support from other sources as they care for people with advanced dementia. Some of the stories suggest that those without dementia receive this support from those with advanced dementia as they find a sense of fulfilment. Charlie talks of his caring role as giving his life meaning, Tamsin feels fulfilled in her ministry and the care staff talk of how they feel like family to those they care for. Leah talks of her work being rewarding.

As I notice the vulnerability and dependence in those without dementia who make meaningful connections, a narrative identity of persons with advanced dementia springs forth that positions them as:

 *Like Me*

Persons who are no different to those without dementia in terms of their dependency on others for support for their physical, emotional and spiritual well-being.

Persons who are the same as those without dementia in that they also often don’t know what to do. Peter expresses his vulnerability when he

says that clowns are “trying to do their best, in a world they don’t understand”. He likens this to the person with dementia who is “trying to ...do their best in a world that may have become less understandable to them”.

Purposeful

Someone who makes a positive impact in the life of those who cares for them and can bring a sense of fulfilment.

5.6 Flexible and Trusting Own Judgment

As the stories make visible the vulnerability of those without dementia, they also draw attention to the flexibility that they demonstrate as they seek to connect with, care for and support persons with advanced dementia. Often, the person without dementia remains unsure about what the person with dementia is communicating and what their needs are. These stories develop to show how the person without dementia, in their vulnerability, tries different approaches and often makes a judgement based on feeling or sensing what seems to be being communicated and what they should do. They do this by being flexible in their approach and needing to trust their own sense of judgement. This sense of judgment appears to be based on the information they do have and a constant questioning of what appears to be being communicated in that moment.

Charlie’s story suggests a great deal of flexibility in his approach to the care of his mother-in-law as he “*developed a craft*” in knowing how to respond to her. Charlie regularly adjusted how he could best care for his mother-in-law as her dementia developed. He was prepared to “*go in her direction of travel*” rather than be fixed in his own theories of what might work to make a connection. Charlie’s story makes visible how he and his wife needed to make decisions based on what they knew of their mother-in-law. Whilst they have no guarantee that their decisions would be what she would have wanted, they use their own judgement. Margaret also flexibly develops

strategies to care for and connect with her mother as the dementia progresses.

The Elderflowers show their flexible approach as they draw on a breadth of different practical ways to form connections depending on the person with advanced dementia, and situation they are presented with on each visit. The Elderflower stories show that they often make a judgment when making connections. Jacob expresses this in his story of having to trust his feelings about whether he has made a connection or not. Peter's story also suggests that there are times when the connection is felt or sensed, rather than having a definite response from the person with advanced dementia.

Spiritual carer Tamsin is prepared to be flexible in her approach to making connections, such as writing a new liturgy to follow, even though this can bring with it a sense of "not being sure".

Rachel's story suggests that she uses her sense of inadequacy as a spur to develop different strategies to support people with advanced dementia in her congregation and community. This has resulted in the creation of a dementia café and a focus on bringing music into her ministry for people with advanced dementia, using it as a new way to make connections.

The care staff stories of seeing people with dementia in distress suggest that they too use flexible skills to comfort and calm the person with advanced dementia. In doing so they can "*give quality of life*" to the residents.

Whilst the people without dementia who make meaningful connections are not always completely certain that they have formed the correct meaning of what the person with dementia is communicating or needing, they show a willingness to trust their judgement. As they do so they consistently pay attention to other subtle cues that might indicate that they are correct or incorrect in their judgement and adapt accordingly.

In hearing the stories of flexible approaches and the judgments that people without dementia must make in making meaningful connections, a sense that the person without dementia does not give up trying to find ways to connect

emerges. This creates a narrative identity about persons with advanced dementia which positions them as:

 **Present in the World and Able to Connect**

Someone who is thought of as able to be reached and still very much present in the world.

 **Loved and Valued**

Someone who deserves to be able to continue to experience relationships and connections with others, and whom others want to share those connections with.

5.7 Acknowledging Sadness and Loss

Alongside the sense of vulnerability that those without dementia might experience as they seek to make meaningful connections, is the sometimes emotional and physical cost of being committed to the care of people with advanced dementia.

Those without dementia not only carry this cost, but it is further compounded by the sense of sadness and loss that dementia can bring.

This sense of sadness and loss is most visible in the stories of the family members as they talk of the dynamics of their past relationships with their loved ones. To a lesser extent, this same sense of sadness runs through the narratives across the other three participant groups.

Margaret is explicit in her dialogue when she talks about how horrific dementia is. Margaret talks of how difficult it was to watch her mother lose her verbal communication. Her mother was “*a public speaker*”, “*a teacher*”, “*she loved words.*” It was “*heart-breaking*” for Margaret to watch. Dorothy’s story echoes this heartbreak as she describes dementia as “*losing everything*”.

Elderflower, Sabrina's story shows how helpless she felt when she couldn't do anything for the lady that was getting distressed as she tried to open the locked door.

Spiritual carer, Tamsin finds it heart-breaking as she considers how the family of the person with dementia might be feeling and imagines herself in that position. Tamsin says of her work with people with dementia that *"it's just exceptionally beautiful but it's heart-breaking."*

Carer, Leah is specific in describing some people with advanced dementia as *"demented"* and that they *"don't get any peace"*. Leah tells that she thinks this is the *"worst kind."* Paul also tells of residents breaking down when they might have realised that they have done something that has made them distressed. He shares how he sees things that impact him; as if they leave a *"scar"* on his brain. Polly's story also makes visible how hard she finds it when a resident comes to the end of their life.

The stories suggest that dementia often brings a sense of loss and sadness to people without dementia, and that loss is acknowledged by those who make meaningful connections. In hearing these stories of loss and sadness, I notice that this does not deter those without dementia in their efforts to stay connected with and spend time with the person with advanced dementia. A narrative identity emerges that positions persons with advanced dementia as:

 **Changing**

Someone who behaves differently than they used to.

 **Loved and Valued**

Someone who was and continues to be deeply loved and valued.

Someone whom despite the sadness and loss that others might experience, continues to be a person with whom others want to be with and care for.

 **Belonging**

Someone who is important to those around them. In some cases the experience of loss appears to add to the desire to continue to be able to make connections. As Dorothy quotes: "I want to keep talking for him to be part of this world."

5.8 Experiencing Joy and Fulfilment

Although there is much sadness and loss made visible in the stories, the analysis shows that people with advanced dementia continue to make a positive impact on those around them and bring deep moments of joy.

Charlie speaks of how fulfilling it is to care for his mother-in-law. Dorothy tells how she enjoys moments on her own with her dad. Her story shows moments of joy as she is keen that the stories of laughter and fun are shared with others. Margaret shares stories of the wonderful feeling she had when she felt she had reached her mum and how her mum's grandchildren said that they enjoyed every minute they spent with their grandparents.

Peter's story speaks of having a "*wonderful engagement*" with a lady with dementia, how they often "*make him laugh*". Peter has learned from his work with people with advanced dementia. They have enriched his life as he has learned that "*the human experience doesn't end because someone has an illness.*" Sabrina talks of it being a "*pleasure and honour*" "*a delight to be with them*" in her stories of working with people with advanced dementia. Jacob talks of moments that are "*very, really beautiful.*"

Spiritual carer Tamsin finds beauty and joy as she shares communion with the lady with advanced dementia. Simon talks of how he has found himself feeling loved following a visit with someone with dementia.

The care staff stories also suggest moments of deep joy as they work alongside people with advanced dementia. Leah's story of the lady who suddenly thanked her after she had bathed her and dried her hair tells of how special Leah felt and what a lovely feeling it was to experience that appreciation. Polly says that people with advanced dementia bring her:

“Oh joy, joy, and that’s the absolute truth.”

The stories of joy and fulfilment bring forth a narrative identity for persons with dementia as:



Loved, Valued and Purposeful

Persons who are deeply loved and valued by others as they continue to bring joy and purpose to the lives of people without dementia.

5.9 Developing Connections

The stories show that as the person with advanced dementia is noticed and met in their own experience in that present moment and the person without dementia seeks ways to be noticed by them, the experience can often become developed into a deeper joint meaningful connection for both the person with and without dementia.

Evidence of this is seen when Margaret’s mum bites into the meringue and Margaret notices that her mother has recognised the taste. Margaret develops this connection as she speaks to her mother about that experience and her mother gives a verbal reply. This allowed them to share a joint moment of recognition.

Elderflower, Sabrina’s story shows how she develops meaningful connections by drawing the awareness of the person with advanced dementia into a wider field of vision as she tries to gain eye contact, and then as she engages with them opens up the engagement to other people in the room and the wider environment.

The spiritual carers show an awareness of the types of things that might be familiar to the person with advanced dementia to catch their attention and that will help facilitate and develop a meaningful connection. Tamsin and Simon use familiar biblical texts and prayers. Rachel tells of a story where she sang hymns which she knew a lady with dementia would have sung when she was in Sunday school. Simon’s story shows that he makes a

connection with a lady with dementia who was non-verbal by reading from the old prayer book. The connection is developed as she responds by making the sign of the cross and beginning to have a conversation with him even though she never talks at any other time.

A rich example how meaningful connections can develop is seen in Paul's story of the gentleman for whom he key works. Through noticing that the gentleman thought that Paul was his apprentice from his previous profession, Paul entered into the role of the apprentice, meeting the gentleman in his experience of the world. In doing so Paul was able to approach the gentleman's care tasks, like getting dressed, by approaching them as though it was one of the "jobs" that they were working on that day. Changing trousers for this gentleman was often difficult and through developing meaningful connections the task was made easier.

Hearing the stories of developing connections creates a narrative identity for persons with advanced dementia as:

 **Relational**

People who continue to relate to other people in the world.

 **Aware of others and the Environment**

People who often show awareness and understanding of what others are communicating, and of their wider environment.

 **Rich Past and History**

People who have a rich past and history with which they can still often connect with.

As I notice the developing connections throughout the stories, attention is drawn to the creative activities that are often used to make and develop those connections.

5.9.1 Music, Rhythm, Humour and Play

Throughout the stories, creative activities such as music, rhythm, humour, play and using objects were often used to make meaningful connections.

Dialogue about the way in which music is a way in which connections are made with people with advanced dementia appears in many stories shared across the participant groups. It is sometimes referred to as “*powerful*” as a way of forming connections.

Margaret tells how her mother would occasionally move to music and “*try and sing along as well*”. Dorothy talks of how her dad loves music. Through music Dorothy and Margaret were able to share a joint meaningful connection with each other.

For the Elderflowers, music is a key tool that they use to try and connect with people with advanced dementia and then develop that connection. Sabrina tells of a musical wash, which is a song that they play as they move around the care home, to let people notice that something is changing in their environment. She talks of noticing a repetitive rhythm that a person with dementia might be displaying and joining them in that rhythm so that they can both develop and expand it and make it more musical.

The spiritual carer’s stories perform how people are often able to connect with older hymns and music that they might have known in the past.

Much of Rachel’s narrative centres on her use of Playlists for Life. She shares stories of how she now uses music at most of her pastoral visits to people with advanced dementia in care homes. In doing so Rachel can have a deeper interaction with people with advanced dementia as music allows a communication between the two of them that is meaningful to them both. The musical interaction often develops to include other people with dementia in the care home setting as they often join in and sing along.

The care staff stories show that they use music as a way of forming connections and lifting the spirits. Polly’s stories show how she sings hymns with the residents. Leah and Paul talk of how music is a good way to make connections with people with advanced dementia.

Using a sense of humour and play to make connections features in the stories of the Elderflowers. Jacob's story about sharing a "close joke", makes this visible and Peter tells that the purpose of the expertise of the Elderflower lies in "being playful with people, using a sense of humour." Peter tells the story of being playful as he creates a rhythm of squeezing hands.

Whilst humour and play are not a main theme in the other participant groups, it is alluded to from time to time.

Dorothy tells the story of communicating through a voice of laughter and Paul talks about entering a playful scenario as the gentleman he key-works appears to act as if he is in a sport changing room when he goes to have a shower. This playfulness is developed in such a way that Paul can then help him shower.

Like Me

The stories of the different practical methods of making connections with people with advanced dementia reinforce that people with and without dementia can connect with each other without relying solely on verbal language. The stories suggest that by drawing on these different methods both people with and without dementia can come together in different ways and develop meaningful connections, positioning the person with advanced dementia as the same as someone without dementia.

5.10 Conclusion – I See You

I have shown throughout this chapter how meaningful connections were made and developed between people with and without advanced dementia. I have drawn attention to the attitudes and approaches of those without dementia who make these connections. In exploring the stories of meaningful connection I have shown that a rich narrative identity is made visible for people with advanced dementia as physical, emotional and spiritual human persons.

The stories make explicit that persons with advanced dementia change throughout the dementia journey, in terms of their behaviours and the way in which they communicate. My analysis revealed that despite these changes people without dementia continue to believe that they can make meaningful connections with people with advanced dementia. They believe that persons with advanced dementia are “*still there*” and persons who continue to be able to relate to other people and their environment. Those without dementia show a strong desire to continually seek new ways to make meaningful connections. In doing this they give time to the person with advanced dementia. They are flexible in their approach and prepared to try different strategies until they find a way to understand and connect. The person without dementia learns the language of the person with advanced dementia. This language is often spoken through the body sometimes through the subtlest of movements. As those with and without advanced dementia communicate through their body, meaning is given to these physical communications. The claim that human beings live in “psychophysical unity” (Sapp, 1998, p31) is reinforced.

Meaningful connections are made as the person without dementia enters into the experience of the person with advanced dementia, or by inviting the person with advanced dementia to notice their wider environment and the people in it. This is often done through touch, music, rhythm, humour, play, vibrant colours, or by using objects, readings or talking with the person with advanced dementia.

A sense of vulnerability is noticed in the stories as the person without dementia is often unsure about what the person with advanced dementia might need or what they are communicating. A sense of sadness and loss also runs through the stories, as the relationship they once had changes its shape.

The stories acknowledge the sense of vulnerability, sadness and loss that dementia can bring and acknowledges that it is not always easy to care for people with advanced dementia.

In amongst the moments of sadness and difficulties however, there are moments of deep joy and fulfilment that the person without dementia receives from being with the person with advanced dementia. I have shown that people with advanced dementia continue to impact the world in a positive way. They offer others the opportunity to notice and learn their way of communication and interaction that is not limited to verbal language. They also often bring purpose and joy to the lives of those who care for them.

An important narrative that runs through the stories is that there is a sameness between persons with and without advanced dementia. People with dementia are recognised as having emotions and feelings. Both people with and without dementia have physical, emotional and spiritual needs and depend on others for that support. This “sameness” is also seen in the way in which those without dementia can relate to what it might feel like to have dementia. As those without dementia show their own vulnerability in not always knowing what to do in certain situations, a parallel is drawn between those with dementia who are also trying to “*do their best in a world that may have become less understandable*”.

In exploring the stories, a narrative identity emerges that positions people with advanced dementia as dependent on others and changing, and who are fully present in the world as physical, emotional and spiritual human persons. The stories show that people with advanced dementia belong to families and communities, just like those without dementia. People with advanced dementia are shown as people who continue to be able to express themselves and communicate with others, and at times they show their own agency in choosing whether they want to engage with another person.

People with advanced dementia are positioned as those who are loved, valued and belong, and as people who continue to enrich the lives of other people in the world.

Having set out the findings of my study, I now move to set these findings within a wider theoretical framework in the following chapter.

Chapter 6 Discussion

6.1 Introduction

The aim of this study was to explore stories of meaningful connection between people with and without advanced dementia and how we might explore these connections if we thought of human beings as created by and held by God. The stories could then potentially be used to counter the dehumanising narratives that exist in our society about people with advanced dementia.

This chapter of my thesis sets out my key contribution to knowledge by drawing on my findings. I set out how the findings trouble the dominant dehumanising narratives that position people with advanced dementia as those who are the “living dead” and a “burden to society”. I argue that the stories in this study make visible a narrative identity that positions persons with advanced dementia as people who belong, who are valued, deeply loved and have purpose in the world.

A key finding in my study was that those without dementia notice that the person with advanced dementia is changing in the way they communicate and behave. The person without dementia works hard to find new ways to make connections through these changes. They remain flexible in their approach towards the person with advanced dementia and there is a fluidity of movement in their use of different strategies to make those connections. As the stories of flexibility and finding new strategies to make meaningful connections develop, the person with advanced dementia is given a narrative identity of a person who is still present and experiencing the world; that they are “still there”.

In this chapter I set my findings within a wider theoretical framework, drawing on the debates set out in the literature review. I frame much of this discussion within the Christian theological concept of showing hospitality to the stranger (Swinton, 2012, Sutherland, 2006). I have decided to set my findings within

this framework as the concept of hospitality offers a space for this fluidity of movement in the different ways in which one might make connections with the person with advanced dementia to be developed more deeply.

Braganza explored the Christian theological framework of hospitality as a way of encountering “diverse others in Professional Social Work” (2018, p33). Braganza argues that it called Christians and non-Christians alike to “explore and understand their own perspectives for encountering diverse others” (2018, p52) and to talk about and learn from one another. Like Braganza, I also draw on the concepts of Christian hospitality in such a way that I suggest may be appreciated by those not just in Christian communities, but by those of all faiths and none.

Using theological concepts blends with my own ontological position, but in no way reflects the position of the participants that took part in this study. The faith of the participants in this study was not relevant or a focus in the discussion.

6.2 Key Contribution to Knowledge

My thesis makes a key contribution to existing academic knowledge as it counters the prevalent dehumanising narratives about people with advanced dementia. It draws together, in one place of study, the qualities that people without dementia from diverse backgrounds bring to engaging meaningfully with people with advanced dementia. In exploring their stories of meaningful connections, my study troubles and responds to the dehumanising narratives about people with advanced dementia that positions them as “not all there” (Swaffer, 2014, p711) or “already in the house of the dead” (Post, 1995, p136). It offers a narrative identity to people with advanced dementia as those who are physical, emotional and spiritual human persons who continue to belong to, experience and engage with the world. This counter-narrative is provided through co-created stories with people without dementia who make meaningful connections with those with advanced dementia and me.

My study also responds to narratives that position people with advanced dementia as a burden to society. It brings forth a narrative identity for person with advanced dementia that positions them as persons who continue to be valued by others in society and as people who others want to spend time with. It shows people with advanced dementia as those who often bring joy and have a positive impact on others and makes visible that people with advanced dementia continue to be an important part of communities, families and society.

Also made visible is the impact that people with advanced dementia continue to have on society. The study shows how people with advanced dementia teach those without dementia much about what it is to be human and the ways in which we are still able to connect and communicate with each other even when this is not through verbal language.

Ultimately a key contribution to knowledge is made as my thesis gives voice to people with advanced dementia who are often unheard. It calls the listener of the stories to notice the human person that continues in each person with advanced dementia. It invites people to shift their own horizons of what might be possible in terms of how we can know, understand and be with people with advanced dementia, bringing them life, love and security as we journey together and do our best in a world that we might not always understand. This study invites us to dare to see people with advanced dementia as human persons who are just like those without dementia.

Having set out the key contributions to this study, I now discuss my findings within the wider theoretical framework.

6.3 The Journey to A Strange Land

Mitchell (2018a), Swaffer, (2016), DeBaggio (2003 cited in Swinton 2012) and (Davis, 1989) are all people who live with dementia who have alluded to the sense that they have become different to the person that they used to be or that it is difficult to have a sense of who they are now. DeBaggio (2003,

cited in Swinton 2012) refers to himself as a stranger. Gray Davidson (1993) suggests that having Alzheimer's disease is like "being a stranger in a strange land...becoming that stranger without having consciously or knowingly gone into unknown territory" (1993, p75).

As people with dementia change, not only might they feel like a stranger to themselves, they are often positioned by others as strangers (Sikes and Hall, 2016). Being positioned as a stranger can cause difficulties for people with dementia as they can often cease to be included in society (O'Sullivan et al, 2014). It can also cause difficulties for those who care for people with dementia as people stop visiting the person with dementia and those who care for them. The caring role becomes a priority over other roles that the person without dementia may have in their life. Often the person with advanced dementia will have a range of complex health issues and the carer will have been caring for them for a long time. "They are likely to have become more isolated from family and social connections" (Alzheimer Scotland 2015, p7). Adding to this experience of isolation is the current crisis in social care that leaves unpaid carers as feeling "abandoned...lonely, isolated and generally out of their depth" (AgeUK, 2019, p5). Family members are being placed under more pressure as there is a reduction in state support (Alzheimer's Society, 2018) and they can feel "disempowered" because they can't always get the information that they need (2018, p25).

In addition to being positioned as strangers by others in society dementia brings with it a sense of strangeness between people with and without dementia because of the changing, often unfamiliar and unpredictable behaviours, personality and self-expression of the person with dementia. The dementia journey may feel like "unknown territory" (Gray Jackson, 1993, p75).

Swinton (2012) acknowledges that the person with dementia is never really a stranger however he does speak of dementia as an affliction that "makes strangers of ourselves and the ones we love" (2012, p267). We need to find new ways to know and understand the person with dementia as their ability

to communicate verbally diminishes and their dependency on others to care for them increases (ICD 10, 2016, Alladi and Hachinski, 2018). My findings reinforce that people with dementia change and people without dementia must find new ways to communicate with them in order to maintain relationships, be able to understand their needs and emotions and to offer good care. They support what Post (1995, p4) suggests that we need to pay attention to the “will, emotion, relationship and creative expression” of the person with dementia to care for them. They also support Gray Davidson’ assertion that the task of the caregiver is to “decode the communication and meet the need being expressed” (1993, p76) by the person with dementia as the way they usually communicate becomes impaired.

My findings suggest that as a person with dementia changes there is often a sense that they are becoming estranged from others around them. My study does not suggest that people with advanced dementia are ever *really* strangers. They are always positioned as someone who is known to others and as someone who continues to belong to society. However, thinking of someone as a “stranger” can also mean that the person is someone “with whom one is not familiar” (Lexico, 2019, para.1) or is a person that we do not understand (Sackreiter and Armstrong, 2010, Swinton, 2012). Throughout the stories in this thesis runs the suggestion that behaviours and expressions of people with advanced dementia can be unfamiliar and initially not always well understood. An example of this unfamiliarity is seen when Margaret talks of how she didn’t always know how to deal with it when her mother was hitting her father with a stick because her mother didn’t know who her husband was as he tried to get into bed beside her. Not only was the behaviour of Margaret’s mother unfamiliar, but her father became a stranger to her mother.

Feeling estranged can be a difficult place to be both for the person with and without advanced dementia. Swinton states that becoming a stranger can be a painful process and learning to love the emerging person “will be painful,

alienating and difficult” (2012, p284). My study reflects how difficult this often is for those who care for people with advanced dementia.

Emotionally, it is difficult for carers to see the person that they knew so well change and behave in different ways. It is also difficult for them to accept that sometimes the person with dementia does not know who they are. The difficulty is compounded as the behaviours and personality of the person with dementia can continue to change and are unpredictable throughout the dementia journey. People without dementia are constantly having to find new ways to understand behaviours and communications.

In addition to the unfamiliarity, the stories in my study speak of the loss and sadness that those who care for people with advanced dementia can often experience. There is a sense of grief as the family members discuss what their relationships were like in the past and what their loved one used to be like. Sadness and loss are echoed in stories from the other participant groups in this study not so much in terms of the changing personal relationship, but in terms of how sad it is that people with advanced dementia are ignored by others. Sadness is also expressed as they talk of the times when the person with dementia appears distressed and it is difficult to know how to help them.

In amongst the sense of “strangeness” and difficulties that the dementia journey may bring, my study shows how those without dementia show a persistency in their attempts to move from a place of strangeness to one where they become familiar with and recognise the person with advanced dementia in their fullness as a human person.

It is this movement from strangeness to recognition that I discuss within the concept of Christian hospitality to strangers.

6.4 Hospitality to Strangers

The principles of hospitality to strangers from a Christian perspective comes from the belief that we once were all strangers and we must therefore treat strangers as equal (Swinton, 2012). The parable of the Good Samaritan that

Jesus told in response to the question, “who is my neighbour?”(Gospel of Luke 10:27-37) invites us to see what hospitality to strangers might look like. Whilst there is not space to develop this theological principle further, I use it as a platform from which to understand people with and without dementia as equal, in that they both experience times of estrangement and can also experience times of coming together as friends.

Throughout the stories in my thesis runs a sense that there is a fundamental sameness and equality in people with and without dementia.

Primarily, the person with dementia is positioned as fully human throughout their dementia journey. Behaviours and personality may be different, however the behaviours and personality currently presented are still considered human behaviours that have meaning and can often be understood as such. This supports Kitwood’s focus on personhood that has shown that the behaviour of people with advanced dementia has meaning (Kitwood, 1997a, Brooker and Snaedal, 2016, Hughes, 2014, Sabat, 2001). It also supports the claims from Swaffer (2016), Taylor (Power 2015) and Davis (1989) that they continue to be human beings.

An important sense of equality and sameness is seen in the shared sense of dependency on others and vulnerability that people with and without advanced dementia experience through the dementia journey.

6.4.1 Vulnerability and Dependency

The findings support what is already known about dementia; that as the illness progresses the person with dementia will become more dependent on and need more support from other people to care for them and to maintain personal relationships with them. The sense of vulnerability and dependency that the person with dementia might experience, also applies to the person without dementia. They too can feel vulnerable as they care for those with advanced dementia. This is seen not only in the physical toll that caring for someone with dementia might have, but also emotionally as the participants question whether they are making the right decisions, not knowing how to

deal with a situation and at times feeling helpless because they are not always able to bring comfort to the person with advanced dementia. The sense of those without dementia not always knowing what to do runs through the stories in my study. Charlie's story shows this as he spoke of his mother-in-law shouting and he was asking himself if he had pushed things too far with her.

The Elderflower, Peter, states that the clown is "*trying to do their best in a world they don't understand*". Peter likens this to the situation of a person with dementia who is also trying to "*do their best in a world that may have become less understandable to them.*" The findings show that the person without dementia is also trying to do their best in a world that has become less understandable to them.

Strangeness can lead to a feeling lost, not knowing quite what to do and searching for support from others as you try to find your way. Brannelly (2011) and McLeary et al (2018) draw attention to the emotional and physical cost that is involved in caring for people with advanced dementia. The recognition that carers too need support is given by Alzheimer's Society (2014), ADI, (2017) and the World Health Organisation (2017). This recognition that carers also need support positions people who care for people with advanced dementia as dependent on others to enable and empower them to carry out their caring role. My study shows that those who care for people with advanced dementia often seek support from others so that they can continue to care in the best way they can.

Being vulnerable and dependent is a fundamental human quality and we are contingent on others to meet us in that place of weakness. Lid, (2015, p1555) writes that "vulnerability can be understood as inherent to the human condition and has its source in the dependency that marks human life". This is echoed in the earlier mentioned quotes by Kelly (2012, p92) who writes that "to be human is to be vulnerable" and de Chardin (1957, p76) who writes that:

The depth of our universality of our dependence on so much altogether outside our control all go to make up the embracing intimacy of our communion with the world to which we belong.

Swinton (2012, p161) suggests that “dependency and contingency” are part of our humanness. He frames this such that human persons are dependent and contingent on their creator, God. Swinton (2012) also suggests that human persons are broken and lost, framing this within the biblical interpretation of the Fall in the Garden of Eden in Genesis and the world’s awaiting redemption. However, I suggest that it is also possible to frame human dependency as a brokenness outside of theological thought in that as human beings, our life cycle necessarily includes periods of decline and deterioration (Post, 1995). As we see those around us go through those periods of decline it is only natural that we feel a real sadness, brokenness and loss as we come to terms with what will no longer be and find a pathway to new ways of being together. It is only natural that we won’t always know immediately what to do for the best to connect with persons with advanced dementia.

Becoming more dependent on others to support us physically, emotionally or spiritually, does not diminish our humanity. It reminds us that part of being a human being involves, dependency, contingency and vulnerability. It reminds us that we all need help whether we have dementia or not.

I suggest that as we acknowledge the loss and sadness, dependency and sense of brokenness that may accompany us through the journey of dementia, we also notice our shared common humanity with those with advanced dementia. Acknowledging our vulnerability and dependency opens our eyes so that we can see the person with advanced dementia as “someone like me”.

Both the person with and without dementia experience strangeness in themselves, both experience a sense of vulnerability, dependency and often loss and both need to be supported by others. Acknowledging this may reinforce our sense of vulnerability. Vulnerability, however, is something that

theologian Mackinlay (2015, p26) suggests “lies at the heart of the Christian journey”. It is something that we must be “willing to experience” (2015, p26) if we wish to support those with dementia.

As we notice our shared humanity, our weakness and vulnerability, we create a sense of equality between people with and without dementia. In seeing another as an equal I suggest that we can often find ways to move from the difficult place of estrangement and unfamiliarity to one of familiarity and knowing. I suggest that this is possible as we enter into a relationship of hospitality, offering welcome and love to people with advanced dementia just as they are and just as we are.

6.4.2 Being Hospitable

In welcoming those from whom we have become estranged and offering hospitality, we create a space for them to not feel like strangers but rather to become known as friends.

Swinton (2012, p277) writes of hospitality:

It is a radical invitation designed to strip persons of their current role as strangers and reposition them as valued members of a community that understands strangeness (because in many ways it is itself strange).

As hospitality is extended among strangers there is an invitation into a place where the stranger truly belongs as a valued and equal member of that community that understands and accepts them. This sense that the person with advanced dementia is valued and truly belongs to community as the person without dementia seeks ways to continue to connect weaves through the findings of this study.

The 1943 seminal work of Abraham Maslow introduced “A Theory of Human Motivation” (Hale et al, 2018, p109) where he indicated that love and belonging, “identifying with a particular group of groups were essential needs” (2018, p112) that all humans have. I argue that understanding dementia through the sociological lens of citizenship also reinforces the belief

that people with advanced dementia continue to be part of and belong to our society and culture as it seeks ways to ensure that people with dementia continue to receive “an equal stake in all aspects of public and private life” (Bartlett and O’Connor, 2010, p37). Whilst citizenship might secure equal rights for the person with advanced dementia on a social level, it is, however, unable to create the personal sense that people with advanced dementia truly belong to a community of other human persons. Alongside the approach of social citizenship, I argue that we need to hear personal stories like those in this study. Personal stories invite the listener to identify themselves within that story. The stories create the opportunity for individuals to notice people with advanced dementia as truly belonging to the human race. In noticing they may be compelled to treat people with advanced dementia as equals. The stories in my study show this sense of belonging as people without dementia continually seek ways to maintain active relationships with people with advanced dementia by visiting, proactively organising inclusive activities for people with dementia and by finding different ways to develop and maintain their relationships.

Often when we develop relationships with others, we begin that relationship as strangers and sometimes develop our friendship as we become more familiar with them. In the case of dementia, that direction of travel is often altered. People whom we once knew intimately, such as our family members become less familiar and more estranged in many aspects of their behaviour. My study shows that in the situations where that has happened, those without dementia appear to practice hospitality intentionally to reverse that direction of travel. For those who don’t have an intimate knowledge with the person with advanced dementia, like the Elderflowers, the relationship with the person with dementia follows the direction from strangers to friends from the beginning of their relationship.

In offering hospitality to strangers, differences are noticed, whilst at the same time recognising that we all belong to our “common humanity” (Carroll, 2011, p522). In order to offer hospitality to a person with advanced dementia

therefore, you need to believe that they always continue to be fellow human persons and that in their difference, or strangeness, you can get to know the person and re-familiarise yourself with them as the dementia journey continues.

The findings from this study show that the people without dementia who made meaningful connections with those with advanced dementia hold a strong belief that people with advanced dementia continue in their humanness even as they change. There is also a sense that people with advanced dementia can be known, and connections can be made throughout the dementia journey. This stands in stark contrast to prevailing narratives that continue to position those with dementia as becoming less than human as they are denied personhood through their apparent lack of autonomy, rationality and self-awareness (Singer, 2011, Hughes, 2011, Birt et al, 2017 and Budić, 2017). Spiritual carer Tamsin tells us that it's up to people without dementia to find a way to reach them and not give up on them. Spiritual carer Rachel tells us that we need to find the key to enable communication.

6.4.3 Relationships

Within Christian hospitality, strangers are welcomed so that we can get to understand and know each other. An important aspect of hospitality is that relationships can “blossom” through the interactions (Carroll, 2011, p522) as we come to know each other.

Swinton (2012, p179) suggests that all human beings have a “deep and primal craving for relationships with God and with others” and relationality is part of being a human person. Relationality shows that we belong to the same species, the same human race that we are interlinked, and all have the “birth right and mutual recognition” that binds “all of its members together”, (Swinton, 2012, p157). It reinforces our sense of belonging.

The stories in my study show the deep desire that those without dementia who make meaningful connections have to maintain or form relationships with people with advanced dementia. They show that they continue to value

being with the person with advanced dementia as they spend time with them offering care, love and relationship. The stories also show that the person without dementia often has a desire that the person with advanced dementia not only becomes known by them but by others too. They sometimes become the voice of the person with advanced dementia, speaking out what others need to know about the person with advanced dementia, telling them who they are and what they need. In doing this they offer others the opportunity to see people with advanced dementia as those who continue to experience the world. Their stories of connection invite those who hear them chance to offer hospitality, welcome and build relationships with the person with advanced dementia too. They invite others to see the person with advanced dementia as someone who continues to be a fully human person.

Relationships are central to the theories of Kitwood (1997) and Sabat (2001) in the sense that it is through the relationship with a person without dementia that personhood is upheld. However, Swinton, (2012) understands that persons exist outside of relationship, a position I fully support. If we apply the concept that there is something of the “divine dynamic” of the Trinity in each human that is created and made in the image of God, relationships enable others to “recognise themselves and be recognised as part of one extended human family” (2012, p158). I argue therefore that as we understand human persons as created by God, we can also understand that whilst it is not relationships that uphold personhood, they create a space for the human person to flourish as the human need to belong (Hale et al, 2019) is satisfied.

As relationships are maintained and formed the person with advanced dementia becomes better understood and noticed as a person who is continuing to experience the world. The person with dementia is also invited to notice that they continue to belong to a wider community of the “human family” (Swinton, 2012, p158). This is noticeable in Tamsin’s story of maintaining relationship with the lady with severe dementia in a care home and continuing to offer the Sacrament of Communion. Tamsin creates a space where the lady can continue to belong to the church community and a

space where Tamsin is then able to notice the subtlest of expressions of the lady connecting with the experience of communion. This brings a narrative identity to people with advanced dementia as being fully integrated and belonging to a wider community *and* continuing to flourish in their relationship with the world and with others.

Christian hospitality involves “creating a welcoming space for encounters to occur such that those encountered feel safe, free, loved” (Braganza, 2018, p35). It is a welcome that involves making space for the presence of the other, just as they are (Reynolds, 2006). A place to stand by another and join them in their struggles (Frambach, 2011). Hospitality is about journeying together as we honour the presence of the other (Reynolds, 2006). It is about delighting in the other person’s differences, letting them be “other”, not forcing them to become like you, rather to “thrive as other” (Mosher, 2011, p643).

Throughout the stories in my study there is talk of learning to go along with the person with dementia rather than working in conflict with them, going in their direction of travel and not trying to force a connection. The people without dementia are keen to offer those welcome spaces for the person with advanced dementia in their difference, just as they are. People with advanced dementia are given the space they need to thrive and be themselves. A space to feel loved as the person without dementia finds different ways to continue to know them and relate with them as they are in the present moment.

6.4.4 Love and Value

In offering hospitality to strangers, we offer them and offer friendship and love (Jones, 1992).

Swinton (2012) writes that to be human is to be “loved persistently”, by God (2012, p181). We are loved by God, even when we may not be loved by other human beings.

Swinton, (2012, p180) describes love as:

“an act of engagement with another at a deep and personal level which states clearly in word and action that “I want you to exist!”

Theologically my position is that people with advanced dementia are persistently loved by God. The findings in this study show beyond doubt that the people with advanced dementia discussed in this study are also deeply loved by other human beings. Not only by those who told the stories, but by wider members of the family and community. I argue therefore that the findings of this study directly rebut narratives that position people with dementia as a burden and waste (Beckford, 2008, Beard, 2017) and instead position them as loved and valued.

Whilst the stories fully acknowledge that it is not easy to care for someone with advanced dementia, they also suggest that those without dementia are glad that the person with advanced dementia exists and that “it’s good that you are in the world!” (Pieper, 1997, p164). The sense of love and value that the participants in this study have for people with advanced dementia is reinforced by their commitment to care for them.

This sense that it is good that people with advanced dementia continue to exist is reinforced in this study as people without dementia share moments of deep joy, humour and a sense of fulfillment and purpose as they spend time with them, care for them and interact with them. The findings echo the writing of McQuilkin, (1998) as he talks of the honour he feels to care for his wife who has Alzheimer’s disease and the delight that she continues to bring him.

Love is often felt as being reciprocated by the people with advanced dementia through the slightest of body movements, a moment of lucid speech or a touch of the hand. These moments could be understood as the person with advanced dementia saying to the person without dementia “it’s good that you are in the world!” (Pieper, 1997, p164).

Swinton (2012, p268) writes that “love overcomes the strangeness” that dementia creates. Romesin and Verden-Zöller (2008) suggest that human suffering is abated when love is restored.

As we offer hospitality, we offer love and friendship, but in order to overcome strangeness we also need to create and maintain a sense of equality, between the person with and without dementia. The offer of hospitality is not only about being the host, but also about becoming the guest in the world of the one we welcome.

6.4.5 Guesting and Hosting

Central to the Christian hospitality is the concept of being the “host” and “guest” in the life of a stranger (Braganza, 2018, p38, Swinton, 2012, p270). Being the guest and host is exactly the dual role of Christ at Communion; He is both the guest at the meal and the One who hosts the meal. The significance of guesting and hosting is visible in the Road to Emmaus story in the Gospel of Luke 24:28-31. Two disciples of Jesus did not recognise him as he joined their discussion and they urged “the stranger” to stay with them and rest. He was, in this moment, their guest. As Jesus joined them at the table He moved into a position of host, as He blessed and broke the bread and gave it to them. The disciples became Jesus’ guests. Jesus invited them fully into His presence, not through words or language but through His body, and it was in this moment of being His guest that they were able to recognise Him for who He was.

Being a host means that you are willing to receive and welcome another person, but as the guest you are the one that is being received by another. As a host you must always be prepared to receive what the guest offers you (Braganza, 2018). I argue that it is when we adopt the position of the guest, we are most likely to see the human person with advanced dementia.

The findings in this study draw our attention to what is being offered by the person with advanced dementia. The Elderflower, Sabrina, actively notices the rhythm a person with dementia is making as they move their body. Sabrina understands this to be an offering of potential engagement.

Becoming the guest and host are not two exclusive dualities (Braganza, 2018). As we offer hospitality to another person, we engage in a fluid

movement between the two roles. Reynolds, (2006, p198) suggests that “hospitality lets the boundaries between host and guest become blurred”, they become more fluid. In the fluidity of boundaries, the one that was the stranger, who seemingly has “nothing to offer...becomes a source of enrichment” (2006, p198).

My study suggests that the person without dementia is highly skilled and sensitive to knowing how to operate in the liminal space of being the host and guest as they visit and spend time with the person with advanced dementia.

In doing so not only are they able to support the person with advanced dementia, but they are able to notice all that a person with advanced dementia continues to offer.

6.4.5.1 Hosting

In finding ways to best care for people with advanced dementia there is a risk that we might only consider “hosting” the person with advanced dementia as they take the position as the guest. I suggest that in remaining the host, the relationship between people with and without dementia is unequal, as the power balance is weighted towards the person without dementia.

My study shows how the person without dementia invites the person with advanced dementia to become their guest as they find different ways to make themselves noticed by the person with dementia. Many of the techniques resonate with those found in the above literature and within Kitwood’s “Elements of Positive Interaction” (2019c, p107-109) as set out in Appendix 2. The people without dementia make their presence known through, music, visual stimulation and by using the different bodily senses; touch, hearing, sight, smell and taste. In addition, the Elderflowers might connect by joining the person with advanced dementia through their breath. In inviting the person with dementia into an interaction, the person without dementia is claiming that the person with dementia can make sense of that invitation and that they will have the ability to respond. My study shows that the person without dementia understands that people with advanced

dementia often need time to process what is being offered and give them space to make a response. In waiting for a response, the person without dementia also adopts the position of guest in the world of the person with advanced dementia.

6.4.5.2 Adopting the Position of the Guest

The findings suggest that in becoming the guest in our interactions with people with advanced dementia, we are often able to notice and gain an understanding of the meaning of their expressions and behaviours so that meaningful connections can be made.

However, becoming the guest in the world of people with advanced dementia becomes a place of vulnerability for many people as it often involves waiting for the host to notice and engage with you. There is always the risk that you will be an unwanted guest. The Elderflower, Jacob, recognises this risk as he talks of worrying that his presence will not be wanted by the person with advanced dementia.

According to Sutherland, (2006) when offering hospitality to strangers we should “see others in such a way that they are visible to us...as a reflection of our own fallen and redeemed humanity” (2006, p37).

In becoming a guest, we are called to notice our shared humanity with people with advanced dementia and acknowledge that we too one day might develop dementia, which for many is too difficult a position to accept (Kitwood, 2019a, Brannelly, 2011).

The findings of this study show that those who made meaningful connections with people with advanced dementia were able to recognise their own vulnerability to developing dementia. Whilst it did cause some angst, there was a sense that in being able to recognise their common human vulnerabilities, they were able to better understand what the person with dementia was communicating and take action to engage in the human connection with them.

The findings show that being the guest in the world of someone with advanced dementia means you become vulnerable as you set aside your own theories and ideas and wait in the company of the host, attentive and ready to notice what they offer you in terms of a doorway to a meaningful connection. Being the guest necessarily involves accepting that initially you may not know what the person with advanced dementia is communicating or how best to respond. Being the guest invites those without dementia to allow themselves to accept that they may not always know exactly how to communicate and make meaningful connections. It allows the opportunity to stand and be curious about what the person with advanced dementia might be offering in terms of their communication and be curious about what the person with dementia may be teaching them about how connections can be made. To counter this sense of vulnerability, there is a sense that the person without dementia can trust that the person with advanced dementia will offer them something with which they can engage. It becomes about giving the person with dementia the “benefit of the doubt” (Swinton, 2012, p30). This theme runs through the stories in this study as those without dementia believe that meaningful connections can be made.

The sense of waiting also runs through this study as the person without dementia often remains the guest in the world of the person with dementia as they stand back, question and take time to notice and form a meaning about what the person with advanced dementia needs or is communicating at that time.

The story of Paul stepping into the world of being the gentleman’s apprentice, offers a rich illustration of the movement between guesting and hosting, as he takes the time to notice the gentleman’s experience of the world and becoming the guest in his world. They both then fluidly moves between guest and host as they get their daily physical care tasks done, whilst remaining in the experience of employer and apprentice.

6.4.5.3 An Invited Guest

Jenkins (2014) and Watson (2016) discuss the dissolution between the carer and cared for, which places persons with and without dementia on a more equal footing. They show how people with advanced dementia can become the host and instigate an action that shows care to another person. Kontos et al (2017) also shows that people with dementia have capacity to “initiate as well as respond to verbal and embodied, emotive and creative engagement” (2017, p13). These studies show that there is a reciprocal nature in interactions between people with and without dementia. Understanding those interactions within the hospitality to stranger’s framework shows both people with and without advanced dementia being both host and guest. My study supports the reciprocity between people with and without advanced dementia. The stories show that people with advanced dementia often initiate an engagement and show agency through their subtle body language, reaching out to touch the person without dementia or through their vocalisations.

As we pay attention to the movement of persons with and without advanced dementia from host to guest, we can notice the impact that people with advanced dementia continue to make on others and in society. We can notice their agency and ability to influence their experience of the world. This troubles the loss and decline narrative (McParland et al 2017, Swaffer, 2016, Bruens, 2013), and instead positions the person with advanced dementia as an “active agent within their relationships” (Watson, 2016, p0).

6.4.5.4 Noticing the Person with Advanced Dementia

The literature has shown that within our current culture the full humanity of the person with advanced dementia continues to go unnoticed or ignored.

However, in my study, people with advanced dementia are noticed as physical, spiritual and emotional human persons. This noticing happens as the person without dementia spends time with the person with advanced dementia and adopts the position of guest and host in their world, watching

for the slightest reaction through the eyes, the body language or even for a change in their breathing and responding to what is being offered.

Paying attention to and noticing what the person with advanced dementia might be communicating helps the person without dementia form a meaning and then often make a judgement as to what needs to be done to connect with the person with advanced dementia.

6.5 Using Judgement Through an Aesthetic Approach

Hughes (2014a) suggests that caring for someone with dementia involves aesthetic judgement in that often there is a need to sense what the person with advanced dementia might be communicating. This involves using intuition, perception and imagination.

Taking an aesthetic approach means that there are times when one needs to sit with uncertainty and be open to a “lack of theory” (Hughes, 2014a, p1407). The findings of this study support the need for a willingness to take the position of sitting with that uncertainty and lack of theory. We see this in the family member Charlie’s story of being uncertain about what to do and taking time to question what would be the best course of action.

Hughes (2014a, p1407) cites Keats (1990, p370) in a letter to his brother in December 1817 as he wrote of aesthetic experience, or his well-known idea of “negative capability”, “...when man is capable of being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason.”

Cornish, (2011, p138) quotes Jackson Bate, (1963, p208) who was Keats biographer who paraphrased Keats use of negative capability:

In our life of uncertainties, where no one system or formula can explain everything...what is needed is an imaginative openness of mind and heightened receptivity to reality in its full and diverse concreteness. This involves however negating one’s own ego.

Hughes (2014a, p1409) suggests that an aesthetic approach is one that is open, receptive and self-negating. He goes on to say that it is here that the “true nature of things” is revealed and “truth and beauty collide into one”.

Hughes posits that in approaching people with dementia “negative capability suggests we do so without theory, without necessarily the use of symbolic language, but perhaps with the possibility of seeing something quintessential to the person”.

Swinton (2014) reflects that as he administers communion to people with severe dementia, he must adopt his posture by either bowing or kneeling before the person. Swinton (2014, p168) describes this as adopting the “postures of worship”. As the posture of worship is adopted Swinton notices the person with advanced dementia in a new way and begins to “see and feel the world” differently. It is in this position on his knees that he notices that the theories he previously held about people with dementia “mean nothing” while he is in that place. In that place Swinton recognises the person with advanced dementia for who they are “a disciple of Jesus Christ, who continues to love and know Jesus even though they have forgotten him. As a disciple, they retain their calling and vocation” (Swinton, 2014, p169).

The musicians in the Music For Life project (Smilde, 2014) noticed that the theories that they had brought with them into the care home meant nothing when they were confronted with Rosamund being hoisted from her wheelchair into a chair. It was at this point that they needed to look at the world in a different way and accept the reality that they were faced with as they saw the fullness of who Rosamund was in that moment.

Taking an aesthetic approach does not mean that all “scientific understanding” is precluded, rather that we really “see the person, hearing her, communicating by touch, explaining something by smell, engaging in a manner that is holistic” (Hughes, 2014a, p1409).

An aesthetic approach means that we take the place of the guest in the world of the person with advanced dementia, we take time to wait and listen as we look for new ways of understanding or gaining a sense of what our host is communicating or needing from us.

The findings show that in taking this aesthetic approach, the people without dementia were often aware of the subtlest of clues and movements that the person with advanced dementia was offering. They used those cues to form a meaning about what was being communicated.

However, there were times when the person without dementia was uncertain about whether they had formed the correct meaning. In being uncertain the findings show that those without dementia continued to pay attention to clues that might indicate that they had made a correct or incorrect assessment of what was being communicated. The participants remained in a position of humility, a position of noticing, taking the lead and learning from the person with advanced dementia as their host and were prepared to make any adjustments to their response to them at any moment.

Making meaningful connections with people with advanced dementia brings to the fore the certainty of uncertainty and draws us away from our cognitive theories and back to senses. The findings in this study show that there will always be uncertainty in knowing the person with advanced dementia. Matthews, (2019, p162) suggests that when we understand people as “made in the image of God”, that “no one can grasp the being of another person. That person however much we know and love them, remains a mystery for us yet that person is wanted by God for his or her own sake”. Just as there is uncertainty in fully knowing a person without dementia the uncertainty in being able know a person with advanced dementia reinforces their humanity.

In taking an aesthetic approach towards the person without advanced dementia, we remain uncertain. We must therefore truly “visit” and “notice” the person with advanced dementia and as we do so lay down our own cognitive theories and expectations of how we will connect and look to our senses to make those connections. There are times when it feels almost impossible to be able to know if a meaningful connection has been made. Despite this, however, the findings show that there is a belief amongst the participants that meaningful connections can be made and that people with

advanced dementia can be reached, even if there is no response in that moment.

This resonates with the Ignatieff, (1993, p59) whose mother has dementia. Ignatieff argues with his mother's doctor that in order to give his mother respect that they should "give her the benefit of the doubt" that there is some meaning in her changing behaviour.

Swinton (2012, p284) suggests that it is when we give people the benefit of the doubt that we can "learn what it means to be with them and to love the emerging person."

6.5.1 Time

The findings suggest that people with advanced dementia often need time to process what is happening in their environment, and often giving time may feel like you are doing nothing. Swinton (2012, p235) writes that "Time is not empty. Each moment is filled with meaning, new possibilities." He suggests that when we pay attention to time and make it meaningful, then "taking time to be with a person with severe dementia is meaningful, purposeful and revelatory even if it might not always feel that way at the time".

The findings show that taking time to be present with the person with advanced dementia, reveals the agency and interdependence of people with advanced dementia. They show that it is as these moments of time are given to a person with dementia that often a response may be seen.

6.5.2 Coming Back to the Body

The sense of becoming the guest resonates in Hughes (2013) suggestion that we can get a feel for what people with advanced dementia want by being with them and not just doing to them. Often those who are close to a person with advanced dementia can gain an understanding of what they might be communicating in a way that others may not because they are engaged:

with the whole surround, grasping the gestures and grimaces of interpersonal space, by the feelings that emerge between people, which in part will reflect deep engagement with the person's narrative history and psychosocial, spiritual and cultural background (Hughes, 2013, p12).

Through being the guest in the world of the person with dementia, the findings show that people without dementia are often able to notice the ways in which the person with advanced dementia is communicating their emotions and experiencing the world in that moment. At times the communication is obvious and clear and at other times the meaningful connections are made by noticing the subtlest of movements, a change in the eyes, or tension in the muscles; changes that Charlie refers to as "*micro-symptoms*" or "*micro-cues*". The findings suggest that the person without dementia has learned the language of the person with dementia and that they continue to learn new ways to communicate throughout the dementia journey.

As the participants attempt to form a meaning from the way in which they notice the person with advanced dementia is communicating they are able to establish whether the participant wants or needs them to engage and they find a way to join them, entering into the relationship of hosting and guesting with each other.

Some of these subtle movements by the person with advanced dementia were given meaning by the participants because they had a historical relationship with the person with dementia and knew what those small movements meant. However, other participants had no historical connection.

Swinton writes that human beings are embodied creatures and that we "experience the world through our bodies" (2012, P165). He writes that it is the "inbreathing of God's spirit into dust which creates a living entity" (2012, p167). When we understand people to be created by God, we understand that all human beings sharesomething of the same essence within them that we can recognise in the other.

Determeyer and Kutack (2018, p1681) suggest that it is possible to notice the "something ineffable" that they suggest is present within each physical body,

and where “flesh meets, two humans encounter each other’s personhood” (2018, p1688).

The findings of this study suggest that meaningful connections were made through the physical body and through the five bodily senses; touch, hearing, sight, smell and taste. They show that it is not only the person with advanced dementia that communicates and understands the other through their body, but so does the person without dementia as they have learned to communicate through their body.

The findings invite us to notice how profoundly both the person with and without dementia can be affected by the other person’s embodied movements as meaningful connections are often felt and experienced in the body of the other.

These findings support existing literature that the body has its own ability to communicate and act separately from cognition (Kontos, 2005), and that there is an intertwining of feelings between people that are felt through the body. They reinforce the sense that the embodied self in people with advanced dementia continues to be “transactive” (Jenkins, 2014, p129) and intertwined (Watson, 2016). Hughes (2013) asserts that understanding people with dementia needs to be achieved through the body and not just cognitive interactions and that this understanding comes from interpreting the nuanced movements and expressions. I agree with Hughes and add that understanding can also develop as we listen to the vocal sounds of a person with advanced dementia as they too sometimes communicate through their voice. The person with advanced dementia also seems to listen to the tone of voice of the person without dementia.

The findings of this study show that people without dementia learned the language of those with advanced dementia by finding ways to understand and interpret their subtle and nuanced movements and expressions. They have learned how to have meaningful connections by visiting, hosting, guesting, waiting, noticing and continually moving

flexibly through those different actions looking for new ways to connect and understand.

As the person without dementia offers hospitality to the person with advanced dementia, fluidly moving within the liminal space of guesting and hosting that they are able to make meaningful connections drawing on a range of different skills. I now discuss some of these different practical ways of making connections within the wider literature.

6.6 Connecting Through Music and Rhythm

Music and rhythm are a key method of connection that the Elderflowers use in their work with people with advanced dementia and the power of music to connect is spoken of in most of the interviews carried out in this study. The findings show that the person with advanced dementia regularly responded to music by moving their body, trying to sing along or by a change in their mood.

Music is heard through the bodily sense and rhythm is also felt throughout the body, reinforcing the understanding that we are embodied human beings. Kontos (2014), Hara (2011), Sacks (2008), Pickles and Jones (2006), support the findings that music and rhythm are a powerful way of making connections amongst people with and without dementia. Pickles and Jones (2006, p89) hypothesise that there is a non-reflective or language-based sense of “being in the world” which is made possible through listening to, enjoying and sharing a musical activity, a kind of musical phenomenology. Kontos (2014) argues that music is incorporated into the bodily schema and musical engagement is a form of bodily consciousness that does not rely on cognition.

The findings in this study, however, go deeper than using music as a way of connection. They draw attention to the basic rhythms that people present to the world, not just in a musical sense, but through their breathing or bodily movements. The Elderflowers are highly attentive to the rhythm of a person’s

breathing or the rhythm of their hand movements. They notice this as a gift that the person with advanced dementia is offering to others in terms of a way of being able to understand what they are communicating in that moment to the world.

Dance Music Therapy is a form of art therapy and sometimes used for people with dementia (Karkou and Meekums, 2017, Melhuish, et al, 2015, O'Maille, 2005). It alludes to this sense of rhythm as a way of understanding another person in that it is based on the principle that "movement reflects an individual's pattern of thinking and feeling" (Karkou and Meekums 2017, p3). Dance Music Therapy is a psychotherapeutic intervention for people with dementia to enable them to engage with the creative process to "further their emotional, cognitive, physical and social integration" (2017, p3). The findings in this study show that the attention to the rhythmic movements of the person with advanced dementia opens a doorway for creatively engaging in a meaningful connection and is also is a way of understanding whether their presence is wanted (or not) in the first place. The subtle bodily movements and rhythms of the person with advanced dementia including the rhythm of breathing were understood to be a source of ongoing agency and choice that could be understood by people without dementia in this study. This reinforces the argument that human beings are embodied beings and our bodies continue to hold our ability to show agency and make decisions.

6.7 Connecting Through Humour and Play

The findings show that humour and play was used as a way of making meaningful connections and sharing in each other's humanity, primarily by the Elderflowers, but was also visible in the story of Dorothy as she interacts with her dad, trying to joke with him and relaying how he laughs a lot. A study by Low et al (2014) that considered the effects of humour therapy on nursing home residents in Sydney Australia confirmed that "humour therapy decreases agitation and also showed that it increased happiness" (2014, p564) however this did not include participants who had "severe

communication obstacles” (2014, p565). A small-scale qualitative pilot study by Person and Hanssen (2015) was conducted to explore the experiences of pleasure for six people with advanced dementia. The study concluded that one of the sources of happiness for people with advanced dementia was humour and that whilst humour will be highly individual, “sharing humorous moments with someone may enhance feeling of togetherness and closeness”(2015, p50). Dorothy also spoke about wanting to share the laughter even though things can be frustrating at times. This is echoed by Vavilla (2016, p299) who states that there needs to be more exploration into “the joy and humor into educational training as a means of developing positive coping strategies that can be associated with the caregiving experience”.

The sense of play comes through at times in the humour that can lead to “playful discovery” (Leow et al, 2016, p.E7). It also comes using objects to engage the person with advanced dementia either through the touch or in the visual appearance or bright colours of those objects. This study shows how people with advanced dementia engage with the bright colours of the Elderflower costume and the coloured scarves that they might use to engage and increase their awareness of the surrounding area. It draws our attention to the way in which using visual senses may facilitate meaningful connections and playful interactions with people with dementia.

6.8 Connecting Through Historical Relationships

One of the main principles of person-centered care is that people with dementia are all treated as individuals and appreciating that each person has “a unique history and personality” (Brooker, 2007, p12). The findings in this study show that when there is knowledge of the unique history of the person that connections can be made meaningful as the person without dementia can use that history to form a meaning for the person with advanced dementia and also understand what the person with dementia is communicating in that moment. They can then join them in that moment.

The family members and care staff are often able to tell how the person with advanced dementia is feeling or understand their distress or joy because they have a historical relationship with them. They have been able to develop an understanding of the embodied responses and nuances that the person with dementia makes. This is supported in academic literature by McCleary et al (2018) who carried out a study to explore family and staff experiences of end of life care for people with dementia in long term care homes. It also supports the comments in Rice et al (2019, p1605) that notes that knowledge about the situation and history of the person with dementia “were key elements to assessing patient awareness of aspects of their lived experience”.

Making connections through a historical relationship means that there is an existing close relationship that has been developed through spending time with a person with advanced dementia and allowing their ways of being to impact you so that you begin to learn their language. You then draw on that to make sense of what they might be communicating at that time. It reinforces that people with advanced dementia continue to belong not only to the community that they are part of now, but also those of their past.

Making connections through historical relationships also draws our attention to the fact that people with advanced dementia have a rich past and history, that continues to reside within them. Whilst dementia brings estrangement, connections through historical relationships are another way to dissolve that estrangement and replace it with knowing and familiarity.

6.9 From Strangers to Friends

In order to see the person with advanced dementia as no longer estranged, the findings suggest that the people without dementia that care for them have a set of attributes that helps see them as equal, fully belonging friends.

These attributes are:

- A belief that people with advanced dementia are fully human and can make connections.
- A fundamental love and care for people with advanced dementia.
- A belief that people with advanced dementia belong to the world and are purposeful in the world.
- A belief that people with advanced dementia can be reached and do relate to the world and the people in the world – they give people with advanced dementia the benefit of the doubt.
- An ability to fluidly move within the liminal space of being the host and guest as they offer hospitality to the person advanced dementia. In doing so they stop and wait in the position of negative capability, seeing this as a strength and a doorway into meaningful connection.
- An ability to become attuned to the language of the person with advanced dementia. This means noticing when it is time to respond and offer a hand of support, all the time continuing to be the guest in the world of the person with advanced dementia learning from and taking their lead.
- An ability to notice changes in behaviour or response that indicate that they need to adapt their way of being to maintain or re-establish a connection.

6.10 Conclusion

In this discussion I have set out the key contribution that my thesis makes to current academic knowledge.

I have shown how dementia might bring a sense of estrangement to the persons with and without dementia, by drawing on the findings of my study and discussing them within the current academic literature. I have used a framework based on a Christian hospitality to strangers and drawn on an aesthetic approach to dementia to discuss how people with and without dementia are able to move from a place of estrangement to one of knowing, familiarity and friendship. In setting the findings of my study within the

broader theoretical framework of hospitality to strangers, I have identified a set of attributes that people without dementia appear to have that help facilitate the movement from strangers to friends.

This discussion shows that as we engage in the practice of hospitality to strangers with people with advanced dementia, we can meet each other in our difficult moments. These moments can often transform from places of not knowing and strangeness, to moments of deep connection and joy as we show the person with advanced dementia that they are seen, known and loved just as they are in the present moment.

Chapter 7 **Limitations, Recommendations and Conclusion**

In this chapter I reflect on the limitations of my study and then make recommendations for future research and practice. I then draw this thesis to a conclusion.

7.1 Limitations

- I limited the stories in my study to those from a small group of people, from only four different backgrounds. I did this to allow for a rich and detailed exploration of their stories. Whilst these findings may not be generalised to larger populations they may be fit for others to use as they will hold resonance with other populations
- I limited the focus of the study to meaningful connections and did not explore in detail the times when no connections are made. The way in which the research aims were positioned to the participant influenced the telling of positive stories. This in some way limited the opportunity for difficult situations and situations of no connection to be discussed. Where they were alluded to, I felt I needed to encourage participants to share these difficult experiences with me through open questioning and a reassurance that it was okay to share these stories too. Further studies that explore the experience of no meaningful connection would be useful to offer balance to this study.
- Throughout the stories there was a sense of loss and grief that the participants expressed as the person that they cared for progressed through the dementia journey. Whilst this area was not explored in detail in this study, it is important that this sense of loss and sometimes grief is acknowledged and the difficulties that the dementia journey can bring are not undermined in any way.

- The research methodology I used meant that stories were co-created between myself and the participant, though not in a way that seemed inauthentic to the participant. The answers would have been impacted by the way I introduced the study and by the line of questioning I used in the interviews. The study should be understood on the basis that stories were co-created between the participant and the researcher.
- The attitudes and approaches of the person without dementia were interpreted from my analysis of the stories. I did not examine how or why these attitudes and approaches appeared to be held by those without dementia in this study.
- It is important that the findings from my study are not understood as a fully developed way of making meaningful connections nor should they be finalised. Further research is required to develop the conclusions I have drawn in terms of how and why meaningful connections are made.
- The meaningful connections that are discussed in this study were not observed by me in real life situations. Therefore, the findings in this study are based on my interpretation of stories that were told about making meaningful connections.

In recognising the limitations of this study and taking into consideration the research findings, I make recommendations for future research and practice.

7.2 Recommendation for Future Research and Practice

- The concept of making connections through a practice of “hospitality” was developed based on the stories co-created in this study. I recommend a study that employs participant observation of people with and without advanced dementia that focuses on how hospitality is employed and the subtleties of guesting and hosting manifest when making meaningful connections. This would help deepen our understanding of the ways in which meaningful connections are made.

- I suggest the development of training programmes for those who care for people with dementia that focuses on the aesthetic approach of caring and the process of becoming the “guest and host” in the world of the person with advanced dementia. Personal stories should form a key part of this training and where possible the stories could be told by those to whom they belong.
- Further studies could be developed that explore the attitudes of people without dementia who make meaningful connections with those with advanced dementia. This would bring insight to how these attitudes developed, and whether there is scope for others who are less able to see the humanness in people with advanced dementia to develop these attitudes. Further attitude research could be carried out that measures whether attitudes towards people with dementia change as someone spends more time with those with advanced dementia.
- The study has shown that people who experience meaningful connections often hold humanising attitudes towards people with advanced dementia. I suggest that focused media campaigns that include the moments of deep joy and connection between people with and without advanced dementia could help counter the current dehumanising narratives.

7.3 Conclusion

In bringing this thesis to a conclusion I reflect on the approach and methodology that I used to explore meaningful connections between people with and without advanced dementia.

I took an interdisciplinary approach and blended sociological and theological theory. I applied this to an empirical study that explores the experience of making meaningful connections with people with advanced dementia. In blending the two theories it is my hope that my thesis can reach and be appreciated by a wide range of audiences that include those of all faiths and none.

The narrative methodology I chose has enabled the “humanness” of people with advanced dementia, and the shared humanity of people with and without dementia to be made visible.

Jesus spoke in Parables so that people might see and understand. The Parables have been described as embracing “the whole duty of man” (Coghlan, 1918, p.vii). Frank tells us that stories “animate human life” (2010, p3) and they “interpellate” (2010, p49) us to act in a particular way. When we hear of the stories of meaningful connections between people with and without advanced dementia, they open our eyes and they call us to act. They help us understand people with advanced dementia and they help us recognise their humanity.

The stories in this study have shown people with advanced dementia as people who, whilst dependent on others and changing in their cognitive abilities and behaviours, continue to engage with and experience the world in embodied ways. People with advanced dementia are seen as persons who are noticeable; who belong; are aware; have agency; are valued; loved; known and have purpose in and impact the world. This counters the dehumanising narratives and narratives of burden that exist in our society about people with advanced dementia.

The stories call us to acknowledge our own brokenness and sense of feeling lost; to acknowledge our sadness about the changes in the person with advanced dementia. They call us to set down our own preconceived ideas about how connections may or may not be made. They call us to become vulnerable, entering a space of not knowing and waiting, of watching and learning the language that the person with advanced dementia now speaks. They call us to trust that connections can be made.

As we hear the stories in this study, we are invited to offer persons with advanced dementia the gift of hospitality, the gift of hosting and guesting. The gift of taking time to truly “visit”, notice and build relationships.

When we hear the stories of meaningful connections between people with and without advanced dementia, we are called to see the person with advanced dementia as someone who is a fully emotional, physical and spiritual human person.

Stories of meaningful connection help us say to the person with advanced dementia:

I SEE YOU.

Appendices

Appendix 1 Elements of Malignant Social Psychology

<u>Interaction</u>	<u>Description</u>
<i>Treachery</i>	<i>Using forms of deception in order to distract or manipulate a person or force them into compliance.</i>
<i>Disempowerment</i>	<i>Not allowing a person to use the abilities that they do have; failing to help them to complete actions that they have initiated.</i>
<i>Infantilization</i>	<i>Treating a person very patronizingly (or 'matronizingly'), as an insensitive parent might treat a very young child.</i>
<i>Intimidation</i>	<i>Inducing fear in a person, through the use of threats of physical power.</i>
<i>Labelling</i>	<i>Using a category such as dementia, or 'organic mental disorder', as the main basis for interacting with a person and for explaining their behaviour.</i>
<i>Stigmatization</i>	<i>Treating a person as if they were a diseased object, an alien or an outcast.</i>
<i>Outpacing</i>	<i>Providing information, presenting choices, etc., at a rate too fast for a person to understand; putting them under pressure to do things more rapidly than they can bear.</i>
<i>Invalidation</i>	<i>Failing to acknowledge the subjective reality of a person's experience, and especially what they are feeling.</i>
<i>Objectification</i>	<i>Treating a person as if they were a lump of dead matter: to be pushed, lifted, filled, pumped or drained, without proper reference to the fact that they are sentient beings.</i>
<i>Ignoring</i>	<i>Carrying on (in conversation or action) in the presence of a person as if they were not there.</i>
<i>Imposition</i>	<i>Forcing a person to do something, overriding desire or denying the possibility of choice on their part.</i>
<i>Withholding</i>	<i>Refusing to give asked-for attention, or to meet an evident need.</i>
<i>Accusation</i>	<i>Blaming a person for actions or failures of action that arise from their lack of ability, or their misunderstanding of the situation.</i>
<i>Disruption</i>	<i>Intruding suddenly or disturbingly upon a person's action or reflection; crudely breaking their frame of reference.</i>
<i>Mockery</i>	<i>Making fun of a person's 'strange' actions or remarks; teasing, humiliating, making jokes at their expense.</i>
<i>Disparaging</i>	<i>Telling a person that they are incompetent, useless, worthless, etc., giving them messages that are damaging to their self-esteem.</i>

(Kitwood, 1997, p46-47)

Appendix 2 Elements of Positive Interaction

<i>Recognition</i>	<i>Person acknowledged, known by name and affirmed in own uniqueness. Achieved by greeting or careful listening. May not involve words, a profound act of recognition is eye contact.</i>
<i>Negotiation</i>	<i>People with dementia consulted about preferences, needs and desires often over everyday tasks such as whether they feel ready to get up, or eat. Takes account of anxieties and insecurities and the slower rate with which information is processed.</i>
<i>Collaboration</i>	<i>Working together on a task rather than doing something to a person with dementia. The initiative and abilities of the person with dementia are also involved.</i>
<i>Play</i>	<i>Spontaneity and self-expression with no goal. The experience has value in itself.</i>
<i>Timalation</i>	<i>Primarily sensuous interaction where intellect is not needed, e.g. massage Provides contact, reassurance and pleasure with minimal demands.</i>
<i>Celebration</i>	<i>A cheerful and lively atmosphere where life is intrinsically joyful. The division between carer and cared for dissolves as all share the same mood.</i>
<i>Relaxation</i>	<i>Low intensity interaction with a slow pace. Many people with dementia can only relax in the presence of others, or when in bodily contact with others.</i>
<i>Validation</i>	<i>Validate the experience of the person with dementia and acknowledge the reality of the persons emotions and feelings and respond on that level. Involves empathy and attempt to understand the person's frame of reference.</i>
<i>Holding</i>	<i>Provide a safe psychological space where the person can know that any difficult emotions will pass without the person doing the holding being driven away.</i>
<i>Facilitation</i>	<i>Provide the parts of an action someone cannot do to enable them to do what the person cannot do. Being sensitive to the potential meanings of a person's movements and interacting at a pace slow enough for meaning to develop.</i>
<i>Creation</i>	<i>This comes from the person with dementia who spontaneously offers something for their abilities and skills. This maybe singing or dancing and inviting others to join in.</i>
<i>Giving</i>	<i>The person with dementia offers help, a gift or expresses thanks, concern or affection. Often people with dementia are sensitive to the mood and feelings of others and are warm and sincere in this.</i>

(Kitwood, 2019c, p107-109)

Appendix 3 Interview Guide

Interview Guide

1. Can you tell me about the context of your experience of being with someone with advanced dementia?
(work, family etc) *Has it been what you expected*
What did you enjoy/not enjoy?
2. Initially how did you see your role in the life of the person with dementia?
What's the most important thing to you in this?
What do you think you bring to their life?
Why do you think that is important?
Has this changed as you have spent more time doing this?
3. How did this perception change as you spent more time with them/in your role/with people with dementia?

Was there anything specific that made it change?
Why did it change?
4. Can you tell me about a time or about times when you really felt that you had really connected one-to-one with a person in the late stages of dementia, in a way that really meant something to you and to them?
Was it unexpected?
How did it make you feel?
Did you feel they had really understood you?
Did you see them differently than before that encounter?
What did that meaningful encounter mean to you?
How do you know it meant something to the person with advanced dementia?
5. Why do you think you were able to have that meaningful encounter?
What were you doing at the time?

What was the person with advanced dementia doing at the time?

How were you feeling at the time?

How did the person with advanced dementia appear to be feeling at the time?

Was there anything specific that you think made this encounter possible?

6. Have there been times when you haven't been able to have these meaningful person-to-person encounters?

What were you doing at the time?

What was the person with advanced dementia doing at the time?

How were you feeling at the time?

How did the person with advanced dementia appear to be feeling at the time?

Was there anything specific that you think made it difficult to have a meaningful encounter at that time?

7. What impact do you think that you have on the life of a person in the advanced stages of dementia?

How do you make their life easier?

Social inclusion?

Recognise that they are still people/have capacity to make decisions?

8. How has someone with advanced dementia made a difference to your life?

Have they made you see yourself in a different light? Skills, abilities to connect/care/perform?

Have they brought you comfort?

Have they changed your view of people in the advanced stages of dementia?

Look out for comments on fragility/weakness/love/relationship etc

9. If I were to say to you that a lot of people think that people with dementia are just a living shell, or no longer fully human, what would you say?

Why do you think that?

Have you always felt that?

Has your view changed over the time you have worked with people with dementia?

Is there anything that a person with advanced dementia does that makes you say that?

10. If someone asked you how they could have these meaningful person-to-person encounters with someone in the advanced stages of dementia what would you say?

What would you say to people in the same line of work?

Could this be related to family members/people in other jobs that spend time with those with advanced dementia?

Why do you think that might work?

Is there anything you would advise them not to do?

Appendix 4 Information Sheet Participant



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by

Frankie Greenwood



School of Health in Social Science

University of Edinburgh

Information sheet for Participants

My name is Frankie Greenwood and I'm a PhD student at the University of Edinburgh. I am interested in understanding how people have meaningful one-to-one encounters with people who live with advanced dementia. I would like to understand how these encounters might be understood if we thought of human beings as created and held by God. Exploring these encounters from a Christian perspective could help us think about dementia and dementia care in a different way.

I became interested in this subject when I used to provide music workshops for people with dementia in care homes and experienced those meaningful connections for myself.

I would like to invite you to take part in an interview for my research to talk about any experiences that you may have of these encounters as they could really help with this project.

You don't have to have a Christian faith or any other faith to take part. I just want you to be sure that you are happy that your experiences will be analysed and explained within a Christian framework if you do take part.

What is the purpose of this research project and the interview?

Dementia, or what it might be like to live with dementia is not always well understood. Sometimes people with dementia are thought of as a "non-person" especially when they can

no longer communicate through words. People with dementia can become socially isolated because people find it difficult to relate to them. I would like to understand the kinds of things that make it possible to have meaningful one-to-one encounters with people in the advanced stages of dementia. It could help improve the lives of those with dementia in our society as it could encourage others to see people who live with advanced dementia as a whole person, capable of communicating and relating with other people in ways that don't need words.

You are in a valuable position to share your experiences of these meaningful one-to-one encounters that you may have had with people who live with advanced dementia. It is important that your experiences are included as this will help me learn about how people can connect with those in the later stages of dementia. The interview will give me the chance to explore in detail how these meaningful one-to-one encounters come about for you. You may also be able to share your experiences of times when these encounters have not happened.

What will happen if I agree to take part?

I will contact you in a few days to check that you have read and understood this information sheet and to ask if you have any questions. If you wish to take part I will ask you to read and sign the enclosed consent form for participation.

You are also being asked to consent to me audio recording and transcribing your interview. I will then use this information as data to base my final findings of the research on.

Why am I asking you to give consent?

It is important that you are clear about the reason for and what is involved should you wish to take part in this research. I therefore ask you to give your "informed consent" to show that you have understood and are happy to take part.

Do I have to take part?

It is up to you to decide whether you take part in the research and you are free to change your mind at any time without giving a reason up until the time the interview is written up.

Will the fact I take part in the interview be held confidentially?

No personal information will be shared with any other organisations except in the exceptional circumstances that serious issues of harm or care come to light during the research. Procedures for the handling, processing and storage and destruction of data comply with the Data Protection Act 1998.

If I use a quote from you in my research findings I will anonymise the information. I will refer to you as a "participant" or use a pseudonym.

Benefits and Risks

You would be making a very valuable contribution to our understanding of the kinds of things that make it possible to have meaningful one-to-one encounters with people who live with advanced dementia. These experiences can be shared and may help make them more inclusive for people with dementia in the future. There aren't really any risks to you taking part, however, if something you are talking about upsets you during the interview process, I will stop recording and you will not have to continue. I would then refer you to an appropriate support team or helpline.

What will happen to the results of the research?

The results will be published as a PhD Thesis, in academic and practitioner journals, briefing papers and other formats for different types of people who may be interested in the experience of dementia. They may also be shared with other organisations, through public engagement and with individuals who are interested in the experience of living with

dementia. If you would like to receive a copy of the results of the research then this can be arranged.

Who has reviewed the research study?

This proposed research has been reviewed by the University of Edinburgh School of Health in Social Science ethics committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact:

Frankie Greenwood,
School of Health in Social Science,
University of Edinburgh,
Medical School (Doorway 6),
Teviot Place,
Edinburgh, EH8 9AG. Email: Frankie.Greenwood@ed.ac.uk

Should you wish to speak to someone else about the research you can contact my academic supervisors:

Professor Heather Wilkinson,
Director of Centre for Research on the Experience of Dementia,
University of Edinburgh,
School of Health in Social Science,
Medical School (Doorway 6), Teviot Place,
Edinburgh, EH8 9AG.
email: h.wilkinson@ed.ac.uk

Rev. Dr. Harriet Harris,
University Chaplain
University of Edinburgh
1 Bistro Square
Edinburgh, EH8 9AL
Email: chaplain@ed.ac.uk

If you have a complaint about this project you should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, Email: charlotte.clarke@ed.ac.uk . Or follow the following link:

<http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Appendix 5 Information Sheet Care Staff



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by

Frankie Greenwood



School of Health in Social Science

University of Edinburgh

Information sheet for Care Staff

My name is Frankie Greenwood and I am a PhD student at the University of Edinburgh. Before I started my PhD, I provided music workshops for people with dementia living in care homes. I became interested in understanding how people with and without a more advanced stage of dementia can have meaningful one-to-one encounters with each other.

I am also interested in Christian theology and I want to explore how these encounters might be understood if we thought of human beings being created and held by God. Exploring this from a Christian perspective could give us as a different way of understanding and thinking about dementia and dementia care.

You are being invited to take part in an interview for a research project that explores what it is like to have a meaningful one-to-one encounter with people who are in the advanced stages of dementia, and to explore the times when these encounters do not happen.

You do not need to have a Christian faith, or any other faith, it is your personal experience of these encounters that will help with this project. However, I want to ensure that you are happy that your experiences will be analysed and explained within a Christian framework.

What is the purpose of this research project and the interview?

Dementia, or what it might be like to live with dementia is not always well understood. This lack of understanding sometimes leads to people with dementia, especially those who can no longer communicate through words, being seen as “non-persons” and socially isolated

because people find it difficult to relate to them. Fortunately, there are people who do relate to people with dementia and have meaningful one-to-one encounters with them. The purpose of this research is to try and understand the kinds of things that make these encounters possible. It could encourage others to develop more meaningful relationships with those with advanced dementia improving the lives they lead within our society.

You are in a valuable position to share your experiences of the meaningful one-to-one encounters that you may have had with people with dementia who can no longer communicate clearly with their words. The interview will give me the opportunity to talk to you and explore in detail how these meaningful one-to-one encounters come about for you. You may also be able to share your experiences of times when these encounters have not happened.

It is important that your experiences are included as this will help me learn about how people can connect with those in the later stages of dementia.

Why am I asking you to give permission?

It is important that you are clear about the reason for and what is involved should you wish to take part in this research. I therefore ask you to give your “informed consent” to show that you have understood and are happy to take part.

What will happen if I agree to take part?

I will contact you in one week to check that you have read and understood this information sheet and to ask if you have any questions. If you wish to take part I will ask you to read and sign the enclosed consent form for participation.

You are also being asked to consent to me audio recording and transcribing your interview. I will then use this information as data to base my final findings of the research on.

Do I have to take part?

No. It is up to you to decide whether you take part in the research and you are free to change your mind at any time without giving a reason up until the time the findings are written up.

Will the fact I take part in the interview be held confidentially?

No personal information will be shared with any other organisations except in the exceptional circumstances that serious issues of harm or care come to light during the research. Procedures for the handling, processing and storage and destruction of data comply with the Data Protection Act 1998.

If I use a quote from you in my research findings I will anonymise the information. I will refer to you as a “member of care staff” or “participant” or use a pseudonym.

Whilst some people may know the care home that I have contacted for people to take part in my research, I will not name the care home in my findings. Rather I will refer to it as a care home in Scotland. You can choose where the interview takes place if you do not want other people in your care home to notice that you are taking part in this research.

Benefits and Risks

You would be making a very valuable contribution to our understanding of the kinds of things that make it possible for those without dementia to have meaningful one-to-one encounters with those with advanced dementia. These experiences can be shared and may help improve our communities to make them more inclusive for people with dementia in the future. The risks to you are negligible. However, should you become upset during the interview process, I will stop recording and you will not have to continue. I would then refer you to an appropriate support team or helpline.

What will happen to the results of the research?

The results will be published as a PhD Thesis, in academic and practitioner journals, briefing papers and other formats for different types of people who may be interested in the experience of dementia. They may also be shared with other organisations, through public engagement and with individuals who are interested in the experience of living with dementia. If you would like to receive a copy of the results of the research then this can be arranged.

Who has reviewed the research study?

This proposed research has been reviewed by the University of Edinburgh School Of Health in Social Science ethics committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact:

Frankie Greenwood,
School of Health in Social Science,
University of Edinburgh,
Medical School (Doorway 6),
Teviot Place,
Edinburgh, EH8 9AG.
Email: s1553052@ed.ac.uk

Should you wish to speak to someone else about the research you can contact my academic supervisors:

Professor Heather Wilkinson,
Director of Centre for Research on the Experience of Dementia,
University of Edinburgh,
School of Health in Social Science,
Medical School (Doorway 6), Teviot Place,
Edinburgh, EH8 9AG.
email: h.wilkinson@ed.ac.uk

Rev. Dr. Harriet Harris,
University Chaplain
University of Edinburgh
1 Bistro Square
Edinburgh, EH8 9AL
Email: chaplain@ed.ac.uk

If you have a complaint about this project you should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, Email: charlotte.clarke@ed.ac.uk . Or follow the following link:

<http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Appendix 6 Information Sheet Elderflowers



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by

Frankie Greenwood



School of Health in Social Science

University of Edinburgh

Information sheet for Elderflowers

My name is Frankie Greenwood and I'm a PhD student at the University of Edinburgh. I am interested in understanding how people have meaningful one-to-one encounters with people who live with advanced dementia. I would like to understand how these encounters might be understood if thought of human beings as created and held by God. I would like to explore these encounters from a Christian perspective as it could help us think about dementia and dementia care in a different way.

I became interested in this subject when I used to provide music workshops for people with dementia in care homes and experienced those meaningful connections for myself.

I would like to invite you to take part in an interview for my research to talk about any experiences that you may have of these encounters as they could really help with this project.

You don't have to have a Christian faith or any other faith to take part. I just want you to be sure that you are happy that your experiences will be analysed and explained within a Christian framework if you do take part.

What is the purpose of this research project and the interview?

Dementia, or what it might be like to live with dementia is not always well understood. Sometimes people with dementia are thought of as a "non-person" especially when they can no longer communicate through words. People with dementia can become socially isolated because people find it difficult to relate to them. I would like to understand the kinds of things

that make it possible to have meaningful one-to-one encounters with people in the advanced stages of dementia. I would also like to explore the effect that these encounters have had on you. It could help improve the lives of those with dementia in our society as it could encourage others to see people who live with advanced dementia as a whole person, capable of communicating and relating with other people in ways that don't need words.

As an Elderflower you are in a valuable position to share your experiences of the meaningful one-to-one encounters you may have had. It is important that your experiences are included as this will help me learn about how people can connect with those in the later stages of dementia. The interview will give me the chance to explore how these meaningful encounters come about for you and what they mean to you. You may also be able to share your experiences of times when these encounters have not happened.

What will happen if I agree to take part?

I will contact you in one week to check that you have read and understood this information sheet and to ask if you have any questions. If you wish to take part I will ask you to read and sign the enclosed consent form for participation.

You are also being asked to consent to me audio recording and transcribing your interview. I will then use this information as data to base my final findings of the research on.

Why am I asking you to give consent?

It is important that you are clear about the reason for and what is involved should you wish to take part in this research. I therefore ask you to give your "informed consent" to show that you have understood and are happy to take part.

Do I have to take part?

It is up to you to decide whether you take part in the research and you are free to change your mind at any time without giving a reason up until the time the findings are written up.

Will the fact I take part in the interview be held confidentially?

No personal information will be shared with any other organisations except in the exceptional circumstances that serious issues of harm or care come to light during the research. Procedures for the handling, processing and storage and destruction of data comply with the Data Protection Act 1998.

People will know that you are an Elderflower, and therefore may know that you are linked to the xxx organisation. However, if I use a quote from you in my research findings I will anonymise your identity by referring to you as an "Elderflower" or "participant" or use a pseudonym. This will reduce the likelihood of anyone identifying which "Elderflower" the quote refers to.

Benefits and Risks

You would be making a very valuable contribution to our understanding of the kinds of things that make it possible to have meaningful one-to-one encounters with people who live with advanced dementia. These experiences can be shared and may help make society more inclusive for people with dementia in the future. There aren't really any risks to you taking part, however, if something you are talking about upsets you during the interview process, I will stop recording and you will not have to continue. I would then refer you to an appropriate support team or helpline.

What will happen to the results of the research?

The results will be published as a PhD Thesis, in academic and practitioner journals, briefing papers and other formats for different types of people who may be interested in the experience of dementia. They may also be shared with other organisations, through public engagement and with individuals who are interested in the experience of living with

dementia. If you would like to receive a copy of the results of the research then this can be arranged.

Who has reviewed the research study?

This proposed research has been reviewed by the University of Edinburgh School of Health in Social Science ethics committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact:

Frankie Greenwood,
School of Health in Social Science,
University of Edinburgh,
Medical School (Doorway 6),
Teviot Place,
Edinburgh, EH8 9AG. Email: Frankie.Greenwood@ed.ac.uk

Should you wish to speak to someone else about the research you can contact my academic supervisors:

Professor Heather Wilkinson,
Director of Centre for Research on the Experience of Dementia,
University of Edinburgh,
School of Health in Social Science,
Medical School (Doorway 6), Teviot Place,
Edinburgh, EH8 9AG.
email: h.wilkinson@ed.ac.uk

Rev. Dr. Harriet Harris,
University Chaplain
University of Edinburgh
1 Bistro Square
Edinburgh, EH8 9AL
Email: chaplain@ed.ac.uk

If you have a complaint about this project you should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, Email: charlotte.clarke@ed.ac.uk . Or follow the following link:

<http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Appendix 7 Information Sheet Spiritual Carers



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by

Frankie Greenwood



School of Health in Social Science

University of Edinburgh

Information sheet for people who provide spiritual care

My name is Frankie Greenwood and I am a PhD student at the University of Edinburgh. Before I started my PhD, I provided music workshops for people with dementia living in care homes. I became interested in understanding how people with and without a more advanced stage of dementia can have meaningful one-to-one encounters with each other.

I want to explore how these encounters might be understood if we thought of human beings being created and held by God. Exploring this from a Christian perspective could give us as a different way of understanding and thinking about dementia and dementia care.

You are being invited to take part in an interview for a research project that explores what it is like to have a meaningful one-to-one encounter with people who are in the advanced stages of dementia, and to explore the times when these encounters do not happen.

You do not need to have a Christian faith, or any other faith, it is your personal experience of these encounters that will help with this project. However, I want to ensure that you are happy that your experiences will be analysed and explained within a Christian framework.

What is the purpose of this research project and the interview?

Dementia, or what it might be like to live with dementia is not always well understood. This lack of understanding sometimes leads to people with dementia, especially those who can no longer communicate through words, being seen as “non-persons” and socially isolated

because people find it difficult to relate to them. Fortunately, there are people who do relate to people with dementia and have meaningful one-to-one encounters with them. The purpose of this research is to try and understand the kinds of things that make these encounters possible. It could encourage others to develop more meaningful relationships with those with advanced dementia improving the lives they lead within our society.

As someone who provides spiritual care to those with dementia you are in a valuable position to share your experiences of the meaningful one-to-one encounters that you may have had with people with dementia who can no longer communicate clearly with their words. The interview will give me the opportunity to talk to you and explore in detail how these meaningful one-to-one encounters come about for you. You may also be able to share your experiences of times when these encounters have not happened.

It is important that your experiences are included as this will help me learn about how people can connect with those in the later stages of dementia.

Why am I asking you to give permission?

It is important that you are clear about the reason for and what is involved should you wish to take part in this research. I therefore ask you to give your “informed consent” to show that you have understood and are happy to take part.

What will happen if I agree to take part?

I will contact you in one week to check that you have read and understood this information sheet and to ask if you have any questions. If you wish to take part I will ask you to read and sign the enclosed consent form for participation.

You are also being asked to consent to me audio recording and transcribing your interview. I will then use this information as data to base my final findings of the research on.

Do I have to take part?

No. It is up to you to decide whether you take part in the research and you are free to change your mind at any time without giving a reason up until the time the findings are written up.

Will the fact I take part in the interview be held confidentially?

No personal information will be shared with any other organisations except in the exceptional circumstances that serious issues of harm or care come to light during the research. Procedures for the handling, processing and storage and destruction of data comply with the Data Protection Act 1998.

If I use a quote from you in my research findings I will anonymise the information. I will refer to you by your role e.g. “Minister”, “Pastoral carer” or “participant” or use a pseudonym.

Benefits and Risks

You would be making a very valuable contribution to our understanding of the kinds of things that make it possible for those without dementia to have meaningful one-to-one encounters with those with advanced dementia. These experiences can be shared and may help improve our communities to make them more inclusive for people with dementia in the future. The risks to you are negligible. However, should you become upset during the interview process, I will stop recording and you will not have to continue. I would then refer you to an appropriate support team or helpline.

What will happen to the results of the research?

The results will be published as a PhD Thesis, in academic and practitioner journals, briefing papers and other formats for different types of people who may be interested in the experience of dementia. They may also be shared with other organisations, through public

engagement and with individuals who are interested in the experience of living with dementia. If you would like to receive a copy of the results of the research then this can be arranged.

Who has reviewed the research study?

This proposed research has been reviewed by the University of Edinburgh School Of Health in Social Science ethics committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact:

Frankie Greenwood,
School of Health in Social Science,
University of Edinburgh,
Medical School (Doorway 6),
Teviot Place,
Edinburgh, EH8 9AG.
Email: s1553052@ed.ac.uk

Should you wish to speak to someone else about the research you can contact my academic supervisors:

Professor Heather Wilkinson,
Director of Centre for Research on the Experience of Dementia,
University of Edinburgh,
School of Health in Social Science,
Medical School (Doorway 6), Teviot Place,
Edinburgh, EH8 9AG.
email: h.wilkinson@ed.ac.uk

Rev. Dr. Harriet Harris,
University Chaplain
University of Edinburgh
1 Bistro Square
Edinburgh, EH8 9AL
Email: chaplain@ed.ac.uk

If you have a complaint about this project you should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, Email: charlotte.clarke@ed.ac.uk . Or follow the following link:

<http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Appendix 8 Participant Consent Form



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by Frankie Greenwood

Consent Form for Participants

Please Tick Box

Yes No

I have read and understood the information sheet for Participants dated 16 th May 2017		
I have been given the opportunity to ask questions about this project and any concerns I have		
I agree to taking part in this research study and understand that taking part will include my original interview being audio recorded and transcribed		
I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked any questions about why I no longer want to take part		
I understand that my personal details such as phone number and address will not be revealed to people outside the project		
I understand that the information gathered from me in this study will be anonymised		
I understand that my anonymised words may be quoted in publications, reports, web pages, public engagement and other research outputs		
I agree that the anonymised data gathered in this project, may be stored in a UK Data Archive		
I understand if I have a complaint about this project I should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, charlotte.clarke@ed.ac.uk . Or follow the following link: http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf		

Name of Participant.....Signature.....Date.....

Name of Researcher.....Signature.....Date.....

Appendix 9 Amended Information Sheet - Elderflowers



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by

Frankie Greenwood



School of Health in Social Science

University of Edinburgh

Information sheet for Elderflowers

My name is Frankie Greenwood and I'm a PhD student at the University of Edinburgh. I am interested in understanding how people have meaningful one-to-one encounters with people who live with advanced dementia. I would like to understand how these encounters might be understood if thought of human beings as created and held by God. I would like to explore these encounters from a Christian perspective as it could help us think about dementia and dementia care in a different way.

I became interested in this subject when I used to provide music workshops for people with dementia in care homes and experienced those meaningful connections for myself.

I would like to invite you to take part in an interview for my research to talk about any experiences that you may have of these encounters as they could really help with this project.

You don't have to have a Christian faith or any other faith to take part. I just want you to be sure that you are happy that your experiences will be analysed and explained within a Christian framework if you do take part.

What is the purpose of this research project and the interview?

Dementia, or what it might be like to live with dementia is not always well understood. Sometimes people with dementia are thought of as a "non-person" especially when they can no longer communicate through words. People with dementia can become socially isolated because people find it difficult to relate to them. I would like to understand the kinds of things that make it possible to have meaningful one-to-one encounters with people in the advanced stages of dementia. I would also

like to explore the effect that these encounters have had on you. It could help improve the lives of those with dementia in our society as it could encourage others to see people who live with advanced dementia as a whole person, capable of communicating and relating with other people in ways that don't need words.

As an Elderflower you are in a valuable position to share your experiences of the meaningful one-to-one encounters you may have had. It is important that your experiences are included as this will help me learn about how people can connect with those in the later stages of dementia. The interview will give me the chance to explore how these meaningful encounters come about for you and what they mean to you. You may also be able to share your experiences of times when these encounters have not happened.

What will happen if I agree to take part?

I will contact you in one week to check that you have read and understood this information sheet and to ask if you have any questions. If you wish to take part I will ask you to read and sign the enclosed consent form for participation.

You are also being asked to consent to me audio recording and transcribing your interview. I will then use this information as data to base my final findings of the research on.

Why am I asking you to give consent?

It is important that you are clear about the reason for and what is involved should you wish to take part in this research. I therefore ask you to give your "informed consent" to show that you have understood and are happy to take part.

Do I have to take part?

It is up to you to decide whether you take part in the research and you are free to change your mind at any time without giving a reason up until the time the interview is transcribed.

Will the fact I take part in the interview be held confidentially?

No personal information will be shared with any other organisations except in the exceptional circumstances that serious issues of harm or care come to light during the research. Procedures for the handling, processing and storage and destruction of data comply with the Data Protection Act 1998.

People will know that you are an Elderflower, and that you work for the xxx organisation. Due to your own unique Elderflower characteristics and experiences it may be possible to identify your Elderflower character from the information that you share with me in this study. However, your Elderflower name and real name will be anonymised in the data I collect from you. Your anonymised words, including those which may identify your Elderflower character may appear in published results and findings and in other formats where details of this study may be shared.

Benefits and Risks

You would be making a very valuable contribution to our understanding of the kinds of things that make it possible to have meaningful one-to-one encounters with people who live with advanced dementia. These experiences can be shared and may help make society more inclusive for people with dementia in the future. There aren't really any risks to you taking part, however, if something you are talking about upsets you during the interview process, I will stop recording and you will not have to continue. I would then refer you to an appropriate support team or helpline.

What will happen to the results of the research?

The results will be published as a PhD Thesis, in academic and practitioner journals, briefing papers and other formats for different types of people who may be interested in the experience of dementia. They may also be shared with other organisations, through public engagement and with individuals who are interested in the experience of living with dementia. If you would like to receive a copy of the results of the research then this can be arranged.

Who has reviewed the research study?

This proposed research has been reviewed by the University of Edinburgh School of Health in Social Science ethics committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact:

Frankie Greenwood,
School of Health in Social Science,
University of Edinburgh,
Medical School (Doorway 6),
Teviot Place,
Edinburgh, EH8 9AG. Email: Frankie.Greenwood@ed.ac.uk

Should you wish to speak to someone else about the research you can contact my academic supervisors:

Professor Heather Wilkinson,
Director of Centre for Research on the Experience of Dementia,
University of Edinburgh,
School of Health in Social Science,
Medical School (Doorway 6), Teviot Place,
Edinburgh, EH8 9AG.
email: h.wilkinson@ed.ac.uk

Rev. Dr. Harriet Harris,
University Chaplain
University of Edinburgh
1 Bistro Square
Edinburgh, EH8 9AL
Email: chaplain@ed.ac.uk

If you have a complaint about this project you should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, Email: charlotte.clarke@ed.ac.uk . Or follow the following link:

<http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf>

Appendix 10 Amended Consent form Elderflowers



Exploring the experience of having meaningful one-to-one encounters with people in the advanced stages of dementia

A PhD Research Project by Frankie Greenwood

Consent Form for Elderflowers

Please Tick Box

Yes No

I have read and understood the information sheet for Elderflowers dated 9 th December 2017		
I have been given the opportunity to ask questions about this project and any concerns I have		
I agree to taking part in this research study and understand that taking part will include my original interview being audio recorded and transcribed		
I understand that my taking part is voluntary; I can withdraw from the study until the interview is transcribed. I will not be asked any questions about why I no longer want to take part		
I understand that my personal details such as phone number and address will not be revealed to people outside the project		
I understand that the information gathered from me in this study may identify which Elderflower I am, although my Elderflower character's name and my real name will be anonymised		
I understand that my anonymised words may be quoted in publications, reports, web pages, public engagement and other research outputs, although these may identify my Elderflower character		
I agree that the anonymised data gathered in this project, including the information which may identify my Elderflower character will be stored in a UK Data Archive		
I understand if I have a complaint about this project I should contact: Professor Charlotte Clarke, Head of School, Social Science in Health, charlotte.clarke@ed.ac.uk . Or follow the following link: http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf		

Name of Participant.....Signature.....Date.....

Name of Researcher.....Signature.....Date.....

Appendix 11 Data Management Plan

Data Management Plan – Francesca Greenwood – March 2017

What data will be produced?

Qualitative data in the form of audio recordings of interviews between myself and the participants.

Sensitive data will be collected to establish contact/interviews and to gain a profile of my participants.

There will be a maximum of 40 separate interviews in total lasting about 1 hour each.

I will also keep a reflexive journal of my own thoughts and feelings after each interview which will be noted in a journal or audio recorded.

1. Data documentation and description?

The raw initial data which will be the interviews with participants will be audio recorded on to a recording device. Reflexive thoughts will also either be written into a note book or audio recorded as above.

I will also obtain sensitive data in the form of names, addresses, dates of birth, telephone numbers, age and possibly details of religious beliefs may come out in the interview process.

Data from the audio recording devices will be downloaded via VPN/Cisco to the University of Edinburgh M drive as soon as possible after the recording has taken place. I will also make a copy onto an encrypted usb which will be kept in a locked cabinet at my home address or at the University apart from when I am carrying it on my person. The recording on the audio device will then be deleted.

Data will be anonymised or pseudonymised before being transferred to my University of Edinburgh M drive computer network which will be accessed through the VPN/Cisco on my lap top at home. This is a secure connection and access to the VPN/Cisco will be password protected on my laptop. My laptop will be encrypted.

I will email ethics applications/data management plans which contain details of the organisations I will approach for research using the Office 365 email facility provided by the University, and also email my supervisors my transcripts and discussions about them. These transcripts and ethics/data management plans are likely to be downloaded and saved onto my encrypted home computer from time to time, or onto my mobile phone, which

has the encryption facility activated. There are occasions when my home wifi has no service and documents are stored to the drive on my home laptop rather than the University of Edinburgh M drive. Should this be the case, as soon as the wifi connection is restored, I will transfer the documents to my M drive, delete it from my home computer files and the recycle bin.

2. **Structure and storage of data**

Throughout the study, all data will be kept in DataStore. Data store is the University's Research Data Management file-store. The University has provided 500GB of high quality storage with guaranteed backup and resilience. The data in DataStore is automatically replicated to an off-site disaster facility and also backed up with a 60-day retention period, with 10 days of file history visible online.

Standard file formats (<https://www.ukdataservice.ac.uk/manage-data/format/recommended-formats>) and naming and versioning conventions <http://www.ed.ac.uk/records-management/records-management/staff-guidance/electronic-records/naming-conventions> will be followed.

Personal data will be stored such as participant names, addresses, telephone numbers and signatures will be stored manually in locked drawers at my home or in my locker at the University of Edinburgh.

Participant names will be anonymised or pseudonymised in the transcription and research findings .

As soon as the audio recordings have been downloaded on the University M drive and onto my encrypted USB, they will be deleted from the audio device. They will be deleted from the university M drive once the research is completed.

The audio recording device will be stored in the locked cabinet at my home address before the recording has been deleted, or in my locker at the University of Edinburgh.

Personal data will be stored in a locked file or locker until the data analysis is complete and any summary report of findings have been given to participants should they want them. All anonymised data will be held in the University of Edinburgh data store during the research period and then will be placed in the University of Edinburgh data vault for a period of 10 years with an embargo not to share any of the data at any time during the future. The by UKRIO Code of Practice for Research suggests that data is held for at least 3 years to validate research findings, however the University of Edinburgh School of Health suggest at least 10 years.

3. **Data sharing and access after submission of thesis**

The nature of the data I am collecting will be meaningful experiences that the participants have had with others and therefore I do not want other researchers to be able to access or use this data in the future for other purposes. To be able to obtain this data, it will be necessary to gain trust and assurance from the participants and I do not feel that it would be appropriate to hand over control of this data at any time in the future to other researchers.

I would however like to be able to gain access to the data myself in the future if needed and therefore will store my data in the Data Vault which I can access whilst at the University.

4. **Special Requirements for the data**

Participants will be asked to sign written consent forms consenting to the interview, that the interview will be audio recorded and later transcribed.

They will be asked to consent to their words being used in publications, web pages, reports, journals etc being used by the public and other researchers

They will be asked to give consent to the transcript being archived at a facility operated by the University of Edinburgh

5. **Plans for long-term archiving of the digital data supporting the thesis**

Original audio files will be destroyed when the study is over and the transcripts will be deposited in the University of Edinburgh Data Vault for long-term archiving with an embargo not to share.

Appendix 12 Letter to Care Home



School of Health in Social Science

University of Edinburgh

Medical School, (Doorway 6)

Edinburgh

Name of Care Home

EH8 9AG

Date

Dear (Care Home Manager),

Exploring the experience of having meaningful person-to-person encounters with people in the advanced stages of dementia

I refer to our conversation on dd/mm/yy about my PhD research that intends to explore the experience of having meaningful person-to-person encounters with people in the advanced stages of dementia and how these encounters might be understood from a Christian theological perspective.

Dementia, or what it might be like to live with dementia is not always well understood by many people within our society. This lack of understanding sometimes leads to people with dementia, especially those who are in the later stages of the illness and can no longer communicate through words, being seen as “non-persons” and being socially isolated because people find it difficult to have a meaningful relationship or encounter with them.

Care staff in your home will be in a valuable position to share their experiences of the meaningful encounters that they do have and how they

come about as well as the times that they do not. It is important that these experiences are explored as it can help us learn about people can connect with those in the later stages of dementia and encourage helpful ways of seeing a person with advanced dementia within our communities.

I am looking to recruit at least 6 members of staff who would be willing to take part in one or two interviews with me to discuss these encounters. I should be grateful if you would have a read through the enclosed letter and if you are happy, sign it and forward on to the care staff that you think may be interested in taking part.

Thank you for your support in this research, it is greatly appreciated.

If you have any questions then please feel free to get in touch with me on the above number or email address.

Yours sincerely,

Frankie Greenwood

Appendix 13 Gatekeeper cover letter

Gatekeeper organisation headed paper

Exploring the experience of having meaningful person-to-person encounters with people in the advanced stages of dementia

Dear (name of care staff)

Frankie Greenwood is carrying out a PhD research project through the University of Edinburgh that intends to explore the experience of having meaningful person-to-person encounters with people in the advanced stages of dementia and how these encounters might be understood from a Christian theological perspective.

As part of her research Frankie would like to be able to interview some care staff for those in the advanced stages of dementia to explore these experiences. She has asked that I send out invitations to ask if you are interested in more information about the study and whether you might be interested to take part in the interviews for her research.

If you would like more information about the research study then please return the reply slip enclosed, in the stamped addressed envelope. Your response does not mean that you have given consent to take part, just that you would like more information. Frankie will then post out a full information sheet about the research study together with a consent form for you to complete. She will then follow up with a phone call to explain things and ask if you have any questions.

Once you have read all of the information, spoken to Frankie and had time to think it over you can decide if you would like to take part in the research study. It is entirely your decision.

Yours sincerely,

Name of organisation Gatekeeper

I would like more information about the research study that Frankie will be conducting that explores meaningful person-to-person encounters with people in the advanced stages of dementia.

YES/NO

I am happy for you to pass on my contact details below to Frankie/

YES/NO

I am happy for Frankie to contact me directly regarding the research study.

YES/NO

NAME: _____

ADDRESS: _____

TEL: _____

SIGNED: _____

DATE: _____

Appendix 14 Gatekeeper for Family Members

Gatekeeper organisation headed paper

Exploring the experience of having meaningful person-to-person encounters with people in the advanced stages of dementia

Dear (name of family member)

Frankie Greenwood is carrying out a PhD research project through the University of Edinburgh that explores the experience of having meaningful person to person connections with people in the advanced stages of dementia.

The purpose of this research is to try and understand the kinds of things that make these connections possible. It could encourage others to develop more meaningful relationships with those with advanced dementia improving the lives they lead within our society.

As part of her research Frankie would like to be able to interview family members of those who are who have been in the advanced stages of dementia to talk about these experiences. The experiences could make a valuable contribution to the research and Frankie has asked that I send out invitations to ask if you are interested in more information about the study and whether you might wish to take part in the interviews for her research.

Part of Frankie's research may also explore how these connections are made from the Christian perspective that human beings are created and held by God, but you do not need to be a Christian or have any faith to take part. It is your experiences that would be valuable to this research.

If you would like more information about the research study, then please email Frankie at:

Frankie.Greenwood@ed.ac.uk.

Your response does not mean that you have given consent to take part, just that you would like more information.

Please do not include your phone number or address on the email response for data protection purposes, Frankie will contact you with her phone number and arrange for a chat on the phone when she will get this information from you.

Frankie will then post out a full information sheet about the research study together with a consent form for you to complete and follow up with a phone call to explain things and ask if you have any questions.

Once you have read the information, spoken to Frankie and had time to think it over you can decide if you would like to take part in the research study. It is entirely your decision.

Yours sincerely,

Name of Care home

Appendix 15 Excerpt from Interview Transcript

F: [yeah] [yeah] [yeah] Like
what happens in that moment? Can you..can you describe it?

P: It's like I want to climb up on his knee again. That's the comfort feeling that
you get. That's the only

F: [right]

P: way I can describe it, that y'know when he's doing it and he's holding your
hand and err..

F: [it's] making me cry

P: [yeah] and I'm maybe going up to his face err and I just want to curl up
and snuggle in, because that bond is still there. Err so I hold on to that.

Appendix 16 Complete Participant DNA

(PWAD = Person with advanced dementia)

Preparing the story for DNA

Step 1: Translate the story into images

See image

Notice which details might have been expected but are omitted

I started this off asking about matching the breathing, but it evolved into talking more about rhythm, so little was said about the breath.

Slow down and consider the context of this story – wait and listen

This story came after the story about the lady who was crying, and she said in that that she was connecting through the breath, so it was that I wanted to explore more. What I hear is that she is telling about something else that the pwad is offering that she can connect with and find a way in with.

What does the story make narratable?

You can connect with pwad – pwad can be reached

PW and pwad can engage with each other

PWAD are still there and human

What is the force of fear in the story, and what animates desire?

The fear seems to be that actions of a pwad may be seen as an irritation by others rather than a gift as the Elderflower sees it, and it animates the desire to use that as a way in for connection. I suppose this is saying that the pwad needs to be noticed and this animates the desire to engage with them.

Capacities:

Trouble – how does the story make or deal with trouble – trouble being that people with dementia are seen as non-persons, can't communicate, not relational.

PWAD are positioned as being able to engage and relate to another person

PWAD are still there and able to flourish and grow

Character – How is each character cast in the story? Who casts them in that way? How do they come to terms with the trouble? Is the character fixed or fluid? How are characters cast in relation to other non-human objects? Can the objects enable other actors (pwd – other people who are with pwd) to be who they are

Elderflower is cast as someone who values pwd and what they offer and respects their space

Participant is someone who is able to connect and engage with pwd

Participant is someone who notices the body language and responses of the pwd

Trouble

Uses music and rhythm to connect and embellish what the pwd offers

Uses touch to connect

Uses objects, colours to connect

Notices the body language of the pwd

PWAD

Participant casts pwd as those who have something to offer

Participant casts pwd as those who can open up and grow

Participant casts pwd as sometimes closed in on themselves

Participant casts pwd as those who can engage with an activity with others

Trouble

Act through their body – hitting chair, getting louder or stronger in response to Elderflower

Show an awareness of their environment by change in body position

Respond to music or change in rhythm from Elderflower

Inherent mortality – What's the inherent morality in this story in the way it is told? What's good and bad and is there any difficulty in seeing the difference?

Must notice the pwd as being there

Symbiotic – How does the story give the participant life and identity, how do they bring life to the story? Which stories were waiting to be told that bring life? How do stories about objects and places bring life to the participants or

other characters in the story and how does the story bring the object or place into being?

The story gives life to the participant as someone who notices the small and subtle movements of the pwad, showing that she believes they can be reached and are still there, but not only that they are someone who can open up and connect with their environment. The story was waiting to be told as it led on from my question about matching breath and brings the identity of the participant to the front as someone who knows how to connect with pwad because she notices their body language and responses. It also shows how she values the pwad and what they offer and takes that and uses it to bring life to the pwad by encouraging them to open up, notice their environment and engage with others and things around them. The pwad goes from someone who is seen as closed in on themselves to someone who is open and engaging.

The scarves and coloured clothes and gentle musical wash enable the participant to take up that role of engaging as they gently enter the space of the pwad, but also enable the pwad to notice that someone is there for them to relate to and with.

Shape Shifting – How does the story change plots and characters to fit many different circumstances which lets people see themselves in the character in the plot? How are the characters fluid and what is it that persists through the stories?

The story moves from talking about breath to a more obvious body movement of rhythm, hitting a chair or leg and helps the listener pay attention to the things we might all do as humans in terms of making small body movements even when we might not be aware of it. The participant shows how noticing these small movements allows her to engage and connect as she looks for a doorway in and encourages the listener to perhaps notice. As she talks about these rhythms perhaps being an irritation it helps others see how they might respond to that repetitive rhythm from them.

The pwad moves from being closed in and perhaps irritating to some, to someone who is offering a gift, who is rhythmic, participating and engaging, noticing and opening up and engaging – dancing with another person.

The Elderflower notices joins in and embellishes what the pwad offers, and what seems to persist is their ability to notice and encourage the personhood of the pwad.

Performative – What is this story doing in terms of the anticipated response from the listener? How is it doing it? What is it doing? What is being hidden and what is being shown?

The story pulls me as the listener into noticing the small responses of the pwad and seeing them as a way in to connect. Whilst it doesn't speak about where no connection is made, it shows the attention that is needed to notice in the first place. It shows the time that is given to join the pwad where they are at rather than forcing something that you want to happen and in doing so it seems to bring life and therefore make the personhood of the pwad more noticeable and therefore narratable.

Appendix 17 Reordering Stories

An example of reordering the stories of one of the Spiritual Carers.

First Order of Stories	Re-ordering of Stories
Story 1 – The Call	Story 1 – The Minister who gets things going
Story 2 – I believe it's all I here so just be and don't give up	Story 2 – I've brought the church to you
Story 3 – The Minister who gets things going	Story 3 – My heart fills with joy but breaks at the same time
Story 4 – I've brought the church to you	Story 4 – The Call
Story 5 - They make my day and a surprise thank you	Story 5 - They make my day and a surprise thank you
Story 6 – My heart fills with joy but breaks at the same time	Story 6 - I believe it's all I here so just be and don't give up

Appendix 18 Capacity of Collective Stories

What the story makes narratable

What is the force of fear that animates desire?

How does the story deal with the trouble?

What character does the participant cast themselves as in the story?

How does the character deal with trouble?

How is the person with dementia positioned (character) by the participant?

How does the participant say the pwd deals with trouble?

What's the inherent morality in the story told by the participant?

How does the story give the participant and people with dementia life and identity, move through plots and the characters perform to the listener?

Appendix 19 What the Story Makes Narratable

Care Staff Elderflowers Family Members Spiritual Carers

There is a Sense of loss with dementia		There is a Sense of loss with dementia	There is a Sense of loss with dementia
emotional cost to caring for pwad	emotional cost to caring for pwad	emotional cost to caring for pwad	emotional cost to caring for pwad
Pwad are loved and valued	Pwad are loved and valued	Pwad are loved and valued	Pwad are loved and valued
PWAD Belong		PWAD Belong	PWAD Belong
PWAD are relational relationships can be maintained		PWAD are relational/relationships can be maintain	
	PWAD can be reached		
PWAD have a past and a history		PWAD have a past and a history	
Dementia is a human experience	Dementia is a human experience		
PWAD are still there	PWAD are still there	PWAD are still there	PWAD are still there

Appendix 20 Choosing the Overall Capacity of the Stories

I have focused on what the stories made narratable, as I felt that this has the potential to change what is possible in terms of how people with advanced dementia can be positioned and understood by others as they hear these stories.

I focused on 8 different capacities of the stories, 7 of which are the dialogic components of what became narratable in the overall story. These capacities were:

1. *What the story makes narratable*

Overall the data analysis of 12 stories makes several ways of understanding people with advanced dementia narratable.

- Pwad are “still there” – they are reachable, relationships can be maintained, show love, have a positive impact on others, respond to others
- Dementia is a human experience – pwad have a rich past and history, dementia affects a lot of people, we can imagine what it might be like to have dementia
- There is a sense of loss with dementia – cognitive loss, just existing, loss of agency, being demented, confusion etc
- Caring for someone with dementia involves an emotional cost – feel vulnerable, physically demanding, awful to see, dealing with aggression, sad and tragic
- Pwad belong – to a family, church community and are still important to them
- PWAD are loved and valued – cared for, nice to be with, thought about, at the centre of decisions, worth making the effort to keep engaging for

These ways of understanding or seeing people with advanced dementia have been derived from the following dialogic components:

2. *The force of fear that drives the story.*

This is influenced by the way that I have introduced the research to the participants both in my conversations with them before the interview, the introduction sheet and my questions during the interview. It also shows the sense of the participants fear in the story that leads them to act or position the pwad in a particular way.

3. *The inherent morality in the story*

This is closely linked to the force of fear in the story and is my interpretive sense of what the story was telling me about what is inherently “good or bad” in the story.

4. *The character of the participants*

Very early on in my analysis I noticed that there was something quite particular to the character of the participants and why they saw the pwad as still there, and why they didn’t “dehumanise” or “write them off.” The participants sometimes characterise themselves in a certain way – saying things like “I believe they can be reached”, or “I believe they are always connecting”, but largely the characters of the participants are my interpretation. The findings are how they came across to me as I spent time going over the transcripts and reflecting back on what I had written after I had interviewed them – for example as being committed to the care of the pwad.

5. *The character of pwad*

This comes from a mix of how the participant positions the pwad and my interpretation of how the pwad comes across in the story. This is important as there seems to be something about the way the participant notices and sees the pwad that makes them persist in trying to connect, but also my own

interpretation shows how hearing someone's story allows us to see a person with dementia's character in a different light.

6. *How the participant makes connections with pwad –(also known as how the participant deals with the “trouble” – trouble being that pwad are often seen as “not there anymore” or ignored and marginalised)*

This was largely based on what the participant told me they do to connect with pwad. It focuses on the practical things, noticing, learning the skills, developing strategies, music, touch etc. A large part of the way connections are made is that the participants “notice” pwad. That can be that they notice their needs, their body movements, slightest changes in the eyes or facial tension etc.

7. *How the pwad is “still there” (also known as how the pwad deals with he “trouble”)*

This is the way in which the participant talks about the kind of things the pwad does to show that they have connected or engaged, that they are aware of their environment or other people. It includes things like turning their head to a voice, facial expression and body language/responses, becoming calmer, singing, touching or moments of lucidity etc.

7. 1 *How the pwad shows loss or vulnerability*

It was not possible to ignore that dementia brings along with it many difficulties that participants spoke about. These difficulties show that pwad are sometimes vulnerable and there is loss associated with the illness. The stories spoke about the distress pwad sometimes show, behaviours that the participants found difficult to deal with such as aggression, the inability to have conversations or make their own decisions and sometimes being vacant or just existing.

8. *How the story deals with trouble*

This section took the stories I had analysed from each transcript as a whole and gives a sense of how the whole narrative speaks back to or reaffirms the dehumanising narrative that exists – pwad are not there anymore, just a living shell etc. The findings echo much of what is made narratable by the story and shows that throughout most of the transcripts the personhood of the pwad is upheld throughout and that whilst there is a sense of sadness or tragedy at times there is also a sense of joy, love and care for pwad, and overall a clear sense that the pwad is wholly human and very much “still there”.

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