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“guid times wi the bad times”: The meanings and experiences of befriending for people living alone with dementia.

Jane Andrew

PhD
University of Edinburgh
2019

Declaration

I declare that this thesis has been composed by myself, that the work within it is my own unless otherwise stated, and that it has not been submitted for any other degree or professional qualification.

Jane Andrew

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Abstract

Befriending is typically a third sector service in which volunteers provide companionship and support usually to people who are lonely or isolated, most often through one-to-one, face-to-face visits. In the UK around a third of people with dementia live alone. Both UK and Scottish governments include befriending in their national strategies to improve the lives of people affected by dementia. From the stance of a social model of disability, befriending is increasingly allied to the ‘dementia-friendly movement’, a broad range of initiatives designed to make communities inclusive, supportive and empowering for people with dementia.

Existing literature on befriending for people with dementia – mainly pilot studies and service evaluations – tends to focus on those with more advanced conditions, and their views are absent or filtered through third parties. Taking a holistic, case study approach, and drawing on a range of methodologies, this study explored the experiences and meanings of befriending for individuals living on their own with dementia, from their perspectives, in the contexts of their wider lives. During a series of research visits, relatively unstructured conversations with three participants, combined with ethnographic and reflexive accounts, generated a wealth of multifocal data. This allowed the meanings of befriending to be understood in a wider matrix of biography, personal community, everyday living, disability, and life events. In enacting aspects of befriending, the research relationships themselves yielded insights into the obstacles, processes, delicacies and rewards of getting to know someone.

As well as befriending, stories about other relationships – formal and informal, past and present – were especially prominent. Detailed pictures of each person’s social network were developed, and their experiential qualities explored. This led to an awareness of relational gaps and loneliness, and to an appreciation of the distinct place of befriending. The research showed that participants were undergoing multiple transitions, in the here and now, and stretching back in time. Hence, the study questioned decontextualized models of ‘successful’ post-diagnostic transition in dementia, and the tendency to view

the lives of people with dementia solely through the prism of ‘dementia’. Relatedly, data analysis also uncovered ‘betwixt and between’ or ‘both/and’ states: for example, individuals were ill and well; coping and struggling. The concept of persistent liminality was used to capture these complex, fluid experiences. Strengths and limitations of the social model of disability were identified. For participants, wellbeing not only involved removing barriers to a full life but also a response to insoluble difficulties and suffering.

The project had three key messages.

1) Befriending was a kind of friendship and a kind of service. Participants recognised and valued befriending as a friendship *and* as a person-centred service: their needs came first in a relationship that was *for them* but also experienced as mutual and two-way.

2) Befriending satisfied unmet needs and wishes for certain kinds of relationship. As ‘facilitated friendship’, befriending enabled individuals to form the sort of closer, compatible, reciprocal social tie they felt they lacked. To different degrees, memory loss affected how much each person could remember about recent visits but everyone recalled what being in their befriending relationship was like and what was good – and occasionally troublesome – about it. The project pointed to the value of using tailored memory aids to reinforce the psychological presence of befrienders.

3) Befriending had the capacity to ‘meet’ individuals in the persistently liminal spaces they inhabited, responding both to surmountable and inherent limitations in their lives.

Befrienders helped to foster wellbeing from within ill-being – or, as one participant said, “guid times the bad times”.

Lay Summary

Befriending is a service in which volunteers provide companionship and support usually to people who are lonely or isolated, most often through one-to-one, face-to-face visits. In the UK around a third of people with dementia live alone. Both UK and Scottish governments include befriending in their national strategies to improve the lives of people affected by dementia. However, at the time the project was conducted, no formal research had explored what befriending was like for people living on their own with dementia from their points of view.

In 2016, I invited three individuals who had memory problems (and other health conditions) to talk to me about their experiences of long-term befriending and what their befriending relationships meant to them. For each person this also involved sharing information on major life changes such as becoming more unwell, moving to sheltered housing, and coming into contact with more health and social care professionals. These changes often negatively affected their identities and how they felt about themselves, and placed limits on what was it was possible for them to do.

Another way I learned about befriending was by spending time with participants doing the same kinds of things they did with their befriender including chatting, reminiscing, going out to a café, getting to know one another, and sometimes me being asked for practical help.

Everyone in the study described losing contact with people who were important to them – friends, neighbours, and members of their local communities – for a whole range of reasons: bereavement, disability, relocation, giving up driving, and being unable to go out unaided. Yet daily, all three participants saw or spoke to at least one person, and normally several: relatives, home carers, a home help, a hairdresser, cleaners, staff and attenders of day clubs, and sheltered housing workers and residents. Despite this, however, they felt lonely some or much of the time because they missed certain kinds of relationship, because they were still on their own a lot, and because their lives were becoming more of a struggle.

The research had three key messages.

1) Befriending was a kind of friendship and a kind of service.

Befriending relationships were experienced as genuine, close, and life-enhancing – actually as friendships; *and* they were viewed as an organised resource. The combination of friendship with person-centred support was seen as especially beneficial: each participant felt their needs came first in a relationship that was *for them* but also felt to be two-way and mutually enjoyable.

2) Befriending satisfied unmet needs and wishes for certain kinds of relationship.

As a result of health, memory and mobility problems, and other social changes, participants found it hard to make rewarding and confiding relationships. Befriending, as ‘assisted friendship’, enabled individuals to form the sort of closer, mutual, compatible social tie they felt they lacked. To different degrees, memory loss affected how much each person could remember about recent visits but everyone recalled what being in their befriending relationship was like and what was good – and occasionally troublesome – about it.

3) Befriending responded to surmountable and unavoidable challenges.

Befrienders supported participants to overcome obstacles that were stopping them from living as full a life as they wished. They helped individuals do ordinary things like shopping, going out for a walk or a meal, and securing company. As their companions, befrienders were also ‘there’ for them as they continued to live with difficulties and unwished for situations that could not be altered such as declining health, the loss of friendships, or the closeness of death.

Befrienders helped to foster wellbeing from within ill-being – or, as one participant said, “guid times wi the bad times”.

Acknowledgements

Doctoral work is so often a solitary activity but nothing about it is done alone.

My deepest thanks go to the individuals who elected to take part in the study and who contributed so much to it; and to the befriending service coordinators who gave up their time to support me and their clients.

Befriending Networks could not have been more helpful. Liz Watson was a constant source of encouragement and assistance, and played an invaluable part in recruitment. Sarah Van Putten kindly invited me to present my research at an annual Befriending Networks conference in 2018, and has offered to help me disseminate my findings in other ways.

Reflections on my relationships with people living with dementia over the years influenced my decision to study befriending. BA, MR, AG and MW touched me deeply, taught me much, and enriched my life.

My supervisors, Heather Wilkinson and Seamus Prior: simply the best. What a privilege for me to have had the opportunity to learn and develop under their guidance and thoughtful, sensitive engagement with my work. My huge thanks to them both for their generosity and for sticking with me.

It is inconceivable that I would have completed this thesis without my partner, Janet Laverick, and I dedicate it to her. I would need an extra chapter to summarise all that she did and endured: suffice it to say, it was extraordinary on so many levels.

I imagine a PhD friend is a friend for life. No one else really gets it. I was fortunate to become friends with Xiubin Zhang and Katherine Porter. We started together, learned a lot from one another, shared highs and lows, kept, and still keep, each other going, and managed – sometimes – to talk about the world outside our doctorates.

It boosted my morale and belief that the project was worthwhile when other people took a genuine interest in what I was doing. Katharine Gill, Anne Howitt and Hilary Mackenzie were not only interested, they helped me with presentations. Ken and Dorothy Laverick always wanted to know how I was getting on as did Mick and Sandria Andrew, Jenny Cook, and Roger and Frances Gill.

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In the morning we built the city
In the afternoon walked through its streets
Evening saw us leaving...

...What did you learn in the morning?
How much did you know in the afternoon?
Were you content in the evening?

– Ewan MacColl and Peggy Seeger, from 'The Ballad of Accounting'

Chapter 1: Introduction

Introduction

When I heard the news that I had been awarded a studentship, I was at work. More precisely, support work. I was ‘working’ – though, by then, it rarely felt like it – with a woman in her late eighties who had Alzheimer’s disease and lived in a care home. We were regular volunteers on a smallholding. ‘Thursday Farmers’, we called ourselves. At that exact moment, we were standing next to two sheep under a huge, old beech tree, having just finished potting on some seedlings. My news felt pretty momentous but, still ‘on duty’, I held the shock of it in. By the end of the day, I had a blinding headache, and, soon after reaching home, threw up. I lay down in a dark room for the rest of the evening. Thus my PhD career was launched. Later, it sunk in that I would have to seriously cut back my work hours and not see nearly as much of the woman I had known for almost eighteen months. Another support worker would take over, but, for the two of us, no more Thursday Farmers, a good deal less chatting, hanging out and going places; and, for me, due to our scaled down relationship, quite likely, a lot less joy.

We were friends of a sort. She was someone for whom I felt – and feel – deep affection, and, to judge from her remarks, she was fond of me, too. But our ‘sort of’ friendship, albeit close and affectionate, took place in a relationship that was also a work-related association, centred on her needs and wishes, and essentially uneven however much the way we spent our time together was mutually negotiated. My leaving was yet another decision that was not hers to make. Big decisions: where to live. Small decisions: when and what to eat. In her situation, small decisions *were* big decisions because what was at stake was decision-making itself. We would enjoy ourselves at the smallholding and then have to return to the nursing home, a place she did not want to be. Soon after, I would set off back home or to see someone else, often with a happy buzz: ‘work’ was going well. I was helping her have a life outside institutional care, helping her regain some control, and opening up the choices available to her. Then again, as I often reflected, I could leave; she had to stay put. She was permitted to go out, but only with me or another chaperone, and not always at a time of her choosing. She could not visit

me; she could not ring me outside office hours.

I tell this story by way of introducing myself and my interest in this study. If, at times, I experienced tensions and discomfort, as well as huge pleasure, in the above and in other relationships with people with dementia that sat on a work-like-friend-like edge, then what might be the experience of individuals on the other side this kind of social tie? I have worked with older people living with dementia for almost twenty years, as a mental health nurse, and as a support worker, in hospitals, care homes, day centres and in the community. Improving the situation for people with dementia, in whatever capacity, is something I have cared about for a long time. But, also, when I look back over my life, the connections that grew between me and some of the individuals I worked with – even if relatively fleeting, and always temporary – constitute a lot of what has mattered, what had intense meaning, what was good about it.

The reason I am writing these words in this space is because of a case study. A few years ago, I completed a counselling skills course. Our final assignment was to put together a case study of a situation in which we had used our new counselling skills. I wrote mine about my relationship, in a support worker role, with another woman with Alzheimer's disease who lived alone in a council house. It was the story of our how our relationship developed, of the gradual building of trust, of what happened between us. Woven into the case study were strands of personal reflection and excerpts of poetry. The work was well-received, and, one-way and another, it was what led me to apply to do a doctorate. In a circular turn, my thesis also came to be based on case studies of individuals living alone with dementia. This was not my original plan. I had intended to explore the contribution counselling could make to the wellbeing of people with dementia from the perspectives of practitioners. My topic changed, though, as I kept remembering people with dementia, such as those I mentioned earlier, whom, I felt, would benefit from social and emotional support in a one-to-one relationship, but not formal counselling. This opinion was reinforced when I came across the *Some One To Talk To* study (e.g., Anderson & Brownlie, 2011; Anderson, Brownlie & Given, 2009; Brownlie, 2014) which found a reluctance among older people to discuss their feelings

with professionals in the form of therapy or ‘emotions talk’, and which suggested that emotional support, for current cohorts of older people at least, might be best provided in ways that blurred formal and informal approaches (Anderson & Brownlie, 2011). I stumbled upon befriending while looking for specialist dementia counselling services. I had heard of befriending but that was all. On learning more, I felt that this type of facilitated companionship, provided in ‘real-life’ settings, was just what I had been looking for. It appeared that no one had researched what it was like for a person with dementia, living at home, to have a befriender, or not from their point of view.

After I had started work on my revised doctoral project, some junk mail was posted through my door. It was from a private home care agency for older people. It said that, in order to obtain a high-quality personal care service, by ‘topping up’ local authority funding, superior private home care, supplied by that agency, could be purchased. I noticed that, for those who could afford to top up, companionship was a buyable option – one example of the various ways in which the market is taking over from the state and public institutions as the basis of care for many social groups (Phillipson, 2015). On one hand, arguably, this liberates services from the restrictions of traditional support – for instance, the move to ‘personalisation’ and ‘independent living’ – but, on the other, neoliberal economics are creating a more unequal old age (Ferguson, 2012; Phillipson, 2015). Phillipson (2015) writes about the importance of “securing new forms of solidarity” (p. 81) in the midst of our “longevity revolution” (p. 81) by finding ways to reconnect with the “original vision of the welfare state” (p. 93), intended to ensure wellbeing for everyone. He quotes Leys (2010, p. 25) who argues for the need for “protected social spaces”: “areas in which communication and co-operation is not commercialised, where services do not have the character of commodities”. It seemed to me, perhaps naively, that voluntary sector befriending, as a non-commercial service, might be one such protected space, in principle, cost-free and available to all.

I want to acknowledge creative influences in my research. One of these was the Radio Ballads (1957-1964), commissioned by the BBC, and researched and put together by Ewan MacColl and Peggy Seeger (MacColl, 1981). MacColl, Seeger and a co-producer

recorded many hours of conversation, or ‘actuality’, with working men, travelling people, and individuals recovering from polio. The finished ballads were montages of recordings and songs, composed by MacColl and Seeger, based on the experiences of each group, often using their words, and guided by “the breathing patterns in a piece of actuality [and the] pulses and rhythms of speech” (MacColl, 1981, para. 28). One of the features that, at the time, was innovative – indeed, controversial – about the Radio Ballads was the absence of “narrators, caption voices or actors” (MacColl, 1981, para. 6). There were doubts that the producers would be able to “get away with” broadcasting “raw actuality” (MacColl, 1981, para. 9). The programmes consisted solely of people’s spoken words intermixed with sounds and singing. That was it. No introduction, no omniscient presenter, no ‘translation’ of the vernacular, no actors playing the parts of ‘ordinary’ speakers. This is a long way from what I do in my thesis; it would not be research if I did, at least not on its own. However, historically, people with dementia have not been considered able to speak for themselves; their speech, stories and experiences have been ‘introduced’, ‘translated’, ‘presented’ and ‘narrated’ by third parties accorded authority to speak for them, typically family caregivers, healthcare professionals and often researchers. And, given that the ‘voices’ of people with dementia, to this day, are seldom heard, seldom influential, despite significant advances in this area, what I wanted to do in the presentation of my study was to make a lot of space for participants’ words as they uttered them.

A further creative experience that fed into the study, this time of my making, was a prose poem I wrote: ‘The Gay Befriender’. My memory of my own befriender, from long ago, was slow to surface. I wrote the poem as part of preparing to carry out the study: to get to know what it would feel like to tell one of my own stories (and one that was related to my research) before asking other people to do the same. Sharing the story also taught me about the significance of ‘addressees’, and about storytelling as a co-created activity. Around the same time, I had the opportunity to tell, as well as write, my story for different people. I recognised that, even though I tried to write freely without ‘composing’, there were differences between writing and speaking: time to reflect, time to remember, the chance to go back and amend. I created the poem

for myself, but always with the option of sharing it in supervision, and so academic supervisors were never not an imagined audience. I spoke versions of the story with an old friend who remembered its ‘life and times’, with my partner, and with a person trained in psychotherapy. Each telling had a different purpose and ‘vibe’, and different aspects were foregrounded: comic, nostalgic, affective, sociohistorical. I noticed how I felt after telling the stories, variously, exposed, accepted, understood, amused, connected, curious, stimulated, uncomfortable. I saw that my sense of who the audience was to me, and who I was to them, and how we responded to one another in the moment, were integral to the unfolding tale. Insights from the ‘The Gay Befriender’ experience contributed to the way I conducted and understood my research.

Finally, I am aware that, in introducing my thesis, I have not included facts and figures about the ‘longevity revolution’, and other demographic trends, to help contextualise the study. Some statistics, such as the proportion of people who live alone with dementia, are provided in my literature review. Although statistical information on dementia is of major importance for governments, planners and researchers – and concerns all of us – I wanted to avoid ‘time bomb’ metaphors and an emphasis on the scale of the issues. To begin with, anyway, I did not want to present the lives of the individuals who took part in the research as instances of problematic social phenomena. Except to say that the term ‘dementia’ covers a range of neurodegenerative disorders, I do not in other ways define it, although I do indicate the health condition that had brought about each person’s memory loss. Readers of the case studies in this thesis will get to know what ‘dementia’ is, how it is experienced, and what it means, from the viewpoints of participants. While this is a study about befriending, it is not a study *about* dementia. It concerns the life stories that dementia is part of, and the place of befriending in these life stories.

My hope was that the research would generate opportunities for me to learn from participants about the impact of befriending on them and their lives, and about the contexts in which befriending took place; and for us, together, to contribute to a better understanding of this kind of relationship for individuals living with dementia in

different circumstances. I reflect on the extent to which these goals were achieved in my conclusion.

Following this introduction, the thesis is divided into five more chapters. In Chapter 2, I discuss general definitions and characteristics of befriending before going on to review the existing literature on befriending for people with dementia. I also review the literature on living alone with dementia since this was a situation common to all participants in the project. The concept of liminality (van Gennep, 1909/1960; Turner, 1964, 1977) was influential in the study, and I look at examples of its application in dementia and health studies in order to illustrate its analytic potential. Alongside this, I offer a critique of dominant models of transition in dementia. The social model of disability is relevant to some key ideas about the role of contemporary befriending, and I critically discuss this model and the ways it has been applied in dementia studies. Lastly, I explain Reader's (2007) notion of 'patiency' which provides the philosophical ground for my thesis. Chapter 3 sets out the study's methodology and voice-centred relational method of data analysis, and includes a reflexive account of how the research was conducted. In Chapter 4, I present case studies of my participants whom I have named Tom, Grace and Jenny. Chapter 5 consists of further interpretation and discussion of the case studies. In addition to making use of the concepts of liminality and 'patiency', in this chapter, I also draw on Bakhtinian theory (Bakhtin, 1984; Morson & Emerson, 1990); Spencer and Pahl's (2006) idea of personal community; and an existential quality of life framework developed by Dahlberg, Todres and Galvin (2009). Chapter 6 concludes my thesis, covering the contribution the study makes to research literature and its implications for practice, as well as its methodological distinctiveness. I highlight limitations of the project, and suggest areas for future research. I close with some personal reflections on taking part in the research, and my thoughts and feelings at its completion.

Chapter 2: Literature Review

Literature Review

2.0 Introduction

The purpose of this study was to explore the meanings and experiences of befriending for people living alone with dementia. In this chapter I establish the context and rationale for the research through a review of relevant literature on both befriending and living alone with dementia. Part of my thesis is concerned with the strengths and limitations of the social model of disability in dementia studies. Rather than provide an exhaustive review of the literature in this field, I highlight important debates. The chapter also presents concepts which were especially influential in the project, namely, ‘liminality’ (van Gennep, 1909/1960; Turner, 1964, 1977) which informed my analytic and interpretive work; and Reader’s idea of ‘patience’ which grounds the study philosophically.

My literature search drew on a wide range of sources. I used a number of databases – CINAHL, MEDLINE, PsycINFO, Social Care Online and NICE Evidence Services – using singly and/or in combination a variety of search terms including: befriending, buddying, friend, friendship, visitor, visiting, dementia, Alzheimer’s disease, older people, living alone, liminal, liminality, transition, model, social model and disability. I followed up references from scoping and systematic reviews, research papers, and websites. I identified relevant grey literature, journal and newspaper articles, and guidelines. Literature was confined to work published in English in the UK, US and Western Europe from the year 2000 to the present day, but includes some material from earlier decades.

2.1 Literature on Befriending and Dementia: Types and Reasons for Inclusion

There are few qualitative studies on befriending for people affected by dementia. Given the paucity of such research, in my review, I also include literature in the form of policy documents; pilot project evaluations; third sector reports; in-house befriending service evaluations; guidelines on befriending for people with dementia; websites; and journal and newspaper articles. This material covers dementia-related befriending in different settings, and concerns the experiences of family members, volunteers and health professionals as well as individuals living with dementia. However, while I recognise that befriending is reported to have beneficial impacts on others, the focus of the review is the experiences of people with dementia. I am also aware of the wider literature on befriending for groups such as older persons, adults and children with learning disabilities, and individuals with mental health problems. Nonetheless, I have chosen to concentrate on befriending and dementia for three main reasons. Firstly, I cannot find an existing literature review on this topic. Secondly, recent systematic reviews on befriending for older people (Moriarty & Manthorpe, 2012, 2017) contain few references to older people with dementia. Thirdly, there is a need to assess current research in this area in view of the growing policy interest in dementia-related befriending. Where relevant, though, I do refer to studies on befriending for other social groups.

I start by examining different definitions of befriending and what have been seen as its main characteristics.

2.2 Befriending: Definitions and Core Features

Befriending encompasses various models and types of activity, and is delivered in different formats: one-to-one, face-to-face visits (the most common), telephone befriending and group befriending (Befriending Networks, 2014). Befrienders and ‘clients’ have regular – usually weekly – contact. Services endeavour to ‘match’

volunteers and individuals who wish to have a befriender according to shared interests (e.g., Cantley & Smith, 2007), or personality traits (e.g., Hill, 2016), or individual preferences with regard to gender, ethnicity, sexuality, age, language spoken (e.g., Moriarty & Manthorpe, 2017). Ideally, matches are reviewed and monitored for compatibility (Befriending NetworkScotland & Alzheimer Scotland, 2010). Volunteers are supervised and given training on the role of a befriender, and it is considered good practice for befriending organisations to provide, as appropriate, specialist training, for example on dementia (Befriending NetworkScotland & Alzheimer Scotland, 2010). The main ingredients of successful befriending for older people – a consistent finding across the literature in this field – are reliability, compatibility, intimacy, reciprocity and support (Andrews, Gavin, Begley & Brodie, 2003; Cattan, Kime & Bagnall, 2009, 2011; Chal, 2004; Lester, Mead, Graham, Gask & Reilly, 2012).

Some people find the term ‘befriender’ dated or patronising or feel it implies a one-way relationship: “poor old person has nothing to offer and is just there to be ‘befriended’” (survey respondent quoted in Campaign to End Loneliness, 2014, p. 9). Alternatives such as ‘buddy’ (Christ, Kandel, Robbins & Stewart, 2013), ‘VIP’ (Vintage Vibes, n.d.) or ‘Side by Side volunteers’ (Alzheimer’s Society, n.d.) have been adopted by some organisations. Throughout this study, I do not use the word ‘befriender’ to avoid suggesting that a person is only a recipient of, not also a contributor to, a befriending relationship. Where necessary, I refer, instead, to volunteer (befriender) and ‘befriending partner’ (befriender). Along similar lines, Phillips and Evans (2016) use the term ‘client-friend’ rather than ‘befriender’.

Balaam (2015) characterises the key features of contemporary befriending as a “one-to-one friend-like relationship”, “an organised intervention” and a relationship which involves a “negotiation of power and agency” (p. 28). A combination of ‘friend-like relationship’ and ‘organised intervention’ is found in other definitions. Befriending Networks (2014), the UK’s umbrella body for befriending services, describes befriending as:

a way of providing the support of an informal social relationship to an isolated or lonely person who might otherwise entirely lack such support. Whilst sharing some of the attributes of friendship, befriending is a professional relationship – between a befriender and a befriended – which is initiated, supported and monitored by a voluntary or statutory agency, usually through a befriending coordinator. (p. 7)

Befriending is usually seen as a reciprocal relationship in which both volunteer and their ‘befriending partner’ benefit (e.g., Dean & Goodlad, 1998; Howard, n.d.). The boundary between friend and professional, and how this kind of formal/informal relationship is experienced by individuals and volunteers, is explored in a number of research studies (e.g., Andrews et al., 2003; Greenwood, Gordon, Pavlou & Bolton, 2016). I discuss this further below. A distinction is made between mentoring and befriending. Whereas the former is a time-limited, goal-focused intervention, the latter is involved with meeting human needs for companionship over a longer period of time, and is seen as having intrinsic value (Mulvihill, 2011b). According to these definitions, a befriending relationship is, in and of itself, meaningful, having “no particular agenda other than to be social” (McCorkle, Dunn, Mui & Gagne, 2009, p. 294); while, in mentorship, meaning is bound up with achieving outcomes (Befriending Networks, 2014). However, there is evidence that some ‘befriending’ is shifting to a goal-centred model in which, over a fixed timeframe, the work of volunteers is to assist individuals to reconnect with previous, or establish new, social networks (Jopling, 2015; Moriarty & Manthorpe, 2017).

My research aimed to explore befriending which was relationship-focused rather than outcomes-based, and which at least had the possibility of being long-term. However, information from community befriending services for people with dementia suggests that the duration of individual relationships varies. One service (Phillips & Evans, 2016) reported that lasting befriending relationships were uncommon and that most were relatively short-term (a year was considered an ‘achievement’), with endings brought about by both volunteers and ‘client-friends’. In Tower Hamlets Friends and Neighbours (THFN) befriending scheme (THFN, 2012), befrienders usually volunteer

for between a year and eighteen months, though some for considerably longer. Length of volunteer involvement in a study by Greenwood et al. (2016), at the time of the research, ranged between ten weeks and four and a half years, although it is not clear whether this represents overall periods of volunteering or the duration of particular relationships. For people with dementia in particular, the impact of shorter or longer periods of contact with a befriender has not been researched, neither has the experience of losing a befriender or being introduced to a new one.

In a systematic literature review aimed at gaining understanding of how ‘befriending’ in mental health care has been conceptualised, Thompson, Valenti, Siette and Priebe (2016) found that the term was applied to a spectrum of practices ranging from professional or therapeutic work to building relationships closer to ‘real’ friendships. Their review excluded literature on befriending for people with dementia but, in my own literature review, dementia-related befriending, likewise, covers a range of practices such as providing person-centred care, diversional activities and companionship (e.g., McDonnell, McKeown, Keen, Palfreyman & Bennett, 2014); building supportive friendships (e.g., Preston & Burch, 2018); conducting reminiscence therapy as in the Knowing Me Knowing You Befriending Project (Life Changes Trust, n.d.); and forming closer, personal bonds (e.g., Greenwood et al., 2016).

Most bendifenders are volunteers but paid bendifenders do exist for different reasons, such as client trust (Befriending NetworkScotland, 2010), staffing capacity and continuity of service (THFN, 2012). I found one example of individuals being asked to pay a small fee to the befriending organisation (not to their befriender) to help ensure its financial sustainability (Vintage Vibes, n.d.). However, for many in the befriending sector, voluntariness is central to the unique value of befriending, creating a “relatively natural setting” for individuals to build social relationships (Befriending NetworkScotland, 2010, p.3), unlike contact with paid professionals who “have their own agenda”, and are only there in a work capacity (Befriending NetworkScotland, 2010, p.3). In a study on older people’s befriending services (Andrews et al., 2003), the voluntary nature of befriending was important to clients as it implied that bendifenders visited out of choice

rather than obligation. This is seen as “more consistent with the notion of friendship” (Cantley & Smith, 2007, p. 25). I am aware that, according to THFN (2012), for example, some ‘clients’ may not distinguish between paid and volunteer befrienders. However, because the majority of befriending services are provided free of charge, and because of the importance of this within the sector, in my study, I limited recruitment to individuals with dementia who did not pay for befriending and whose befrienders were unpaid.

Studies often comment on power imbalances and the ‘negotiation of power and agency’ (Balaam, 2015) in befriending relationships. These relate to choice in the time, day and duration of visits (e.g., Andrews et al., 2003); asymmetries in the disclosure of personal information; and the decision-making powers of befriending organisations (e.g., Thompson et al., 2016). 6 (2004)¹ suggests that, while befriending is assumed to be offered and entered into voluntarily, in practice, individuals may be encouraged to, or cajoled into, accepting the service. Power imbalances may be less ‘felt’ by clients in befriending relationships which are closer to friendship (Thompson et al., 2016); and may not be problematic if negotiated sensitively (Andrews et al., 2003). The literature on dementia and befriending has addressed the perception and experience of power imbalances from the perspectives of volunteers (Greenwood et al., 2016; see Section 2.5.4) but not individuals with dementia.

Finally, in the context of UK Government austerity measures and decreased public sector funding, befriending is increasingly viewed as an example of a ‘low level’, ‘low cost’, ‘low intensity’, preventive service (e.g., Moriarty & Manthorpe, 2017). However, ‘low level’ and ‘preventive’ services are understood in different ways including assistance to remain at home and maintain independence; support to meet needs that are below the threshold (Clough et al., 2007) or a low priority for (Cantley & Smith, 2007) statutory services; the prevention of ill health, falls (Clough et al., 2007), and crises (Department of Health, 2015); and the need for higher, ‘professional’ levels of care (Clough et al., 2007; Mulvihill, 2011a). Just what ‘preventive’ means in the lives of older people with long-term, degenerative health conditions, such as

¹N.B.: Author’s name is Perri 6

dementia, is not clear. And, as Clough et al. (2007) point out, using the term ‘low level’ for services, such as befriending, which do not require high technical or professional skills appears to suggest that services deemed ‘high-level’ are more important. There is, then, a need to explore the ways in which, from their points of view, people with dementia value (or not) their befriending relationships rather than simply accepting policy perspectives.

While it can be seen that ‘befriending’ embraces diverse models, roles, and activities, common to many of these is the integration, or co-existence, of formal and informal elements – the subject of the next section.

2.2.1 Informal / Formal

Befriending is regarded as an intervention that is distinct from other services and of value in its own right (e.g., Cantley & Smith, 2007; Mentoring and Befriending Foundation, 2010). The distinctiveness of voluntary sector befriending is often expressed in terms of its amalgamation of friend-like and ‘professional’ features. Indeed, the Association of Volunteer Managers (2012) characterises volunteering as a whole as “at the interface between” (para. 4), and a “unique blend” (para. 33) or “nuanced interplay” (para. 10), of formal and informal elements. In befriending literature, a recurring theme is the formal/informal boundary in befriending relationships and the potential for this boundary to be crossed, straddled or blurred in both positive and adverse ways. Bell (1975) articulates a difference between friends and befrienders with regard to what he calls ‘reactive’ – “spontaneous and unreflective” (p. 420) – and ‘objective’ or detached attitudes which, he argues, in Samaritan befrienders, may be in “uneasy balance” (p. 420). Something of this tension appears in research on befriending for people with mental health problems by Mitchell and Pistrang (2011) who found that volunteers sometimes “struggled to find a balance between being ‘non-judgemental’ and ‘being themselves’” (p. 164), and did not experience their befriending relationships as entirely reciprocal.

In dementia services, this has been explored from the perspective of befrienders (Greenwood et al., 2016). For volunteers, the meld of the personal and the formal could be difficult to put into words, being both “like and unlike” other relationships (Greenwood et al., 2016, p. 6), involving “the development of a personal connection within a professional context” (p. 9). Volunteers spoke of their discomfort, at times, in having to manage both ‘professional’ responsibilities and friend-like elements. However, a degree of non-reciprocity was also seen as part of person-centred care and their commitment to putting the needs and wishes of the person with dementia first. Yet little is known about how people with dementia experience – or whether they even distinguish between – formal and informal aspects of befriending. Recent research (McCall et al., 2017) on the experiences of volunteers working with people with dementia in various settings, many of whom were befrienders, found that people with dementia did not discern category differences between people in their social networks,

thus blurring the boundaries between volunteers, staff, carers and people living with dementia. From the perspectives of those living with dementia, these were simply supportive people within their social networks whose interaction with them was often much appreciated (p. 77)

However, the main focus of this research was volunteers, and although people with dementia were consulted, they are not quoted in the finished study, making it unclear to what extent these findings represent their points of view. Hence, one gap in the research literature is whether, from the perspectives of individuals with dementia, befriending is distinct among other relationships in terms of its formality and informality or other characteristics.

Befriending services establish and monitor various formal/informal boundaries in befriending relationships, for example, in relation to confidentiality, the sharing of personal information, volunteers taking on care or domestic roles, and confining contact to agreed times. Dementia-specific befriending guidelines (Befriending NetworkScotland & Alzheimer Scotland, 2010) suggest that befrienders may be more tempted to abandon protocols in order to help clients with dementia who may,

themselves, be less aware of overstepping boundaries. The guidelines highlight the particular importance of boundary awareness in volunteer training. Giving clear signals about boundaries aims to ensure that individuals with dementia are not “hurt by misunderstanding the extent of the relationship” (Service Coordinator quoted in Cantley & Smith 2007, p. 25). However, in research on befriending for older people, Andrews et al. (2003) found that befrienders often engaged in activities outside the remit of the service such as exchanging small gifts, going out, or doing shopping. This could result in tensions and dilemmas “when psycho-social parameters of a relationship (friendship) conflict with the structural parameters of a formal service (befriending)” (p. 359). Yet, for some clients, it was the willingness of the befriender to ‘do extra’ that cemented their relationship, and made it feel more natural, equal and special. Hence, for Andrews et al. (2003), ‘bending the rules’ of a service might foster equality and reciprocity in befriending relationships. Equally, volunteers working with people with dementia appreciated having both role boundaries and also scope to cross them if they felt it appropriate (McCall et al., 2017). Again, though, no studies have explored what individuals with dementia expect of their befrienders, their understanding of the role of befriender, and whether they recognise a line between friendship and service.

Research on befriending for various social groups points to the potential for individuals to mistake befrienders for friends, and hence to be disappointed, bewildered or distressed when the relationship came to an end (e.g., Heslop, 2005; Jamieson, 2008; Thompson et al., 2016). This is all the more likely when, over time, befriending develops into a ‘natural’ relationship much like a friendship (Mitchell & Pistrang, 2011) and has a significant place in the lives of ‘client-friends’ (Heslop, 2005). Guidelines on befriending for people with dementia (Befriending NetworkScotland & Alzheimer Scotland, 2010) draw attention to the possibility that the termination of relationships may cause intense emotions for all concerned, and emphasise the need for well-managed endings. To date, in view of memory loss, any particular impact on individuals with dementia of the cessation of a befriending relationship has not emerged in research studies and project evaluations.

I have already identified some significant gaps in what is known about how people with dementia experience befriending. Yet, in recent UK, Scottish and Welsh Government policies, befriending has variously been seen as an effective approach to tackling loneliness; fostering ‘living well’ with dementia; enabling individuals to live active, healthy, independent lives; and providing carer respite. I now take a closer look at the policy context of dementia-related befriending

2.3 Befriending and Dementia: Policy

Befriending is increasingly allied to the ‘dementia-friendly movement’, a broad range of initiatives designed to make communities inclusive, supportive and empowering for people with dementia (Alzheimer Scotland, 2019; Alzheimer’s Society, 2019), and seen by the Mental Health Foundation (2015) as “a manifestation of the social model of disability in practice” (p. 25). In its second National Dementia Strategy: 2013-2016 (Scottish Government, 2013), the Scottish Government announced that the Life Changes Trust was set to administer a Big Lottery endowment for the benefit of people affected by dementia living in Scotland, one of two recipient groups. The Trust was expected to invest in areas such as “dementia-friendly and dementia-enabled communities, peer support and befriending” (p. 8) with the aim of helping people with dementia, and their significant others, to be “visible, connected and active participants in their local communities” (p. 8). In its third National Dementia Strategy: 2017-2020 (Scottish Government, 2017), as part of plans to support dementia-friendly initiatives, the Scottish Government made a commitment to working with partner organisations to explore possibilities for nurturing, promoting, and increasing participation in “dementia befriending” (p. 22). In both strategies, the role of befriending is linked with the dementia-friendly movement, and there is an emphasis on enabling those living with dementia to remain active and part of their communities. Similarly, the Local Government Association (2015), covering England and Wales, also understands befriending in terms of assisting people with dementia to lead active lives. Arguing that people with dementia consistently identify one-to-one support as key to their ability to participate in community life, it regards befriending, or buddying, as a way to enable

individuals to stay involved in their local areas, both post-diagnostically and as their dementia progresses. It suggests that recruiting volunteers with different backgrounds creates opportunities to engage people with dementia in a wider range of activities.

Meanwhile, in the UK Government's Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015), befriending, along with peer support, is given a remit more in line with the idea of low level, preventive services described above. Here, befriending is viewed as a means to "provide practical and emotional support to people with dementia and their carers, reduce isolation and prevent crisis" (p. 26). Finally, in relation to dementia-specific policies, the Older People's Commissioner for Wales: Comisiynydd Pobl Hŷn Cymru (2018) identifies befriending as a way to increase respite options for carers of people with dementia. It maintains that some individuals with dementia become disorientated and unsettled in unfamiliar respite settings causing carers to worry, and that befrienders may be able to provide a person with meaningful social contact in the familiar surroundings of their own home.

Befriending for people with dementia also falls into broader anti-loneliness policies. These policies reflect the abundance of research evidence showing, firstly, that social isolation and loneliness have a negative impact on physical and mental health and mortality (e.g., Davidson & Rossall, 2014; Windle, Francis & Coomber, 2011); and, secondly, that friends and acquaintances – and the social, emotional and practical support they provide – increase a person's wellbeing and chance to thrive (6, 2004). Across the UK population as a whole, and among older people in particular, loneliness is now regarded as a major health and social concern (e.g., Campaign to End Loneliness, 2019). Both the UK (HM Government, 2018) and Scottish (Scottish Government, 2018) governments have recently brought out national loneliness strategies. In a Connected Society (HM Government, 2018), links between poor health and/or disability and loneliness are seen as multilayered and mutually reinforcing. Befriending is recognised as one of a number of responses with the potential to ameliorate loneliness, and a service that health and social care professionals may 'socially prescribe'. A Connected Scotland (Scottish Government, 2018) flags up the high risk of people with dementia

and their families losing contact with friends, wider family and their communities with knock-on effects on their mental health. A main priority in this loneliness strategy is creating opportunities for people to make social connections with regard to which promoting befriending is seen as an important initiative.

Dementia-related befriending is positioned at the intersection between current policy drives to reduce loneliness and remove barriers to social inclusion. However, as Ward, Howorth, Wilkinson, Campbell and Keady (2011) note, for people with dementia, friendships, relationships outside the family, and the kinds of social ties that constitute friendship are under-researched. In my project, I wanted to explore what befriending meant to individuals with cognitive impairment from their perspectives, rather than assume that contact with befrienders mattered to them purely in terms of policy objectives. This is important because, as I have indicated, their views and first-hand experiences have rarely been included in befriending research.

2.4 Absent Voices

The ‘voices’ of people with dementia are generally missing in the literature on befriending including ‘dementia befriending’. They may be indistinguishable from the experiences of older people, filtered through third parties, or simply not there. It is possible that some research on generic older people’s befriending services includes people with dementia. Andrews et al. (2003), for example, stress the importance of befrienders as reliable visitors for older persons who are “forgetful or confused” (p. 356). But, as Moriarty and Manthorpe (2017) point out, befriending research often lacks detailed demographic information on those using services. However, in one study on older adults’ experiences of befriending (Pennington & Knight, 2008), a diagnosis of dementia was an exclusion criterion, though this was not explained.

Several befriending service and pilot befriending scheme evaluations described challenges in gathering information from, or conducting interviews with, people with dementia. Cotswold Befrienders (Howard, 2014) used a survey method to evaluate

service effectiveness. While volunteers were able to complete postal questionnaires, for clients with long-term conditions, including dementia, the survey had to be implemented via face-to-face interviews lasting up to an hour. The author suggests that the need for this more time-consuming approach explained why many befriending services did not undertake client surveys. Evaluating the impact of a pilot volunteer programme in care homes, Hill (2016) referred to the difficulties of interviewing residents with ‘moderate’ or ‘severe’ dementia.

All the accounts of befriending projects reviewed here include the views of people other than individuals with dementia, and some projects largely, or entirely, relied on the perceptions of third parties – volunteers, paid staff, family members – to assess the impact of befriending (e.g., Hill, 2016; McDonnell et al., 2014; Phillips & Evans, 2016; National Alzheimer Buddies, 2018). However, as Murphy, Jordan, Hunter, Cooney and Casey (2015) point out, combining third-party data with data from individuals with dementia can make it difficult to determine whether some ‘voices’ are prioritised over others. Some accounts appeared to report the experiences of people with dementia but their views were paraphrased or summarised so that it was not clear who was ‘speaking’. For example, listing the benefits of an intergenerational care home befriending scheme, Weir, Goode and McDonald (2010) described how, for “those with dementia, they have the pleasure of being able to talk about the past, which they often find easier to recall than more recent events” (p. 72). Direct quotations from people with dementia which can support the credibility of interpretations and findings (Murphy et al., 2015) were quite rare but, when these did come through, could be powerful. In Hill’s (2016) evaluation of a pilot care home befriending scheme, one resident movingly expresses her feelings about the impact of her befriender’s visits in the context of her social environment:

If I didn’t have the volunteer my morale would be very low. I’d be shouting at everybody – all of us in here have some form of dementia. I ring this bell and nobody comes and nothing happens and then I scream at the matron and say you haven’t got enough staff and she gets very annoyed when I say that but it is true. (Care home resident quoted in Hill, 2016, p. 4)

Methods – or a combination of methods – other than surveys and structured

interviewing are available for conducting research with people with dementia. These include participant observation, open-ended conversations, multiple research visits, and ethnographic approaches. Although more time-consuming, they may be the most effective, appropriate and sympathetic ways of including and supporting the participation of people with dementia in research (e.g., Moriarty & Manthorpe, 2012; Nygård, 2006). Some researchers (Phillips & Evans, 2016) and evaluators (McDonnell et al., 2014) did use participant observation. However, intensive methods over a longer period are likely to be beyond the capacity of small befriending schemes (Howard, 2014; Moriarty & Manthorpe, 2017). As a funded, external researcher, I had the scope and an extended timeframe to develop a methodology which was conducive to an exploratory, as opposed to an evaluative, study, and which, in design and execution, could maximise the involvement of participants with dementia. I discuss this in detail in Chapter 3.

Having pointed to the general absence of the direct views and experiences of people with dementia in the befriending literature, I turn now to look at what is known about the work of befrienders in this field as reported in individual studies, consultations, and pilot project evaluations. These cover befriending in care homes, hospitals and the community, and the experience of volunteers.

2.5 Befriending Services for People with Dementia

2.5.1 Community-Based Befriending

My research focuses on befriending for people living with dementia in community settings which has an especially sparse literature. In terms of formal inquiry, I identified one research study (Phillips & Evans, 2016) and an evaluation (Lingard & Milne, 2004) with an associated guide (Cantley & Smith, 2007), that related entirely or partly to community-based ‘dementia befriending’. I also located a third sector report of a consultation with people living with dementia (Age UK, 2017) which highlighted the importance of making new relationships including through befriending.

From an urban studies perspective, Phillips and Evans (2016), set out to “examine relationships between cities, curiosities and friendships through the lens of befriending practices, directed at people with dementia and those that support them” (p. 3). Most of the accounts in the study were derived from interviews with charity staff, volunteer befrienders, and health and wellbeing professionals. Data on the ways people with dementia experienced their befriending relationships were generated through participant observation, the researchers joining in befriending sessions. One befriending session is described: a man with young-onset dementia is accompanied by his befriender and another male befriender on a walk through the city. The study found that befriending enabled people with dementia to go out and keep in contact with their communities; to have a “free-flowing conversation” (p. 2) with someone who was interested and willing to listen; and to take part in a mutual relationship outside their family and formal care. Walking together in the city could facilitate communication, helping to “reignite exchanges when memory fails” (p. 20), and strengthen the tie between a person living with dementia and their befriender through a shared interest in the city.

The evaluation (Lingard & Milne, 2004) concerned six, geographically dispersed, early dementia advice and support services, piloted by the Mental Health Foundation, in which befriending was an integral component. Difficulties with recruiting and retaining volunteer befrienders were identified, but there were examples of befriending relationships that worked well especially where the individuality of service users was taken into account, and individuals and their befrienders were well matched in terms of shared interests. In a subsequent guide on developing early dementia support services (Cantley & Smith, 2007), befriending was seen as valuable in terms of providing opportunities for people with dementia to engage in stimulating conversation, and extending the range of services open to individuals wishing to participate in activities and have more social contact.

Lastly, an Age UK (2017) report based on consultations with people living with dementia, including those with more advanced dementia, (n = 54) and family members

(n = 12), brought together their views on ‘what made life good’. Findings were used to formulate domains of ‘living well’. Experts in the field then assessed the evidence for, and found examples of, ‘promising approaches’ to supporting individuals with dementia to ‘live well’ in each of the domains. One domain was ‘positive relationships’: people with dementia wanted to maintain their existing relationships and build new ones. Befriending was viewed as a promising approach in this area and considered to be:

often the only viable service intervention for socially isolated people with dementia who have significant personal care needs, as many group based activities are not able to meet the needs of these individuals, and social care packages are rarely sufficient to support people in accessing services outside the home. (p. 38)

I also carried out online searches and found a variety of information on befriending services for people with dementia in the community which gave a flavour of what they offer, who their clients are, and the situations in which they work. This included an online newspaper article announcing the launch of a service aimed specifically at people living alone with dementia (Kelly, 2016), and mini case studies in a journal article (Gillett & Dixon, 2009) and in organisation reports (e.g., Alzheimer Society, 2013; Life Changes Trust, n.d.; THFN, 2012). The case studies provide examples of the range of ways in which volunteers spend time with their befriending partners (e.g., attending appointments, going out for coffee, listening to music, helping with correspondence, chatting at home, swimming, sharing knowledge and experiences); and include some details on the circumstances of ‘client-friends’ (e.g., living alone, having no family in the UK, being housebound, and experiencing language barriers, loneliness, low mood or bereavement).

However, virtually none of the above literature presents the personal views and experiences of individuals with dementia in their own words, and provides only limited information on the wider contexts of their lives. The aim of my research was to capture what individuals with dementia actually had to say about befriending in as much detail as possible, and to gain a fuller understanding of the circumstances in which their befriending relationships took place.

2.5.2 Care Homes

The literature on befriending for people with dementia in care homes consists of evaluations of pilot projects (Downey, 2011; Hill, 2016) and accounts of established befriending schemes (Weir et al., 2010; Christ et al., 2013). Many of the residents participating in these services and pilot projects had more advanced dementia (Christ et al., 2013; Hill, 2016). Only one care home befriending service, the Harvard College Alzheimer's Buddies Program (Christ et al., 2013), was specifically provided for people with dementia. Another befriending service based in care homes, the Midlothian Student Befrienders programme (Weir et al., 2010), involved final-year school students visiting older residents with various physical and mental health problems, though the majority had dementia. Neither of the pilot projects exclusively targeted individuals with dementia. However, Hill (2016) highlighted the large proportion of care home residents with some form of dementia or severe memory problems, while the Relatives and Residents Association (R&RA) project (Downey, 2011) was based on the findings of an earlier survey on isolated older people in care homes (R&RA, 2010) which, likewise, referred to the high numbers of residents with dementia. This means, though, that, in many instances, little or no distinction is made between older people and older people with dementia in evaluation findings.

All the projects and services reported a range of benefits including, for residents, having: a regular visitor who dedicated time to them and who was not a health or social care worker; someone to talk to about a range of issues such as bereavement, loss, loneliness, and their families; opportunities for reminiscence; someone to sit with or hold hands with; something to break-up the day and to look forward to; more purpose and pleasure in life and greater wellbeing (Christ et al., 2013; Downey, 2011; Hill, 2016; National Alzheimer Buddies, 2018; Weir et al., 2010). Hill (2016) points out that residents with dementia enjoyed the company and social stimulation of befriender visits even when they were unable to recognise the volunteer, an observation also noted by McDonnell et al. (2014) in relation to hospital befriending (see Section

2.5.3). In these circumstances, taking pleasure ‘in the moment’ was important (see Befriending NetworkScotland & Alzheimer Scotland, 2010). However, for individuals with dementia who initially can recognise and remember their befriender, the impact of progressive memory loss on their befriending relationship is unknown.

The timescales of befriending in care homes varied, but, in all cases, was bound either by the duration of the pilot project or by limits set by the befriending service. In both the Midlothian Student Befrienders Program and the Harvard College Alzheimer’s Buddies Program, volunteers were students and their visits took place, respectively, for six months and (usually) one semester. The longevity of befriending relationships, and the impact of their endings, are not discussed except by Hill (2016) who reported that the only detrimental outcome for residents in the project was the emotional effects of volunteers withdrawing after close ties had been formed. However, as indicated, while befriending organisations are aware of the potential for upset or confusion when befriending relationships end, which may be complicated by memory loss, this is not something which has especially come to light, or been considered, in studies or evaluations on befriending for people with dementia.

Lastly, a Relatives and Residents Association (2010) survey found that, in care homes in England, as many as 40,000 residents were without – or effectively without – kith and kin. This suggests that of potential relevance to the meaning and experience of befriending is the extent and composition of individuals’ wider social networks, and, if any, the level and kinds of contact they have with members of these networks.

2.5.3 Hospitals

In the UK, up to a quarter of hospital beds are occupied by people with dementia over the age of sixty-five for whom hospitals are often challenging environments (Dewing & Dijk, 2016; Digby, Lee & Williams, 2018; Lakey, 2009). Two pilot initiatives involved volunteers visiting in-patients with dementia. In one (McDonnell et al., 2014), volunteers were asked to provide a mix of befriending, companionship and

diversional activities for orthopaedic patients with dementia as well as support for family caregivers. In the second (Preston & Burch, 2018), ‘buddying’ on two specialist dementia wards was understood as a form of befriending with the purpose of “building a strong and supportive friendship” (p. 141). In both initiatives, the role of befrienders was to provide, enhance or promote individualised care that nursing staff did not, or did not have time to, deliver.

Patients were reported to value the company of volunteers and to enjoy taking part in various activities (McDonnell et al., 2014). While talking with nurses often had a care-related agenda, with volunteers, patients could engage in relaxed, social conversation (McDonnell et al., 2014). Volunteers treated patients as individuals with rich past lives, engaged in pastimes meaningful to them, and recognised that patients unable to communicate verbally were still able to reciprocate in their buddying relationship through laughter, smiles and handholding (Preston & Burch, 2018). According to ward staff, volunteers, families and other professionals involved in the projects, befriending, companionship or buddying were thought to make a valuable contribution to the experience of individuals with dementia in a hospital environment, providing a well-received, person-centred service, which was complementary to, not a substitute for, the work of nurses. All volunteers visited on a weekly basis, and while hospital stays for some patients lasted a matter of weeks, others continued for months (Preston & Burch, 2018). I wondered whether this created the possibility for closer relationships to form and, as a consequence, for endings to have a greater impact, perhaps especially where individuals were isolated or lonely in their normal place of residence. This, though, was not commented on.

Given that the research study and pilot project evaluations on befriending services in all the above settings were designed to assess the impact of befriending relationships on people with dementia (and often formal and informal caregivers), understandably, less attention was paid to conditions for individuals – what they were able to do, what was going on, who else was present or absent, and how they felt – when their befriender was *not* there. This aspect of befriending research – what befriending means to people

as an ‘event’ in their lifeworld – was one of my research questions, and something I wanted to explore holistically.

2.5.4 Volunteers

Studies on the perspectives and experiences of volunteer befrienders of people with dementia are of relevance to my research because they provide insights into reciprocal and mutual aspects of befriending which have consistently been found to be valued by older befriending clients (e.g., Andrews et al., 2003; Chal, 2004). In phenomenological research by Greenwood et al. (2016), volunteers felt that they took on different roles in their befriending relationship such as carer, friend, lunch buddy, and confidante; while, for them, their befriending partners were variously perceived as being, or being like, a friend, an educator, a ‘counsellor’, or a parent, grandparent or partner. Volunteers experienced different degrees of intimacy in their befriending relationships, ranging from pleasant acquaintanceship to social ties in which befrienders spoke of treasuring, even loving, their befriending partner, and sharing their personal lives with them. The subtheme, ‘two-way but not equal’ conveyed volunteers’ experiences of reciprocity combined with their sense of a power imbalance in their befriending relationships, in part derived from a feeling of ‘professional’ responsibility. While participants experienced emotional challenges – for instance, anxiety in particular situations, guilt that they were not doing enough, and boredom at lack of conversational variety – befriending was often a profound source of personal learning, challenging their assumptions about people with dementia, and prompting them to reflect on existential needs for human contact, closeness and belonging. Similarly, in their reflective journals, student befrienders involved in the Harvard College Alzheimer’s Buddies Programme described “formative, life-enhancing experiences” (Christ et al., 2013, p. 649).

A three-year study on volunteering in dementia care (McCall et al., 2017) highlighted other facets of volunteer experiences. This study covered various kinds of voluntary work in different settings (though befriending was one of the main types) and, by and large, the findings are presented in terms of generic volunteering experiences, rather

than specific volunteer roles, so it is not possible to pick out findings pertaining to befriending in particular. In terms of mutuality and reciprocity, while participants often spoke of being motivated through altruism, most felt that the impact of volunteering was two-way, and benefited them in a number of ways including the rewards and enjoyment of social interaction; pleasure and satisfaction from feeling they were improving the lives of people with dementia and their families; greater wellbeing, and opportunities for learning and self-development.

From the perspectives of volunteers, these studies affirm the widely held understanding of befriending as, distinctly, a both work-like and informal relationship, though with marked variation in how individual ties were experienced. The aim of my study was to explore perceptions of befriending from the other side of the relationship by inviting individuals with dementia to talk about what it was like for them to have a befriender.

2.6 Summary

Focusing on the experiences of people with dementia, my review of the literature on befriending suggests that this kind of formal/informal relationship can have multiple positive effects, in different settings, for individuals living in, or spending time in, what may be challenging situations. The potential of ‘dementia befriending’ as a response to a range of social issues has seen it incorporated into current government initiatives on active ageing, dementia-friendly communities, loneliness, and providing breaks for family caregivers. However, throughout this section, I have highlighted gaps in research on befriending and dementia, chiefly the absence of the perspectives of individuals with dementia on a range of topics, and a lack of contextual information. One context for befriending in this study was that all participants lived on their own. I turn now to the current literature on living alone with dementia.

2.7 People Living Alone with Dementia

2.7.1 Introduction

In this section, I review qualitative studies on the experiences of people with dementia who live alone. For those taking part in my project, this was the situation in which their befriending relationships took place. I did not target this subgroup. As described, people with dementia who have a befriender do not necessarily reside in single-person households. However, coincidentally, all those recruited to the study lived on their own, and it became clear that, even though befriending was my primary interest, the research could also contribute to the small but steadily accumulating body of qualitative studies in this area. People living alone with dementia, while they have experiences in common with people with dementia who live with another person, are regarded as a distinct subpopulation with particular support needs (Nourhashemi, Amouyal-Barkate, Gillette-Guyonnet, Cantet & Vellas 2005). However, researchers have reported a number of difficulties with recruiting members of this subgroup to studies (Soniati, 2004; Harris, 2006) including potential participants declining to take part due to fears that involvement with professionals will result in loss of independence; and challenges associated with the extra precautions required to ensure that participant consent is valid (Soniati, 2004).

Some qualitative research has focused on the experience and perceptions of health and social care workers involved in the care of individuals with dementia residing by themselves (de Witt & Ploeg, 2016; Evans, Price & Meyer, 2016); and two qualitative studies concentrated on very specific aspects of living alone with dementia: difficulties and response strategies in telephone use (Nygård & Starkhammar, 2003), and difficulties in using household technology (Nygård & Starkhammar, 2007). My review focuses on qualitative research concerned with living alone from the perspectives of people with dementia. This relates to daily experiences and perceptions of risk (Gilmour, Gibson & Campbell, 2003; n = 10); concerns, experiences and coping strategies (Harris, 2006; n = 15); the spatial (de Witt, Ploeg & Black, 2009; n = 8) and temporal (de Witt, Ploeg

& Black, 2010; n = 8) meanings of living alone with dementia; individuals' lives, strengths and capacities (Duane, Brasher & Koch, 2011; n = 19); identity and coping (Frazer, Oyebode & Cleary, 2011; n = 8); perceptions of domestic environments and surroundings (Lloyd & Stirling, 2015; n = 7); and the phenomenon of living alone with dementia and a manifest care need (Svanström & Sundler, 2015; n = 6). First, though, I provide information on demographic features of people living alone with dementia, and discuss ways that 'living alone' has been defined.

2.7.2 Living Alone with Dementia: Demographics

In the UK, an estimated third of people with dementia live on their own (Miranda-Castillo, Woods & Orrell, 2010, 2013). Living alone with dementia is an increasing social phenomenon, in part due to a general trend towards single-person households in developed countries, and, in part, the result of population ageing (Gabriel, Stirling, Faulkner & Lloyd, 2014). A French study (Nourhashemi et al., 2005) found that older people living alone with Alzheimer's disease, compared to those living with someone, were significantly more likely to be women, poorer and older. In the UK, individuals with dementia who lived by themselves were found to be at increased risk of unmet social, environmental, psychological and medical needs in comparison with those with co-residents (Miranda-Castillo et al., 2010). According to an Alzheimer Society (2013) survey of more than five hundred – relatively well-connected – people with dementia, while overall a third felt lonely, for those living on their own, the figure rose to almost two-thirds. Similarly, in their review of qualitative research on the experience of living alone with dementia, Ohtonen and Oloffson (2017) concluded that a main difference between those living without and those living with another person was that perceptions of loneliness were greater in the former although experiences varied between individuals. In general people with dementia are more likely to feel lonely because factors linked with loneliness are common in people with dementia: living alone or in a care home; poor health; reduced mobility; and cognitive impairment. Loneliness due to dementia is associated with loss of friendships after diagnosis, social withdrawal, diminished confidence, worries about going out alone,

difficulties with motivation and initiating activity, and not remembering visitors (Alzheimer's Society, 2013).

2.7.3 Living Alone with Dementia: Definitions

People with dementia live alone in different social circumstances. Following Newhouse, Niebuhr, Stroud and Newhouse (2001), some studies (Duane et al., 2011; Harris, 2006) placed participants in one of three subcategories: those who live alone but receive frequent support from local family caregivers; those who are supported by long-distance caregivers, typically adult children or siblings; and those who have no close family members. However, Evans et al. (2016) argue that the definition of living alone with dementia should be broadened to reflect more complex realities. They outline an extensive range of 'living alone situations' in which, for example, a person with dementia may be alone during the day, alone at night, temporarily alone (as when family members go on holiday), unexpectedly alone (as a result of a sudden life change such as bereavement), and even alone with another person (as when both husband and wife have dementia, or when a person lives with someone who provides no support).

In the studies reviewed here, apart from Duane et al. (2011) and Harris (2006) – see above – and de Witt et al. (2009, 2010) who specified in their recruitment criteria that participants could receive formal and informal support but had to spend the night on their own, other studies did not define their understanding of living alone. Piecing together information on participants' social networks reported in each study, there appeared to be wide variety in the number, type and frequency of each person's formal and informal contacts, and in the relative proximity or distance of family and friends. One study (Duane et al., 2011) chose to include people with dementia resident in supported accommodation who were classified as living alone by an assessing nurse. This was deemed to be an unexpected aspect of recruitment, raising the question of whether, for research purposes, those residing on their own in sheltered or assisted living accommodation are thought of as 'living alone'. In my view, the perspectives

of people with dementia should contribute to what is understood by living alone. In the research that I carried out, two of three participants lived in sheltered housing and regarded themselves as living alone. Although support was available to them in sheltered housing, each described being on their own in both the negative sense of lacking certain relationships, and in the positive sense of having their ‘own front doors’ and, in principle, the freedom to come and go and live as they please (see Leibing, Guberman & Wiles, 2016, p. 15).

I move on next to discuss key interconnected topics in the ‘living alone’ literature: loneliness, home, mobility, changing sense of self, relationships, and coping and meaning.

2.8 Studies on Living Alone with Dementia

2.8.1 Loneliness

According to Age UK (Davidson & Rossall, 2015) and the Campaign to End Loneliness (2019), loneliness can be defined as an unwelcome subjective feeling which arises when there is a gap between a person’s wished for and actual relationships. Loneliness is said to be ‘emotional’, when the company of a particular person is missed, or ‘social’, when a wider social network is lacking. Social isolation refers to the number of contacts a person has, and may or may not be linked to loneliness: some people elect to be solitary. In the ‘living alone’ studies, many people lived by themselves as a result of the death of their spouse or partner in the recent or more distant past, but some had always lived alone, never marrying or having children, and some were divorced or separated (de Witt et al., 2009; Duane et al., 2011; Frazer et al., 2011). Loneliness was not always strongly associated with living alone. Many participants had access to support networks of family, friends and other people (Duane et al., 2016; Frazer et al., 2011; Harris 2006), though the latter was especially true of those with more advanced dementia (Svanström & Sundler, 2015). Frazer et al. (2011) found that loneliness was linked to both the quantity and the quality of a person’s relationships.

A connection between loneliness and dementia was identified in some studies. Some people felt they were ‘doing this’ – living with dementia – on their own, and wanted someone to talk to (Harris, 2006). Around half the individuals in Harris’ (2006) study spoke of withdrawing from social activities as a result of dementia, putting them at higher risk of loneliness. Some participants in research by Frazer et al. (2011) reported that memory problems were one reason why they had difficulty going out to meet people. In their phenomenological study on people living alone with more advanced dementia, Svanström and Sundler (2015) found that, on their own, individuals experienced an unremitting, dehumanising loneliness and inner emptiness, unable to remember people who had visited or that people were going to visit, and finding it hard to bring to mind individuals they could not see. Participants felt safer at home, had difficulty initiating activity, and were reluctant to seek out nearby friends and family, no longer sure of how to get there. They yearned for company. Attending a day centre provided temporary relief from loneliness but emptiness set in again back at home.

Across the studies, there was considerable variation in participants’ social networks, coexisting health conditions, levels of cognitive impairment, ability to go out, and experience of bereavement, all of which had a bearing on whether or not, and the degree to which, a person felt lonely. Many participants were relatively well-connected and, as others have pointed out (e.g., Harris, 2006), there is a need for research on people living alone with dementia who are more isolated. Also, a more complete picture of individual social networks was missing from the studies, meaning that it was not easy to understand the experience of loneliness within diverse social contexts. In my project, I did not assume that participants would be isolated or lonely. While befriending services are often established to meet the needs of people in this situation, some offer befriending to any individual with dementia which may, at the same time, provide respite for caregivers.

2.8.2 Home

For people with dementia in single-person households, home could be both a sanctuary (Frazer et al., 2011) and a place of confinement (Lloyd & Stirling, 2015); a site of comfort, rootedness and connection with past family life (de Witt et al., 2009), and an empty space of boredom and loneliness (Svanström & Sundler, 2015); a source of both security and threat (de Witt et al., 2009). Lloyd and Stirling (2015) witnessed the breaching of private areas of participants' homes by care workers who entered without invitation. For a number of participants, 'home' was a threshold or transitional space – some were described as “living on the edge” (Harris, 2006, p. 88) – a space between “being here”: managing to live alone at home ; and “being there”: the unwished for, or dreaded, destination of a care home (de Witt et al., 2009, p. 276). The boundaries of these spaces, more than physical, were “created, ‘lived’ or ‘felt’” (de Witt et al., 2009, pp. 273-274). As their dementia progressed, individuals endeavoured to ‘hold onto’ – sometimes “at all costs” (Harris, 2006, p. 88) – the “middle ground” between managing and not managing (de Witt et al., 2009, p. 278), aware that living alone at home would, in time, become impossible. Some of those who were lonely and isolated “preferred to fight on alone” (Frazer et al., 2011, p. 691) rather than give up their homes. ‘Home’ was often a deeply significant place – symbolically, practically and emotionally – not easily yielded, yet not always homely or homelike. Being confined at home was usually the result of mobility difficulties and the impact of cognitive impairment, the subject of the next section.

2.8.3 Mobility

The literature on befriending for older people and people with dementia often points to the beneficial role of befrienders in helping clients go out. Hence it was instructive to look at findings relating to mobility in ‘living alone’ research. The lost or limited capacity of individuals to leave their homes and get about in their local areas was a common topic. Lloyd and Stirling (2015) reported that ‘the will to mobility’, an intrinsic human desire for self-directed movement, permeated participants’ accounts, enhancing life when satisfied and blighting life when frustrated. Frazer et al. (2015) found that loss of independence through reduced mobility and lack of confidence had

a huge impact on participants' lives including making it more difficult for people to reach places where existing relationships could be sustained and new ones formed. Giving up driving was a major hindrance to mobility, signalling the encroaching loss of autonomy, decreasing self-reliance and limiting social life (Frazer et al., 2011; Harris, 2006; Lloyd & Stirling, 2015). Some individuals with dementia feared going out, finding outdoors bewildering and daunting (Lloyd & Stirling, 2015; Svanström & Sundler, 2015). Some worried they would not be able to find their way to places (Svanström & Sundler, 2015) or get home again (de Witt et al., 2009; Frazer et al., 2011). Not all constraints on movement and travel were directly linked to cognitive impairment. Given that over 90% of people with dementia have at least one other health condition, physical and/or mental, and almost 17% have six or more (Browne, Edwards, Rhodes, Brimscombe & Payne, 2017), perhaps surprisingly, only Frazer et al. (2011) and Duane et al. (2011) reported that participants were restricted in their ability to mobilise due to physical limitations. Local infrastructure also had an impact on mobility both for car drivers and pedestrians. Levels of traffic, the complexity of road layouts, the adequacy of street lighting, the redevelopment of familiar environments, and the accessibility of public transport could all enable or hinder independent travel for those living alone with dementia (Lloyd & Stirling, 2015).

The main focus in the studies was independent mobility. It was not always clear whether individuals preferred to stay at home or whether they did not want to go out alone. Individuals in Svanström and Sundler's (2015) study, for example, felt safer at home, yet they also looked forward to going to a day centre using organised transport. Beyond outings arranged by day centres, the benefits, pleasures, or downsides, of going out with the support and company of another person did not appear in the studies; nor did interventions, such as befriending, for people with dementia living on their own who wished to, or had to, remain at home.

2.8.4 Changing Identities and Sense of Self

With regard to changing experiences of self and identity, many findings concerned

phenomena which are not unique to living alone with dementia but common to people with dementia in general. These included changes in self expressed in terms of loss, or the threat of loss, of independence and decision-making powers (de Witt et al., 2009; Duane et al., 2011; Frazer et al., 2015; Harris, 2006); and the negative impact of cognitive impairment on how participants saw themselves and what they felt they were able to do (Frazer et al., 2011; de Witt et al., 2009).

Some studies, however, sought to understand the particular effects on sense of self of living with dementia without a cohabitee. Frazer et al. (2011) were interested in the impact on individuals of having no co-resident to reflect their identities back to themselves. This does, though, presuppose that a co-resident would necessarily reflect back to a person an identity which accorded with their internal sense of self (Josselson, 1992). In fact, in all the studies, participants were described as having some, if not multiple, relationships each capable of a ‘mirroring’ function. Frazer et al. (2015) focused in particular on participants’ friendships in which, they suggest, processes of reflection were two-way and mutually affirming: “the camaraderie of being with others like themselves who might reflect back [...] in a more understanding and sympathetic light than those who were younger and fitter” (p. 691). Svanström and Sundler (2015) found that living alone with more advanced dementia had a profound effect on both a person’s inner sense of self and their embodied self. They describe how participants physically and mentally slowed down, markedly reducing their activity levels and their capacity to gather their thoughts and memories. As a result, their identities “fragmented” (p. 150), and their existence became “vague” (p. 151).

Cognitive impairment, co-existing health conditions, and age-related physical changes affected participants’ sense of self in the present (de Witt et al., 2009; Frazer et al., 2015; Harris, 2006; Svanström & Sundler, 2015); and also through comparisons with their past selves (Frazer et al., 2015), and their imagined future selves (de Witt et al., 2009, 2010; Duane et al., 2011). However, it can be seen from the ‘living alone’ literature as a whole that, very often, individuals’ changing experiences of self occurred in their ongoing relationships with other people (Grenier, 2012). This is another reason why

developing a more comprehensive understanding of a person's social network is so important.

2.8.5 Relationships

The relational contexts of befriending were a particular area of interest in my study. In my review of befriending literature, I indicated that befriending research tended to concentrate on the befriending relationship, itself, rather than in relation to other ties and contacts in a person's life. Hence, information on individuals' experiences of different kinds of relationships in 'living alone' studies was pertinent to my research. None of these studies set out to formally map each person's social network. However, taken together, it seems that many participants had regular contact with a range of people – face-to-face or by telephone or computer – often on a daily basis, though some were more isolated. The make-up of their social networks in terms of formal and informal contacts varied.

A reduction in informal relationships over time, through bereavement, loss of contact, and limited opportunities to form new ties, was noted in several studies (Duane et al., 2011; Frazer et al., 2011; Harris, 2006; Svanström & Sundler, 2015). Individuals who continued to be able to live at home alone were considered to be maintaining their independence but it is evident that most participants increasingly relied on informal and formal supports. The level of detail on people's social networks differed between studies, and so it was difficult to get a sense of the experience and impact of a person's relationships within the network as a whole. For example, de Witt et al. (2009) reported that individuals in their study received community health and social care services as well as support from family members, yet the study findings include no further information about these relationships, a point acknowledged by the authors who explain that participants did not talk about them, possibly, in part, due to the presence in most of the interviews of a family member.

Some studies referred to participants' relations, positive or otherwise, with non-family

groups such as neighbours (Frazer et al., 2011; Lloyd & Stirling, 2015). However, arguably, more important than establishing whether people with dementia living alone have supportive, distant or non-existent ties with their neighbours – clearly this differs from person to person – is coming to understand the place of neighbours, and any other kind of relationship, within individual social networks.

In the ‘living alone’ literature, there was often a focus on whether or not people in the lives of participants provided them with support. As a consequence, reciprocity, ambivalence and complexity in relationships tended to be neglected. Harris (2006), for instance, found that friends as well as family played an important role in supporting people with dementia to live alone at home, but the value of friendships for reasons other than ‘support’ did not feature in her findings.

Although befriending did not appear in any study on living alone with dementia, other ‘solidarity shaping’ interventions (6, 2004) did: adult day programmes, day care, pensioners’ clubs, memory clubs and planned activity groups. Here again, individuals’ experiences were mixed, making it important to understand these interventions in relation to a person’s other social contacts and relationships. Even when participants enjoyed attending organised social groups, this did not necessarily lead to closer ties, meaning that other relational needs and wishes might not be being met. For instance, Frazer et al. (2011) concluded that social contact in pensioners and memory clubs was both “vitaly important” and “fairly superficial” (p. 689). Another example is provided by Svanström and Sundler (2015) who describe how participants liked going to a day centre but, once back home, felt lonely again, unable to ‘hold onto’ memories of being with others at the centre. This points to the importance of the interstices of social networks: what life is like for a person living alone with dementia when they are on their own even if they appear to be well-connected.

Several studies described participants’ experiences of formal care. Home care and other community services were tolerated but not always well-received. Home carer visits were brief and task-related and did not provide conversation or companionship

(Svanström & Sundler, 2015). Individuals had a lot of different home carers (Gilmour et al., 2003) and were not always sure of the reason for their visits (Gilmour et al., 2003; Svanström & Sundler, 2015) or convinced of their necessity (Gilmour et al., 2003). Care workers were observed to enter people's home without permission (Lloyd & Stirling, 2015) and some participants felt pushed aside by home carers who took over household activities (Svanström & Sundler, 2015). Individuals felt that the support provided by care workers and health professionals was based on their priorities (Duane et al., 2011). There were no positive accounts of relationships with home care workers.

Many 'living alone' studies highlighted the ways a person's world could be populated by people not physically present in what has been variously called "communities of the mind" (Spencer & Pahl, 2006, p. 45), "imaginative co-presence" (Lloyd & Stirling, 2015, p. 1808) and the "social world of memory" (Duane et al., 2011, p. 128). This took a range of forms and, to some degree, could help individuals to continue to feel in contact with others and less lonely. People turned on the television and radio 'for company' (de Witt et al., 2009; Svanström & Sundler, 2015) and also tuned into specific programmes (Lloyd & Stirling, 2015) including church services enabling them to participate in a virtual congregation (Harris, 2006). Some accessed the 'social world of memory' through objects, photographs or the sense of significant others embedded in the fabric of their homes (Duane et al., 2011; Lloyd & Stirling, 2015) "whereby the lost embodiment of a deceased person is evoked by a particular setting or material object in a way that consoles, reassures or is otherwise satisfying to the perceiver" (Lloyd & Stirling, 2015, p. 1814). Some participants described being able to consciously draw on a repository of memories of people and places (Duane et al., 2011; Lloyd & Stirling, 2015), bringing them to mind in the present to overcome loneliness, including through sharing reminiscences (Duane et al., 2011). Individuals also had meaningful relationships with God (Harris, 2006), pets (Duane et al., 2011), and personified soft toys (Lloyd & Stirling, 2015); and some experienced a sense of social connection by watching people from their windows (de Witt et al., 2009; Duane et al., 2011). One participant spoke of taking care of her long-dead parents suggesting that they remained alive to her (Gilmour et al., 2003); poignantly, others waited for

their deceased spouse to come home from work and eat dinner with them (Svanström & Sundler, 2015). However, the progression of memory loss could cloud a person's memories of the people in their life, past and present, making it harder to hold them in mind and benefit from the feeling of support and connection this affords (Svanström & Sundler, 2015). Not only their existing social networks but their 'communities of the mind' were shrinking. None of the studies touched on the involuntary 'presence' – in the form of hallucinations (Taylor, 2014), dreams, memories, flash backs – or the conscious recollection of less positive figures or scenarios which might be accompanied by sadness, guilt or distress.

The literature on living alone with dementia exhibits the diversity, quality and quantity of 'on the ground' relationships in people's lives, and also the presence of 'invisible' others in their minds (Spencer & Pahl, 2006). I have highlighted a number of reasons why a fuller picture of individual social networks would be useful especially in terms of identifying relational gaps, and understanding the meaning of particular relationships – in my study, befriending – in the 'system' as a whole.

2.8.6 Coping and Meaning

Most 'living alone' studies addressed how individuals managed living on their own with memory loss, and how they found meaning in their lives. Participants coped by using a range of practical, social and psychological approaches. These included: accepting support (de Witt et al., 2009, 2010; Gilmour et al., 2003; Harris, 2006); keeping busy and active (Duane et al., 2011; Harris, 2006); making use of memory aids (Frazer et al., 2011) and assistive technology, and devising personal 'systems' (Harris, 2006); taking medication (de Witt et al., 2010); practicing religion (Harris, 2006); and using psychological means such acceptance, denial and humour (Frazer et al., 2011; Harris, 2006). Frazer et al. (2011) emphasised the importance of social coping strategies and meaningful human ties. Of particular significance was a feeling of belonging, relationships with "kindred spirits" (p. 689) and "like-minded people" (p. 689), and, for some, "doing things together" (p. 688). Duane et al. (2011) used a "capacities-based

approach” (p. 132) to focus on the skills and strengths participants spoke of using to adapt to changes in their health and continue to live at home independently. However, it can be seen that as well as their skills and strengths, what helped participants adapt was a specific set of circumstances. For example, “the vast majority were able to source comfort, social contact and support, even as they lived alone” (p. 128), and none “indicated that their decline in memory or diagnosis of dementia resulted in negative experiences for them” (p. 130). Duane et al. (2011) argue that focusing on the capacities of marginalised individuals is a way of recognising them as social agents, rather than bearers of deficiencies or recipients of care. This rightly recognises the ways in which individuals with dementia actively shape their lives, challenging the stereotype of passive dependency. However, one problem with privileging capacity in this manner is that it draws ‘capacity’ into a binary with ‘deficit’ or incapacity, seeing them as separate as opposed to coexistent or inextricably linked (Reader, 2007). Alternatively, Frazer et al. (2011) found that ‘coping’ took place amidst, rather than eliminated, feelings of loss, alienation, frustration and exclusion. Participants in their study were ‘just about managing’: resourceful, ‘still’ coping, and finding ways to ‘keep going’, but aware that they could not perform as well as they used to.

Individuals living alone with dementia found meaning in a range of ways such as going for walks or attending a day centre (Gilmour et al., 2003); deriving satisfaction from completing domestic tasks (Duane et al., 2011); having a faith (Harris, 2006); maintaining interests, hobbies, activities or getting involved in voluntary work or dementia activism (Duane et al., 2011; Harris, 2006); and having meaningful relationships (Frazer et al., 2011). However, for those with advanced dementia, coping and finding meaning were much more challenging. Svanström and Sundler (2015) found that participants gradually lost their ‘foothold’ on life as they slowed down physically and mentally. It was the physical presence of, and interaction with, others that ‘spurred’ them into action, and helped restore their identity and meaning in their lives.

In different ways and to differing degrees, participants in all the ‘living alone’ studies

were resourceful and played an active part in coping with dementia, and other health-related difficulties, even those who were at the limit of being able to manage by themselves. But a capacity to cope and lead a meaningful life was also contingent on the character of a person's social network, the severity of cognitive and other impairments, the occurrence of other life events, the presence or absence of various socially generated barriers, and the ability to maintain continuity with previous ways of living.

2.8.7 Summary

From the perspectives of participants in the studies reviewed here, living alone with dementia did not necessarily equate with loneliness, nor was it always undesirable, but some people often or persistently felt lonely. Participants faced everyday challenges relating to dementia and other health conditions and difficulties. Individuals were resourceful but also restricted in their lives, to differing extents, by social, practical and psycho-emotional constraints, some of which could be overcome while others were intractable. The literature on living alone with dementia provides information on the kinds of social contact that participants appreciated or found unhelpful, but has less to say about reciprocity, negotiation and ambivalence in relationships. And, apart from traditional day centres and social clubs, participants were not involved in other forms of 'solidarity shaping' interventions such as befriending. Given wide variation in the composition of individual social networks, and variable experiences of loneliness, there is a need for a more comprehensive understanding of how individuals living alone with dementia experience their relationships within their particular 'system' of social ties.

2.9 Dementia: Transitions and Liminality

2.9.1 Introduction

The concept of liminality was a significant influence in my research, and this part of

the chapter is given over to explaining liminality and its anthropological roots, and to providing an account, with examples, of its analytic capacity to make sense of complex experiential and situational phenomena. Liminality challenges dominant ideas about transitions in later life (Grenier, 2012), and, first of all, I take a critical look at leading dementia-related transition models, analysing their usefulness and limitations.

2.10 Dementia Transition Models

2.10.1 Illness Stages

From a biomedical perspective, dementia is an umbrella term for different kinds of degenerative neurological conditions which progress along a more or less linear course typically divided into stages. Roughly, individuals move from being able to live independently, to requiring assistance with everyday activities and eventually continuous support and palliative care as they move through ‘early’ (or ‘mild’), ‘moderate’ and ‘severe’ (or ‘advanced’) dementia (Innes & Manthorpe, 2012; Kitwood, 1997). Qualitative researchers, too, typically refer to participants’ stage of dementia as an approximate guide to degree of cognitive and/or functional impairment (with implications for research consent), and as a way of targeting particular groups of people with dementia – for instance, Godwin and Poland (2015) set out to explore the self-experiences of people living with ‘advanced dementia’. However, it has been pointed out that illness stages do not correspond with, or capture the diversity of, the individual experiences and capabilities of people with dementia (e.g., Lyman, 1989); that dementia has an unpredictable, uncertain course (e.g., Samsi & Manthorpe, 2014); and that, very often, other health conditions exist alongside dementia (Bunn et al., 2014) which complicate stage-models. Minghella and Schneider (2012) go further, arguing that the biomedical conception of dementia as progressive and life-limiting is oppressive, “anathema to the hope and the notion of life after the diagnosis” (p. 123).

2.10.2 Pre- and Post-diagnostic Transitions

In recent years, partly due to technological advances that have enabled earlier detection of dementia, considerable attention has been given to ‘transitions’ before and after diagnosis, from symptom recognition, to receiving the results of diagnostic investigations, to seeking professional support (Manthorpe et al., 2011). A number of psychotherapeutic and psychosocial models and frameworks are orientated to this ‘pathway’, and focus variously on the emotional, practical and social consequences of being diagnosed with dementia. These include use of an Assimilation of Problematic Experiences Model (Stiles, 2001) in time-limited psychotherapy groups (Cheston, 2004; Lishman, Cheston & Smithson, 2016; Yale’s (2013) structured counselling framework; and the Adaptation-Coping (adjusting to change) Model (Dröes, van Mierlo, van der Roest & Meiland, 2010; Brooker, Dröes & Evans, 2017). In different ways, these provide steps, processes or goals to help individuals to come to terms with, adjust to and cope with a dementia diagnosis. Such adjustment models construct optimal ways of acknowledging, processing and coping with a dementia diagnosis based on individuals adopting appropriate attitudes and behaviours or possessing certain skills and insights. They primarily focus on dementia, not other life issues and situations. I discuss these points further below.

2.10.3 ‘Journey’ Models: Critical Transitions

Some models conceptualise the entire span of ‘the dementia journey’, from diagnosis to end of life care, as a series of phases and key transitions. Fortinsky and Downs’ (2014) ‘transitions typology’ also includes various transfers between home, hospital and residential care during which people with dementia have been found to be at risk of poor outcomes. Rose and Lopez (2012) understand transition as a passage between one life phase, situation or status and another. They describe what they see as a number of “predictable transitions” (p. 1) in the course of dementia which nurses can anticipate and intervene in. Minghella and Schneider (2012) similarly view transitional periods in dementia care as ‘windows of opportunity’ for effective service interventions. Conversely, Samsi and Manthorpe (2014) highlight the uncertainty that often characterises the experience of dementia, and its unpredictability with regard

to symptom stability and levels of progression. For Samsi and Manthorpe (2014), dementia care pathways, another type of model, are attractive precisely because they seem to provide order, clarity and certainty for people with dementia, their significant others and professionals. Care pathways have multiple meanings – guides, mechanisms, manuals – but in essence are ideal “sets of rules or navigation aids” (Samsi & Manthorpe, 2014, p. 2061) or “a linear route along services” (p. 2058).

Mapping out phases, transitions and pathways in dementia has a number of advantages. It helps to focus professional support and guide clinicians (Minghella & Schneider, 2012; Rose & Lopez, 2012; Samsi & Manthorpe, 2014); to establish what people with dementia (and informal caregivers) can, and should, expect from services (Department of Health, 2011); and to set standards and outcomes for practice, service evaluation, and policy (Fortinsky & Downs, 2014; Ponce & Gove, 2016). However, as with stage and adjustment models, individuals with dementia may not ‘fit’ or follow predictable patterns of transition, or subjectively experience their lives in these terms (Grenier, 2012). The ‘journey’ may be characterised by instability and uncertainty without discernible phases, and is shaped by multiple life contexts. At this point, I want to draw out further limitations of ‘stages’, ‘adjustments’ or ‘journeys’ through a more focused critique of two dementia models which construct ‘successful’ and ‘failed’ transitional processes.

2.10.4 The ‘Dementia Journey’: Bridges, Balance and Post-Liminality

Keady, Williams and Hughes-Roberts (2009) use metaphors of bridging and balance to capture the dynamic ongoing processes of adjustment made by people living with Alzheimer’s disease. “Losing Balance Finding Balance Keeping Balance” (p. 147) are transitional experiences which are ‘bridged’ by ‘strong’ or ‘weak’ personal resources, social support, actions, and decisions. Individuals lose balance, for example, when they or others suspect that ‘something is wrong’ with their memory or other cognitive and/or sensory abilities. They find balance again through seeking and receiving a

diagnosis, securing support, and increasing self-understanding. Keeping balance involves acceptance, coping, active decision-making, keeping control, openness about the diagnosis, focusing on quality of life, and maintaining a positive outlook. Successful bridging is described as “biography-centred and relationship-centred” (p. 156) and increases the time a person spends in a state of balance. Having “a well-developed sense of self” (p. 156) grounded in personal life stories, and access to close and loving relationships which support personhood and identity are key elements of strong bridging. ‘Weak’ bridging results in a struggle to regain balance and occurs for a range of reasons including lack of support and information, and individual limitations such as “the re-treading of previous biographical ‘footprints’ of poor adaptation/coping/relationships” (p. 156). Along similar lines, Birt, Poland, Csipke and Charlesworth (2017) explore conditions across the ‘dementia journey’ which support or impede agency and social participation. Transitions around the time of diagnosis are seen as a rite of passage through which, following diagnosis, ‘successful’ individuals emerge from a liminal period of uncertainty and status ambiguity with a new identity, and the potential to reintegrate into society as active citizens. People who do not receive, or who are unable to accept and disclose their diagnosis to others, they suggest, remain in extended liminality with an indeterminate status and a higher risk of social isolation

2.10.5 Critique

Keady et al. (2009) formulated their model from their analysis of four cases in all of which participants with Alzheimer’s disease were well-supported. Birt et al. (2017) developed a rites of passage model for social citizenship subsequent to a scoping review of qualitative dementia research on social participation. The biographical and relationship-oriented and social citizenship approaches advocated in this work are important. However, both models assume, or produce, a common ‘dementia journey’, and experiences tend to be seen through the prism of dementia. There is an implied ‘healthy’ or ‘optimal’ way to adjust to an early diagnosis of dementia based on ‘good’ personal choices, exerting control, particular behaviour patterns and personality features, and a robust sense of self, as well as supportive social surrounds.

Keady et al. (2009) propose that their model is applicable to people with Alzheimer's disease "throughout their experience of living with the condition" (p. 147), and do not differentiate between 'early', 'moderate or 'advanced' dementia when support is increasingly required. Birt et al. (2017) categorise individuals with dementia as living either as "active citizens" or in "the shadow of the fourth age" (p. 203). They recognise that agency and citizenship might look different as dementia progresses but suggest that 'post-liminal destinations' are at least possible – and recognisable – at any point. While each model incorporates the idea of dynamic change within and between transitions, both envisage clear movements into and out of 'balance', uncertainty and ambiguity. Birt et al. (2017) acknowledge that changes beyond the dementia trajectory – comorbidity, loss of social networks, and "micro-social events" (p. 208) – shape individual experiences and may produce "negative narratives" (p. 208). These changes, they argue, can also perpetuate uncertainty and ambiguity, and stall movement along "the journey to post-liminal states" (p. 208). However, incomplete transitions or persistent liminality are regarded as antithetical to 'living well' or agentic social citizenship, not everyday realities. The 'dementia journey' displaces other events and life changes or becomes the lens through which they are rendered meaningful. The contexts and situations which hinder 'Keeping Balance' or 'post-liminality' represent suboptimal conditions in which people fail, or are unable, to live positively with dementia: they are the settings for the dementia journey, not integral to much bigger personal stories. An either/or logic of succeeding or failing to live well with dementia – in balance, post-liminal – does not entertain the spaces 'betwixt and between' ill-being and wellbeing, and takes little account of different kinds of constraints in people's lives.

2.10.6 Summary

While I have indicated that different models of transition in dementia have a range of uses, I have also been critical of normative constructions of the 'dementia journey' which eclipse the heterogeneity of individual experiences, downplay life contexts and

constraints, and regard liminal states as resolvable in clearly recognisable ways. I now examine a rites of passage model of transition, focusing particularly on its liminal, or interim, stage as a fruitful “position from which to think” (Thomassen, 2009, p. 18) about experiences of change. I begin by explaining the model.

2.11 Dementia: Rites of Passage and Liminality

2.11.1 Anthropological Concepts

The anthropological constructs of rites of passage and liminality have significantly influenced understandings of transition in a wide range of fields (Grenier, 2012; Thomassen, 2009). In his seminal work on rituals in small-scale societies, van Gennep (1909/1960) proposed that rites of passage involving the transition of individuals (‘ritual subjects’) or social groups from one status to another status occurred in all societies and shared the same basic structure irrespective of their specific purpose. This structure is tripartite, consisting of phases of separation, transition and reincorporation (Thomassen, 2009; Turner, 1964, 1977). During a separation stage, ritual subjects become detached from, or stripped of, their existing status. In the middle or liminal stage, ritual subjects are positioned ‘outside’ society where they acquire relevant skills and attributes. In the third stage, now with a new status, subjects are reintegrated into society.

For Victor Turner, who further developed the concept of liminality (Thomassen, 2009), transition broadly applied to a change from one state to another where ‘state’ referred to “any type of stable or recurrent condition that is culturally recognised” (Turner, 1977, p. 36). ‘States’ included legal status, profession, and life stage, but also physical or emotional conditions – good or bad health, for example – or times of war or peace, famine or plenty. However, Turner (1964) did not regard ‘transition’ itself as a ‘state’ viewing it, instead, as a “process, a becoming” (p. 46). In the liminal phase, a subject is a “transitional-being” (Turner, 1964, p. 47), or ‘liminar’, neither here nor there or even nowhere, “at once no longer classified and not yet classified” (p. 48). Liminars

are outside and invisible to society, if not physically, then socially since “as members of society, most of us see only what we expect to see, and what we expect to see is what we are conditioned to see when we have learned the definitions and classifications of our culture” (Turner, 1964, p. 47). Liminal-beings, and betwixt and between states, may escape recognition. In ‘tribal societies’, symbols of transition included those of death and decomposition, and those of birth and suckling, often combined in a single representation. A tunnel, for example, might simultaneously signify a tomb and a womb – death and life – and this “coincidence of opposite processes and notions in a single representation characterises the peculiar unity of the liminal: that which is neither this, nor that, and yet is both” (Turner, 1964, p. 49). Hence, liminality is characterised by paradox and ambiguity. Transitional-beings evade, transgress and muddy customary categories.

Thomassen (2009) highlights two key features of van Gennep’s model. First, ritual subjects undertook a rite of passage knowing in advance its purpose and point of initiation; and second, ritual subjects understood that their transition would ultimately be consummated. In other words, such rites had established routes into and out of liminality. However, in other settings and situations, beginnings and endings of transitions may not be clear. In health contexts, for example, individuals often become unwell unexpectedly or imperceptibly, and ‘exits’ from ill-health may be uncertain or impossible. Turner (1977), himself, advanced the idea that liminal or threshold states may cease to be a phase in a process, becoming, instead, more permanent or even, in the case of monks, pilgrims and anchorites, a “set way of life” (p. 37). With regard to more contemporary applications of liminality, Thomassen (2009) outlines how the concept can relate to different subjects – individuals, groups, whole societies – and has spatial and temporal dimensions. Liminality can apply to moments – for example, a sudden life event; to periods such as the time between puberty and adulthood; or to decades, centuries or epochs. Liminal spaces include thresholds such as doorways and orifices; areas or zones including prisons, holiday resorts or borderlands; and larger regions – countries or continents, for example.

In what follows, I provide examples of how a rites of passage structure, and liminality in particular, has been applied in a selection of dementia and other health-related studies. These illustrate the versatility and conceptual richness of liminality as an analytic device. A number of the examples – for instance, research on frailty, life-limiting conditions and ‘interim’ housing – overlap with dementia studies making use of liminality.

2.11.2 Application of Concepts

2.11.2.1 Persistent Liminality: Betwixt and Between

Research on the subjective experience of ill-health, particularly long-term, life-limiting or life-threatening conditions, has found in liminality a fertile concept with which to capture feelings and views which are enduringly ‘in-between’: complex, paradoxical, hard to classify or put into words. Rather than pass through a liminal phase as part of a transition from illness to restored health – a ‘restitution narrative’ (Frank, 1995) – participants in a range of health-related studies remained in persistent states of liminality, for some, even though they had survived their illness. Individuals with chronic kidney disease receiving treatment to sustain life while they waited for a kidney transplant, described ways in which their experiences were neither this nor that and yet both (Molzhan, Bruce & Sheilds, 2008). They were simultaneously ill and well; living and not living; dependent and independent; restricted and free; normal and not normal; alone and connected; better off and worse off. Similarly, in a study on living with life-threatening illness (Bruce et al., 2014), participants articulated complex, non-binary experiences which fluctuated and overlapped. Those living with cancer in remission both had and did not have cancer: cancer was present even in its absence, known and unknown, visible and invisible. Individuals felt at the same time alive and yet taken over by the world of illness: tests, health checks, medical appointments. In this situation, participants endeavoured to take control of their lives within an overall sense of loss of control, experiencing moments of wellbeing against a background of fear.

2.11.2.2 Ambiguous Categories

As previously described, liminal subjects are ambiguous, no longer classified and not yet classified, neither one thing nor another, or simultaneously both. Those who fall outside, or transgress, familiar sense-making categories are often found confusing, disturbing or nonsensical, or simply not ‘seen’, and may be stigmatised (Jackson, 2005; Harjunen, 2003). Jackson (2005), for example, described how people living with chronic pain moved around in “classificatory space” (p. 344) confounding and transgressing divisions between mind and body; physical and emotional; deserving entitlement to pain relief, and undeserving addiction (Jackson, 2005). In biomedical models, in cultural representations, and in popular imagination, people with dementia are ambiguous figures. For many, dementia is quintessentially a condition in which the ‘self’ is progressively lost even as the ‘body’ lives on. Newspapers and television programmes commonly portray dementia as a ‘living death’ (Hillman & Latimer, 2017; Peel, 2014; Zeilig, 2015). Drawing on Turner’s (1969) work on ritual processes, Sweeting and Gilhooly (1997) describe the ambiguous social position of people with dementia as like that of ‘liminars’, in their case making the transition between life and death. As liminal ‘non-people’, they ‘die’ socially well before their biological death, losing attributes such as rights and obligations, sex, status, sexuality, sagacity, autonomy and complexity. Taylor (2014) used the lens of liminality in research on hallucinations in people with dementia. She argues that both dementia and hallucinations confer a stigmatising ambiguity on individuals who are seen to occupy multiple threshold spaces between life and death, health and illness, normal and pathological, and consensus and hallucinatory realities.

2.11.2.3 Space and Time

Liminality has spatial and temporal dimensions. Liminal time is provisional, temporary: ‘liminars’ are ‘between times’. Leibing et al. (2016) developed the idea of “liminal homes” (p. 11), or “threatened” homes (p. 10), to capture the meaning of home for community-dwelling older people whose health was declining. Older people in this

position were described as “in-between” (p. 17) or “hybrid” (p. 18) citizens who lived with the constant possibility of having to move to a more supported living space. In assisted living accommodation, too, Frank (2001) found that residents were similarly suspended in time and place with their homes experienced as “prolonged residence” (p. 5), or residential limbo, rather than permanent housing. Liminality has been used to make sense of spatiotemporal aspects of the experience of people with dementia. Shomaker (1989) explored age and time disorientation in people with dementia. Using the concept of liminality as a timeless, in-between state, temporally neither ‘here’ nor ‘there’ but combining elements of both, Shomaker (1989) found that, as a result of short-term memory loss, individuals with dementia made ‘logical’ sense of the present through their memories of the past, living a “social existence of fused information gathered across the reaches of time” (p. 97). Temporal and spatial dislocation was a theme in Godwin and Poland’s (2015) phenomenological research on the self-experience of people with moderate to advanced dementia living in care homes. In this study, “a feeling of liminality or of uncertainty” (p. 239) was associated with ill-being and insecurity, but not always distressing. I have previously discussed the work of de Witt et al. (2009, 2010) on people living alone with dementia (Sections 2.7& 2.8). I make brief reference to it again, here, since participants in their studies, like liminal-beings, lived ‘threshold’ lives, temporarily and spatially. However, unlike ‘liminars’ in rites of passage, they sought to hold onto the ‘middle ground’ between ‘here’ and ‘there’, and ‘now’ and ‘then’. Further transition only brought them closer to a feared future time and place.

2.11.2.4 Resolving or Exiting Liminality

Up to this point, I have focused on liminality in health studies as an experience of perpetual ‘inbetweenness’. However, in van Gennep’s three-part model, “liminality needs to end somehow” (Thomassen, 2009, p. 18). In the final phase of rites of passage, transitional-beings moved out of liminality and were reincorporated into society with a new status. A rite of passage is a socially constructed process, and some studies have analysed the structural conditions which can either stall or freeze it, or bring it

to completion (e.g., Barrett, Hale & Gauld, 2012; Murphy, Scheer, Murphy & Mack, 1988). For Murphy et al. (1988), based on a three-year anthropological investigation on people with acquired disability (paraplegia and quadriplegia), the advantage of van Genep's model is that it helps conceptualise disability as "a juncture within a process – an arrestment in life history that is dramatized in a rite of passage frozen in its liminal stage" (p. 241). Hence, they argue that disability is not an impairment of the body but a condition imposed by society which disabled people can "fight their way out of" (p. 241). This ties in with a later part of this chapter (Section 2.12) which examines the social model of disability.

In a dementia context, different studies take different views on the possibility of 'exiting' liminality at structural and experiential levels. Using a social citizenship lens and a rites of passage framework, Birt et al. (2017) construct 'post-liminal destinations' for individuals with dementia at different points in their 'journey' (the subject of an earlier critique not reprised here). Birt et al. (2017) were interested in identifying sociocultural barriers, but also individual behaviours, which halt or facilitate the process of post-diagnostic transition for people with early-stage dementia, preventing them from, or enabling them to, form new 'citizen' identities and to reintegrate into society. They outline characteristics of 'post-liminality' after early diagnosis (e.g., realising active citizenship, developing new social networks, maintaining social status), and also in those with more advanced dementia (e.g., achieving agentic interdependence, acknowledging frailty). Living in extended liminality is characterised negatively (e.g., uncertainty about cognitive changes and increasing social isolation), and, to an extent, seen as a matter of personal choice, hinging on ability or willingness to accept and be open about a dementia diagnosis, or to acknowledge frailty. Meanwhile Taylor (2014) looks at both structural and subjective dimensions of the experience of people with dementia and hallucinations. For her, on the one hand, diagnosis clarifies unexplained 'symptoms' and in that respect resolves a liminal phase of uncertainty, with individuals acquiring a new status as 'person with dementia' or 'person with hallucinations'. On the other hand, however, she maintains that, at an experiential level, liminality persists both in day-to-day life with dementia and in hallucinatory

phenomena. Finally, Svanström and Sundler's (2015) study on living alone with more advanced dementia (outlined earlier) suggests, in terms of subjective experience, a different kind of resolution to liminal conditions. Participants could temporarily 'exit' a suspended state of disconnection and inactivity through face-to-face contact with another person with time to talk and listen. This enabled individuals to reconnect with their identity, their past life and their surroundings, and, thereby, to momentarily move out of liminality.

A number of other dementia-related studies, not described here, utilise the concept of liminality: a 'Dementia Grief Model' for family caregivers (Blandin & Pepin, 2017); the experiences of in-patients with dementia in rehabilitation hospitals (Digby et al., 2018); the experience of 'living loss' in people affected by AIDS dementia (Kelly, 2008); and the experience, for individuals with dementia, of creative activities. (Phinney, 2014).

2.11.3 Summary

The purpose of this part of the chapter has been to illustrate how the analytic lens of liminality can capture complex, ambiguous, paradoxical, non-dualistic experiences and situations which may be persistent. The idea of change processes as enduringly liminal undermines models of transition in dementia as a series of stable stages which are predictable, recognisable and achievable. Typically, the 'dementia journey' is also a decontextualised, 'dementia-centric' narrative. The framework of a rite of passage as a socially constructed process has been applied to direct attention to what hinders or permits particular social groups from exiting a position of liminality, and, hence, can shed light on preventable or modifiable barriers to social inclusion and citizenship. For social groups with impairment, this framework is understood in terms of what is known as the social model of disability. In view of this, and in view of policy and research aimed at enabling people with dementia to overcome various obstacles to participating in society, next, I critically discuss aspects of the social model and its application in dementia studies.

2.12 Dementia and the Social Model of Disability

2.12.1 Impairment and Disability

A pivotal move in the disability rights movement was to separate ‘impairment’ from ‘disability’. Disability came to mean social oppression, or ‘disablism’, not a form of impairment (Shakespeare & Watson, 2002). This represented a shift from the medical model to the social model (e.g., Crow, 1996). In the former, individuals are disadvantaged by their functional limitations or impairments which can be overcome by treatment or cure. In the latter, individuals are disadvantaged by social, environmental or attitudinal ‘barriers’ which can only be rectified by barrier removal and social change. The social model attends to the collective experience of disablement, that is, oppression, as opposed to the personal experience of impairment (Oliver, 2004). The powerful idea of a disabling society is the political basis of disability rights campaigns (e.g., Shakespeare & Watson, 2002).

However, within the disability movement, a criticism of this approach was that it sidelined some of the realities of living with impairment including the ways that impairment, as well as barriers, could restrict lives (e.g., Crow, 1996). A counter-argument made by Thomas (2004) was that the view that disabling barriers restrict activity does not preclude the view that restrictions may be directly caused by impairment. Both are possible because “disability only comes into play” (p. 580) when restrictions are social in origin. Crow (1996) called for a renewed social model, one that included the lived experience of impairment, arguing that this need not detract from disability rights activism, that it was feasible “to be honest about the experiences of impairment without underplaying the overwhelming scale of disability” (p. 16). Thomas (2004) uses the term ‘impairment effects’ to refer to non-socially imposed constraints in the lives of disabled people, and, in her ‘social relational model’ of disability, ‘disablism’ to refer to “the social imposition of avoidable restrictions on the activities, aspirations and psycho-emotional wellbeing of people categorised as ‘impaired’ by those deemed ‘normal’” (2010, p. 37). Psycho-emotional dimensions of living in a disabling

society relate to the ways in which internalised oppression damages the self-esteem, confidence and sense of security of individuals living with impairment (Thomas, 1999). Hence, for Thomas (2007), disablism results in both barriers to ‘doing’ and barriers to ‘being’ (as cited in Hanisch, 2014, p. 211). Along with psycho-emotional disablism, Ferrie and Watson (2015) also describe ‘psycho-emotional impairment effects’. In their research on the experiences of people with motor neurone disease, they describe how impairment, itself, had psycho-emotional dimensions, constraining – even overwhelming – individuals in “private spaces and in their private lives” (p. 3). Like Crow (1996), they argue for the need to understand the “visceral experience of impairments, of what it is actually like to live with an impaired body” (p. 4).

Shakespeare (2006) and Shakespeare and Watson (2010) propose a more nuanced conception of disability, one that breaks down the binary between the social model (“contextual essentialism”) and the medical model (“biological determinism”) (Shakespeare & Watson, 2010, p. 57). They contend that, while at a theoretical or political level it is possible to distinguish between impairment and disability, in the everyday lives of disabled people it may be harder to tease them apart. Ferrie and Watson (2015) and Shakespeare (2006) also point out that, in practice, impairment effects, impairment-related psychological distress and socially produced disability and psycho-emotional ill-being may be closely entwined. There have been calls for a “dynamic and multifactorial model of disability” (Shakespeare & Watson, 2010, p. 66) which supports a range of interventions in many different domains – political, cultural, medical, environmental and so on – any and all of which have the capacity to reduce levels of disability. Furthermore, the importance of recognising the heterogeneity of disabled individuals has been emphasised, both in terms of race, class, age, gender, and sexuality (e.g., Thomas & Milligan, 2018), and in terms of the various forms of impairment that individuals have (e.g., Shakespeare & Watson, 2002). These differences affect self-identity, personal experiences, wider social relations and relative advantage and disadvantage across the life course (Thomas & Milligan, 2018). Hence, disability can be seen as a complex, multifaceted phenomenon demanding responses and interventions on a number of different levels. I next examine this conception of

disability in relation to people living with dementia.

2.12.2 Dementia as a Disability

It has taken some time for the disability movement to recognise as disabled and include social groups other than those with physical impairments such as people with learning disabilities, sensory impairment, long-term health conditions, and mental health problems. And while, according to Shakespeare and Watson (2002), the majority of disabled people in the UK are older people with long-term illness, until recently, older people and people with dementia have been marginalised within disability studies (Bartlett & O'Connor, 2010; Thomas & Milligan, 2015). Shakespeare, Zeilig and Mittler (2017) suggest that, generally, individuals with dementia are not seen as part of the disability rights community by professionals, the general public or other disabled people; and may well not consider themselves as disabled. However, within dementia studies, the social model of dementia has long been influential. Indeed, Innes (2009) points to parallels between ideas within the disability movement and conceptual shifts in thinking around dementia. The social model of dementia challenges the biomedical concept of 'dementia' as forms of degenerative illness, and offers a psychosocial understanding of these conditions, emphasising the impact of the social and physical environment on the 'personhood' of people with dementia. Kitwood (1997) coined the phrase "malignant social psychology" (p. 46) to describe a range of attitudes and behaviours that deeply damage the personhood of individuals with dementia, including 'infantilisation', 'invalidation', and 'objectification' (pp. 46-47). Kitwood (1997) understood these processes as "disablement" (p. 46). Sabat (2002), too, contended that the social surrounds of people with dementia could support or jeopardise selfhood, arguing that dementia affected the ways individuals were able to present themselves to the world, and that sustaining their various "social personae" (p. 27) – for instance, 'teacher', 'friend', 'parent' – required the "cooperation" (p. 27) of others. And, as far back as 1994, at an Alzheimer's Disease International Conference, Marshall drew attention to the benefits of regarding dementia as a disability. For people with dementia, she asserted, this would bring a focus on abilities not losses, and recognition

of discrimination and marginalisation, of the value of listening to personal experiences, and of the enabling or disabling impact of the social and built environment (as cited in Gilliard, Means, Beattie & Daker-White, 2005, p. 576).

Spurred on by dementia activism, there is increasing interest in regarding dementia as a disability (e.g., Keyes, Clarke & Gibb, 2019; Mental Health Foundation, 2015; Shakespeare et al., 2017; Thomas & Milligan, 2018). This means acknowledging that “people with dementia are a minority group in society, who are poorly served in many environments, and who consequently face exclusion, even oppression” (Shakespeare et al., 2017, p. 6). Thomas and Milligan (2015) provide numerous examples of attitudinal, behavioural, and institutional barriers which operate in the lives of people with dementia. These include lack of understanding by non-disabled people of the impairment effects of dementia; failure to find ways to communicate with, and to seek the views and wishes of, those with dementia; failure to adapt and design objects, building interiors and external environments to enable people with dementia to remain active and feel comfortable; and the circulation of stereotypical and stigmatising representations of dementia. Recognising dementia as a disability is argued to bring a string of benefits. It promotes a focus on identifying and removing disabling barriers (Shakespeare et al., 2017; Thomas & Milligan, 2015). It gives people with dementia a collective voice and supports self-advocacy (Shakespeare et al., 2017). Disability status can also help to secure rights and legal protections (Shakespeare et al., 2017; Thomas & Milligan, 2018).

Arguably, at least some of these benefits apply to people with dementia whether or not they self-identify as disabled (Mental Health Foundation, 2015; Thomas & Milligan, 2018). Another take on this relates to individuals’ familiarity with the language and concepts of disability rights. One report on ‘dementia capable communities’ (Innovations in Dementia, 2011) found that most consultees with dementia said they had stopped being active in their communities due to their dementia and concerns about how others might react. According to the report, this suggested that “thinking around a social model of dementia has had little impact on those who responded”

(p. 31). Yet it was clear from respondents' quotes that, while individuals did not use the terminology of a social model perspective, they were able to identify barriers – including concerns about others' reactions and lack of understanding – that restricted their activities. They were also able to envisage what a barrier-free community might look like. Of particular relevance to my own study was that all respondents identified a need for volunteers or befrienders, on a one-to-one basis, to help those with dementia go out, take part in activities, and in other ways continue to live their lives as before.

Shakespeare and Watson (2002, 2010) advocate for a nuanced, holistic, multidimensional conception of disability which moves beyond the dualism of medical and social models. This is echoed, in a dementia context, in calls by McParland, Kelly and Innes (2017) for the dismantling of the dichotomy between 'tragedy' and 'living well' narratives. Doing so, they contend, will help enfranchise all people with dementia, not just those who are active, healthy, and 'ageing agelessly'; and, just as importantly, engender recognition of the "the myriad of experiences and the inherent complexity of living and dying with dementia" (p. 266). These diverse realities are not only comprised of the experience of dementia and disablism, but also, across the life course, the impacts of race, sex, class, age, gender, and sexuality which include discrimination. Individuals with dementia have also lived, and often continue to live, through different kinds of significant life events such as the co-existence or onset of other health conditions and the loss of close relationships.

2.12.3 Summary

Treating dementia as a disability has the potential to drive transformative change in multiple areas of the lives and experiences of people living with dementia. However, voices within disability and dementia studies also point to inescapable restrictions and emotional effects that result from impairment. Findings from studies on living alone with dementia flag up a range of constraints such as lack of transport and access to meaningful relationships which give rise to social exclusion. Such constraints diminish wellbeing but are avoidable, modifiable or reversible. However, dementia

and health studies also show that the realities of ‘living and dying’ with dementia and other conditions can include persistently liminal experiences with no assurance of resolution. This overlaps with arguments that it may be hard to prise apart socially imposed limits and harms from the difficulties and distress that accompany impairment and challenging life situations. In other words, while tackling limitations in the lives of people with dementia is urgently needed, resolving them can be complicated, partial or not possible.

2.13 Philosophical Grounds: ‘Patience’ - the ‘Other Side’ of Agency

The final part of this chapter presents Reader’s (2007) concept of ‘patience’ as the ‘other side’ of ‘agency’, which, along with liminality, particularly influenced my thinking in the study. In a sense, the notion of agency-patience underpins my earlier discussion on imposed and inherent limits. From a philosophical perspective, Reader (2007) argues for the need to integrate passive or ‘patiential’ aspects of human experience into an understanding of what a person is. She maintains that features taken to be central to personhood – agency, capability, freedom, choice and independence – presuppose, and are essentially linked to, non-agential or patiential features – incapacity, vulnerability, necessity, constraint and dependency. Reader (2007) contends that agential aspects of personhood are culturally valued as ‘positive’ while their non-agential correlates are seen as ‘negative’ and misinterpreted as “fallings away or privations” or “regrettable lapses” (p. 588). For Reader (2007), the ‘other side’ of agency is ‘patience’. Broadly, to be a ‘patient’ is to ‘suffer’ in the sense of being acted on. For example, a person lifting a cup ‘suffers’ its weight, and a person’s lips ‘suffer’ the cup. Hence individuals suffer as they act and suffer in being acted on. In this way, all persons are always ‘patients’, ‘suffering’ in ordinary, benign or pleasurable ways. Reader (2007), though, was particularly interested in suffering in its abject sense: experiences of vulnerability, pain, weakness, constraint, incapacity and dependency. Such experiences, she maintains, are often marginalised and disavowed, regarded as “somehow less human, less valuable, less our own” (p. 604). She argues that what she sees as a pervasive

cultural bias towards viewing persons as agents means that patiential experiences – vulnerability, passivity and so on – are seen as undoing or threatening personhood rather than being integral to it.

[This bias] says: when I am an agent, I am, I count. But when I am passive, incapable, constrained, dependent, I am less a person, I count less. The bias is so strong and so deep, that even compassionate thinkers strongly committed to acknowledging dependencies and meeting needs, still think our political task must be to ‘enable’ anyone who is passive, suffering, subject to necessities, etc. to get a bit more agency, and to become, thereby, more of a person. (p. 580)

For Reader, patiential experiences are not diminishment of personhood but part of a realistic, more complete conception of what it is to be a person.

‘Suffering’, as in ‘suffering from dementia’ or ‘dementia sufferer’, is a term which people with dementia have objected to, seeing it as having various negative consequences (Innovations in Dementia, 2014). I want to stress that in my thesis I use the word ‘suffering’ in Reader’s philosophical sense and in the broader sense of human affliction.

2.14 Chapter Summary and Rationale for Study

In order to provide a context for and to justify my research, in this chapter, I examined a range of formal studies and related material on befriending for people with dementia, and on living alone with dementia. My critical discussion of models of transition in dementia and the social model of disability also helps to contextualise the study. In addition, I introduced the concepts of liminality and patency as these particularly shaped my thinking as I worked on the project.

The literature on befriending anticipates or reports numerous benefits of befriending for those affected by dementia as well as volunteers. However, I flagged up various aspects of the experience of befriending for people with cognitive impairment which

research has not yet explored. As indicated, individuals taking part in my project all lived on their own. Some ‘living alone’ studies generated similar findings but what was also apparent was the diversity of participants’ circumstances, pointing to the value of focusing on the particular as well as commonalities in people’s experiences.

In summary, the following issues emerged from my literature review:

- While there is increasing interest in expanding befriending services for people with dementia, there is a dearth of research in this area in all settings, particularly community-based befriending.
- The perspectives of individuals living with dementia are largely absent in befriending studies and evaluations of befriending projects. Government and third sector bodies identify various outcomes for befriending but little is known about whether these are meaningful for people with dementia.
- Befriending literature tends to focus on the befriending relationship, itself, with limited attention given to the wider circumstances in which particular relationships take place. There is therefore a need to learn more about the experiences and meanings of befriending for people with dementia in the contexts of their everyday lives, social networks and life stories.
- Research on living alone with dementia does not provide a comprehensive and detailed picture of the social ties, both visible and invisible, in people’s lives, making it difficult to understand loneliness and the meaning of particular relationships with regard to a person’s social network as a whole. There is thus a strong case for exploring relationships between befrienders and individuals living on their own with dementia in their relational contexts.
- I have argued that the experience of dementia as schematised in dominant transition models is ‘dementia-centric’. In my view, the subjective experiences of people with

dementia are better understood, first, by an openness to allowing research participants to identify and prioritise experiences that matter to them, and hence to guide the focus of a study; and second, by taking a holistic approach to inquiry, as I do, in the form of in-depth, context-rich case studies.

In view of these knowledge gaps, the aim of my study was to learn more about the experience of befriending, and the contexts in which befriending is meaningful, from the viewpoints of people living with dementia. Chapter 3 sets out, in full, how I went about doing so.

Chapter 3: Methodology

Methodology

3.0 Introduction

In the last chapter, I made a case for the need for research on befriending which focuses on the views and experiences of individuals with dementia in a holistic, participant-led way. The aim of my study was to explore and gain understanding of the meanings and experiences of befriending from the perspectives of people with a diagnosis of dementia. I wanted to address two main research questions:

- How do people with dementia or memory loss experience befriending?

- What are the contexts in which their befriending relationships are meaningful?

In what follows, I explain in detail how I devised and conducted my research. The chapter is divided into three parts. First, I outline the onto-epistemological basis of the study which grounds its theoretical perspective, methodology and methods. In doing so, I draw substantially on Crotty's (1998) work on the foundations of social research which I found to offer a particularly lucid explication of the philosophical and theoretical underpinnings, and processes of producing, knowledge. I discuss my research design and the methodological resources I utilised. Second, I provide a reflexive account of the way I carried out the study and attended to ethical issues that arose. In the third part, I describe my method of data analysis which integrates self-reflexivity.

3.1 Onto-Epistemology

Integral to all research activity are assumptions about the nature of what is being studied and how it can be known (Crotty, 1998; McLeod, 2001). Ontology is concerned with the nature of being, with the essence or basic properties of things in the world, with

‘what is’ (Crotty, 1998; Mason, 2002). Crotty (1998) argues that researchers often find it hard to hold apart ‘what is’ from ‘what can be known’. The epistemological perspective that knowledge about the world is constructed (see below) can appear to imply that both knowledge about reality, and reality itself, are constructs (Crotty, 1998). However, as I go on to discuss, this need not be the case. In contrast to an ontologically idealist stance – the view that ‘things’ exist only in the mind as ‘ideas’ – the position this study takes is one of ontological realism, the view that social and material phenomena exist external to the human mind.

Ontological and epistemological concerns often emerge together (Crotty, 1998). Madill (2008) points out that, in research terms, realism refers to a range of ontological and epistemological perspectives. This includes the stance, which I take, that there is a socially and materially ‘real world’, which limits what is possible, but that humans interpret or construct this world in different ways (Madill, 2008). Individuals create meaning through their interactions with, and experiences of, the real world. Knowledge does not simply reflect reality but is not divorced from it either.

Epistemology is concerned with what can be known and how it can be known, with the legitimacy of knowledge, and with the status of the knower (Crotty, 1998; McLeod, 2001). My study is premised on a relativist, constructionist understanding of knowledge. Constructionism posits that the meanings associated with objects and realities are fashioned by diverse human knowers, at different times, and in different places. Truth, or knowledge, is contingent on the social, cultural and historical conditions in which it is produced, and can never be objective, disinterested or value-free (Gergen, 2009). Phenomena have multiple meanings constructed by subjects who experience differing realities. In some constructionist thought there is an inextricable relationship between subject and object in the generation of meaning: meaning “comes into existence in and out of our engagement with the realities in our world” (Crotty, 1998, p. 8). This means that ontological realism – the idea that reality exists outside the mind – is compatible with a constructionist epistemology: “there exists both an external world independently of human consciousness, and at the same time a dimension which includes our socially

determined knowledge about reality” (Danermark, Ekström, Jakobsen & Karlsson, 2002, pp. 5-6).

Given that my study seeks to explore and understand the meanings and experiences of befriending from the perspectives of participants, I want to make clear my constructionist stance on, firstly, the relationship between ‘real-life’ experiences and human meaning-making, and, secondly, the extent to which the experiences of others can be known. Like Todres and Galvin (2005), I maintain that subject and object – individuals and their lifeworlds – are indissolubly linked:

the relationship between self and world is reciprocal, with neither taking primacy in meaning making [...] Human living appears to be this kind of mutual circularity, in which we are always in the middle of attempting to make sense of our experiences, while living through the “flesh” of the experiences, which are beyond our construction and which, in a sense, construct us. (pp. 29-30)

Todres and Galvin’s (2005) notion of a reciprocal relationship between lived experience and human sense-making activity applies no less to research activity. In the course of my research, I made – and re-made – sense of my experience of living through the ‘flesh’ of my encounters with research participants. My interpretations of these meetings, and my lived experience of them, were grounded in, but not reducible to, one another (Todres & Galvin, 2005). ‘Realities’ and ‘real-life’ experiences always exceed what can be said, or known, about them (Todres & Galvin, 2005).

Doucet and Mauthner (2008) address the epistemological issue of what can be known about the subjective experience of persons both ‘inside and outside’ the stories they tell. For them, the idea that individuals’ stories are transparent reflections of their ‘real selves’, and that skilled research interviewers can fully access ‘deep’ experiences ‘beneath’ the stories, is flawed. They, too, take a constructionist view that while ‘real selves’ – thinking, experiencing subjects – may exist, they can only be comprehended through a person’s narratives and through interpretations of these narratives. For Mauthner and Doucet (1998), while a researcher’s intellectual and emotional – and, I

would argue, sensory and imaginary – responses to individuals constitute sources of knowledge, again, this knowledge is brought into being through interpretive activity.

In short, the epistemological position of my study is relativist and constructionist: knowledge is not discovered but constructed in particular social and historical contexts; it is co-constituted in the relationship between subjects and the real worlds they inhabit; it is unavoidably ‘prejudiced’; and it is plural and ‘unfinalisable’ (Bakhtin, 1984), always exceeded by that which it seeks to make sense of (Todres & Galvin, 2005). Finally, as Todres and Galvin (2005) contend, the enmeshment of subject and object, the sense in which individuals both construct, and are constructed by, lived experience, resonates with the idea that persons both act and ‘suffer’, are both agents and ‘patients’ (Reader, 2007) (see Section 2.13). This is a fundamental idea in my thesis.

3.2 Theoretical Perspective

The ontological and epistemological premises of a research project influence its theoretical perspective. This, as Crotty (1998) describes it, is the way that a study conceives phenomena of interest which, in turn, guides its methodology. Broadly speaking, my study adopts an interpretivist perspective. Interpretivism, in contrast to positivism, maintains that social phenomena, unlike natural phenomena, are not susceptible to explanation by general laws or predictable cause and effect relationships. Instead, individuals construct and ascribe meanings to their experiences and social life (Halperin & Heath, 2012; McLeod, 2013). Hence, interpretivist research does not produce objective findings but “versions of an interpreted reality, or life-world” (McLeod, 2013, p. 110).

One influential variant of interpretivism is hermeneutics. Hermeneutics, sometimes described as the art or science of interpretation, is concerned with interpretive principles and methods. McLeod (2001) makes a distinction between a ‘true’ hermeneutic approach and a looser understanding of hermeneutics as interpretation. Hermeneutics ‘proper’ is “tradition-informed interpretation” (p. 23) which is interested in historical

understandings of the past from the position of the present, and is emphatically uninterested in autobiography and self-reflection (Crotty, 1998; McLeod, 2001). However, Crotty (1998) recognises a quite different kind of hermeneutics in the methods of literary criticism and reading comprehension theory. He refers (p. 107) to work by Straw (1990) and Straw and Sadowy (1990) which identifies different phases in the history of literary criticism based on the status of author, text and reader in communicative and interpretive processes. Literary texts have been read as direct expressions of authorial intent: texts mean what authors intend them to mean. Alternatively, meanings have been thought to emanate from the interaction between readers and the writing itself, independently of any extra-textual information. Lastly, the meanings of works of literature, rather than given or discoverable, have been seen as generated in the inter-relationships between author, text and reader. Crotty (1998) contends that any and all of these methods of interpretation are transferrable and of utility to qualitative human science research. Not only written texts – interview transcripts, field notes and reflexive writing – but situations, activities and interactions can be ‘read’ in these different ways. For Crotty (1998), in research terms, these literary readings translate, respectively, into showing empathy, openness and a willingness to understand an individual’s views and experiences from their perspectives; engaging in a dialogue with a person’s words; and cultivating awareness of the ways in which, for participant and researcher, new understandings emerge in and out of their encounter. Indeed, the method of data analysis I use in this study, the voice-centred relational method (see Section 3.5.2 & 3.5.3), is part inspired by literary criticism and reader-response theory, and involves all these interpretive modes.

Reader-response theory, or more correctly theories, is premised on the idea that readers do not passively consume texts but actively participate in making the meanings they ‘find’ in them (Tyson, 2015). These approaches include the notion that it is the interpretive activity of readers that creates texts which are regarded as having no independent existence (Bleich, 1975, as cited in Tyson, 2015); and also the view that the meaning of texts is the result of a ‘transaction’ (Rosenblatt, 1978, as cited in Tyson, 2015) between the text and the reader. In the latter, texts act as a stimulus to which different

readers respond in different ways. In other words, while texts support any number of meanings, nonetheless, the text is an intrinsic part of the process of interpretation (Tyson, 2015). It is the ‘transactional’ model which my study most closely follows but with the additional understanding that ‘texts’ – the words and activities of participants and researchers – are co-created in particular research relationships and in particular situations. Hence, in my study, researcher reflexivity was crucial to my becoming aware of both the personal impact on me of the ‘stimulus’ of my encounters with each participant, and of the co-produced and context-specific nature of the data generated in and through our interactions.

However, interpretation, as conceived in this study, is at odds with the hermeneutic idea that interpretive work involves clarifying a text which is in some ways ambiguous or incoherent or which harbours implicit or unstated meanings (McLeod, 2001). The position I take is that, while interpretation involves a so-called ‘double hermeneutic’ (Smith, Flowers & Larkin 2009) – researchers are aiming to make sense of the experiences of individuals who are at the same time making sense of their own experiences – this does not mean that participant ‘texts’ are unclear, confusing or carriers of hidden meanings. For me, after Frank (2010), acts of interpretation are less about decoding participant stories than they are about engaging in an ongoing dialogue with them; less about unifying their meanings than ‘re-tellings’ which open up connections with other ideas and narratives. Paradoxically, stories, as much as they invite interpretation, also resist it (Frank, 2010).

3.3 Methodology

Crotty (1998) defines methodology as the design or strategy used to address research questions, which is informed by, and consistent with, the study’s ontological and epistemological grounds, and its theoretical perspective. While recognised research designs exist, it may be necessary to adapt, combine or create new or bespoke methodologies (Murphy, Jordan, Hunter, Cooney & Casey, 2015) in order to meet certain research aims, work with particular individuals or social groups, or develop a

multifaceted understanding of specific topics. My research project used an ‘emergent design’ (Simons, 2009) whereby an initial research strategy has in-built potential to shift focus or adapt methods in response to an unfolding research relationship; to changes in emphasis by participants; and to unanticipated events and situations. Flexibility was particularly important in my study, as with other studies involving people with dementia (e.g., Nygård, 2006), since it enabled me to maximise the ways individuals could communicate their views and experiences, and to prioritise areas of importance to them.

The study incorporated various methodological resources – narrative, ethnographic, longitudinal and reflexivity – a combination which enabled me to address my research questions in a creative, multifaceted and multilayered way, and one that fitted well with the case study approach I opted to take. Case study research is designed to explore a particular topic, or case, in depth and from many angles, and can make use of a range of methods. I provide a fuller account of case study below but, first, I want to describe the multiple methodologies I drew on and highlight their contribution to the study. My starting place was to use a narrative methodology. However, once the project was underway, and a number of research visits had taken place, it became clear that ethnographic and longitudinal elements could be added to the design. Possibilities for reflexivity to have a more extensive application as a methodological ‘tool’ also became apparent. In what follows, I explain each of these methodologies, my rationale for selecting them, and their fruitful combination in the project. I then describe the merits of a case study approach, and how a mix of methodologies can generate the illuminating detail, complexity and rich contextual material that case studies – my own included – can hold.

3.3.1 A Narrative Approach

There were a number of reasons why a narrative methodology was important for my research. Because relationships were a main topic of interest in the project, the concern in narrative inquiry with the co-created and context-dependent nature of

stories (Clandinin, 2006; Riessman, 2008), and other research data, was especially relevant. One of my research questions concerned the contexts in which befriending was meaningful. In this respect, a narrative approach was valuable in that it preserves the complexity and vividness of “the story-as-a-whole” (McLeod, 2011, p. 189) rather than fragments accounts into themes separated from contexts (McLeod, 2011; Riessman, 2008). One of my research interests, as a context for befriending, was participants’ life stories. Since identity is fluidly constructed through storytelling (Riessman, 1990, 2008), using a narrative methodology enabled me to explore the influence of life experiences on how participants saw themselves, and the ways in which befrienders connected with their continuing and changing selves. Finally, given the marginalisation of people with cognitive impairment, and the delegitimising of their words and stories (e.g., Baldwin, 2006; Hydén, 2013), focusing on the narratives of participants, independently of third-party views, was a way to prioritise and accord authority to their accounts (Bartlett & O’Connor, 2010).

In narrative-based research, ‘narrative’ can, and in this study does, refer to methods of generating data (participants are invited to share life stories or accounts of personal experiences); to data (stories and accounts are treated as primary data sources); and to forms of data analysis (a range of narrative techniques) (Bartlett & O’Connor, 2010; Elliott, 2005; McLeod, 2011). In addition, in my research, ‘narrative’ operates at different levels. There are individual stories in interview transcripts; my reflexive accounts of research visits; the narrative case studies I assembled; my report of the overall research process; the ‘fiction’ of the thesis, itself; and the narratives that the research may generate in readers (Frank, 2005; Riessman, 2008).

There is however, no single definition of narrative or what makes a story a story. At its most basic, narrative is often understood as a form in which speakers or narrators organise “a sequence of events connected to each other over time” (Frank, 1995, p. 98) as a means to interpret their experiences and make them meaningful (Clandinin, 2006). Yet some narratives are ordered episodically, rather than temporally (Riessman, 2007); and stories which lack a clear sequence or plot – ‘chaos stories’ – are said to

have an ‘anti-narrative’ character (Frank, 1995). According to Labov and Waletzky (1967), a speaker’s stories have a grammatical structure consisting, in a ‘fully formed’ story, of six elements: an ‘abstract’ or summary of the story; orientation information; a complicating action or sequence of events describing what happened; a resolution or result of the action or events; an evaluation, capturing the meaning or point of the story; and a coda, a signal that the story is over, returning the listener back to the present moment. Many of the stories told by participants in my research, even extremely short ones, contained many or all of these elements. But this ‘story grammar’ implies that stories necessarily report something out of the ordinary or involve a ‘complicating’ circumstance. Bruner (1991) argues that stories must be ‘worth telling’ in that they breach an “implicit canonical script” (p. 11) or deviate in some way from the norm. However, participants also related stories which were ‘habitual’, accounts not of a remarkable occurrence but of repeated everyday activities, or which were ‘hypothetical’, referring to events which had not yet taken place (Riessman, 2008). I do not use a particular definition of ‘narrative’, taking it to loosely mean ‘a reportable experience’ (Riessman, 2008). Instead, I focus on the ‘functions’ of storytelling in terms of the information it communicates, its expression of feelings and identity, its ordering and sense-making capacity (McLeod, 1997), and its role in relationships (Frank, 2000). Elliott (2005) suggests that narrative inquiry in social research has three main focal points: the “temporal nature of social life”; “evaluative or subjective dimensions”; and “social processes surrounding the production and consumption of stories” (pp. 36-37). In my study, for example, participants narrated accounts of changes in their lives and identities, over time, which expressed their views and feelings about these changes (Bartlett & O’Connor, 2010; Elliot, 2005); and contextual and relational dimensions of storytelling also came to the fore.

Narrative methodologies vary in their onto-epistemological assumptions (McLeod, 2011). The narrative component of my research design was informed by, and commensurate with, a realist ontology, a constructionist epistemology, and an interpretivist theoretical perspective. As indicated, the position I take in this thesis is that people construct narratives as a sense-making activity in response to, and in

reciprocal relationship with, the lived-through realities of their lifeworlds (Todres & Galvin, 2005). Hence, individuals always have a degree of agency and freedom in how they understand, organise and report their experiences but always within ‘real world’ constraints (e.g., Bartlett & O’Connor, 2010; McLeod, 2011).

As stated, part of my research focus was the impact of life history and befriending on participant identities and sense of self. For Somers (1994), not only are narratives a means by which people come to understand and make sense of their social world, also “it is through narratives and narrativity that we constitute our social identities” (p. 606). A narrative understanding of self moves away from the idea of individuals possessing a fixed, essential identity, and towards the concept of self as always in the process of becoming (McLeod 1997; Polkinghorne, 1991; Somers, 1994). The notion of a bounded, unitary self is replaced with a “multiple-storied self” (McLeod, 1997, p. 46): people create and recreate manifold identities in the stories which they tell in different social situations, drawing on the stock of narratives and the discourses available to them. For Bakhtin (1984), living persons are ‘unfinalised’ in that they can always undo any defining version of themselves, including those self-generated. Hence “a man never coincides with himself” (Bakhtin, 1984, p. 59). Attending to narrative aspects of identity can focus attention on continuities, discontinuities and fluctuations in self-understanding and self-feeling in participant accounts, and on the ways individuals resist being categorised or defined by certain social identities – such as ‘person with dementia’, ‘old’, or ‘care recipient’.

I have pointed to the importance, in the study, of relational contexts, and hence to an understanding of narratives as co-produced in different settings and to different ends. Plummer (1995, p. 170, as cited in Mauthner & Doucet, 1998) writes of “the constant readjustment of stories to be aligned with the time and place of their telling”. And, for Bakhtin, ‘addressivity’, the idea all utterances – even those which take place in the mind or in solitude – are addressed to, and anticipate a response from, a listener, (Morson & Emerson, 1990), meaning that “the role of *others* for whom the utterance is constructed is extremely great” (Bakhtin, 1986, p. 94, as cited in Irvine, n.d.,

emphasis in original). This applies as listeners become speakers and speakers become listeners again. In understanding the research data as co-generated, I critically reflected on the relationship between participants and myself, focusing on our interaction, on social and power differences, and on the settings, style and functions of our research conversations. In the study, telling stories was part of how we got to know one another. When storytelling is primarily seen as a source of data for analysis, researchers risk disregarding its role in relationships and relationship-building, including any developing tie between participant and researcher (Frank, 2000):

people tell stories to reaffirm, possibly to create, and possibly to redirect the relationship within which the story is told. [...] Storytelling is the recursive elaboration of the relationship between those sharing the story [...] Stories reaffirm what people mean to each other and who they are with respect to each other. (p. 354)

Telling stories, as described, was a means by which I got to know participants and they me. This mutual ‘getting to know’ took place over a number of visits, making the longitudinal aspect of the research, for this and other reasons, highly significant. I discuss this next.

3.3.2 A Longitudinal Approach

There were two important aspects to the longitudinal dimension of my study: promoting inclusivity (ethical), and a focus on process (methodology). Firstly, I envisaged that a series of meetings, rather than a one-off research visit, would enable people with dementia to more fully participate in the research: multiple interviews would help to foster rapport and build trust, and allow participants to recall and share their experiences over a longer period. Repeat meetings would also provide an opportunity for me to review research data with each person. However, the number of research visits was determined by those taking part so that multiple interviews could not be guaranteed. As it happened, I met each participant on five occasions which meant that, secondly, there was scope for me to focus reflexively on the research process, particularly the development of the research relationships over time. Hence, the longitudinal aspect of

the study emerged as the work proceeded. Thomson and McLeod (2015) note that not all qualitative longitudinal research (QLR) is ‘longitudinal’ in a ‘known-in-advance’ way. They understand QLR less as a specific research design and more as a “sensitivity and orientation” (p. 247) or an “approach to attending to temporality” (p. 247). QLR offers a means to understand the “lived experience of change and continuity in the social world” (Neale, Henwood & Holland, 2012, p. 5), and to explore processes as well as outcomes of change (Thomson, 2007). For Saldaña (2003), what defines ‘longitudinal’ in research is not an extended timeframe but a focus on time and change, for example, in seeking understanding of the ways time interplays with the ‘gathering’ and analysis of data; and of the influence and effects of time on human interactions. As I outline next, this was especially relevant to my own research.

Often qualitative longitudinal studies involve repeat interviews over long timeframes but, as McLeod and Thomson (2009) point out, data production in longitudinal research can also be continuous such as in ethnographies (see Section 3.3.3.) This was the case in my work where repeat research visits were part of a continuous research project, not separate instances of data generation. McLeod and Thomson (2009) also highlight that a “characteristic of QLR is that the researcher and the research process form part of the data” (p. 77). In my study, weekly meetings with each participant over five weeks created opportunities to learn about the mutual process of getting to know someone, which all participants identified as important in their lives, and to reflect on the ways the research relationships enacted aspects of befriending relationships. Another feature of the study, made possible by its longitudinal element – and one I reflect on later in the thesis – is that, even within the short duration of the project, in my developing ties with participants, I was always, to paraphrase McLeod and Thomson (2009, p. 68), standing in a new place from where I could capture a new perspective.

As indicated, ethnographies can be thought of as continuous QLR. I turn now to ethnographic aspects of my research.

3.3.3 An Ethnographic Approach

I did not set out to conduct a classic ethnography which involves extensive fieldwork in a particular setting in order to describe and interpret cultural behaviour (Harrison, 2018; Wall, 2015) and gain insight into “how cultures or communities ‘work’ and how ‘social actors’ make and derive meaning from their practices” (McLeod & Thomson, 2009, p. 101). However, as the research process unfolded, and I found I was able to spend time with participants over several meetings, the opportunity to use ethnographic methods – or what Nygård (2006) terms “an ethnographically inspired approach” (p. 103) – presented itself. The advantage of an ethnographic approach for my study, in conjunction with narrative, longitudinal and reflexive methodologies, was that it enabled me to address my research questions through an evolving understanding of the complexity of participants’ ‘real-life’ situations; through coming to know how individuals, as meaning-makers, made sense of their circumstances and their cultural and institutional worlds; and through my reflexive focus on the research relationships. Indeed, storytelling, temporality and critical self-reflection are, or can be, integral to ethnographic research. Saldaña (2003) describes how, in ethnography,

we focus on how people think, feel, and act from moment through moment to capture in-depth perceptions and meanings, to extract stories for narrative inquiry, and to log rich details for individual biography. Additionally, we learn how human actions and participant perspectives might change during the course of a study to reveal temporal-based themes and patterns of human development or social process. (p. 15)

In ethnographic studies, a researcher is a participant observer, participating in people’s everyday lives, asking questions, watching, conversing with and listening to individuals, and joining in with different forms of activity (Brewer, 2000; McLeod, 2011). The researcher is able to gain close-up (McLeod & Thomson, 2009) and first-hand experience of a person’s lifeworld through immersion in, and openness to learning from, a particular social or cultural setting (Mason, 2002; McLeod, 2011). In ethnography, there is a focus on immediacy, on meaning, on capturing change as

it occurs, and on learning about events and interactions as they happen (McLeod & Thomson, 2009). During the time we spent together, participants and I engaged in some of the activities they shared with their befrienders, and that their befrienders supported them with. I witnessed, as well as listened to their accounts of, the everyday difficulties they experienced. I came to know their homes and other residential spaces, and collected information on the surrounding area and local facilities. Ethnographers generate understanding through ‘thick’ descriptions of the “richness, texture and detail” (Ortner, 2006, p. 43) of human behaviour in the everyday contexts of participants’ lives (Brewer, 2000). Hence, my field notes on my experiences of taking part in the research, and ‘being there’ with each person, were a key source of data (Mason, 2002). These included descriptions of events and environments, and records of my thoughts and feelings immediately after and in the days following research visits. In the next section, I discuss the importance of reflexivity as a methodological resource in my study; here, I highlight the centrality of reflexive practice in ethnography. As Ortner (2006) describes:

ethnography has always meant the attempt to understand another life world using the self – as much of it as possible – as the instrument of knowing [...] in which the whole self physically and in every other way enters the space of the world the researcher seeks to understand. (p. 42)

My accounts of the immediate impact on me of taking part in the research as a ‘vulnerable observer’ (Behar, 1996, as cited in McLeod & Thomson, 2009), and other reflections on ‘using’ my ‘whole self’ as ‘an instrument’ of understanding, are threaded through the case studies, and integrated into my subsequent interpretations and discussion. An ethnographic approach permitted me to reflexively attend to the character of the research relationships, and emotional connections (McLeod & Thomson, 2009) that developed within them, generating insights into relational aspects of befriending.

Having pointed to the significance of reflexivity in ethnography, I now provide a fuller description of the kinds of reflexive practice I undertook during my research.

3.3.4 A Reflexive Approach

Reflexivity was a practice I sustained throughout the project, and, specifically, formed a key part of the strategy I used to address my research questions. As described above, reflexivity was integral to the narrative, longitudinal and ethnographic methodologies used in the study; and, as I later discuss, was an essential part of ethical decision-making, as well as a built-in component of my data analysis method. In this section, I focus on the importance of reflexive practice as a source of knowledge about my research topic, and as ongoing critical reflection on the research process.

Reflexivity is conceived and practiced in different ways. For my purposes in this study, I understood it to be, as Finlay (2002) puts it, “methodological self-consciousness” (p. 210), a researcher’s recognition of, and reflection on, their research as co-produced with participants in a particular time, place and situation. Reflexivity involves awareness by researchers that they are participants in their own research (Finlay, 2003). This may be viewed as a problematic bias, but, it can also be regarded – as I did – as a methodological opportunity (Brownlie, 2011; Finlay, 2002).

There were a number of overlapping ways in which reflexivity generated insights into my research topic, and extended the methods by which I could come to know different aspects of it. Finlay (2002) identifies several modes of reflexivity of which ‘introspection’ and ‘reflexivity as intersubjective reflection’ were especially relevant to my study. In ‘introspection’, a researcher’s subjective experiences and reactions which arise during the research are viewed as primary data. Mauthner and Doucet (2003), too, see researchers’ personal responses to individuals and their stories – emotional, intellectual, sensory, imaginary – as sources of knowledge in their own right. And Bondi (2005) points to “the potential relevance of researchers’ emotions as analytic resources” (p. 239). In my case studies (Chapter 4), I provide different examples of the ways in which the impact of research visits on me were kinds of knowledge. In ‘intersubjective reflection’, a critical awareness is brought to the encounter between researcher and participant, focusing on the ways that meanings are negotiated and

emerge within their relationship, in particular situations, and taking into account power imbalances. One application of this approach, which particularly influenced my thinking, appeared in a study on emotional support in which emotions were both topic and methodological resource: emotional aspects of the research relationship, itself, generated insights into different facets of emotional support described by participants (Brownlie, 2011, 2014). I came to realise that, in a similar way, research relationships in my study enacted features of befriending relationships. In other words, relationships were both a focus of my study and a methodological tool.

Part of the critical awareness in ‘intersubjective reflection’ is directed at how the researcher’s social position, unconscious assumptions and personal experiences are implicated in data analysis and interpretation. For Doucet (2008) and Mauthner and Doucet (2003), it is incumbent on researchers to identify what they ‘bring to’ their research in order to show to how this affects the knowledge they produce. This is not straightforward, or even always fathomable. Mauthner and Doucet (2003) suggest that aiming for ‘degrees of reflexivity’ might be more realistic. Not only this, researchers, as well as participants, are complex, ‘multi-vocal’, dynamic beings. As Cousin (2013) puts it:

Empathy comes from many sources. What we bring to the research table or to our professional relations is context sensitive, mobile and interactionally determined. We do not have to freeze our positionality into one dimension of our self. Research and professional encounters vary enormously and social positionality is one element among many that shape them. (p. 5)

Indeed, my ‘intersubjective reflections’ on my relationships with participants, as they developed over time, suggested that how we saw each other, and what we ‘brought to’ our encounters, constantly evolved.

A reflexive understanding of my relationships, both ‘introspective’ and ‘intersubjective’, required a level of self-disclosure. Self-disclosure in research has been criticised for solipsistically privileging the researcher’s experiences, and obscuring the voices of

participants (Finlay, 2002). However, it can be justified if researchers draw on their personal experiences to produce insights that have a wider relevance (Finlay, 2002; Brownlie, 2011), and to focus on what seems to matter in the research process (Doucet, 2008). In this study, I felt that writing about my own experiences, drawing on field notes, added extra layers to my understanding of the nature of befriending and aspects of participants' everyday challenges. It also made visible some of my assumptions, expectations and frames of reference. However, as will become clear, the ways in which I disclose these 'prejudices' also communicates something about the process of 'getting to know' someone, salient to all participants. Again, this underscores the value of the research relationships as a methodological resource.

Using different research methods can capture the richness of people's lives (Brownlie, 2014); and is a means to maximise the inclusion of people with dementia in research, by providing different ways in which a person's views and experiences can be communicated, and by giving individuals greater opportunity to lead the research. In order to meet the aims of my project, I drew on a range of methodologies each of which fed into the case study approach I used in the research. In the next part of this chapter, I explain what case study research is and its advantages for my inquiry.

3.3.5 A Case Study Approach

Case study is an approach to inquiry in which a phenomenon is comprehensively investigated in its real-life context with a focus on its singularity and complexity (e.g., Simons, 1996, 2009; Stake, 1995). Hence, case study was a 'good fit' as an overall strategy for my project since, as well as wanting to learn more about the befriending experiences of individuals living with dementia, I also wanted to explore, in-depth and detail, the particular contexts in which their befriending relationships took place and were meaningful. Depending on what individuals wished to share with me, these contexts could include other relationships, everyday life, health conditions and biographical experiences. Participants also had the option to 'show me', by us doing similar sorts of activities together, how they spent their time with their befriender.

I wanted an approach that would enable me to generate and use data from different sources, to focus on the unique circumstances of individual participants, and to consider different facets of each person's befriending experiences. It seemed to me that case study research was conducive to this holistic way of producing knowledge. In addition, the narrative presentation of findings in qualitative case studies (McLeod, 2010; Simons, 2009; Thomas, 2011) allowed me, as I had wished, to create a rich, evocative, multidimensional picture of both befriending in context and the research process, itself, such that the material, in all its minutiae, 'came to life', enabling readers to 'get inside situations' (Thomas, 2011) .

I will next describe what is meant by the study of cases and further explain why I chose this way of finding answers to my research questions. The aim of qualitative case studies is not to produce generalisable findings but to generate insights from exploring one thing – the case – in-depth, in contextual detail, and from different angles (e.g., Simons, 1996, 2009; Stake, 1995; Thomas, 2011). The approach is holistic and idiographic: cases which are "properly described" (Stake, 1978/2000, p. 23) produce a "full and thorough knowledge of the particular" (Stake, 1978/2000, p. 22) and have an "irreducible quality" (Flyvbjerg, 2006, p. 21). Rather than "overwhelm the uniqueness inherent in objects and events in the social world", and reduce them to "similar instances of the same general phenomena" (Ragin, 1992, pp. 1-2), case study research is committed to holism, to the idea that the whole is greater than the sum of its parts.

A strength of case study is its capacity to hold, without trying to resolve, uncertainty, ambiguity and tensions in human affairs, to "embrace the paradoxes inherent in the people and events we study" (Simons, 1996, p. 237). This meant that, at the reporting stage of the study, I was able to retain the many-sidedness and interwoven quality of the material. Case study is especially well-suited to exploring processes of change, unfolding situations and 'experience in action' (Simons, 2009). This allowed me to incorporate into my 'findings' actions and events and the development of research relationships as they took place over the course of the research, thereby creating complex, layered understandings. Importantly, too, the versatility of a case study

approach (Simons, 2009) makes it particularly able to facilitate the inclusion of people with dementia in research – and thereby better comprehend their experiences – by providing flexibility of focus: the option to ‘follow’ where participants lead; flexibility of methods: the ability to include and be open to different ways of generating data; and flexibility of research role: the opportunity to adapt and improvise, as necessary, in order to support and empower individuals during the research process (Murphy et al., 2015; Nygård, 2006).

In keeping with my view of interpretation as ‘re-tellings’ or ‘ongoing dialogue’ (Frank, 2010, see Section 3.2), qualitative case study research has been seen as a way to stimulate thinking rather than produce conclusive results (Simons, 1996). In the scope it offers for methodological eclecticism, in its capacity to embrace different kinds of data and different perspectives, and in the variety of ways it can be reported, case study research has the potential to “maximise the possibility of different ways of seeing” complex situations and encounters (Simons, 1996, p. 233). Lastly, the concept of narrative, integral to this study, is also a core feature of qualitative case studies, not only because participants’ and researchers’ stories often appear within them, but because, implicitly or explicitly, case studies themselves take a narrative form (McLeod, 2010; Simons, 2009). Indeed, for Simons (2009), the implications of a case study are derived from its narrative: “the story must be there” (p. 5). One of the benefits of richly and ‘properly described’ case studies is that they permit readers to ‘enter the world of the case’, to experience it vicariously (Moriarty, 2011). I hoped that readers would come to know participants, me, and our relationships as the story of the research unfolded.

So far, I have explained case study and justified taking this approach in my research. Before I move on to the second part of this chapter, which sets out how I conducted the research, I am going to outline the basis on which I ‘chose’ or ‘found’ my cases. This was relevant to my sampling methods and to my subsequent interpretations of my case studies.

3.3.5.1 Case Finding

Cases are not representative samples of a wider population: they are selected – ‘purposive sampling’ – as particular examples of the phenomena of interest in a study. I was interested in the experiences of people with dementia who lived at home and were participating in long-term, face-to-face befriending relationships. Cases may be chosen on various bases, for example, on the grounds that, within their field, they are typical, unusual or extreme (Flyvbjerg, 2006), although, as Simons (2009) indicates, typicality is a misleading descriptor since all cases are unique though they may share common features. McLeod (2010) makes the point that researchers often cannot choose specific cases but have to work with those that are available. While this was true of my study, it was not problematic. Because the topic had not previously been investigated, the research was exploratory: I could not know in advance or even at later stages of the research, the extent to which my cases were unusual or typical, nor on what basis such a claim could be made. Stake (2005) distinguishes between intrinsic, instrumental and collective case studies (or multiple instrumental cases) depending on whether the case is of interest in its own right, or whether investigating a case is a means to explore particular issues or research questions. My research fell into the category of collective case studies in which, ultimately, the focus is more on the topic of inquiry than the uniqueness of cases, although I hope that, by keeping discussion of commonalities between the cases separate from the individual case studies, something of the singularity of each person’s circumstances is retained.

Cases consist of both a subject – a person, place or institution, for example – and an analytic frame or object (Thomas, 2011). In other words, a case is a case of something, and it is this, rather than the subject itself, which marks the boundaries of the case (e.g., Simons, 2009; Thomas, 2011). Different views exist on the stage at which, in a qualitative study, a case is, or should be, identified (Thomas, 2011); and on whether cases are ‘found’, ‘made’ or ‘imposed’ on empirical data during the course of the research (Ragin, 1992). For Simons (2009), cases do not need to be delineated at the outset of the work beyond stating the research focus or problem, and may have to be

reconceptualised during the study and data analysis. Similarly, Ragin (1992) holds that case study researchers may not know what their case is about until later in the research process, or even whether a case will actually emerge. In this situation, as the case is investigated, there may be uncertainty about what information is relevant (McLeod, 2010). And, as Bakhtin (Morson & Emerson, 1990) contends, there is an ever-present tension between ‘centripetal forces’ which aim to impose order on a messy, heterogeneous world, and ‘centrifugal forces’ which constantly disrupt and exceed order. In my project, I entered the research field with open, exploratory questions about the experiences and contexts of befriending for people with dementia or memory loss. My ‘analytic handle’ (Mason, 2002) on my research evidence evolved over time. My cases studies were the outcome of intense analytical and interpretative work, grounded in my data, and drew on a range of theories and concepts that appeared to me to be a ‘good fit’ in terms of sense making.

In the second part of this chapter, I set out the onto-epistemological foundations of my study, and explained how my research design was conducive both to exploring different facets of my topic and to involving participants with dementia. I now provide a detailed account of how the work was carried out in practice.

3.4 Conducting the Research

3.4.1 Ethics

Guillemin and Gilliam (2004) distinguish between, but see as interrelated, ‘procedural ethics’ and ‘ethics in practice’. They argue that procedural ethics, those pertaining to research ethics committees and professional codes of conduct, cannot address the variety of everyday ethical issues that arise in conducting research, that is, ethics in practice. Yet the principles, the abstract concepts, on which procedural ethics are based – non-maleficence (doing no harm), beneficence (doing good), justice, and respect for persons and their autonomy – inform ethics in practice. For Guillemin and Gillam (2004), what links them is reflexivity. On the ground ethical issues, or ‘ethically

important moments', are often challenging, subtle, and unpredictable, and involve "the researcher's willingness to acknowledge the ethical dimension of research practice, his or her ability to actually recognize this ethical dimension when it comes into play, and his or her ability to think through ethical issues and respond appropriately" (p. 269). My reflexive understanding of the continuity between ethical principles and ethics in practice is foregrounded throughout the thesis. I do not confine ethical considerations to a separate section as such considerations informed the whole conduct of the research.

Ethical approval for the study was granted from the University of Edinburgh School of Health and Social Sciences Ethics Committee on 7th January 2016.

3.4.2 Inclusion Criteria

Recruitment was limited to individuals who met the following criteria:

- known by befriending service to have a diagnosis of dementia
- had the capacity to consent to participate in the research
- met volunteer befriender through a befriending organisation
- did not pay for befriending service and had an unpaid befriender
- in a relationship-centred not a goal-focused befriending relationship
- in a befriending relationship for at least one month
- lived in the community
- lived alone or with another person
- were able to communicate verbally and in English
- were willing to talk about their befriending relationship and life experiences
- were willing to allow research interviews to be recorded.

My decision to exclude people who did not have capacity to consent to take part in the research was made in accordance with the Adults with Incapacity (Scotland) Act (2000) which states that research on people without capacity to consent to participate in a research project should not take place unless similar research cannot be carried

out on people who do have capacity to consent to take part in the research. Also, the exclusion of individuals who did not want interviews to be recorded was necessary because the form of data analysis used in the study requires verbatim transcripts.

3.4.3 Sampling and Recruitment

I initially planned to recruit around six individuals to the study but this number was flexible since many aspects of the research were unknowable at the outset, such as how many times participants would be willing to meet me, and the frequency and duration of research visits. That aside, a small sample size was appropriate for methodological, practical and ethical reasons. I wanted to conduct case study research in order to generate detailed, contextualised accounts of befriending, and to focus on the particularity of individual situations. I was not aiming to recruit participants on a statistical basis in order to represent a wider population (Thomas, 2011) or to produce findings from which generalisations could be made. Multiple interviews were a feature of the research design, though decisions about the number of interviews rested with those taking part, including the option of a single interview. Because my chosen method of data analysis – the voice-centred relational method (see Section 3.5.2 & 3.5.3) – is labour-intensive and time-consuming (e.g., Jankowska, 2014), I anticipated that interviewing a larger number of people, on several occasions, would generate more data than could realistically be accommodated within the project, resulting in a more superficial analysis (Jankowski, 2014). A small sample would allow the investment of time in which to develop research relationships based on trust and respect in which participants with dementia, and quite possibly other health conditions, felt valued, supported and in control. It was also the case that there was a relatively small pool of people from which the sample could be drawn.

I recruited individuals via befriending organisations in Scotland as this made sense geopolitically and logistically. However, as I began to learn more about individual befriending services, the need to establish further inclusion and exclusion criteria became apparent. As well as catering to diverse client groups, these services differed

in terms of:

- specialism in working with people with dementia
- requiring individuals to have been formally diagnosed with dementia
- restrictions based on degree of cognitive impairment or age
- priority given to clients who were lonely or isolated
- option of self-referral
- limits on maximum duration of befriending relationship
- provision of befriending on a one-to-one basis or in pairs or groups
- focus on companionship or on time-limited interventions to strengthen individuals' social networks

In addition, I identified befriending organisations which targeted particular client groups that potentially included people with dementia, such as: people over the age of sixty-five experiencing loneliness; lonely older people living in sheltered housing; isolated physically disabled people; ex-servicemen and women; LGBT+ people over the age of fifty; people living with chronic obstructive pulmonary disease; and people who had, or were at risk of, alcohol-related dementia and who continued to drink. I limited recruitment to any service which offered long-term befriending to people known to have dementia based on companionship rather than short-term social interventions.

I initially approached befriending services in one geographical area as it was served by a variety of organisations. From this area, I recruited one participant while two potential participants dropped out before I had chance to meet them due to the lengthy period it took to resolve 'disclosure' (criminal record checking) issues (see Section 3.4.15). No new candidates came forward and I widened the search, managing to recruit two more individuals from different parts of Scotland. Befriending Networks, a UK-wide befriending resource organisation, was very supportive of the study, and assisted me with recruitment, advertising the research on their Facebook page, and inviting me to their annual conference, to a National Loneliness Summit, and to talk to attendees at a regional befriending service forum. A further potential recruit was

identified but, in my view, did not have capacity to consent to take part. At this point, I made a decision to stop recruiting. The data generated from completed research work with three participants was rich and holistic. The recruitment period was also limited by the time and financial constraints of full-time doctoral research.

3.4.4 Recruitment Process

Once I had identified interested services, I explained the inclusion criteria and what the research would involve for them and their clients. To reduce my influence in recruitment, potential candidates were identified and approached, in the first instance, by someone from the befriending service who knew them well. For Tom, this was the volunteer coordinator; for Grace this was the service manager. I initially took the view that befrienders should not be involved in recruitment due to my concern that individuals might feel pressure to participate in the research in order to please, or retain, their befriender. However, in Jenny's case, it was her befriender, rather than the volunteer coordinator, who spoke to her about the research as the volunteer coordinator felt that Jenny would find it easier to decline to take part, if that was her decision, if she was approached by her befriender. As well as an information leaflet for participants (Appendix A), I produced another leaflet to explain the research to interested third parties such as family members, friends, volunteers and professionals (Appendix B). Once potential participants had been identified, introductory meetings were arranged with each of them during which I discussed the research process; individuals had the opportunity to begin to get to know me and ask questions (Hubbard, Downs & Tester, 2003; Proctor, 2001); and I was also able to assess research capacity. All the initial meetings were held in the presence of a trusted person: the service manager (Grace), the volunteer coordinator and her befriender (Jenny), and a sheltered housing manager (Tom). All three people were willing to take part although Jenny and Grace had concerns about whether they would be able to 'do it'.

Demographic information on participants is provided in Table 1. All names in the thesis are pseudonyms.

Table 1: Information on Participants

Name	Age	Type Of Dementia	Other Health Conditions	Type of Housing	Living Alone	Befriending Service
Tom	69	Alcohol-related	Multiple alcohol-related	Sheltered housing	Yes	Any Person with a dementia diagnosis
Jenny	90	Parkinson's disease-related	Parkinson's disease	Private bungalow	Yes	Any person 65 and older; priority given to isolated people
Grace	79	Vascular/Stroke	Multiple	Sheltered housing	Yes	People over 60 who are lonely and/or isolated

3.4.5 Consent

According to the Nuffield Council on Bioethics (2009), the “ability of people with dementia to make their own decisions (if necessary with plenty of support) as to whether or not they wish to participate in research should not be underestimated” (p. 135). In research involving people with dementia, the issue of decision-making ability arises because dementia is an umbrella term for progressive neurological conditions which affect cognitive functions such as memory, reasoning, communication and comprehension, all of which have a bearing on whether individuals can give informed consent (Hubbard et al., 2003). In order to consent to take part in research, participants must be fully informed, able to decide freely, and have capacity (e.g., Bartlett & Martin, 2002; Mental Welfare Commission for Scotland, 2010). These elements were carefully considered in the study.

In Scotland, there is no ‘all-purpose test’ for incapacity (Patrick, 2006). Underpinning the Adults with Incapacity (Scotland) Act (2000) (Scottish Government, 2008a) is a

presumption of capacity, and capacity is assessed in relation to a specific decision at the time that decision has to be made. Individuals are deemed to lack decisional capacity when they become incapable of acting or making, or communicating, or understanding or retaining the memory of a specific decision. However, while an inability to retain the memory of a decision is a legal determinant of incapacity, people with dementia with short-term memory difficulties are not deemed incapable of making a decision to take part in research if, with support, time and explanation, they consistently understand what taking part means and consistently agree to take part (Mental Welfare Commission for Scotland, 2010; Scottish Government, 2008b). Capacity has also been conceived as being on “a sliding scale where the threshold takes account of the complexity of the decision, the risk involved, the significance of and consequences of that decision” (Mental Welfare Commission for Scotland, 2010, p. 9). Because befriending organisations (or a nominated trusted person) were asked to identify potential participants, I prepared a guide (Appendix C) covering key aspects of consent and assessing capacity in people with dementia. These were the guidelines that I also used to establish consent and assess capacity on meeting possible candidates prior to recruitment, and during the research.

One component of decision-making capacity, the ability to understand a decision, involves grasping facts, weighing up options, and understanding the consequences of a decision (Scottish Government, 2008b). The Nuffield Council on Bioethics argues that “the detailed information currently required by research ethics committees can exclude people with dementia who are in fact quite capable of understanding the broad concept of a study” (2009, p. 140). In preparing information leaflets for participants, there was a need for a balance between providing sufficient information about the nature and purpose of the research to inform decision-making (Mental Welfare Commission for Scotland, 2009; Warner, McCarney, Griffin, Hill, & Fisher, 2008), and providing information which was accessible so that individuals interested in taking part in the study were not excluded from the research process (Nuffield Council on Bioethics, 2009). The Scottish Dementia Working Group (SDWG), a national campaign group run by people with dementia, has produced a set of core principles for research involving

people with dementia (SDWG, 2014) which recommends that printed information for research participants is clear and accessible and uses layperson's language.

However, information leaflets were not a substitute for other means of ensuring individuals understood the nature and purpose of the research and their rights as participants. From the beginning, I made sure that each person had at least one trusted person, independent of the study, with whom they were in regular contact (or able to contact), who could talk through the research with them, and remind them about it if necessary. I also made it clear to participants that they could ask me questions, and pull out of the study, at any time. The trusted person was equally someone to whom individuals could communicate concerns about, or a wish to withdraw from, the research which they might have found difficult to address with me. I followed Dewing's model (2007; 2008) of process consent in research with people with dementia in which establishing consent is seen as an ongoing process rather than a one-off determination at the outset. At the start of each visit, I sensitively reminded each person who I was, the purpose of the research, and what we had done during the previous visit, checking for understanding and willingness to continue to take part, and alert to fluctuations in ability to give consent. I was aware, for example, that Tom could temporarily lose research capacity through alcohol intoxication although his sheltered housing manager assured me that, for the most part, he did not drink enough to impair his competence to make decisions.

A core principle of Scottish capacity legislation is the requirement to "maximise the capacity of the adult to make his or her own decision" (Scottish Government, 2008a, p. 30). This involves creating favourable conditions of support, communication and environment, and assessing capacity at times of optimal functioning and wellbeing for each person (Scottish Government, 2008b). Research capacity may be context-dependent and therefore enhanced by supportive, enabling relationships. In the study, familiar, trusted persons, chosen by participants, were in a position to provide ongoing social and emotional support during and after the research (Pratt, 2002; Mason & Wilkinson, 2002), and to provide reassurance that individuals continued to

understand and consent to take part in the research (Pratt, 2002). My role was also to find appropriate ways to enable each person to take part in the study if they wished to, but also to be sensitive to signs of reluctance or discomfort which might indicate disengagement from the research visit or withdrawal of consent. Dewing (2007, 2008) highlights the importance of conducting research when individuals are in their usual state of wellbeing. Everyone who took part in the research had long-term health conditions in addition to cognitive impairment: ‘wellbeing’, ‘ill-being’ and research participation were complex ethical issues in the study. I discuss this aspect of the work in further detail in Section 3.4.9 on participant wellbeing and safety, and at other points in the thesis.

I devised consent a form (Appendix D), and a modified version of the form for Jenny (Appendix E), for each person to read and sign but was aware that, for different reasons, some participants might not be able to, or want to, sign, and I was open to recording verbal consent on the voice recorders I used in the study. Tom did not want to read the consent form, so I read it out to him and recorded his oral agreement to take part. Grace, a former nurse, was familiar with consent forms, and read and signed the consent form. I did not invite Jenny to sign a consent form until my last visit as I felt that her agreement to ‘try’ taking part did not constitute proper consent which I regarded as provisional until our final meeting. On that occasion, we read through a typed summary of our research conversations which, together with her experience of ‘doing’ the research, gave Jenny a much better understanding of what she was actually consenting to. At that point, Jenny asked a number of questions about the research before giving consent for her contributions to be included in the study. She also preferred to consent verbally, which I recorded.

3.4.6 Number of Research Visits

In addition to introductory meetings, I visited each person on five occasions. Multiple interviews over time with people with dementia can enhance rapport; increase opportunities to meet individuals on a ‘good’ day; allow researchers to get to know

participants and to bring that knowledge into subsequent interviews; create more time for participants to convey their experiences (Pratt & Wilkinson, 2001) and to go at their own pace (Clarke & Keady, 2002); and enable a fuller understanding of the contexts of a person's accounts (Murphy et al., 2015). However, I also considered the possibility that too many visits might be onerous or intrusive, lead to confusion about my role, or make it hard for me to exit the research without causing upset. The number of visits was negotiated between participants and myself, taking into account the factors above, and whether individuals felt they had said enough about what was important to them within the remit of the study.

3.4.7 Conducting Research Visits

Researchers working with people with dementia need to meet them in their physical and emotional 'safe zones' (SDWG, 2014), places where a person feels relaxed, comfortable and in control, and which provide privacy. Part of ensuring this involves finding out from participants where they wish research visits to take place and at what time of day. At the time of the research, neither Tom nor Jenny were going out by themselves and I met them in their own homes. As directed by Grace, our conversations and activities took place variously in her flat, in communal areas within sheltered housing, and on a visit to a local café. Preferred times for research visits were negotiated with each person, and, in Tom's case, advice from his sheltered housing manager who suggested afternoons would be best based on her knowledge of his daily routines. I describe in Grace's case study, in Chapter 4, how the timing of my first meeting with Grace was, unwittingly, made without an understanding of her system of remembering daily events, making her feel "lumbered".

I arranged research meetings as closely as I could to befriender visits to aid recall though this was not possible for Grace who did not know when her befriender visited and could not find any reference to past or forthcoming visits in her diary. Jenny, Grace and Tom all used memory aids – calendars and diaries – and I ensured that research meetings were marked on these with each person's permission. As 'back-up'

reminders, I notified sheltered housing staff and befriending organisations of the dates and times of research visits, and any change in arrangements. I also made telephone call reminders of my visits on the evening before, or morning of, my visits – both for Grace – directly to Jenny and Grace, or, for Tom, on his instructions, through sheltered housing staff. This contact also enabled me to check whether each person felt well enough and still able to meet me that on that particular day (SDWG, 2014). Mobility difficulties meant that Jenny could not get to the telephone in time to answer my calls – she told me that many callers rang off for this reason – but I learned to ring again, after a few minutes, or to allow extra ‘walking’ time, or else Jenny used ‘1471’ to find my number and rang me back.

To create emotional ‘safe zones’, each person could elect to have a trusted person with them during research conversations, though not, for ethical reasons, their befriender, but no one chose this option. Jenny initially wanted her befriender to be there, not sitting in on our conversations, but present somewhere in her home. However, after our introductory meeting, she changed her mind and we met on a one-to-one basis. As they were involved in maintaining the wellbeing of participating individuals, I kept in regular contact with befriending organisations, informing them, briefly, without breaking confidentiality, how visits had gone. On one occasion, after Jenny had become unwell during a visit (see her case study in Chapter 4), I contacted her volunteer coordinator, the following day, to apprise her of events and how the situation had been dealt with.

I did not plan to have any contact with volunteer befrienders, though I was concerned that my exclusive focus on the views and experiences of people with dementia might make some feel under scrutiny or excluded from the process. I raised these concerns with befriending organisations. Jenny’s befriender was aware of and fully supportive of the research. With Tom’s permission, his volunteer coordinator sent copies of research information leaflets to his befriender. I had understood that Grace’s befriender was aware of and supported the research but, after two meetings with Grace, I received a forwarded email, originally sent to the service manager, in which the befriender

raised her concerns about the research. These were based on misconceptions of how the research was being conducted – multiple researchers asking a lot of questions, unaware of the impact of memory loss and the potential for distress – which suggested that she had not received information about the research. The service manager and I felt that the befriender wanted to protect Grace, and I endeavoured to allay her concerns in an email, attaching copies of information leaflets, and copying in the service manager. No further contact ensued. The service manager was content for me to continue with research visits.

This situation was compounded because Grace often asked me to find out when her befriender was coming as there were no entries in her diary on previous or planned visits. On one occasion, at Grace's request, I contacted the befriending organisation to find out the date of her befriender's next visit, something they were not able to tell me as befrienders make their own arrangements with their befriending partners. With Grace's permission, and on her urging, I asked the service manager whether he would consider asking the befriender to make a note of her visits in Grace's diary to help her take part in the study, on the understanding, at that time, that the befriender supported the research. This would also help Grace know when she could expect to see her befriender, a concern she had raised with the manager during our introductory meeting. The manager responded by asking for the befriender's permission for me to contact her about the matter. It was then that the befriender expressed her concerns about the research. For me, there were ethical tensions in this situation between wanting to avoid 'interfering' in the befriending service; respecting the position of the volunteer befriender; maintaining confidentiality; confining the study to that which had gained ethical approval; being transparent; honouring Grace's wishes; and supporting her emotional wellbeing during the research – inseparable, in this instance, from her day-to-day wellbeing. Prior to my final visit to Grace, I met with the manager who was keen to know if the research had suggested areas for service improvement. Although I could not break confidentiality, I felt it was ethically appropriate to refer to Grace's remarks at our introductory meeting at which she had asked to know when her befriender was going to visit and for this information to be written down for her.

The service manager was surprised that this was not being done and said that he would ensure that it was in future.

3.4.8 Endings

I gave careful thought to preparing Tom, Jenny and Grace for the endings of research relationships (Calman, Brunton & Molassiotis, 2013). These endings are described in more detail in subsequent chapters. Each person was alerted to the final research meeting in advance (the week before), and also on the day of the last visit. During final visits, we reviewed our research conversations and individuals were able to reflect on taking part in the research (Pratt, 2002) and to ask questions. I explained what would happen next, including the possibility of a return visit to share initial findings. To mark the occasion and express my appreciation, I also presented individuals with a card and small gift, and shared an activity with them, which I hoped would have a personal meaning: photo books, flowers, an outing to a café, reminiscence. The ‘gifts’, themselves, generated further research material which appears in the case studies. At our last meeting, I re-emphasised the value of the contributions each person had made (Clarke & Keady, 2002; Murphy et al., 2015; Nygård, 2006), which seemed particularly reassuring for Jenny and Grace who had both expressed concerns at the outset that they would not be able to ‘get it right’ or have much of importance to say.

3.4.9 Participant Wellbeing and Safety

A major ethical dimension of the research was fostering a safe research environment for participants with dementia and also myself (Calman et al., 2013; Pratt, 2002; SDWG, 2014). Research has the potential to take people out of their ‘safe zones’; equally, individuals’ physical health and emotional wellbeing may fluctuate in the course of their everyday lives. While it was not possible to anticipate all eventualities, I found it helpful to think through, in advance, potential difficulties and dilemmas which might arise during the research, how I might respond (Guillemin & Gillam, 2004), and appropriate sources of support (Cridland, Phillipson, Brennan-Horley & Swaffer,

2016; SDWG, 2014). As indicated, Tom, Grace and Jenny were able to identify at least one trusted person in a position to provide information and emotional support to them, as necessary, throughout the study.

Prior to visits, I checked that each person felt well enough to meet me. Despite this, however, Tom, Grace and Jenny all experienced periods of ill-being or escalations of their health problems when I was with them. For each, this was a reflection of the challenging everyday realities of living with long-term health conditions. I did not feel, at these times, that the research had to be suspended altogether (Pratt, 2002): sometimes it was important, on a human and a professional level, that I stayed with a person in a supportive role until they felt better, and able to resume research conversations, if they wished. During visits, I was alert to signs of changes in wellbeing, and regularly checked with each person how they were feeling and whether they were happy to continue. I sometimes found it hard to gauge from Jenny's non-verbal communication whether she, at times, felt uncomfortable talking to me. Her tremor, reduced facial expression, and long pauses in her speech are all associated with Parkinson's disease but could also have indicated disquiet, or reflected the time she needed to gather her thoughts, or been her normal way of speaking. There were moments when I felt caught between risking being oversolicitous and risking prolonging any discomfort Jenny might have been experiencing.

Sometimes, I felt that the boundary between being a researcher and being a support worker was becoming blurred. Once, when I rang Jenny ahead of a planned meeting that day, she was ambivalent about my visit, initially reluctant to see me as she felt unwell and had not been expecting me due, I later discovered, to a calendar mix up; then sounding upset as visitors she expected to see had not arrived; and then inviting me to come round, hoping that by the time I reached her she would feel better. (My subsequent visit is described in detail in Jenny's case study.) I have revisited this telephone conversation, and my own ambivalence about visiting Jenny that day, on numerous occasions. It seems to have become a focal point for uncomfortable tensions I experienced when conducting the research. In this conversation (and in others with

Grace and Tom, too), as both a student researcher and a person with a much longer history as a health and social care worker, I was drawing on, and responding from, more than one role and set of experiences. These overlapped and created an ethical edge between supporting each person to take part in the research, which could also involve supporting them in other areas of their life, and exploiting their vulnerability. The discomfort was fitting, helping to keep questions about ethics and integrity alive in the research encounters, although these were never entirely resolved. At the same time, however, I felt it was important to recognise that Grace, Tom and Jenny, as well as ‘vulnerable adults’, were also competent, experienced and resourceful.

The study looked at Tom, Grace and Jenny’s experiences of befriending in the contexts of their everyday lives, other relationships and life histories. I wanted each person to feel able to talk about these broad topics in whatever way was meaningful for them, and to set their own limits on what they disclosed, including in relation to intimate or painful topics. I was aware that the events and situations associated with coming to have a befriender might be sensitive areas. I did not deter individuals from talking about difficult issues if they wished to but aimed not to probe unduly into personal material. However, on one occasion, I inadvertently brought back upsetting memories for Grace, and, on another, I persisted, more than I realised at the time, in asking Tom about a topic he did not, then, wish to talk about, and resisted answering. This raised the question of how easy it always is for individuals to limit or control what they say (or what comes to mind). I reflect on these conversational moments in the next two chapters. It is also important to acknowledge that Tom, Grace and Jenny all referred to positive experiences in taking part in the project such as enjoying having company and someone to talk to, and the sense of making a contribution: helping me with the research (Tom); helping people (Grace); and helping to stop others feeling lonely (Jenny).

3.4.10 Using the D, F and B Words

Thought needed to be given to using the terms ‘dementia’, ‘friend’, and ‘befriender’

in research conversations. A significant ethical issue in research involving people with dementia is whether and when to refer to a participant's diagnosis or use the term 'dementia' (Bartlett & Martin, 2002). Failing to present the study as being concerned with the experiences of people diagnosed with dementia can be regarded as perpetrating a deception (Bartlett & Martin, 2002). However, there are many reasons for being cautious and sensitive about language in research with people with dementia. While some participants may be aware of and able to talk about the impact of a diagnosis of dementia on their life, for others, the term 'dementia' may be alien, confusing or insulting since, for a variety of reasons, individuals may have a fluctuating (Phinney, 2002), or no, awareness of their dementia (which is, in any case, an umbrella term not an actual diagnosis), may reject or not have a medical understanding of a dementia diagnosis (Preston, Marshall & Bucks, 2007), or may regard the word 'dementia' as a stigmatising label (e.g., Sterin, 2002). Guidelines for befriending services for people with dementia (Befriending Networks Scotland, Alzheimer Scotland, n.d.) recommend that efforts are made to find out whether new service users have been given a diagnosis of dementia, whether they know they have dementia, and how they want other people to approach the subject of dementia with them. In my study, there was a need to address the issue of how to respect participants' own awareness and understanding of 'dementia' while being open about the project's ties to dementia studies. In the interests of transparency and inclusion, my participant information leaflet (Appendix A) used two terms: 'people with a diagnosis of dementia' and people with 'memory difficulties'. However, as part of gaining consent, when describing what the research was about, I referred to befriending for people with 'memory problems'. I was conscious, though, that befriending might not be meaningful to people in relation to their dementia. As the focus of the research was befriending in the multiple contexts of a person's life rather than 'dementia', I did not ask anyone taking part direct questions about 'dementia' or 'memory difficulties', using these terms only if and when they did (Pratt, 2002), and always adopting their terminology. Grace talked about her memory loss every time we met. Tom sometimes mentioned memory problems, but also used other words: 'seizures' and 'black outs'. Jenny did not speak at all about her memory.

I also had concerns about how to refer to each person's befriender, not wanting to assume that individuals used this term, or that they understood their relationship with their befriender as befriending rather than friendship, or other form of social tie. At the start of the research, I used benders' first names obtained from befriending organisations. Tom sometimes forgot his befriender's name, and Grace was unsure, having had two benders, who her current befriender was, but sometimes recalled her name. However, forgetting names did not mean forgetting actual befriending relationships or the role of befriender. Grace was the only person to use the word befriender. Tom referred to his befriender by his first name, and also as a 'carer', a 'friend' and a kind of visitor he could not recall: 'what do you call em?' Jenny did not mention the term 'befriender' and always called her befriender by her first name.

3.4.11 Multiple Roles

I remarked earlier on an ethical concern I faced regarding the line between supporting individuals to take part in the research and supporting them in other ways which involved drawing on different roles, identities and types of experience. Lavis (2010) writes of the "precarious space" (p. 327) in which researchers may be required to 'perform' multiple identities to "make possible research with participants of different status and background while at the same time maintaining [...] moral integrity" (p. 327). However, while recognising this 'precarious space', I came to the view that, as a researcher, providing practical and emotional support, being friendly or friend-like, and having professional knowledge and skills, as a support worker and ex-nurse, were all involved in facilitating research participation, maintaining safe research practice, and learning about befriending and everyday life for Tom, Grace and Jenny.

Reinhartz (1997) introduces the idea that researchers' selves, their multiple identities, are both brought to, and created in, their field of study. Similarly, as Lavis (2010) points out, particular identities and roles are not simply adopted by researchers to facilitate interviews but emerge in interactions with participants. Jenny, Grace and Tom all played an active part in our research relationships: they shaped how we spent our

time together and what we talked about; they invited me to talk about my life; and they sometimes asked me for help. In addition, the importance of following a participant's lead in dementia research requires flexibility and the ability to improvise and adapt to situations (Nygård, 2006), and calls on researchers to act beyond a narrowly conceived research role.

Bending or blurring the boundaries of the research role may be part of sustaining, rather than compromising, ethical practice. But, as highlighted, this way of working always takes place on an ethical edge, warranting ongoing critical reflection. A serious ethical concern was the potential for role confusion on the part of participants who might come to mistake the research relationship for friendship, particularly those who were lonely or who might have difficulty remembering who I was. Multiple visits might increase this risk but, on the other hand, over time, could actually enhance a person's understanding of my, and their, role in a research process. As part of process consent, each time we met, I reminded Tom, Jenny and Grace of the purpose of my visits and what topics we had discussed during our previous meeting. Inviting each person to reflect on visits and review our work, and valuing their contributions, also served to foreground the nature of our relationship. As well as telling me about befriending, individuals also 'showed me' (Nygård, 2006) how they spent their time with their befriender, an option given on the participant information leaflet, which included reminiscing, going out for afternoon tea, looking at photographs, practical assistance, confiding concerns, and being asked to share something of myself. In this regard, I had to be careful not to extend, or give the impression of extending, our relationships beyond the scope of the research, especially since, on both sides, our encounters could be interesting and enjoyable, or involve me providing a – modest – degree of support.

I experienced short-lived concerns that Grace and Jenny had begun to regard me as a befriender or new friend. Jenny, for example, told me I could stay with her if ever I was in the area and could not get home. Grace, too, told me I was welcome to visit her. On reflection, though, I saw these invitations as expressions of hospitality, personal identity and positive feelings about the research relationships, particularly

as both women understood that I was doing research and that my visits would come to an end. Yet it was also possible that such hospitality was related to each woman's wish to have contact with people they could talk to and get to know. Duncombe and Jessop (2002) raise the issue of researchers 'faking friendship' in order to obtain 'good' data. They argue that the idea of the warm, caring researcher co-creating relationships with participants based on trust and reciprocity, with mutually beneficial outcomes, is ethically naïve. Certainly such a view ignores power imbalances in research relationships, the potential for role confusion, and the influence researchers have in shaping the content and dynamics of interviews (Brinkmann & Kvale, 2005). However, to suggest that 'friend-like' qualities in research relationships are always insincere, misleading or bound up with eliciting 'good' data, I think, is unduly cynical. Indeed, part of Chapter 5 is devoted to a critical reflection on the ways that, like participants' befriending relationships, our research relationships blurred the formal and the informal. This meant that the relationships could be experienced by each of us as genuine and negotiated even though they were bound by formal limits and not fully equal. I argue that these were not friendships, faked or otherwise, but involved authentic human connection.

3.4.12 Research Conversations

Ezzy (2010) differentiates between 'conquering' and 'communion' styles of qualitative research interview. He describes how each style – the 'active probing' of the former, the 'attentive openness' of the latter – has a different 'emotional framing'. When "individuals in interaction experience themselves as mutually interdependent", through this mutual recognition, "the act of knowing can be felt as communion, not conquest" (Benjamin, 1988, p. 192, as cited in Ezzy, 2010, p. 164). I use the term research conversation, rather than interview, to reflect the relatively unstructured, person-centred approach I took to generating data through talking, and also to highlight the co-created 'coming together' in research interactions. Surr (2006) argues that, in research with people with dementia, especially rich and revealing data can be generated by letting the person set the agenda, rather than respond to questions on a pre-determined topic. My study was

in keeping with this kind of approach. I wanted to enable each person to talk about having a befriender, and their day-to-day life and associated life history in whatever way made sense to them and in whatever way they were able to. While, to begin with, I did direct our conversations, in an open-ended way, to befriending experiences, a primary research focus, Tom, Jenny and Grace had the space to, and soon did, speak freely about other areas of their lives, voluntarily, or in response to open questions on broad topics (Nygård, 2006) such as ‘how are you finding it living here?’ or ‘what do you get up to?’ My follow-up questions aimed to further explore and clarify situations, events and experiences introduced by individuals. I was careful not to ask a lot of questions, or complex, multi-part questions (Cridland et al., 2016) or questions which relied on an ability to remember details, as these can be stressful and embarrassing and ‘test-like’ (Taylor, 2014) for people with dementia, putting them on the spot and exposing memory problems. I also used a range of basic counselling skills such as attentive listening; attempting to emotionally ‘tune in’ to the experiences individuals were sharing with me; and checking out with participants what I had heard them say, allowing them the opportunity to agree or disagree with me and restate what they meant (McLeod & McLeod, 2011).

Attentive listening and being willing to follow the conversation where each person took it (Nygård, 2006) was an important aspect of the research, though one that posed ethical issues with regard to the boundaries of the research inquiry. On the one hand, “creative possibilities in research interviews for extended narration requires investigators to give up control” (Riessman, 2008, p. 24) which, correspondingly, might give participants with dementia more “authority over what gets said and relayed and how it gets said and relayed” (Bartlett & O’Connor, 2010, p. 111). On the other hand, as Lewis (2003) argues:

Interviews can have a certain seductive quality: participants may appear comfortable and may disclose information apparently willingly during an interview, but may later regret having been so open [...] Participants should be given a clear understanding of the issues a study will address before being asked to take part. (p. 68)

However, as Riessman (2008) points out, it is not always easy to judge, in advance, what is relevant and, for narrative researchers, apparently irrelevant digressions often turn out to provide rich material, and bring participants priorities to the fore. In our conversations, accounts of everyday life were enmeshed with stories about the past and more recent changes in personal and social circumstances, providing a vivid, multilayered impression of the contexts in which befriending relationships were embedded and meaningful. However, as indicated above, there were occasions when privacy became an issue for participants. I discuss this further in Chapter 4 and Chapter 5.

Before, during, and after research conversations, and in rest breaks, Tom, Grace and Jenny, unprompted, also switched between different kinds of talk: reminiscing, confiding, humorous storytelling, sharing nostalgic memories and so on. Grace and Jenny also spontaneously chose to show me photographs and ornaments and other features of their homes which were significant to them. Drawing on Gubrium and Holstein's (2009) concept of 'narrative environment', Davies and Heaphy (2011) show how the data generated in research studies are inevitably shaped by their methods and temporal dimensions, and by "the social and research contexts in which narratives are constructed and communicated" (p. 7). In my project, a series of one-to-one, weekly visits, combined with my person-centred interest in individual participants, and my openness to sharing aspects of my life, in certain respects, mirrored facets of each person's befriending relationship, giving rise to the variety of talk and activity in our meetings.

All research conversations were recorded, apart from my visit to a café with Grace, and lasted between one and two hours, though usually the visits lasted longer as I needed to re-establish consent at the start of visits, and we often chatted before or after the 'official' work was done. Not uncommonly, people living with dementia experience difficulties with speech and comprehension such as problems with word finding, abstract thinking and following what others are saying (e.g., Bartlett & O'Connor, 2010). This can cause loss of social confidence (Fox, 2011), inhibit self-expression, and make conversing

with others tiring. Jenny, Grace and Tom were all able to express themselves clearly and understand me, although it may well have been that this was more difficult for them than it appeared to be. I referred earlier to the impact that Jenny's Parkinson's disease had on her speech and non-verbal communication. Tom had lost many, if not all, of his teeth making it harder for him to enunciate certain sounds, more so when he was speaking quietly or quickly. This was compounded by the effects of long-term smoking and a broken nose, an old injury. Understanding Tom could be hard, especially at the start of our relationship, but I became more attuned to his voice over time and by listening to recordings over and over again. Grace's marked memory loss affected her confidence, could be stressful, and put her at a conversational disadvantage (Clare & Shakespeare, 2004). Grace and Jenny sometimes worried about whether what they were sharing with me was 'enough' or 'boring', and hence, providing appreciative feedback was part of bringing compassion, empathy, and understanding to research encounters (SWDG, 2014). I hoped that using counselling skills, such as those listed above, and coming across as a genuinely warm and non-judgemental listener, would help make each person feel more at ease in our conversations.

3.4.13 Reviewing the Data with Participants

Part of my final visits to Grace, Jenny and Tom was spent reviewing summaries of research conversations. These documents were written in short statements, using each person's words as much as possible, and covering the main views and experiences they had expressed in our meetings. Rather than giving individuals the summaries to read themselves, with their permission, I read them out loud, making the review a conversational activity, and creating opportunities for us to talk about the material and the experience of doing the research. Each person had the chance to agree, disagree or add to the summaries or ask that information be removed, as well as to reassess their original consent. Jenny found one factual inaccuracy, Tom reiterated that his befriender was 'guid a friend and that', and Grace added that she sometimes felt lonely. The idea behind this activity, known as participant validation or member checking, is that it allows those taking part in research to check the accuracy of data or interpretations,

and can be used to support the credibility of findings (Birt, Scott, Cavers, Campbell & Walter, 2016). In my study, in my view, each person's confirmation that the summaries reflected their views and experiences did not 'authenticate' my subsequent interpretations of the material, but it did redouble my efforts to ensure that their perspectives, albeit as I interpreted them, remained central to the 'findings'. Because analysis and interpretation of the data were expected to be time-consuming, and because each person had progressive memory loss and other long-term health conditions, I felt that sharing summaries at that point was a way to capture their initial responses to the data, bearing in mind that seeking their opinions on future interpretations might prove difficult. In addition, since I had promised to provide feedback to participants about the results of the study (Cridland et al., 2016; SDWG, 2014), around one year after the research visits (well before thesis completion), I produced an interim findings newsletter (Appendix F) which I dispatched to participating befriending organisations to pass on to Tom, Grace and Jenny (although I did offer to deliver them in person). As will become clear, by then, their circumstances had changed.

3.4.14 Confidentiality

Maintaining confidentiality and protecting the identity of participants is paramount in any research (Social Research Association, 2003). This is challenging in case study research in which the 'cases' concern individuals, their everyday lives and life histories, and hence contain a lot of personal and contextual detail including information about other people (McLeod, 2010). Stories and non-narrative material were kept intact in each case study, rather than fragmented into themes, also making participants more identifiable. In my thesis, persons, quotes from interview transcripts and ethnographic information have been anonymised through the use of pseudonyms, replacement terms, and vaguer descriptors (UK Data Archive, 2015). I have also excluded information about Tom, Grace and Jenny disclosed by gatekeepers and professionals, often unsolicited. I informed participants that, while the information they shared would be treated as confidential, and would be anonymised in the thesis and any publications, I could not guarantee that no one would be able to identify them.

The consent form I produced made each person aware of the circumstances in which I would have to break confidentiality (British Sociological Association, 2004; Economic and Social Research Council, 2015), which I couched as my concern that they might come to harm. I considered in advance at what level of concern it would be appropriate for me to take action, and what kind of action to take, including breaking confidentiality (Boddy et al., 2010). I drew on my professional background to think through a range of scenarios, particularly around deteriorating health and forms of abuse. On one occasion, I was concerned about Jenny's health – as she was, too – and did speak to a third-party but only with Jenny's permission, only to a person of her choice, and only after we had discussed the situation together, and I had solicited her views on what she wanted to happen to make her feel safer.

3.4.15 Criminal Record (and Non-Conviction Information) Disclosure

Before they would let me proceed with the research, some befriending organisations asked me to provide a higher level of disclosure – membership of the Protecting Vulnerable Groups Scheme – than Disclosure Scotland would sanction. Disclosure Scotland insisted that my research work warranted a basic disclosure and that advanced police checks, in my situation, may have been unlawful. Through a convoluted process, lasting six months, the issue was eventually resolved, during which time two potential participants dropped out.

3.4.16 Researcher Wellbeing and Safety

The research was conducted in accordance with the University of Edinburgh Health and Safety Policy. The main risks to me were identified as my safety as a lone worker and my emotional wellbeing. These were addressed through: discussion with gatekeepers about potential health and safety issues, both for myself and participants; undertaking not more than two, well-spaced, research visits each week in order to allow time for

emotional processing and reflection (Cridland et al., 2016); a checking-in procedure arranged with my academic supervisors and a back-up person; identifying, and drawing on, sources of emotional support within and without the university; and my professional knowledge of safe practice in lone working in the community.

3.4.17 Data Management

Study data consisted of digital recordings of interviews, electronic and paper copies of anonymised interview transcripts, paper copies of personal details of participants (names, addresses, and limited demographic information), one signed consent form, written field notes, and brief reflective jottings. The data were managed in accordance with the University of Edinburgh Data Management Policy, as specified in my ethics application.

The third part of this chapter is devoted to data analysis and includes how I went about transcribing voice recordings, and an explanation, with examples, of my method and process of analysing my data. I end with an introduction to the three case studies which form Chapter 4.

3.5 Data Analysis

3.5.1 Transcription

I transcribed audio recordings as soon as possible after research visits, usually the following day. Transcribing is an interpretive act, a process of reducing, fixing and altering the flow of a living conversation (Kvale, 1996; Riessman, 2008). It is difficult to capture non-verbal features of conversations, which may be subtle, and to represent evaluative or in other ways meaningful sounds – for example, ‘sssfff’, ‘ach’, ‘tsss’ – and the ‘atmosphere’ of interpersonal exchanges. I recorded obvious or striking non-verbal communication – laughter, sighing, tearfulness – in brackets. Indistinct words and phrases are placed in brackets, and inaudible speech is indicated by a bracketed space.

Pauses and their approximate duration are shown as different lengths of space, rather than dotted lines, as a way to suggest silence in speech rather than gaps in text. There were cultural, if not political, dimensions to transcribing Scots language words and colloquialisms. The use of apostrophes in written forms of Scots – for instance, a’ready not awready (already) – suggests that the language is substandard English (or a dialect of English) rather than a language in its own right (e.g., Education Scotland: Foghlam Alba, n.d.). I made use of online Scots dictionaries to transcribe my conversations with Tom in particular. Longer verbatim extracts quoted in the chapter are transcribed as ‘stanzas’, with utterances separated into lines where there were pauses or hesitations, to reflect the rhythms and poetic qualities of spoken language (Gee, 1986).

3.5.2 Voice-Centred Relational Method of Data Analysis

There were a number of advantages to using the voice-centred relational method of data analysis (VCRM) in this study. Before I identify what these were, it makes sense, first of all, to describe the ideas behind VCRM.

The voice-relational approach to data analysis (e.g., Brown, Debold, Tappan & Gilligan, 1991; Gilligan, Spencer, Weinberg & Bertsch, 2003; Mauthner & Doucet, 1998) has been described as “a ‘relational method’ for reading and interpreting interview narratives of individuals’ lived experiences” (Brown et al., 1991, p. 25). The approach is predicated on an understanding of human society as characterised by dependency and interdependency (Butler, 2012), and, hence, that a person’s sense of self is intimately bound up with their relationships with other people, and the society and culture in which they live (Gilligan et al., 2003). Originally devised within psychological methodologies as a new way to come to know the ‘inner world’ of participants (Gilligan et al., 2003), the method was subsequently developed for sociological use in relation to individuals’ sense of agency and social location (Mauthner & Doucet, 1998). The method draws on clinical psychotherapeutic concepts, and on literary theory – in particular, reader-response theory (see Section 3.2) and Bakhtin’s concept of polyphony. Indeed, VCRM is viewed as a form of narrative analysis (Riessman, 2008), providing a

systematic, though flexible, means to explore different facets of relationships in people's narratives: their relationships with themselves, with other people in their lives, and with their wider social, cultural and institutional milieux.

The concept of 'voice' is central. 'Voice' is seen as 'polyphonic', rather than unitary, and shaped by a person's specific history, culture and society (Gilligan et al., 2003). People speak about their views, their experiences and their relationships in complex, nuanced, ever-changing ways. Different 'voices' co-occur, may be in tension, and fluidly change and fluctuate in any one moment and over time (Gilligan et al., 2003). A series of readings 'tunes into' and 'amplifies' various aspects of voice in relation to self, others and society, allowing a researcher to attend to a story on multiple levels (Gilligan et al., 2003), and to explore different slants on the same narrative material (Byrne, Canavan, & Millar, 2009). The voice-relational method teases out the uniqueness and multiplicity of participants' narratives, staying close to, and holding the complexity of, their views and experiences rather than reducing the material at an early analytic stage into themes (Mauthner & Doucet, 1998). Crucially, the responses of the researcher on reading and/or listening to the life stories a person shares with them are explicitly and reflexively brought into the data analysis process (e.g., Mauthner & Doucet, 1998). This foregrounds a sense of 'who is speaking and who is listening' (Gilligan et al., 2003). It also enables researchers to 'witness' the shift between their personal connections with a person's narratives and their formal interpretive work (Brown et al., 1991; Byrne et al., 2009). For Mauthner and Doucet (1998), the challenge lies in keeping participants' "voices and perspectives alive, while at the same time recognising the researcher's role in shaping the research process and product" (p. 1). An ethical facet of the method is its acknowledgement that, as both co-contributor and interpreter, a researcher is a person who is "involved with, and therefore accountable to, a complex life story; a story s/he has, at some level, participated in" (Brown et al., 1991, p. 42).

For my study, VCRM had several strengths. It offered a means to attend to both 'broader' narrative and 'deeper' experiential aspects of participant stories (Todres & Galvin, 2005). It was capable of capturing, without the need to resolve, the complexity,

ambiguity and ambivalence in each person's 'voice' – its “irreducible polyphony” (Brown et al., 1991, p. 29) – and could, therefore, generate holistic, multifaceted understandings of a person's experiences and situation. Hence, it was a method of data analysis which was well-suited to case study research; indeed, its series of 'readings' (see Section 3.5.3) readily form the basis of in-depth case studies (Jankowska, 2014). The high degree of reflexivity built-into the analytic process allowed me to critically reflect on, and include as 'findings', not only my responses to Grace, Tom and Jenny's stories, but the ways I experienced our actual relationships, which, in turn, illumined aspects of befriending, and getting to know people. Finally, one of the method's potential drawbacks, its time-consuming nature, was not an issue in this study due to the relatively small number of transcripts – twelve – which meant that the depth and detail of the analysis was not compromised (Jankowska, 2014).

The voice-relational method can be modified to suit the needs of different studies and research questions (Gilligan et al., 2003). Three previous dementia studies have made use of VCRM. In her research on hallucinations in people with dementia, Taylor (2014) found that the method was particularly helpful in enabling her to attend to emotional aspects of participant's experiences; and that its holistic approach was in keeping with her values as a nursing practitioner. Both Proctor (2001) (in her work with older women with dementia in a day hospital) and Clare and Shakespeare (2004) (in their study on how couples where one had a diagnosis of Alzheimer's disease co-constructed their experiences through talk) utilised VCRM to explore issues of power in relationships, and to listen to and 'amplify' the speech of the 'less heard'.

3.5.3 Readings / Listenings

As specified in a 'Listening Guide' (Brown & Gilligan, 1992), voice-relational analysis is based on a sequence of readings and/or 'listenings' of the narratives (in my case, entire transcripts) generated in research interviews. In the next sections, I will describe each reading, giving examples from the study.

3.5.3.1 First Reading

The first reading has two parts: reading for the plot (‘narrative’) and reader-response (‘reflexivity’).

3.5.3.2 Narrative

Following McLeod and Balamoutsou (1996), I use the term ‘narrative’ to refer to the interview transcripts as a whole, and the term ‘story’ to refer to a person’s accounts of particular events, situations, and life experiences. The focus in this reading is the overall sense of the story, or stories, the settings, the people involved, the action and events, the timeframes – in short: the who, what, where and when. A range of narrative analytic techniques can be used to examine story elements such as metaphors, synecdoche, mimesis, genre, recurrent themes, structural features, and personal pronoun shifts. This allowed ‘breadth’ understandings of individuals’ lifeworlds, through a focus on the content and organisation of their stories, alongside ‘depth’ understandings of their experiences (Todres & Galvin, 2005), or what McLeod (1997) refers to as “the affective side of narrative” (p. 44). For example, the way in which Tom structured his stories around a series of binaries – for example, movement/stasis – communicated his experience of stark changes in his life; his metaphors of ‘falling’ conveyed existential dimensions of his situation (Johannessen, Möller, Haugen, & Biong, 2014); and his use of ‘they,’ not ‘we’ or ‘us’, denoted the social distance he felt between himself and other sheltered housing tenants. These examples, and others, are described more fully in each case study. While others using the voice-relational method worked with narratives on a particular topic – for instance, care and justice (Brown et al., 1991), and experiences of day hospital services (Proctor, 2001) – my research conversations, of a broad, exploratory nature, encompassed stories on a wide range of subjects in a variety of genres. I took this into account when carrying out each of the readings, aware of the different ways that, for example, Jenny spoke about herself in her accounts of her present health problems, and in her nostalgic stories of past activities.

3.5.3.3 Reflexivity

In the second part of the first reading, researchers record their own thoughts and feelings in response to texts of a person's stories, and which arise in their actual relationships with participants. The idea is that, by placing their own background, history and experiences in relation to the participants they interview, researchers may come to understand some of the assumptions and viewpoints which might be influencing their interpretations (e.g., Doucet, 2008; Mauthner & Doucet, 2003). As indicated, while other studies using the voice-relational method tend to focus on narratives on a single topic, in this study, those taking part shared stories on a host of topics which stimulated, in me, diverse thoughts, feelings and associations, not easily corralled into identifiable interpretive 'filters'.

My reflexive accounts were necessarily selective, temporary fictions, not fixed positions (Doucet & Mauthner, 2008). They were also, to use Bakhtin's term, 'dialogic' (Morson & Emerson, 1990) in the sense of always being, even if implicitly, addressed to someone, and in dialogue with other ideas and other people's words. Both participants and my own stories were "ever-changing and continually constituted in relationships" (Mauthner & Doucet, 1998, p. 21). Further, my reactions to Jenny, Grace and Tom, occurred not only in relation to texts of their stories, but also to direct encounters with them, and within our developing research relationships over a series of meetings. Our understandings of each other changed during the course of research visits. As Josselson (1992) points out, individuals in a relationship continually modify and adapt to one another. To paraphrase Brown et al. (1991), in relation to Tom (as with Grace and Jenny), as Tom's words about himself enter my "psyche a process of connection begins" (p. 41) between his feelings and thoughts and my feelings and thoughts in response to his, so that Tom affects me and I begin to learn from him – about Tom, *about myself*, and about the world we have in common, as well as differences between us. In this study, the reflexive work I engaged in focuses less on attempting to identify my social location and perspectives as specific filters or biases affecting my interpretations, and more on the ways that my, and Tom, Grace

and Jenny's assumptions, beliefs, interests and frames of reference came into contact during our relationships, not as static differences or similarities but as opportunities for learning and reappraisal. For Bakhtin (Frank, 2005), dialogue "depends on perpetual openness to the other's capacity to *become someone other* than whoever she or he already is" (p. 967, emphasis in original).

3.5.3.4 Second Reading: 'I-Voice'

This reading – reading for the 'I' voice – focuses on the ways individuals speak about themselves. Research texts are underlined each time a person uses 'I' or other self-referencing term – 'me', 'mine', 'my', and also 'we' and 'you' when these refer to self – along with the accompanying verb and other salient words. I highlighted whole statements or utterances. The 'I' phrases are then copied and pasted onto a separate document, line by line, in the order they were spoken. I separated I-statements into different stanzas when there was a change in topic (Gee, 1986). This reading brings to the fore the terms on which people present and speak about themselves (Doucet & Mauthner, 2008; Mauthner & Doucet, 1998), creating a space between participant and researcher in which the participant's perspectives and ways of speaking can be 'heard' before the researcher 'talks about' them (Gilligan et al., 2003; Mauthner & Doucet, 1998). I found that the method usefully slowed me down, allowing me – requiring me – to attend very closely to the several, fluctuating, nuanced, 'ebbing and flowing' (Edwards & Weller, 2012) ways Tom, Jenny and Grace spoke of themselves; and preventing me from simplifying their experiences, from 'tidying them up' (Reader, 2007). Working through the process with each person's interview transcripts brought to light co-existing 'opposite' or multiple self-feelings and 'betwixt and between' states, that led me to the concept of liminality (see Chapter 2 & Chapter 5). This reading also drew attention to 'addressivity', to the ways that, as indicated, the 'I-voice' is shaped by, and bears the traces of, someone else's words (Bakhtin, 1984).

3.5.3.5 Third Reading: Relationships

While the first two readings are common to all data analyses using the voice-relational method, subsequent readings can be adapted for different projects (Mauthner & Doucet, 1998). The Listening Guide suggests two further readings: reading for relationships, and reading for the impact of institutions and/or wider social, cultural and political discourse. In practice, my third and final reading combined both of these, focusing on how each person spoke about their relationships with other people, and about their experiences of institutional support and ageism. I conducted the same process of underlining and copying, this time, relationship-utterances, in order, onto a new document.

In Appendix G, I provide a section of transcript. Then, on separate sheets, I show how ‘I’ and ‘relationship’ utterances were selected, copied and pasted onto a new document in their original sequences, and divided into stanzas according to subject matter. I also select one ‘I poem’ story, and describe some of my initial thoughts and feelings on narrative features of this story, and on other parts of the transcript.

Having explained, with examples, the VCRM method, I now describe the overall process of analysis, from initially familiarising myself with my data, to forming case studies.

3.6 Process of Analysis

The process of analysis involved long periods of immersion in the research data. The data comprised: transcripts of research conversations, notes made immediately after visits and at later times, ethnographic observations and reflective writing. Drawing on all this data, to begin with, to get a ‘feel’ for the material, I wrote lengthy descriptions of the research visits incorporating my initial thoughts and feelings about the transcripts, reflections on the impact of the research encounters on me and my part in the research conversations, and initial analysis of striking narrative features

of Jenny, Grace and Tom's accounts. I then conducted two separate 'voice-relational' readings of each participant's transcripts – for 'I' and for 'relationships' – and, after further immersion in, and close reading of, this newly configured data, I was able to bring together material which related to particular aspects of self-experience and to relationships with various people. This was different to identifying themes (Mauthner & Doucet, 1998): it was a way to organise information unique to each person on the terms they specified. For example, for each person, keeping stories and stanzas intact, my approach was to pick out utterances about similar aspects of self-experience, and utterances relating to particular relationships – for instance, everything Grace said about her daughter – and to group these under main headings drawn from a person's words and expressions. 'I-voice' utterances were harder to organise, partly because it was often difficult to separate them from talk about relationships (in which case I placed them in both groups), and partly because they sometimes related to more than one subject. The 'I-voice' headings related, for example, to life changes (Tom: "things are turning a bit thingy"), health problems (Grace: "my memory's so bad"), or important identities (Jenny: "I was very active").

The research conversations covered many different topics, and stories were not always 'finished' in a single telling, or told in linear sequences, often unfolding during the course of a conversation, or a series of conversations, and sometimes repeated with additional content or different emphases. I did not aim to allocate 'I-voice' and relationship statements to main headings with exactness. Instead, grouping utterances in the way that I did enabled me to 'hear', or trace, different 'voices' – experiences, feeling, views – on similar subjects, and to organise the material prior to building the case studies. Based on close reading of the rearranged data, at this point, I wrote long descriptive accounts of the ways individuals spoke about themselves and their relationships, and the interrelationships between self and others – accounts which also included some initial interpretations. In the final stage of analysis, which culminated in three in-depth case studies, I integrated synthesised versions of these descriptive accounts with parts of my earlier writing on narrative aspects of the material, observations made during visits, and critical reflections on conducting the research

and building research relationships.

In addition, drawing on Spencer and Pahl's (2006) concepts of 'communities on the ground' and 'communities in the mind', described in Chapter 5, I created personal community maps (Maps 1-3) and diagrams of 'on the ground' relationships (Diagrams 1-3) for each person which represented different features of their social networks. These are included in Chapter 5. My initial intention in doing this was to visually represent my findings on network changes, and the relational contexts and other dimensions of befriending relationships. However, the maps and diagrams also came to be analytic tools in the sense that, once completed, striking aspects of each participant's personal community became visible which fed into, and supported, my interpretations.

3.7 Introducing the Case Studies

The case studies presented in the next chapter – Tom, Jenny, Grace – do not have identical structures. Each contains descriptive, reflexive and interpreted material but this is put together in different ways. Overall, the case studies first present a picture of a participant's everyday life, personal history, social ties, and living circumstances using their and my words. They then explore what befriending relationships mean to individuals with reference to these contexts. However, the meanings and experiences of befriending are also explored through my reflexive accounts of the research relationships. These are woven into the fabric of each case study, sometimes episodically and sometimes chronologically. There are, therefore, shifts in 'voice' or register between the utterances of participants, my first-person narration and reflections, my analytic, interpretive voice, and passive descriptions.

I purposely kept academic and other references out of the case studies. Like Taylor (2014), I wanted to reserve the space for Tom, Jenny, and Grace's – and, to some extent, my own – stories. I also wanted readers to have the chance to 'get to know' each of us, as the case studies unfolded, on the terms in which we saw and presented ourselves (Mauthner & Doucet, 1998) in those circumstances and at that time. However, the

case studies are implicitly informed by concepts such as personal community (Spencer & Pahl, 2006), addressivity and dialogicality (Bakhtin, 1984; Morson & Emerson, 1990) and liminality, which are explained elsewhere. By using Grace, Jenny and Tom's words as much as possible, by providing a high level of detail and personal openness, I hoped that reading the case studies, as well as thought-provoking, would be a compelling, immersive, empathy-evoking experience (Mason, 2002). Befriender names (pseudonyms) are given in Table 2.

Table 2: Befriender Pseudonyms

Participant	Befriender
Tom	Stuart
Jenny	Liz
Grace	Former befriender: unnamed Current befriender: Shona

Chapter 4: Case Studies

TOM

Tom

“did ye see anybody when you came in?”

Tom’s accommodation lay just beyond a housing scheme in a regenerated industrial area. Nearby amenities included a discount supermarket, fast-food outlets, a cut-price off-licence, and a pub with barred windows. Tom had “never been in” the pub though he passed it on his way to buy beer. Regular buses to different parts of the city could be caught beside the shops but Tom’s ‘bad legs’ made travelling by bus, and all but short walking distances, unfeasible. His flat in modern, well-maintained ‘extra care’ housing was light and spacious and came with a balcony. A ground floor dining room and a roof garden were shared with other tenants. One afternoon, to drive home his point about the building being deserted outside mealtimes, Tom asked me whether I had seen anyone when I came in. It was true that, over the course of five weekly visits, I had observed few people: a tenant and one or two staff in the office, a man sitting alone in the dining room, and, outside, a man in an electric wheelchair chatting to a support worker on a cigarette break. Tom was usually lying on his settee when I arrived, his multi-channel television turned up, and often seemed to have been dozing. While we talked, he sipped from a can of beer and smoked roll ups.

“a travelling man”

Tom “travelled near enough all my life”. He was “never hame”. At a young age he “went intae the buildin trade” and was known for his willingness to travel: “if there was any jobs away fae hame well we’ll get Tom fer it”. Tom worked to “chase the money”, to pay “for the hoose”, to send his wife “some money up” as “the bills just come in come in come in”. But journeys were also alluring and driven by a kind of restlessness: Tom got the “hots fer” travelling, he got “itchy feet”. Again and again, he talked about moving – leaving, returning, going away, going out – and being stationary or “stuck”. What he missed intensely now was “I’d jist get tae go where go *anywhere* I want like”. Once, Tom “wis always up and doon the country”, nowadays he journeyed

between his living room and his bathroom, between his flat and a shared dining area, between sheltered housing and a nearby off-licence.

‘Oot’ had been less a particular place and more a protected domain:

ma wife used tae say tae me
“Whar are ye goin?”
“Oot”
“Whar’s oot?”
“Oot oot!” [laughs]

Some of his stories on going out as young man were almost entirely carried by a succession of open-ended questions, spoken with rhythm and animation, conveying an exciting sense of possibilities:

we used to go tae a place
now “Where will we go this evenin?”
“Where will we go the morn?”
“Are we goin tae eat the night?”
or “Are we goin somewhere else like?”
you ken huhff

There is a marked shift of agency in the questions Tom asked in his youth – “Where will we go the morn?” – and those he now asks of sheltered housing manager, Jackie: “When are we gonnae go somewhere?” Then he could go “anywhere I want”, now he relies on others for “days oot”. Although, in the past, his wives and his mother questioned and criticised his departures – “Whar are ye going?”, “When are you gonnae come hame?”, “Are you goin away again Tom?”, “Will you be back?”, “Are you in fer dinner?”, “What’s the matter wi ye?” – Tom still went. These days, in a total reversal, Jackie urges him: “Tom go oot go oot”.

“things are turning a bit thingy”

Tom stopped travelling in his late fifties. Even though “there wisnae much work up here”, he returned to his home town, moving, at some point, to a hostel. This was

“doon tae me like ken cos ma legs were getting bad then anyway”. “I didnae fancy travellin again ken so I jist signed on the broo and that was it like ken”. For Tom “it’s jist in the last say ten years ken things are turnin a bit thingy”. Five years ago what brought him to sheltered housing was:

I got transferred
fae the hospital like
tae here like ken
[J: oh right were you not very well or ?]
aye I wisnae
I collapsed er
I was a
maybe I’ll say alcoholic [laughs]
ah naw
I wis
I had a bit o a
a bit o a drink problem
but that was years ago like ken
aye that was years ago
and er then ma legs went ken

The second time we met, Tom stood up and walked to the bathroom. I witnessed his lurching gait, the result of long-term heavy drinking. I silently wondered how he managed to reach the off-licence, let alone carry beer, but on a later visit he showed me his four-wheel shopping trolley which doubled up as a mobility aid. As Tom saw it, his drink problem was behind him since, while he still drank daily, he limited the amount and type of alcohol he consumed. Not going out at least prevented him from “I’d jist get into my auld habits again”. Even so, he doubted his drinking would escalate now because alcohol interfered with “all these pills” he was taking, because he had been advised to cut down, and because he was “sick o drinkin”.

Tom volunteered that “ma memory’s no right” due to a condition he could not initially recall, though at one point said was “seizures”, a word written down for him on his calendar. Tom thought his memory loss was getting worse but did “not really” make much difference to his day-to-day life. He told me that “I cannae remember pills”, and joked that it once took him two days to wash his clothes, although “usually I’m not too

bad”. He sometimes felt he was “mixed up fae ill”, mistaken for an ill person, when what was actually the matter was that he was demoralised and bored. Yet he also knew that “I’m no really that well really when you come tae think o it”, though he would rather not “think o it”:

I ken I’m ill
but I dinnae wannae go on about it
ken jist knock it oot ma mind like ken
cos if ye dwell on it
ah you jist end up goin doon an doon an doon an doon

Tom found it hard to disentangle ‘being ill’ from a general malaise or a failure of will or growing old or the sapping effects of his environment. Sometimes there was something definitely wrong with him – memory problems or seizures: “that’s it that’s whits the matter wi us”; and sometimes, “I dinnae ken what’s the matter wi us”. In trying to make sense of the man he experienced himself as having been, as continuing to be, and as becoming, Tom moved between different perspectives: social (“bein here”), medical (“black oots”, “seizures”, “a memory problem”) and ‘common sense’ (“it’s jist old age”).

“aw I do aw day”

Tom told, and re-told, the story of his day-to-day life:

aw I do aw day
aw I do nowadays
is go doon there
and get a cerry oot
and come back
and watch television
I’ve tried that pub
I’ve tried that pub
ach!

In his “aw I do aw day” stories, Tom artfully made known just how much he felt his life had dwindled and emptied. The very brevity of these stories, the paucity of

words, suggests diminution. The scope of his activities was reduced to buying beer and watching television. The force of the stories lies in the blend of the habitual and the extraordinary: it is Tom's unvarying daily round that is remarkable. Efforts to escape routine come to nothing; his story has no resolution, only an evaluative "ach!"

"aw that money"

Tom was satisfied with his self-contained flat, his "ane front door", but, as for money, felt "I've got too much actually". Paradoxically, having too much money was symbolic of the contraction – the poverty – of Tom's life as it moved into the future: "that's what gets me like ken I've got aw that money but I'll never use it like ken". Tom lacked not possessions but someone to talk to:

it's all right here like ye ken
cos I've got a television an that
and I've got ma bed an that ken
but there's naebody tae talk to
or anything like that
ken what I mean
yer jist
maist o the time yer on yer tod
twenty-four hours a day
cos aw yer seein is at dinner time tea time

"the mind's always thinkin"

The contrast between movement and stasis extended to Tom's mind and body. While his body was motionless – "I jist lie there" – his mind was active – "always thinkin". While Tom no longer travelled, his "mind wanders". Tom had retired but his mind was "on overtime". On his own, in his flat, "ye pit yer mind back like ken": "I wis thinkin of what I wis daein aboot twenty year ago like ken"; "I wonder how so and so's daein"; "I wish I wis so and so place ye ken". These days, journeys and friendships take place in Tom's inner life.

“a place where you die”

Ennui pervades Tom’s accounts. He described being “jist bored”; “doon in the dumps”; “ye just want to sleep”; “I’m tired all day long”; “I cannae be bothered”. Loss of vitality was inseparable from “this place”. The proximity of people older than him raised the spectre of death:

there’s some of them a lot older than me like ken
kinda depressin really like ken
kinda depressin really ken
I’ll probably die here and that’ll be it [laughs]

Tom had reached an age where “there cannae be many years left in me”. Many friends were already dead and others who “might be aw deid by noo like ken there must be same age as me like”. For Tom, the process of decline, of becoming “auld”, was accelerated by living among residents who were governed by routine:

they just go up to their rooms and that’s it
come doon at tea time
and back up to their rooms
and it’s
I’m tellin you
you’ll grow old before your age
I tell you that

Communal meals were regimented gatherings from which members “disband” and go their separate ways. The institutional habits of those around him had permeated his own way of being: “I’ve gone the same way it’s amazin how you faw into it eh?” Tom had ‘fallen into’ an alien life; ‘falling into’ step with his neighbours, he was losing his “ane self”. Cessation of movement was also devitalising: “stuck here”, he was succumbing to lassitude, painfully, and on a downward course; there might be no way back:

I think it gets bad when I’m in here like ken
I’m no goin anywhere noo like ken
I can see me goin doon the thingammy like ken

and that
cuts me ye ken
eh I've just gone
“Och I'm no wantin tae go oot ken”

Living in “this place” meant being withdrawn from society, removed to a place “tae die”, separated from phenomena – “different places” “aw different people”, “company”, “chit-chat” – which made his life vital and meaningful. “This place” provided food and shelter but not, for Tom, the elements that made life worth living, so that “gettin oot of this place” was a matter of keeping himself alive:

but I says tae Jackie
“I'm gettin oot o this place” ken
I says “I got tae get oot”
like I say
I'm goin doon an doon an doon an doon”
aye this is only a place tae pit yer heid doon
an get yer dinners
and that's it ken
apart fae that
there's nothin

Yet some vital elements had become stale. Tom described the souring, the routinisation, of former pleasures. Drinking was “jist a habit” for which he, now, had no energy or enthusiasm: “I cannae be bothered drinkin”.

“I dae it aw mase!”

Cleaners and carers had usurped household tasks – “hooverin and washin and flairs” – when “I can dae it mase!”. This, for Tom, was an attack on his self-sufficiency, on his selfhood, which further voided his life of “somethin tae dae”, and shook his trust in his abilities:

ye feel like you've lost yer confidence
ye know like ken
yer ane self

Tom resisted enforced inertness as “I dinnae want to be a vegetable here ken”. To accept this would be to give up on himself, to be defeated: “you might as well lay doon and die”. With “nothing aw day tae dae”, drinking was a means to obliterate the hours. In “a place where you die”, Tom was “killin time”.

“oot oot oot oot oot oot!”

Tom often spoke of the possibility of visiting the pubs of his home town. He was always on the brink of “goin doon” to his “auld haunts”; yet there were always reasons why he could not, or did not, or preferred not to go. In a series of narrative refrains, “I wis thinkin o goin doon”, Tom rehearsed his reasons for wanting to go and deciding not to:

I was thinking of going doon on Saterdag like ken
I go [and see] some of my old haunts like
to see what’s happening there like yeah
[oh I tell you] “Oh he’s alive!” ken ye ken
and it’d be aw changed noo anyway ken
ken you used
ken you used to get a singsong
now you get nothing really ken
you get nothing really

One of the central – and intensely felt – tensions in Tom’s accounts was that, irreconcilably, he both wanted, and did not want, to go out. Listening to these refrains, to begin with, I tuned in to Tom’s optimism, his upbeat tone. As he came up with reasons for not going – “I cannae walk that far”, “if I had a car”, “ages on a bus”, “everybody’ll be eighteen”, “it’s no the same”, “aw ma friends are deid”, “that lassie’s comin the day”, “I’m sixty-nine” – I began to imagine ways round these obstacles, to mentally invest in him leaving his lonely confinement. I wondered whether Tom ventured out with his befriender. But the cumulative effect of hearing so many refrains, each with the same cycle of quashed ambition, left me – like Tom – feeling stuck and frustrated. It was hard for me to accept, as it was for Tom, that “to tell you the truth,

I'm no that bothered noo actually to tell you the truth I'm no that bothered noo".

"it's aw changed noo"

Tom's home town lay a few miles and a short bus journey away from his sheltered housing flat but, in many ways, it was a distant place. Though nearby, it was no longer on his doorstep and too far to visit with bad legs. Now absorbed into a city, it remained a distinct community, but with a quite different character to the town of Tom's past: "it's changed noo it's upper class noo". This is the place where Tom was born, the base from which he travelled and to which he returned. Tom's identity was rooted in his home town. He told me where he came from reiteratively:

I'm fae [town]

I'm fae [town]

I'm fae [town]

He said that "I dinnae hing onto memories very much" because "I enjoyed ma time when I wis there like ken and that was it like ken". Yet, at the close of our final meeting, when I gave him a book of photographs of his home town, he was visibly moved. The pull of home was so strong that even though "it's aw changed", "you still want tae go back there funnily enough you still want tae go". Tom was homesick for a place which was no longer there.

"there's only two o us alive"

Tom was a survivor. Apart from Ron, "aw ma mates are deid": "there's jist only two of us left like ken". Tom and Ron belonged to a dwindling body of pub goers – 'regulars' – from a pre-gentrified era of his home town. When Tom imagined going back, it was in the hope of finding "auld mates", fellow survivors; of discovering "Oh he's alive! He's alive! [laughs]". What stood out about the way Tom talked about himself was his collective sense of identity; the extent to which he saw himself as one of a group bound together through work, recreation and community. Tom's 'we' was usually "guys", and

his stories as a whole were shot through with the loss of male company. There was no one left now to hail him, to call out his name: “see those pals they says “Come oot Tom!” There was no ‘us’ to rejoin.

“you used to get a singsong”

Pubs played a prominent part in Tom’s stories, less as drinking venues than sites of company, community and entertainment. He talked about pubs with energy and intimacy. For Tom, pubs were lively hubs of shared activities: “sing-songs”, “cabaret”, “dominoes”, “darts”, and “we’ll have a guid chat”. In sheltered housing “they aw keep to theirselves”, but in pubs “you could always find somebody” due to the ties that grew between regular pub goers, and because of the connection between pubs – ‘locals’ – and surrounding communities: “we used tae go tae [pub] on [street] we kenned aw the people there cus I came fae [home town] anyway”. Pubs held memories of married life. Tom recalled with exactness the area of a pub where “I used tae drink there wi ma wife sittin in the back in the lounge”, then an acceptable area for women in what were mainly male spaces. Much of the activity of Tom’s mind was taken up with pubs: debating whether to go, imagining social scenarios, remembering where “the beer’s rubbish” and where “they’re all drinking noo”. But the company and entertainment now missing from his life could not be found in the pubs of today. Tom’s memories of familiar pubs were ousted by more recent images of the same pubs, these days, emptied of all that drew him to them: “there’s naebody to see usually like ken no one really”; “I couldnae feel the atmosphere”; “nothing there really”. He had no common ground with younger, “upper class” drinkers who had turned his pubs into “bistros”.

Dialogues

There was a dramatic quality to Tom’s accounts. He frequently performed his stories, enacting dialogues between himself and other people in his past and present life. These were selective recreations of social exchanges not verbatim extracts. Nevertheless, the dialogic nature of his narratives admitted the perspectives of others – wives, in-laws,

parents, friends, paid staff – albeit as rendered by Tom, and in this way he gave them a voice, and allowed situations to be seen from different viewpoints. His relationships were presented as many-sided and often ambivalent. His dialogues were performed within our own dialogues with Tom playing the parts of both interlocutors while holding a conversation with me. While we talked, Tom stepped in and out of the drama to comment on the action, lending his accounts immediacy, and making them very persuasive.

“Ron an mase!”

Tom had known Ron, a “best mate”, since they were young men. Ron visited Tom in his flat, and was the only person Tom drank with, either bringing beer along, or else Tom got “a couple o cans in there fer him”. Ron was one of Tom’s last links with his home town: he gave him “aw the gen”: “he comes in for a couple of oors ken and tells me what’s happening in [home town] and that”. Tom had lost contact with his family, and it was Ron who broke the news to him that his brother had died: “Tom he jist died the other week there it wis in the papers”. Tom told me that Ron came both regularly – “once a week” – and, because he worked and went fishing, sporadically – “och he’s no very much here like”, “he’s a bit his own thing”. He was pleased to see Ron but stressed the benefits were mutual: “he gets to see me he gets to see me an aw like ken”. But Ron did not grasp Tom’s predicament:

that’s what I wis sayin tae Ron like ken
I says
“I’m getting oot o this place ye ken”
so he says
“What’s the matter wi it like?”
It’s awright”
“Aye ye say it’s awright
but you’re no the one who stayin there
I am!
You’re no stayin like ken”

“aw ma mates are deid”

Over and over, Tom returned to the loss of “best mates” he had known for “years and years and years”, and to the deaths of so many – “four or five o them” – so recently: “they aw seemed tae pop off at once like ken”. Some friends had disappeared for other reasons: one was “in his bedroom and cannae get oot”; another, like Tom, “he’s in a home or something like that ken”; and yet another, “he’s lost his wife [name] and ye never see him noo”. Tom’s social ties had been severed through death, dispersal and disability. A vanishing cohort of friends, and the finality of this situation, was captured in, often-recited, catechismal dialogues:

“Where’s so and so?”
“Deid”
“So and so?”
“Deid”
“Where’s [man’s name]?”
“Deid”

“you’ve got tae make friends”

I wondered about the place of friendships in Tom’s history of moving, returning and moving on again. For Tom, away from home, making friends was both necessary and “really quite interesting”, but had not been possible in sheltered housing:

that’s one thing
if ye work away fae hame
you’ve got tae make friends
or you’ll be on yer toddy
well it’s like here
naebody says boo tae yer here

Work was an initial source of friends but pubs, too, were places for cementing and enlarging social ties which “jist expanded expanded”. Through his contacts and friendships with men, Tom picked up work in new places, leading to further travel. The lure of travelling and spending time with “a couplie guys” sometimes meant “instead

of goin hame I used tae go tae [city] wi em [laughs]”. A world of male friendships existed outside Tom’s marriages. He missed the “guys” and his memories of them connected him with times of freedom, fraternity, and belonging.

“go back hame and want tae go away again”

Though he no longer saw or heard from them, Tom often brought family members into our conversations: his brother, his ex-wives, his children and his parents. His memories of family life helped to contextualise his present circumstances, and resonated with his feelings about more recent relationships. In Tom’s accounts, it was not the effects of his drinking but his travelling which strained family relationships. Recreated dialogues with his wives and parents echoed exchanges with present day figures, particularly in the way that they coalesced around going and staying.

“ye jist drift away”

Back home for just “three days every month”, Tom reflected on the impact his travelling had on his wives, and the part it played in his divorces. There was a parallel experience between his wives left at home then, and Tom stuck by himself in his flat now. He considered that, for his first wife, being married to an absentee husband “couldnae have been much o a life fer the missus when I come tae think o it”. For Tom, married life seemed to be a kind of background presence. He missed his wives in the sense that “it’s always somebody to go hame to like ken”. But, “once ye work away fae hame”, marriage was hard to sustain:

ye jist drift away
drift away
drift away

Physical distance led to emotional separation: “when I came back there was nae feelings”.

“apart fae the bairns”

Tom had three children, including a stepchild, from his second marriage. He described his involvement in their upbringing, even though he was away a lot, taking “the bairns tae school” during a period of unemployment, and having contact with them when “I stayed wi ma ma and dad fer a while” after his marriage dissolved. Tom’s children were “grown up noo and they’ve got their ane families an that”. He thought that they knew, or could find out, where he lived, but had not seen them for “aboot twenty years”, and “I never even think aboot them noo to tell ye the truth”; “it’s aw in the past noo”. Perhaps because of the part alcohol played in my own family history, I wondered whether Tom was at all curious about his children. It seemed he had reached an impasse: “I’d like to see them but I’m no goin oot o ma way tae go and see them like”. Yet memories came back to him, “lyin here”, “you start thinkin”. Not seeing his children was part of having to “take guid times and bad times”, but did not sit well with him: “apart fae the bairns it was awright”.

“ye watch me like a mother hen”

Many of Tom’s stories about his parents (and wives) centred on the contentious issue of his absences. Dramatised conversations with his mother provide multi-perspective cameos of critical moments. Tom gave voice to his mother’s annoyance at his coming home late; her scrutiny of his behaviour; her sadness at his departures; her concerns about him moving and changing jobs: “but Tom yer travelling all ower the shop there ken”. And, in these emotionally charged dialogues, as Tom explained why he had to go, familiar themes emerged: surveillance, confinement, restlessness, monotony, missing friends:

Dad says

“Dae what ye want son
it’s your life”

“I ken Dad

but ken I jist get sick o stayin here
aw the time like ken

ye jist
ye jist dae the same things an that
it's guid tae come hame right enough
but" I says
"Dad I jist want tae go away again"

"a different life fae mine ken"

The death of Tom's older brother added to the tally of recent bereavements, but, while the loss of friends brought sadness, the death of his brother "disnae matter I hadnae seen him fer thirty years anyway like". Tom and his brother led separate lives: "even when we were laddies ken we never played together". They met up in pubs during Tom's visits home, had "a wee chat and that talk about old times", "and that wis the only time really we were ever close together like ken". Tom's memories of his brother sparked thoughts of his own mortality. Tom was "goin like" his brother who, as he now did, took "aw these pills".

Jackie (Sheltered Housing Manager): "she's all right"

I first met Tom with Jackie. She stayed with us while I explained the research, and we all talked together for a while, each of us sharing something about our personal lives. Their relationship seemed warm, respectful, playful. Tom's enacted conversations with Jackie often focused on his intention to "find other digs", and on the ways she both supervised and supported him. He repeatedly returned to certain exchanges investing their voices with various emotional qualities – irritability, fury, pleading, cordiality, gentleness – creating a vivid sense of the texture of their relationship. These reproduced dialogues reflected her importance in his life; and also his different understandings of how unwell he was, and the degree of help he needed. When I asked Tom who he would turn to if he was worried or upset, he told me "I'd have to go an see Jackie", and performed this aspect of their relationship, voicing her words softly, almost whispering:

[she's the one]

visits to the hospital
“Have I got tae go?”
“You’ve got tae go
you’ve got tae go Tom
you’ve got tae go fer yer ane guid”

Jackie was both a sympathetic and an authority figure, an interface between institutional aspects of sheltered housing – rules, regulations, monitoring – and supportive aspects – care, assistance, encouragement. Jackie, and other housing support staff, “come up and check on you an that” in both reassuring and reproachful ways: “they’ll phone up an get help” as well as “you’re drinking too much beer”. Jackie was “all right” – good, sound – but “it’s her joab isn’t it?”

“naeboddy says boo tae yer”

Tom understood that moving to “this place” “was supposed to be” about meeting new people. Organised social events and outings “used to be guid”, but Tom told me, again and again, that days trips and a social club had been cancelled, and not restarted, because “naeboddy wants tae go”. But one group outing was not enjoyable:

there was the long boat on the canal like
with the OAPs
but once was enough like ken?
once was enough

Tom was bored with “nothin tae see bar fields” and the company of “OAPs”, but ‘oldness’, itself, was no obstacle to enjoying life. Co-residents might be “auld like ken but ye still och go oot and enjoy yerself”. While living with older people was “depressing”, he missed “the auld cronies” in pubs where “auld” applied to people he knew in places he liked to go to. Where Tom lived, sheltered housing flats were allocated on the basis of age – sixty and over – and the higher level (‘extra care’) of support that individuals required.

The communal dining room and other shared spaces created opportunities for tenants

to forge new relationships. Tom expressed some interest in the general flux “in here” – the comings and goings, people who had died, moved elsewhere, or behaved in eccentric or comic ways (“the sweetie wife”; “Little and Large”) – but felt he had not much in common with them. “Chat” at mealtimes was limited: “ye just ‘hello awbody’ and that’s it”. For Tom, other tenants led lives which were antipathetic to him, but exerted a gravitational pull on his own: “I’m getting the same way I’m getting like them”.

“he gies you a bit o a chat”

Yet Tom was on friendly terms with two male tenants, though he downplayed the substance, and emphasised the rarity, of contact between them. A neighbour fetched a daily newspaper for him, posting it through his door, or handing it to him with minimal conversation: “we have a wee talk and that’s him off like ken”. Even in the shared dining room “he doesnae sit and talk tae you he just ‘here’s yer paper Tom””. Tom talked for longer with another man who shared his interest in sport: he is “awright he gies you a bit o a chat and that but apart fae that there’s nothin”.

“they come in”

Tom had four daily visits from home carers who came to “gie me ma pills”, and a weekly cleaning service all of which were provided by outside agencies. Most of my meetings with Tom took place a few hours after the cleaners had called, and he usually spoke angrily about their visits, still fresh in his mind. For Tom, ceding domestic chores to paid workers had contributed to the demoralising curtailment of activities in his life, and to his overall experience of “goin doon an doon an doon”. Cleaners and carers intruded into his private space. His recreated dialogues replayed clashes over disputed tasks, the care workers cajoling and reasoning with him, Tom arguing back. And Tom had other complaints:

I get that many carers noo
I used tae get jist

I told [Jackie]
just gie us the one
cos ye get one different one every time ye ken
as I say I've just get used to the one carer
and the next thing ssss [gesture with hand]
[]
cus that's what I told one o their
one o their bosses that came
I says
I says
"I only want one carer at a time"
"Aye Tom aye"
but that was it like ken
that was it

Having "that many carers" prevented the formation of familiar relationships, based on trust and respect, with a social as well as instrumental aspect. In the past, Tom had "one carer aw the time" and he explained why this mattered:

cos it's
different people
if it's the same anes
the same anes
aw the ken
thingammy eh
och
jist it's
it's no the same ken
Christ!
"Take yer tablets Tom"
and so an so
two o them
there's
sssss
you
you get tae ken people ken

In Tom's experience, home carers treated him as an object of care, speaking to him in the imperative – "Take yer tablets Tom", "Take them!" – using brisk tones of command – "it's no like I'm a pet". Then again, Tom had learned from Jackie about work conditions for home carers, and he also aligned himself with them, worker to worker: "they pay

them sweeties like ken”; “they dinnae gie them a bloody bus pass, see?”; “nae wonder they’ve got nae staff eh huh!” If partly to dissuade his carers from carrying out, in his eyes, needless tasks, he found ways to cut down their work load or take a break:

I says “Away ye go through tae so and so ken
an come back an dock yersel oot ken”
I says “You can sit doon and have a smoke if you want”
“I dinnae smoke”
“Well jist sit doon then
and watch a bit o television”

Tom was critical of the briefness, and unpredictable timing, of home care visits but insisted, too, that longer visits were not always better because they were superfluous – “I dae it aw masel” – and because he did not want the company “young lassies” were “supposed” to provide him:

and noo they’re jist in an oot ken
well I’m no worried aboot that
I’m no bothered aboot
interested aboot that
ken cus “We’ve got tae tidy up Tom”
I say “What?”
and they says
“and gie you a bit o company”
I says “Company?”
I’m no really bothered aboot that”
[]
and she’ll just sit and talk
when Stuart comes back
we talk aboot fitba and boxin
and things like that

Tom rejected this kind of “company”, company attached to care work, and one-sided: “she’ll just sit and talk”. Carers were a generic “they” unlike Stuart – Tom’s befriender – who was a named person, and, together with Tom, formed a “we”.

“gets you oot o here”

Once a week Tom attended a day club run by a charity for people with dementia. Going there was “guid aye that’s not too bad”, “all right when we go places”, it “gets you oot o here like”, and “I enjoyed myself last week like”. Tom also looked forward to seeing a male member of staff there who came from Tom’s home town: “I kenned him since I was a man like ken he used tae work in [establishment]”. But the club was also “a bit dodgy noo”, “it’s getting a bit thingammy noo”. The downsides of attending the club echoed the drawbacks of living in sheltered housing: feeling out of place with the ‘client group’, the experience of confinement, and the lack of novelty. Tom told me that he used to go to the club twice weekly but “once is enough” now because:

they’ve no got any
up and go
if ye ken what I mean like ken
ken
ach
I don’t know
ken it’s just aw the same thing like
it’s just er
pff ach
ken I’m tss
I’m getting bored [gaein there] masel like ken
cus I’ve been there fer a few years like ken
it’s awright [sneezes]
it’s awright if they go places
but if yer stuck
if yer stuck in a hall like ken
ach!

The day club released Tom from being stuck in “this place” but sometimes was, itself, a place of ‘stuckness’.

“just cut doon yer drinkin”

Alcohol-related brain damage is an umbrella term for a host of physical, mental and cognitive health problems linked to long-term heavy drinking. Tom reported having

memory problems, “black outs” and seizures, not being able to walk far, taking pills for his stomach, being underweight, and feeling “doon in the dumps” and tired all the time. The last time I saw him, I learned from a staff member, and then from Tom, that he had a seizure earlier that week, falling and badly bruising his ribs.

Tom was ill but continued to drink. He transgressed norms of health-seeking behaviour. He was culpably ill. Every day, Tom risked exceeding the limits of what medicine could do to counteract the harm of his drinking, and what his body could withstand. But I was struck by how much he mourned his lost vitality, by his many grievances against ‘devitalisers’, and by his struggle to rekindle a life force dimmed by stasis, malaise and loneliness. There was a striking contrast in Tom’s stories between ‘told’ – deadening experiences – and ‘telling’ – his animated narrating. He was desperate for movement but drained of energy. He yearned for company but was socially marooned. He suspected he was “goin like” his “deid” friends and brother.

“red milk”

I was struck, too, by the mundanity of Tom’s drinking – his “red milk” (red, the colour of his beer cans) – which from the outside was toxic and alarming. He received medical treatment, personal care and housing support which together addressed real risks of homelessness, self-neglect, and rapid health decline. But what Tom identified as critically lacking was “somebody to talk to”. On his terms, life would get better not so much by following medical advice, more than he already had, but by having more company: his kind of people; and more things to do: his kind of activities.

“I look forward to him coming”

Tom’s befriender, Stuart, visited him for an hour each week, early in the evening. At the time of the research, they had known each other for four years. Tom thought that Stuart was roughly the same age or perhaps slightly younger than him, and was sure he did not come from his home town. Tom could not remember whether he had seen Stuart

that week in any of our conversations, often speculating that he was “on holiday” (one week he actually was on holiday). He told me that “since he’s been away like ken I quite miss him”. While Tom knew when Ron was coming to see him by looking at his calendar, which also showed day club dates, there were no entries for Stuart’s visits, or at least not for that calendar month, which meant that Tom could not check, himself, whether Stuart had been, or was due to come. But Tom was clear that “I look forward to him coming”. Although memory loss made it hard for him to remember specific befriending occasions, even so, Tom trusted that Stuart would be back, knew how often he came, and had a distinct sense of who he was, his presence in the room, how they related to one another, and the sorts of things they would do together: “he comes doon ken once a week like ken”; “we talk fer about an oor or something”; “he sits there and has a cup o tea”; “we talk about sport and things like that like ken”.

Tom’s dramatised interactions typify, as he sees them, the ongoing quality of different relationships in his social network. Compare, for example, enacted exchanges between Tom and generic home carers, and between Tom and Stuart. Tom’s dialogue with home carers suggests a hierarchical relationship; their utterances are task-focused, finally taking the form of an order:

they’ll come in like ken
“There’s yer pills Tom”
“Ah yeah leave them ower there”
“Take them!”

Stuart’s exchange with Tom takes place on the same ‘plane’ (“we sit”); his visits are relationship-focused; and his utterance takes the form of a question inviting Tom to express his preferences:

[Stuart sits down]
and we sit and talk about
“Do you want tae see the boxin?”
I says “Aye”
we’ll see the boxin

“we sit and talk”

For Tom, one of the most prized activities that he and Stuart did together was “jist talk about things”: “we have a chit chat”, “a wee chat”, “a guid chat”. I noticed how often Tom specified that Stuart sat down – “he sits and talks tae ye”, “we sit and talk about” – in contrast with a neighbour who “doesnae sit and talk tae you”. ‘Sitting’ meant time was available for – had been made for – talking. When Stuart sat, he was on the same level as Tom, physically and socially, alongside him, not standing above. Tom talked so much about wishing to go out, but chose to stay in with Stuart, acknowledging that:

to tell you
I’m no that bothered
Stuart comes doon to see me
and that’s fine for me ken
makes a wee change
means I can talk to somebody
and things like that ken

What Tom actually wanted from his befriending relationship was someone to talk to. Stuart and Tom shared an interest in sport, and watching and talking about “fitbaw boxin” was a focus of befriending visits. But chatting with Stuart went beyond conversing about sport. They spoke “about aw different things”, “kind of everyday things usually”, “whit ye getting up tae?”, “jist life actually jist life”, and “men things”. They talked about “memories” and “the guid times”.

“means I can talk to somebody”

Tom repeatedly expressed his frustration, his disappointment, that “naebody talks to you in here”, that “I hardly speak tae any o them doonstairs like”. Home carers “only come and gie you yer pills”, and those who do ‘sit with’ him are obliged to:

and they sit there like ken
“What ye daein sittin there like ken?”
“Well we’ve got tae sit here”

The ‘company’ carers provided was tagged on to personal care, quite different from the companionship of long-term befriending which served no other purpose than the relationship itself, with mutual social rewards. Tom enjoyed seeing Stuart, and thought that Stuart liked being with him:

he sits fer an oor
and has a wee chat away like
it jist shows you
how the time just flies like ken
and I think he quite enjoys hisel an all like ken

On his own, Tom was “killin time”; with Stuart, “time flies”.

“a man-tae-man thing”

Tom told me that he did not especially mind whether his befriender was a man or a woman, but his relationship with Stuart was “a man-tae-man thing”: “it’s like talkin tae yer brother”; “we can talk about things ken men things like”. “Men things”, for Tom, included sport but the mutual experience of watching and talking about sport, as men together, seemed as important as an interest in sport in itself. While Stuart and Tom did not share a common background, and did not drink together, nonetheless, their relationship was a mutual “man-tae-man thing”, congruent with Tom’s friendship history, and one which in some measure mirrored back to him the kind of person he felt he was.

“it gies me a break”

Spending time with Stuart gave Tom a break. Stuart’s visits interrupted the long, unvarying sameness of “aw I dae aw day”: “I look forward to him coming like it breaks the day up like ken”. In the past, Tom’s antidote to boredom was “tae go away”. Nowadays, “no wantin tae go oot”, and with few friends left, he struggled to find relief from monotony. Stuck in his flat, the stimulation of his relationship with Stuart, as with Ron, was possible only because “he comes tae see us”. Stuart provided respite from

institutional life and clashes with support staff. Talking about “life and sport” was a present day “change o air”.

“a friend and that”

Tom understood his befriending relationship as a friendship and a service. Stuart was both a sort of “awright” care worker and “guid a friend and that”. Tom’s relationship with Stuart was different from his friendship with Ron, not only in its shorter duration and non-shared background, but also because Tom was aware that Stuart was partly there to provide a service, to ‘give him’ reliable company, a break from everyday routines, and someone to talk to: “you need somebody like that”. Apart from Ron, and a neighbour, Stuart was Tom’s only unpaid companion.

“you need somebody like that”

Stuart and Ron, along with Jackie and other sheltered housing and day club staff, provided relationships of continuity. They were ‘there’ for him, “the same anes aw the time”, people Tom could “get tae ken”. This was important because so many historical social ties had been lost to Tom – family, friends, people in the pubs and quarters of his home town – and with them his ‘biographical anchor’. Formerly, his wives and family had an important but often background presence in his life. Due to his nomadic work pattern, a series of divorces, estrangement from his children, and the deaths of relatives, these days, Tom had no contact with his family at all. Having “a bit o a drink problem” might also have contributed to this situation, though Tom referred to this obliquely. Family, as a first line of support, was unavailable to him. Ron and a day centre worker were Tom’s last living connections to his early life. His friends had vanished from his home town, and ‘home’, too, had disappeared in what was now an upmarket neighbourhood. Tom seemed stranded in time and place.

As a traveller, making friends was necessary and interesting for Tom, but his customary routes to forging new contacts – work and pubs and the freedom to move – were now,

in practice, inaccessible to him. Opportunities for him to enlarge his social network through day club attendance and communal events in sheltered housing had limited success, in part, because Tom did not seem to regard his ‘peers’, in these settings, as his kind of people. His new social environment – “this place”, “in here” – provided little sense of belonging. For Tom, with few exceptions, sheltered housing residents – “they” – were “boring”, unsociable, self-secluding, in the grip of routines, and depressingly older than him. In sentences he did not finish, he hinted at other differences: “he’s a bit ”; “they aw talk about their ”.

Tom played down his health problems but was aware he was unwell and that professionals had a part to play in his life. Sheltered housing was pulling Tom “doon”, but was also “all right” as “I’m getting fed here I’m getting looked efter here”. In his view, there was a difficult trade-off between receiving care and support, and losing, or failing to regain, company, autonomy, movement and stimulation, such that a place where you get “looked efter” could also be “a place where you die”; a place where “I’ve got tae stay”, and a place “I got tae get oot” of.

In Tom’s stories were strands of biography which gave life to important past relationships, and provided a sense of who was missing now, and what Tom might be seeking in new social connections. These accounts revealed the significance of brother-like relationships, and the extent to which male friends sustained him. While most of these ties had been lost, they were present in his thoughts and memories. Tom valued a number of relationships with formal workers, especially those he had been able to get to know over time. It was often ‘professionals’ over ‘peers’ with whom he had the strongest bonds. Jackie, in particular, was someone Tom thought “all right”: caring, likeable, trustworthy. But as a manager she also upheld institutional rules, and, for Tom, at times, represented watchfulness and restriction which resonated with past familial experiences. Many of his day-to-day contacts were with women – “young lassies” – paid to be there: carers, cleaners, on-site staff, with whom he clashed but also sympathised, often rejecting their help and ‘company’ but also endeavouring to meet them on the same social level. What Tom strongly disliked about his home care

service – getting “that many carers”, “a different one every time” – was not an issue with his befriending service: he always saw Stuart.

Tom’s narratives teemed with binaries: then/now; free/stuck; movement/stasis; alive/dead; young/old; interesting/boring; variety/sameness; travelling/returning; we/I. By organising his experiences around these contrasts, Tom presented his life as utterly transformed. He described the empty repetitiveness and contraction of his life, nowadays, reduced to a daily round of buying beer and watching television on his own. In the past, his response to sameness was to act on his “itchy feet”, to “jist go”, to seek a revitalising “change o air” through travel and the company of his “old mates”. Tom viewed these strategies as hypothetically still open to him and, at the same time, not a realistic or even desirable option, leaving him emphatically “stuck”, and reliant on visitors, and organised trips and social events.

As formal ties had come to dominate Tom’s ‘on the ground’ social network, there was a corresponding shift in the underlying basis of his everyday relationships. In Tom’s stories, friends and acquaintances are social ties of choice, mutuality, and belonging. But, as a sheltered housing resident, with progressive impairments, Tom was increasingly the focus of care: a person with risks and needs which had to be managed. This brought into Tom’s private, personal space people and activities which he could not choose or influence. However, Tom was active within his relationships; able to discern what different relationships did and did not offer him; and clear about the kind of social contact he was looking for. For Tom, companionship was based on mutual connection, not the unilateral provision of ‘company’ tacked onto instrumental care visits, and not being placed with people deemed ‘peers’ based on perceived common needs and risks. ‘Company’ involved being able to get to know people in ongoing relationships. And ‘company’ took place between people on the same ‘plane’ as Tom, people who “sat down” with him, who made time for talk and being together.

Tom’s befriending relationship with Stuart distinctively occupied a place on either side of a formal/informal divide. Both chosen and provided, it encompassed elements of

friendship and person-centred service. Stuart played a part in meeting Tom's 'need' for company and activity, and in 'managing' his risk of social isolation, yet this was achieved through a long-term reciprocal relationship which was 'all about' the relationship, not tasks or problems. For Tom, both Stuart and the day club staff member offered compatible relationships which blurred the boundaries, and hierarchies, between formal and informal, creating opportunities to relate on the same social level. With regard to Tom's continued drinking, befriending was one of the few services to address loneliness, and other relational needs, without requiring sobriety or a commitment to quit consuming alcohol as a condition of contact. In this respect, Stuart accepted Tom as the person he was, not for what he did: their relationship had intrinsic not instrumental worth. In this respect, too, Stuart's dual role – friend-like worker – was different from Jackie's dual role. She provided a supportive, meaningful relationship but also had a professional duty to supervise Tom's tenancy. However, Tom did not see Stuart as a friend like Ron, and not only because of the difference in their backgrounds. Tom was aware that Stuart was a kind of friend and also a kind of carer.

While Tom did not draw any absolute distinctions between 'friend' and 'worker', in his accounts, friend-like aspects of their relationship were compatibility; sharing interests and activities; mutual pleasures to which they both contributed; and being able to talk about "aw different things" and have a "guid chat". Stuart and Tom had a "man-tae-man" bond, in keeping with Tom's history of male friendships, which reflected back to him a more accurate sense of the person he experienced himself as being. Stuart was someone from outside "this place" and did not share what, for Tom, were the undesirable characteristics of residents. Tom also pointed to service-like aspects of his befriending relationship. Stuart's visits were regular and reliable (although without calendar entries, Tom was unsure when Stuart was coming), and limited to an hour weekly. Stuart came to see Tom, and the focus of his visits was Tom and their relationship. How their time was spent was guided by Tom though also enjoyed by Stuart. As was not the case with some of his services, Tom could influence what happened.

In Tom's eyes, Stuart provided much needed respite from institutional life. Befriending visits were dedicated to "company": Stuart 'sat down' with Tom. Their encounters had an egalitarian feel: they interacted on the same 'plane'. In these ways, the 'relational environment' of their ongoing association was distinctly different from both professional relationships and friendships in Tom's life. Tom's relationship with Stuart had developed over a number of years. Despite his memory loss and difficulties with recalling particular, even recent, befriending visits, he was able to keep their relationship in mind, to hold onto it as a positive presence in his life, and to trust in its 'thereness' as a social resource. While Tom's attention so often turned to the lost relationships of his past, his awareness of Stuart's visits enabled him to look forward, to anticipate an encounter that would actually happen. Many of Tom's biographical anchor points had disappeared, and many were irreplaceable. Within the parameters of his befriending role, Stuart offered Tom the chance to form a new male 'we', a new social mooring in the life he felt he had 'fallen away' from. Their relationship accommodated aspects of Tom's past and present selves, his life then and now, being well and being ill. It responded to both; it mediated between: friend and resource; chosen and needed.

"I'm sorry for the times I misunderstood you"

Tom was a heavy smoker and had a broken nose and few teeth. To begin with, I found it hard to make out what he said. Sometimes, I misheard in glaring ways. The first time we met, mishearing a name, I took Tom's oldest friend to be a woman instead of a man. Tom did not correct me but continued to converse, and eventually I got the name right. Another time, my mishearing led me to inadvertently respond in the same way as support staff over a money matter. Tom took issue with me, as he had done with them, and while this did generate an important insight, Tom was clearly frustrated at not being heard. It struck me that a further advantage of having regular support staff was that this might improve communication. The last time we met, I apologised to Tom but he seemed to have no memory of my mistakes.

“a load of old nonsense”

On one visit, Tom seemed exhausted and low. I offered to come back at a better time but he did not want me to go. His memory was hazy and he was very down on himself. When I reminded him about the research as part of re-establishing consent, he told me that “we’re only going to talk a load of old nonsense”, and that there was “nae much tae publish fae my life”. Tom was getting “awbody aw mixed up”. I changed the topic of conversation to sport which I knew was an interest of his. He talked about boxing as a young man, telling me at first that “I wisnae that good”, but later admitting to winning crystal glasses, which his mother displayed in a cabinet, and remembering his father’s praise: “you weren’t that bad”. We both shared childhood memories of playing tennis, making bonfires and learning to swim. Tom’s mood and energy picked up, and we moved on to talking about how he made friends when he travelled.

“I was enjoying yer conversation there”

Sometimes Tom spontaneously remarked on his experience of the time we spent together, and sometimes I asked him how he was finding taking part in the research. There were similarities between his accounts of Stuart’s visits and his comments on meetings with me: for Tom, both provided novelty, respite, company, and social exchange. I ‘sat down’ with Tom and, for a while, I was the “same ane” for him. Research conversation “breaks up the day”, and “it’s been a change for me and all like”. Time stopped dragging: conversing for an hour and half seemed more like “aboot twenty-five minutes”. Talking with me was a chance to talk to “tae somebody” – “naebody talks to you in here apart fae Stuart” – and to engage in varied conversation: “talk aboot aw different things and that talk aboot life and that”, “aboot auld times really”. Tom usually rebuffed any compliments I paid him but when I told him I had enjoyed meeting him, his dismissive “ach!” gave way to: “well put it this way I’ve enjoyed it masel actually”, and he knew that “it’s helped wi the research hasn’t it?”

On my final visit, Tom, again, invited me to stay even though bruised ribs from a recent seizure-related fall made it painful for him to laugh, cough, sneeze or bend. He applied himself to reviewing my summary of our research conversations. Afterwards, aware that home was so important to him and that he had no records of his life at all, I gave him a book of photographs of his home town. Tom was surprised and became quite emotional, tearful initially, and then excited as he recognised shops and buildings and streets, and pointed out where he used to live: “well I’ll hae tae hae a guid look at that the night I’ll tell you”. I made a move to end the visit. I felt close to tears myself. Tom wanted to talk more, and in a long series of stories he described his relationships with people he had left behind, his parents in particular, over the years he was travelling and working away from home. Tom always came back – just as he always came back to this topic when we met – and in these stories, as before, his enacted dialogues with family members reflected the tensions and upset caused by his going. He explained to them, again and again, why he could not stay for good. This time I was leaving, promising to return with research findings.

“you get tae ken people”

Tom and I began to get to know each other, to strike up a brief relationship. He made me laugh with his comic travel stories and his quick wit. He found ways to connect us, expanding his knowledge of me by asking about topics meaningful to him – journeys, transport, places – allowing us to compare our stories, and bringing our lives into contact. We experienced the things we had ‘in common’ in different ways. I disclosed to Tom that, like him, I had also moved many times between cities and countries. For me, these moves created rootlessness, while for Tom they signified escape and adventure. We had both lived in the same city, but whereas Tom enjoyed “sunshine there twenty-four hours”, I felt out of place; while Tom was working for himself, I dropped out of my studies. We did not have to be ‘the same’ to form a relationship or to get on. Both of us liked “meeting aw different people”.

Talking with Tom made me wonder quite what it was to get to know someone. For me,

part of the process seemed to be continuously revising a ‘fantasy’ Tom: confronting hidden assumptions; taking in new impressions; re-imagining him. I was surprised, for instance, to learn that Tom danced at discos. He liked the places I guessed he would hate; he was glad to leave a city I thought he would love. And he welcomed me into his life when I worried that many of my features – my nationality, my gender, my accent – might put him off me. I became aware of unspoken common ground. Where else did my life cross Tom’s? What stories of mine were revived and revised in the light of his? I knew that Tom had alcohol-related cognitive impairment before I met him. I dreamt about my father, also “alcoholic”, a man who died alone in a room with a bottle. I thought about the chequered histories of alcohol in my own life and the lives of friends, colleagues and other family members. I anticipated the reek of alcohol. Tom was never a ‘blank shape’ to be filled. He put me in mind of the pleasures of drinking and its toxic aftermath. I was gladly seduced by Tom’s picaresque tales – the open road, the roguish anti-hero – but kept on wondering about the people left behind, his children in particular, and the harm that might have been done.

After meeting Tom for the second time, in my notebook, I wrote down ‘marooned’ and ‘finitude’. Craving freedom, craving life, Tom was reaching limits. I remembered the euphoric sense of limitlessness induced by alcohol, and was brought up sharp in that moment by limits, social and physical, that I had pulled back from. Strangely, as meetings with Tom came to an end, I was left with a new kind of respect for a life bound to alcohol; and a fresh awareness that a health-defying – life-defying – life was nonetheless, as it was, a life. Without realising it, I had wanted to recognise ‘Tom’, to find ‘him’ in the stock of ‘drinkers’ I had known, seen in films, and read about. Instead, his changing stories became part of my changing stories with neither of us reducible to any one of them.

Afterword

I intended to return to share my findings with Tom. I was looking forward to going. In a short period, I had grown fond of him. I did not get there in time. A few days before

I started to write up his case study, he died. Tom spoke such a lot about missing lost friends; sadly, his name could now be added to one of his oft-repeated roll calls of the departed:

so and so's deid
so and so's deid
so and so's deid

Tom was dead too.

JENNY

Jenny

Beginnings

Jenny lives alone in a small town close to the city where she once held secretarial and shop assistant jobs, and where she went to picture houses, and danced to big band sounds at the palais: “like going into a palace all the lights it was magic”. I turn off the high street, lined with shops, cafés, pubs and a church, and walk through a leafy, residential area, up a long, steep hill. There is a bus stop just outside Jenny’s modest bungalow. When I arrive with the volunteer coordinator, Jenny’s befriender, Liz, is already there, and we gather in Jenny’s living room. Liz goes off to make us a cup of tea. While she is gone, Jenny tells me that Liz is “one of the kindest people you could meet” and “I wish I could see her more”. We talk about the research and what it would involve. Jenny says she will give it a “try”. She shows me framed photographs of her father and husband, both deceased, and of family celebrations of her recent ninetieth birthday. We soon discover a connection between us: the rural town where members of her family still live, and where I spent part of my childhood. Jenny tells us she has been feeling dizzy, and recently fell to the floor in her kitchen, cutting the back of her head. She still has to be careful, she says, when she is brushing her hair. She is waiting for her son to book an appointment with her doctor.

When I leave with the volunteer coordinator, Jenny lets us know she has enjoyed our company. We make it clear that I am not going to replace Liz. I will visit her a few times to do the research and then stop, while Liz will continue to visit as usual. She agrees to meet me next week but asks, “will I have to pay?” Outside, sitting in her car, the coordinator informs me that Jenny has good and bad days. Neither of us think she has fully understood the research, but the coordinator feels it will be easier for me to explain it to her if no one else is there. It is. The following week, Jenny understands enough, and still wants to “try”, but I treat her consent as provisional until I feel, and she tells me, that she knows what the study, and taking part, means.

“how can you go about your life like that?!”

Jenny has Parkinson’s disease, a complex, progressive condition with myriad symptoms such as: slowness of movement, stiffness, tremor, anxiety, mood swings, cognitive impairment, dizziness, gait changes, balance problems, loss of manual dexterity, reduced facial expression, hallucinations, softening of speech, and delays in initiating speaking. The long-term use of anti-Parkinson’s medication often causes unwelcome side-effects, including involuntary jerking, twitching and twisting. Drugs may ‘wear off’, and ‘on-off’ switches can occur causing symptoms to suddenly reappear.¹

“yet this dizziness restricts you”

Once, Jenny could “jump on a bus and away you go!” Now, “I haven’t been out by myself for a wee while because of this dizziness”. Dizziness is ever-present, on some days in the background, on other days severe and combined with loss of balance and disturbing sensations:

I mean I can sit here and feel all right
and whenever I get up to go through there
well
you’d think it was something to do with
rise and fall
you know what I mean
because it causes you to
it’s like a spring inside you
as if they’ve
they’ve pulled it
cuz I
I just feel this
horrible feeling
[indistinct]
because it’s happened to me
even when my daughter’s been here
and your
heart beat
heart beat goes

¹See <https://www.parkinsons.org.uk/>

Jenny's metaphors – rise and fall, a pulled spring – suggest she is losing her ground, her stability. Bouts of dizziness come out of the blue so that, walking along a path near her house, “even though I had a stick you were you still were frightened cuz anything could happen to you at the back there”. She falls at home, without warning: “I walked forward to the table and the next thing I was on the floor”. “This dizziness” restricts her: she is “fed up”; “frightened”; “can't make plans”; “I'm wanting to get out”; “you feel “trapped”.

“you wonder what's caused it”

One afternoon when I visit, Jenny's dizziness has flared up. She feels off-balance and nervous of walking. She asks me to fetch her blister pack of tablets from a kitchen cupboard. She tells me the drugs are for Parkinson's disease. I notice the pack contains anti-dementia medication but Jenny says nothing at all about memory loss. Her “Parkinson's doctor” suggests that her pills might work better if taken four hourly. For Jenny, “this dizziness” is somehow separate from her Parkinson's disease: “I've still not got to the bottom of it”. It does not make sense to her. A brain scan showed “everything was all right” for her age; blood pressure-readings have been “normal”; copying shapes as a part of a memory test, “they were amazed how I got it right”. There is a puzzling and troubling disparity between her far from normal dizziness experiences and her understanding, and memory, of medical evidence that nothing is wrong. A normal blood pressure-reading “weeks and weeks ago” was not reassuring: she still feels unwell, and “they haven't done anything more about it”. She is frustrated with doctors and nurses who do not seem to respond to, explain or treat her symptoms. After her brain scan, no one told her she had Parkinson's disease: “I had to phone up to find out what the result was they should've let me know”. It seemed “almost impossible” to get an appointment with her doctor: “how long have you to go before they'll pay any attention?!” She prefers to see her “usual doctor” and “didn't get anywhere” with a “new one altogether” who not long ago came to her house. Jenny wants to understand what is wrong with her and, as much as she can, get well: to stop feeling dizzy, to regain weight, to feel better, to go out again.

“so hopefully something happens”

Jenny spoke of hoping her health would pick up, of waiting for – tentatively counting on – improvements the future might bring. She holds on to the possibility that something can be done, that “hopefully something happens for to help me”, and even that “I’d like to think I was going back to normal”. She does what she can, attending a specialist clinic, adhering to new medication timings “to get the pill to work better”, but cannot be sure it will “make any difference”. Twice yearly she sees a Parkinson’s doctor who is “very good” because he takes time to explain things, recognises – believes – her symptoms, and knows that “you do get nightmares with it – dreams that can be nightmares”. She wants to recover but doubts she can completely retrieve good health. She both resists, and is resigned to, loss of wellness. She looks ahead with wishfulness and uncertainty. She would love to dance again but “I don’t think it’ll ever happen”. Her oldest and closest friend: “I’d like to go and see her again – I don’t know if it’ll ever happen”. As her health gets worse, Jenny has both ‘dreams’ and ‘nightmares’.

“I was very active”

“I went to the dancing every week – that’s the first thing I missed”. Jenny is less active now than before, and less and less able to be active. Over time, she has given up volunteering in a charity shop; shopping with her brother and sister-in-law; using public transport; walking outdoors by herself; going to “the keep fit – I went to a lot of things”; baking and cooking and cleaning. At home, though, she keeps as active as she can. On the days home carers visit, before they arrive, “I’m up and doing things”, “I do quite a few jobs”. Staying active is a way of keeping going through the bad times, of chivvying herself along, of not letting “dizziness” get the better of her: “you’ve just got to get on with it – it’s no use sitting around moping about it – that doesn’t get you anywhere”.

Jenny is a storyteller. In her stories, she connected with an active, energetic self,

affirming her self-image, and tapping into vital experiences. Her reminiscences were immersive, joyful, activity-based. At a social club:

they got this Mr Music Man
you know
and he was singing and playing
and you got up to dance if you could
so whenever I went into the room
and heard the music [laughs]
it does something to me
I thought well that sounds great
so I was up dancing

The contrast between her, then, uninhibited and, now, cautious movement was poignant.

Jenny spoke of being active in her relationships – the ‘strong one’ – who took the lead in supporting her “so shy” school friend, and, latterly, a charity shop colleague: “I got her out of a situation she missed a friend that’s when I stepped in”.

“having to rely on somebody else”

Poor health means that Jenny has no option but to heavily depend on other people. Her choices and say over what happens, and when, are restricted, from more ambitious plans – travelling to see a friend – to routine acts of showering or shopping. She appreciates good support, formal and informal, but this does not take away the unwelcome sense of “having to rely on someone else to do it for you”. She has to fit in with the free time and timeframes of others:

“Are you needed anything mum?
I’ll get it for you”
But you only see her on a Saturday or a Sunday.

“Trapped” at home, Jenny is far less able to decide who she sees and spends time with, relying on people who can and do, or are paid, to visit her, and going to a day centre. Family members call in regularly but she still has to wait for them. Her sister and brother-in-law:

I wondered if they'd maybe come today
but there must be something else on
so it'll be next week before they come

“you're on your own and that's it”

On the face of it, Jenny's social world is well-populated. She tells me that she, mostly, has some form of face-to-face contact every day. This does not stop her, sometimes, feeling lonely: “loneliness can drag you down”. Not all visitors keep her company, and she still spends long periods alone. Part of her loneliness, despite support, is feeling she is coping on her own with a life that – physically, practically, socially, emotionally – is hard to live. During lulls in our conversation, the ticking of clocks, loud against the silence of the room seemed, oddly, to be marking the passage of time that was standing still. When no one is with her, Jenny listens to music or watches television as engaging, or soporific, distractions from worries or being by herself.

[J: how is it for you when you're on your own in the house?]
you just feel
you're on your own
and that's it
you can sit and watch the television
and doze off
without realising it you're even dozing off
and there's not a lot of great things on now anyway
so I have my have my music on
that's the first thing that goes on in the morning
and if there's nothing good on television at night
I go and put that [points to radio] on again you know
until I get to my bed

The reason Jenny gives for wanting to take part in the research was “if it stops people feeling lonely”.

“they're for me if I'm needing anything”

Jenny has a close extended family. Many family members live nearby or within a

thirty-mile radius. One of Jenny's daughters and some of her siblings have died, but she has weekly contact, in person, with her son and younger daughter and, almost as often, her sister and brother-in-law. Less frequently, she sees her brother and grown up grandchildren. Jenny rarely mentioned her late husband but showed me photographs of him. Her accounts gave the impression of a tightknit family, all contending, in different ways, with the impacts of ageing and ill-health. Jenny was conscious of the strains, time pressures and competing demands on her adult children, and their spouses, who have full-time jobs, children of their own, and in-laws with serious long-term health conditions. Jenny's son, and his wife, make it clear "that they're for me if I'm needing anything". They call in on Sundays, while on Saturdays they visit his father- and mother-in-law who is "worse than me with her health". Jenny's daughter visits her on Saturdays, does her weekly shopping, and sometimes brings her grandsons to see her. Both adult children help Jenny with practical tasks and liaise with health care services. The decline in her health, and constraints on her children's spare time, means there are few opportunities for Jenny to be with them outside her home.

I can only go at the weekends
when they're free
there's always been something on
if it's not me
it's something to do with them

Jenny felt that her family were 'there' for her, but having to depend on her son and daughter was guilt-inducing – "terrible" – as it took up their limited free time: "it's only at weekends that they can do things away from their work". Jenny keeps her worst experiences to herself: "I don't like to worry any of them".

"I can't come to you"

Jenny does not want to worry her family, but she does want to see them, and looks forward to their visits. Her sister and brother-in-law are often weekly visitors, able to make the thirty-mile drive, but her sister now has walking difficulties due to painful knees. A recent visit from her grandchildren and their partners was a lively occasion:

“all the chat was goin here on Sunday”; “they were in a wee world of their own yeah telling all their stories”. Jenny’s brother and his wife live nearby. They all used to go shopping and to tea dances together in her brother’s car but “they don’t come and visit me now”. The couple do not have children and her brother’s time is taken up with caring for his wife:

there’s just the two of them
on their own
and [wife’s] got dementia
I don’t think she gets out either now
so [brother] has to do everything

Jenny has some sympathy with her sister-in-law – “she goes away back to her childhood it’s a shame” – but misses her brother, and though “somebody said to me that he maybe doesn’t like leaving” his wife by herself, she has also “heard that he goes shopping on his own”.

and I’ll say to him
“Come round and visit me”
I said “You’ve just to get in the car
and you’re five minutes here”
I says “I can’t come to you”
so I’m still waiting for him coming

They are simultaneously proximate and apart. Jenny is conscious of her status as a widow. Like her brother’s wife, her son’s mother-in-law “has her husband to see to her” while she is without a spouse.

“she was full of life”

A few years ago, Jenny’s eldest daughter died, leaving behind her a son and husband. Jenny misses her “terribly”. Her daughter lived locally, and Jenny saw her every week and “sometimes oftener”. Jenny looked after her daughter during her illness “and I didn’t realise it in caring for [daughter] I lost my weight couldn’t believe it”. (I saw the dramatic extent of her weight loss when Jenny showed me older photographs of

herself.) Jenny spoke of the part they played in each other's lives. She looked after her grandson and her daughter "would come and pick him up and have some dinner as well"; "we used to have some good fun". Her daughter was spirited and made her feel included:

she was full of life
and she never left me out of anything
even goin out at night
and the weekend
Friday night and Saturday night with her pals
they'd go to a club and get up dancin
"Come on mum you're comin too!"

Jenny sometimes senses the presence of her daughter. She used to visit her house to "go and sit in the garden for a while", a way of feeling near her, in contact with her. Now she cannot manage to walk there which is "most annoying", or even get out to see her grave. Her younger daughter brought back photographs of flowers she left at the cemetery.

"we're qualified to help you"

Twice each week, Jenny attends a small day centre attached to a care home. She talked about her relationships with staff members and other attenders, "the same crowd there's about eight of us". Jenny's dizziness and fear of falling make her reluctant to leave her bungalow, and she is grateful that staff reassure her and encourage her to go:

I didn't know what to do on Monday
but [staff] said
"Come to the centre
because if you stay at home
you're just going to be looking at four walls again"
and she says
"We're qualified to help you"
so I went
and it was all right there

Different staff are: “good at her job”, “a nice person”, and they keep in touch if she is unwell and stays at home: “it was nice of her to phone up and ask how I was”. Going out in the day centre transport – “the ambulance bus that’s comfortable you know strapped in” – is a chance to travel to local places and further afield: to eat out – “a lovely lunch”, breakfast “was nice”; to drive through countryside – the “views are beautiful”.

“they don’t speak about their life”

I asked whether Jenny had made any friends at the day centre. She told me “well we all just muck in”, and described, with faint distaste, a group cake-making activity: doing it was “messy”, the cakes were “too sweet”, the task infantilising: “I was just thinking of children playing with them”. All ‘mucking in’ was not the same as friendship or camaraderie:

the people at the day club
they don’t speak about their life
or what’s happened to them
that’s what I find strange
because I feel that I’m not
getting to know anybody

Jenny finds it disappointing that “there’s no conversation going on”. A day at the centre, at times, sounded more like a sequence of meals, rooms and activities – “breakfast first”, “lounge area”, “papers to read”, “a game”, “lunchtime”, “dining room”, “lounge”, “bingo or make something” – than a social occasion. Jenny used “we” when she spoke about day centre attenders, but the image in my mind was of people enclosed in their own worlds, near to each other but not connecting. Apart from members of staff, Jenny did not mention anyone she had especially bonded with. On one of the days when Jenny goes, her next-door neighbour also attends. They have known each other for many years, and always sit together on the bus, but conversing is difficult as her neighbour has had a stroke:

her speech is not awful good either
cuz I sit beside her on the bus
going to wherever we have to go
and make conversation with her
but I don't always know what she's saying
she's to repeat it

“who's it going to be?”

Twice a week, in the morning, home carers help Jenny to shower. Jenny views their visits as purely for assistance not company. Home carers do not chat while they work as “they are too busy watching to see what you are doing”, and there is no time to talk after her shower as the carers have to hurry to “just get to the next person”. There is slim chance of Jenny getting to know her carers “cuz I never know who I'm going to get”. She likes home carers who provide helpful guidance (“never to stretch over cuz you could lose your footing”); speak to her respectfully (“they tell you though in a nice way”); anticipate her needs (“they get the towels ready”); and give her moral support (“she was praising me for the way I got through it and getting dressed and that she said you're really doing very well”). She is pleased when she sees the same carer: “there's the one that came on Tuesday she had been the Friday before so that was that was good just seeing her again”. As a rule, though, having multiple carers means that when Jenny has established a way of showering with a particular carer, she is not sure this information will be relayed to the home care team: “so whether she gets in touch with another one and explains it to her I don't know”. Having one or two regular carers would relieve her worries. Jenny would “know what she expects of me”, and:

I think I would relax more
cuz you're left wondering
who's it going to be
could be somebody
that I met months ago

She is unhappy with the timing of home care visits. Carers “don't come 'til about eleven o'clock and you have to go about in your dressing gown until they come”. Not

knowing who is coming is compounded by not being able to identify their names:

they should have badges on with their name
that's what I said to her
I said "I'm having to ask your name again"

Jenny has clear views on what makes a good home care service, but minimal influence over her own, despite the intimate nature of the personal care provided.

"we get a chat"

Unlike Jenny's home carers, her private home help is able to make time, after finishing her work, for conversation. Her home help has been coming weekly for two years. Over that time the women have developed a friendly relationship, exchanging details about their lives and mutual acquaintances. This home help was previously employed by Jenny's brother, and relayed news of his health: "he was thinner"; looking after his wife "must be telling on him now". Jenny looks forward to seeing her. "We get a chat". She is "easy to speak to" and once the house is cleaned, they sit down together for a ritual "tea and a biscuit". She is cheerful and vivacious, bringing sounds and life into the house; even while she works, she "chatters on sings":

la la la!
no words
just la la la! [laughs]

"she chats while she is doing my hair"

Jenny's hairdresser "comes to the house she has for a long time now": twelve years. I meet her, briefly, once, when I arrive as she is finishing setting Jenny's hair. Jenny likes seeing her, and feels better for having her hair done. Her hairdresser does not have time for "tea and a biscuit" afterwards but "chats while she is doing my hair". While chatting, they share ordinary experiences from the flow of their lives, each a kind of constant for the other. Jenny told me about her hairdresser's recent holiday; her

hairdresser knew Jenny's usual weekly schedule.

Jenny pays for the services of her hairdresser and home help but this has not prevented the formation of more personal, mutual ties. Hearing about the lives of others, through contact with them, vicariously extends Jenny's social circle. Contact with the same person over time, the unhurried talk, the friendliness and ease of conversation have created relationships which blur the distinction between employee and companion. Yet, as with her family, Jenny decides on the sorts of information she is prepared to share with her home help and hairdresser: with them, "I don't say a lot there are things that are private".

"the crowd that was with me"

Jenny's once wide circle of friends and acquaintances is steadily shrinking. Familiar faces at the tea dances disappeared as

the crowd that was with me
well I was with them
they're either ill or have
they've died

One of her two oldest, closest friends "died with her bad legs" and the other, now living thirty miles away, has "got something wrong with her". Jenny wants "to find out what's going on" but the problem with visiting her "was getting there it was the travelling". She has not been able to reach her by phone. Seeing her again would depend on access to transport, and Jenny's and her friend's state of health. In the past, her next-door neighbours were friends:

so we'd all get on the bus
down to the main street
and come up here and get off
and when we were crossing
over the grass there
he would say
"So the Mrs Never In!"

He was “a good pal” – “I could ask him anything to do with the house and that he’d help me” – but he died eight years ago, and though his wife still lives next-door, for all their propinquity, they are separated as a consequence of their health conditions. Jenny is “a bit wary of going round” as her neighbour “has to have a Zimmer to go about” and could not help Jenny if she fell down: “I don’t like to put that on make that a burden for her”. A few feet apart, they cannot visit one another.

“I don’t know what happened to her”

Illness and death and travel restrictions were not the only cause of disappearing friendships. Jenny twice told the story – one of her longest – of how a newer friend, someone she worked with at a charity shop, abruptly terminated their relationship, leaving Jenny with “nobody to go in the town with like I did with her”. Jenny felt badly let down. Her sense of loss was doubled: having helped and befriended her co-worker following a family death – inviting her for coffee and to tea dances, offering to accompany her to the cemetery – when Jenny’s daughter died, “having this awful thing happen to me”, her friend “hadn’t supported me at all” and “made no effort to get in touch with me”. Their shared experience of bereavement separated rather than drew them together:

so I phoned her up to tell her about [daughter’s death]
and she just burst into tears
so I hoped that she would phone me back
but she didn’t
so I phoned her
but got no answer

she burst into tears
as if it was her daughter

Jenny felt “it might have helped me a lot if she’d got back to me and we got on visiting terms again”. She missed her company, a “thing that happened every week”, “a regular thing and I looked forward to it”.

“the times that we had”

At the beginnings and endings of our meetings, during tea breaks, and in the middle of conversations, Jenny told me detailed, nostalgic – ‘feel good’ – stories about her past, rich in social history and sketches of rural life, with a cast of important figures: parents, school friends, her own family and the families of her friends. In her storytelling, people lost or out of reach to Jenny vividly existed in her mind; the border between ‘then’ and ‘now’ seemed porous. Jenny was as absorbed in her stories as I was engaged by them. A brighter past was brought to life in a difficult present, and, with it, feelings of social connection, relational warmth, and reminders of a life well spent. Her friend:

she just thinks back
and the times that we had
she says they were
the *happiest* years of her life

Liz

At the time we met, Jenny had known her befriender, Liz, for around two years. Liz is a middle-aged retired nurse. She sees Jenny once a week for an hour or two, on the same afternoon, and “pops up” at other times. She makes a note of her visits on Jenny’s calendar. Jenny could recall Liz’s most recent visit as well as how they had spent time together over the years. She remembered being introduced to Liz by the volunteer coordinator. Her first impression was “how easy she was to get on with”. I noticed she often smiled when she talked about Liz.

“she took me out a lot”

Since Jenny has known Liz, “quite a lot of things happened” – both changes in her life, and what she has done with Liz. Before she met Liz, Jenny had stopped going out as much as she used to. Being “away from your usual environment” was something

she missed. Having a supportive companion with access to a car enabled Jenny to get out to places she wanted to go to, and those suggested by Liz. Liz “took me out a lot”: by the river, to “get an ice cream”, to buy a pair of comfortable shoes, “afternoon tea”, “something in the evening”, “and Christmas and the New Year there’s usually something on by the school and we’ve been to that and enjoyed it”. Going out with Liz, in some ways, filled the gap left by her lost charity shop friend. Jenny told me she wanted “to get better just to get out with” Liz, “to enjoy things like that”. In the last year, though, Jenny’s dizziness had worsened, and, at the time of the research, apart from attending the day centre, she did not feel well enough to leave her house, even with Liz. But Liz was a constant ally, committed to her relationship with Jenny, irrespective of the care she needed, or what she could accomplish.

“I know she’s not far away”

Liz was ‘there’, reachable, available, close by:

I know she’s not far away
she said to me
“You know
if you’re ever worried
about anything
or you’re not feeling good
I’m on the other end of the phone”

Jenny’s dizziness and fear she might fall means that support, physical and psychological, is a matter of having someone, or something, to hold onto, or to hold her. She can hold onto Liz, “link into her”, arm in arm; and is ‘held’ by the feeling that Liz is “only a phone call away”. Knowing Liz is there is “a good feelin”. Liz invites Jenny to ask for help: “she keeps on saying you know if you do you need me get in touch”. This kind of befriending might not be typical. The volunteer coordinator told me that Liz is especially dedicated and does more than she expects of volunteers who are not required or encouraged to provide this level of service. She recognised that some befrienders ‘did extra’ and this was accepted, within limits, as long as both parties agreed and it

was not to either's detriment.

Jenny's family, too, provide practical help and a background feeling of support, but one difference with Liz is that, as well as living "just around the corner", unlike Jenny's children, she is retired. Jenny does not "like to worry any of them", but contacting Liz when she is "worried" or "not feeling good" feels less "terrible". Jenny thinks about how to 'spare' or 'protect' people from her needs and anxieties, and also about how she can mobilise the resources available to her, seizing opportunities as they come along. She knows she has a community alarm service and can summon help if she falls or becomes unwell. Aware that I was visiting on a good drying day, Jenny washed some clothes and asked me to hang them out and bring them in again before I left. At a basic level, Liz is an additional person in the social network across which Jenny can distribute requests for assistance and support. On one of my visits, Jenny felt dizzy, "horrible" and anxious, and told me that, at times like this, she "wouldn't hesitate" to ring Liz who would call round, if she could, or speak to her over the telephone. Jenny is aware that Liz used to be a nurse and has experience of taking care of people, and can talk to her – Jenny – about her health.

"she knows what I can do and what I can't do"

Jenny values the practical assistance which Liz provides. She does what she can at home but many household tasks are now beyond her: making meals; opening cartons of milk; bending to reach the lower shelves of her fridge and cupboards; hanging out washing. Jenny said that Liz "likes to be in charge", not that she usurps control, or over-helps, but that she knows what assistance Jenny needs without her having to ask: "she knows what I can do and what I can't do so she takes over". Liz and Jenny collaborate. For mid-week shopping, Liz takes "a note of all the things I'm needing on a notepad". This makes less work for her daughter who "doesn't have a lot to get for me cuz I get from Liz" during the week. Jenny has a daily meals on wheels service and "so I just need a sandwich at teatime" which Liz makes up for her for a day or two in advance, sometimes bringing "enough soup for two days". Liz's support

reduces Jenny's reliance on her family, although not entirely the uncomfortable feeling of "having to rely on someone else to do it for you".

"she helps you feel good"

Jenny enjoys Liz's way of being. She is "full of life"; "easy to get on with"; "a comic at times just comes natural to her"; "she's got a nice way with her". More and more, Jenny sees herself as a source of concern or burden to others; increasingly, she is subject to a fickle, unruly, alarming body. With Liz, Jenny feels cherished. Liz "helps you feel good" by listening to her stories, her "happy memories"; by being playful and indulgent. With evident delight, Jenny recalls how

[Liz] says
"We're going to have a cup of chocolate" [laughs]
so we had a mug of chocolate
and the froth
the creamy stuff on top
and the froth
she skooshes that in it! [laughs]

In some ways, Liz is daughter-like. "Full of life" is also how Jenny described her late daughter. She feels included in Liz's life. She showed me a postcard Liz sent her from a recent holiday, and mimed her swiping through holiday photographs on her smart phone: "amazing that gadget isn't it?" Jenny has met Liz's husband and son, and Liz brings her "lovely soup" made by her husband.

"she's thoughtful for me"

Sometimes Liz "pops up", making extra visits, such as calling in a second time, one week, to wash and set Jenny's hair when her hairdresser was on holiday. Jenny appreciates that she has a place in Liz's thoughts. She knows that Liz thinks about her when they are not together, and that she keeps in mind the sorts of things Jenny would enjoy or find helpful:

so while she's in her own home
she's thoughtful for me
in preparing soup and that
and bringing it up

she's very thoughtful
and when she goes shopping for me
she'll buy things
cuz she well
she wanted me to have them
whatever it is you know
it's just biscuits
or a bar of chocolate

Jenny also takes care of their relationship, taking an interest in Liz, respecting her life outside their friendship, and contacting her only in extremis. She knows that Liz is 'there' for her but "I wouldn't take advantage of her she's got her life to live", and "she's got her friends to go out with as well".

"different altogether"

Among the social ties in Jenny's life, her relationship with Liz is distinctive. Both a service and a friendship, it is different to kin, peer and formal care relationships. Jenny is aware that Liz's visits were instigated by a befriending service. She knows the volunteer coordinator, and remembers her role in introducing Liz to her as a potential companion. She understands that befrienders provide a service to other people as well as her: "that's another thing you get taken out to a café having a cup of tea and something". She recalled that Liz formerly befriended another woman who passed away.

Jenny's family are reliably 'there' for her, yet she is aware of pressures on their time, limits to their availability, their role in taking care of other people, and their own health problems. She does not want to impose, any further, on the lives of her adult children, concealing from them how unwell she sometimes feels. She finds it frustrating, too,

to have to rely on and wait for them. The death of Jenny's daughter was a profound event, and she misses "terribly" her daughter's vibrance and the closeness of their relationship. In some ways, Liz is a family-like figure, but one who is also outside Jenny's family. Her perception that Liz is nearby, and more reachable, adds to the background feeling of support created by her family and, to some extent, services. By encouraging Jenny to contact her when she is "not feeling good", Liz gives her permission to seek support, helping her to experience her needs as less intrusive and burdening. Liz's nursing background enhances the confidence and trust Jenny places in her. Jenny's longstanding relationships with her hairdresser and home help are closest to befriending in that there is a blurring of boundaries between providing a service and providing company. But, for Jenny, contact with Liz is different because, with them, she does not share intimacies:

I don't say an awful lot
there are things that are private
I know that Liz wouldn't spread anything

Liz is someone Jenny can confide in: "I can talk to her all right". Unlike her charity shop friend, Liz was 'there' in the years after the death of her daughter.

Chances for Jenny to maintain ties with existing friends, neighbours and familiar faces, even those nearby, have dwindled due to deaths, ill-health, a break-up, mobility problems, and transport issues. Jenny would like to make new and rewarding relationships but requires the assistance of others to foster this process. Social activities at her day centre have not generated new friendships. Even going twice a week, she is "not getting to know anybody". Jenny's relationship with Liz, itself a facilitated tie, is "different altogether". Jenny and Liz have been able to get know one another through meeting weekly over an extended period, sharing experiences, and disclosing aspects of their personal lives. But Jenny's personal stories take precedence. Jenny qualifies that Liz talks about her life: "well in a way she does". Liz does not disclose, or talk, 'too much': Jenny comes first. Day club attenders "don't speak about their life", but, because "she's just interested in them", Jenny can share with Liz "lovely memories",

life-affirming stories of past times:

I can talk to her about things that happened
when I lived in [village]
and all the fun we had

Jenny thinks that Liz enjoys coming to see her, and uses ‘we’ a lot when she talks about what they do together, strongly suggestive of mutuality.

For Jenny, loneliness is only partly due to living alone. Feeling lonely is linked with feeling that, much of the time, she is having to cope with an everyday life that is challenging on multiple levels. And feeling lonely is not only the result of an absence of people, but the absence of particular kinds of relationships. Jenny’s relationship with Liz is a friendship that is fused with a person-centred service. It is important to her even though she has regular and frequent contact with her family, and assorted forms of social care and private service. Organisation protocols set the boundaries of befriending relationships to protect both befriending partners. Under the auspices of this particular befriending service, Jenny and Liz have had the flexibility to extend the boundaries of their partnership, by mutual agreement, on the condition that this benefits Jenny, and is acceptable to Liz.

A bad day

Jenny told me her dizziness was worse on some days than others. On my third visit, she was having a bad day. She felt very dizzy and had to be careful when she stood up. She had discovered that her calendar was open at the wrong month which had confused her about who was coming that day. Her home help had not arrived as expected whereas, until I phoned to remind her, she was not expecting to see me. In past conversations, Jenny was sure in her mind that Liz visited weekly, but, today, she told me “she comes when she can so I don’t know when I’ll see her again”. She sounded upset. When I got there, she said, “Make yourself at home which is where you should be”. She half-laughed as if she was teasing me, but was also, I felt, expressing her ambivalence

about my presence – then, at least. I made us a cup of tea, and listened to Jenny talk about old school friends. She became engrossed in her storytelling and soon seemed brighter. We worked for a while on the research, and, from time to time, Jenny broke off to reminisce.

As I made a move to leave, she wanted to show me a photograph of herself and her two daughters, and set off to fetch it from her bedroom. I saw how unsteady she was, and helped her return to her seat. She said she felt shaky and that her heart was racing. We talked about what helps her on a bad day. I offered to stay with her until she had taken her teatime Parkinson's medication which, she said, sometimes made her feel better, and, in the meantime, we watched her favourite television quiz program. I placed items Jenny told me she would need later on a table beside her: a cold drink, her medication, and a filled bread roll which Liz had made. Even feeling "horrible", Jenny was able to forward plan, asking me to take two rolls out of her freezer to thaw in time for tea tomorrow, and to open a carton of UHT milk. I could see the kinds of simple tasks she would find difficult: bending and stretching to reach food, opening tight or fiddly lids and seals.

Jenny worried she was stopping me from going home, and, after she had taken her tablets, she attempted to walk me to the door, but started to sway: "I'm going to go!" I helped her sit down again. I asked her what she would do if she was having a bad day, like today, and was by herself. She expressed concerns about disturbing people when they had just got in from work, or were making their evening meal, but eventually asked me to contact her daughter. After I had done so, she wanted to know the effect my call had on her daughter: "How did she sound?" Her daughter arranged a GP home visit, and I stayed with Jenny until the doctor left. Afterwards, Jenny wondered whether she might be made to move to a care home, but hoped, now that the doctor had seen her, that something would happen to improve her health. As we said goodbye, she hugged me, tightly, and thanked me for staying with her.

A better day

The next time I saw Jenny, she was busy in the kitchen and seemed cheerful and not at all anxious, although, as always, she felt dizzy. The day before, she told me, she had enjoyed sitting out in her garden in the sunshine, and, today, she had done a small load of washing. Before we sat down to go over a summary of her views and experiences, Jenny asked me if I would do her a favour: hang out her washing – she cannot raise her arms above her shoulders – and bring it in again before I left. I felt glad to be of use, to be giving something back to Jenny who was helping *me* with my research. She proudly showed me lines she had rigged up in her airing cupboard to finish drying her clothes.

“all these stories”

At Jenny’s instigation, we always stopped for “a cup of tea and a biscuit” – the same ritual she shared with other visitors – a way she created time for talking and storytelling (aside from the research). She spoke of herself as embodying a store of memories, there to revisit, to draw on, through “telling you all these stories”. One of our conversations included separate instances of Jenny pointing to her head, first, as the site of potential disorder, and, second, as a repository of ‘feel good’ stories. She told me that a brain scan was done “because they thought it was all coming from the head [points to head]”, while, later, she said “I’ve got all lovely memories in here [points to head]”. ‘The head’ might fail but, so to speak, the memories lingered on. Nostalgic memories, and sharing them, were an emotional resource; a creative response to suffering; a means to continue to find pleasure in living. Telling “these stories” took Jenny “back to happier times” and “I know I can go there again”.

“a cup of tea and a biscuit”

Tea breaks were openings for Jenny and I to get to know each other; for her to talk about ordinary occurrences – her daughter’s holiday, receiving a clinic appointment, tissue fluff on a newly washed jumper – and to ask me, non-intrusively, about my life,

and invite me to contribute my own stories. We discovered that, forty years apart, as children, we had both lived in the same rural area, both spent time, as teenagers, in the same city, and both liked cycling. I found Jenny's stories fascinating: her memories of village life almost a century ago – reactions to the arrival of the first telephone, the first electric cooker. And, where our lives crossed, her stories brought back some of my forgotten past. Between visits, I found myself remembering my adolescence in a new and warmer light: recollections of films, concerts, volunteering, local history, walks, cycle rides, campaigns, all of which I seemed to have redacted from my usual memory of that time; as uniformly fraught and empty. That part of my life started to appear more varied and 'well spent', as projects and enthusiasms came to mind. Though I often feel rootless, I began to recall an earlier attachment to place. These newly released memories generated fresh connections both with Jenny and with my younger self.

“it's like having Liz round”

At the end of my first visit, I asked how Jenny had found taking part. She said it was “fine I've enjoyed it” and “it's like having Liz around”. I reflected on the ways our research relationship, formed over five weekly meetings, was a version of aspects of Jenny's befriending relationship with Liz. Spending time with Jenny as a researcher involved taking on extra roles. As Liz 'did extra', providing more than companionship, so, too, I quickly found myself doing, and being asked to do, 'more than' research. My visits to Jenny were part formal research, part informal social contact, part practical help, part 'crisis' response, all within a reciprocal, albeit time-limited, personal relationship. In certain ways, this 'showed me' what befriending was like, and meant, for Jenny. It also reflected the degree to which Jenny was living on the edge of managing to live alone at home, the delicate equilibrium of her vulnerability and her resourcefulness. My different roles, activities and responses were required to support, and take ethical responsibility for, Jenny taking part in the research; and ethical responsibility, too, for entering and being present in her life.

I was there when Jenny felt anxious and unwell, and witnessed what she tried to spare her family. At that time, like Liz, I was someone outside her family she could speak to; I was near, available and someone to hold onto to steady herself, and later to hug. On my second visit, I literally ‘stood in’ for Liz who was, that week, on holiday, arranging to see Jenny on the day Liz would normally have visited. My following two visits, in some sense, filled the spaces left by her home help and her hairdresser who were both on holiday for a fortnight. I began to learn, like Liz, what Jenny “can do and what I can’t do”, and became a person she felt she could ask for practical help. Jenny was interested to know that, also like Liz, I had been a nurse. I found myself being “thoughtful for” Jenny, imagining small ways to help or make her “feel good”, bringing her flowers the week after she felt unwell; asking if there was anything she wanted me to get for her on my way to her house; making a thank you card based on her dancing experiences, and giving her a gift of a book of old photographs. Like Liz, who was “just interested in them”, I listened to Jenny’s stories which took her back to “happier times”. Unlike attenders at Jenny’s day centre, we spoke about our lives, and the things we had in common. Jenny showed me hospitality, and told me I was welcome to stay with her if ever I could not get home. I expressed my gratitude for her contribution to my research, and the pleasure of her company. Jenny thanked *me* for coming.

Endings

We hug goodbye. Jenny wants to hear about my research findings, and we agree to meet again in roughly six months’ time. I go feeling confident that Jenny is clear about my role, not expecting me to carry on visiting, nor overly sad that our relationship has come to a close. It is how I want the ending to be. But I notice my own sadness that, now that our time together is over, now that our work is done, I am, after all, only a researcher.

GRACE

Grace

Being there

I first meet Grace, accompanied by the befriending service manager, at the day centre she attends twice weekly. We find her sitting in the common room, tapping her feet to Scottish country music, watching people get up to dance. We move to the dining room, vacated after lunch, where we talk about the research. Grace immediately tells me she has memory problems and has to “write things down”. She worries that she might not be able to remember enough to be of much help but decides to try taking part because “I like helping people”. We begin to get to know each other. Grace asks me about my studies and where I live. She talks about her family. “I love my family”. We find out that we both were once nurses, as, too, she tells me, was her befriender, “so we’ve a lot in common”. I tell Grace that, like her, my mother had been a district nurse. Grace has known the service manager for many years, and the warmth between them is plain to see. Grace asks him if he knows when her befriender is coming because “I’ve nothing in my diary”. She is not sure she still has a befriender. He reassures her that she does, but cannot say off hand which day she visits. Grace asks “but how will I know?” We arrange to meet the following week in her flat. I write down the time and the day on the information leaflet I have given to Grace, and she accepts my offer to ring to remind her.

The week after, half-way into a long train journey – with a very early start so I cannot contact Grace before I leave – when I ring to let her know I am on my way, she tells me she was planning to go a sheltered housing coffee morning. She offers to change her plans but, once I arrive, she feels that she should put in an appearance at the event, at some point, in case the organisers are worried by her absence. I understand that this is a drop-in event, and we agree to work on the research for half an hour and then go down for coffee. Grace reads and signs a consent form, and we start our recorded conversation. Ten minutes later, Grace intimates that she does want to go to the coffee morning, not drop-in later, but arrive at the start, at the time written down in her diary.

Not sticking to her diary makes her “all mixed up”. We decide to attend together but discover that coffee mornings are not being held this month, though Grace’s diary had not been updated.

Although arrangements for my visit had been made with the advice of the service manager and a sheltered housing coordinator, and, apparently, with Grace’s agreement, I quickly realise that we – I – had not consulted Grace in a way that would allow her to make a decision that was best for her. Grace needed to look at her diary and write my visit down in it. While we talk, Grace keeps her large, page-a-day diary open on her lap. She reads out loud today’s entries: four home care visits, a coffee morning, a dental appointment, and a taxi trip to her cousin’s for tea. Grace makes me feel welcome and wants to help me but I have turned up on a busy day: “as I say my memory’s so bad sometimes it’s okay if it’s a plain day but if I’m going out places it can be quite ”.

We return to her flat. “So what questions do you want to ask me?” We talk for a while, and then Grace wants to make sure she has booked a taxi, and to find her taxi vouchers. I help her find the vouchers, and she rings to book a taxi, discovering that “someone’s already ordered it so that’s fine we can settle down now”. But the feeling that she has done what she needs to do and can “settle down” does not last long. Looking at her diary, and sometimes asking me, she breaks off to check – and recheck – what she has to do, where she needs to go, who is coming, and what has already happened. She scores out entries and adds more notes. I try to allay Grace’s doubts about the taxi booking, and remind her that the taxi vouchers are now in her handbag. I am moved by how hard it seems for Grace to get on top of ordinary affairs, the mental effort involved, the ever-present doubt.

Grace is not sure about her befriender and thinks she might have left. She asks me to find out. I ring and speak to the volunteer coordinator who assures me that Grace has a new befriender and tells me that volunteers and clients make their own visiting arrangements. For much of our conversation, Grace talks to me about her health, her move to sheltered housing, her home care service, her family and her nursing career.

Then, out of the blue, she looks at the information leaflet, now tucked inside her diary. “Would I like to have a befriender? That was you the university”. “Well without my befriender I would be lost”. “I wouldn’t know when I was going out because my befriender comes and takes me out and she is a friend”.

Oddly, despite the spells of anxious checking, something about Grace makes me feel calm and at ease with myself. I wonder whether taking part in the study will be too taxing for Grace. I do not want to add to her difficulties. But, I remember Grace saying “sometimes it’s okay if it’s a plain day”, and that she likes helping people. I have to consider her feelings if we do not proceed. We arrange to meet again, next week, this time sitting down together with Grace’s diary so that she can pick a suitable day.

Afterwards

As soon as I leave, the calmness I felt in Grace’s presence gives way to other reactions. I walk into the town to buy a cold drink. I find myself wandering up and down streets rather than heading for a shop. I feel dazed. In a high street store, I pick up a bottle of water. A shop assistant comes over to me and offers to help me pay for the water at a self-service till. I imagine I look lost or puzzled. I am half-aware that I am reading and re-reading my own pieces of paper, scrawled with train times and people I need to contact, but the information does not fully register. Leaving the shop, I hear someone talking to me as if through water. A woman is pointing out that I have dropped some papers.

The next day, I feel tired and tearful. I shuffle and recompose all my lists, and endeavour, ineffectually, to attend to my work. I imagine Grace engaged in the process of trying to get to grips with her day, checking and re-checking, writing and re-writing, with short-lived relief from uncertainty. I wonder if everyday life is always like this for Grace. Over the next few days, I still feel tearful on and off, and am often lost in thought. One morning, out walking, I stop on a bridge and look across to hills in the distance. I have been preoccupied with memories of times when I could not be

reassured, when my doubts were stayed but quickly returned in a continuous, fretful loop. I am struck in a powerful way by how much, at such times, moment by moment, my attention was caught up in – bound to – these loops. I notice the view from the bridge and the difference it makes when my senses are free to notice.

“and I moved in here”

More than once, Grace tells me the story of how she came to live in sheltered housing.

The move, two years ago, still seems alive in her mind. Her previous address

was a good street
and I had a very good neighbour
[name] was my neighbour
but she was kind of like me
she had a daughter
she had a big family
and two of them come every day
and they stay with her
they take it turn to stay with her
and remind her things
so she couldn't remind me about things what I was doing
and I was getting very mixed up
who was coming and who wasn't coming
so my daughter said
“I think you should move out of there
and go into this sheltered housing”
so I had to put my name on a waiting list
and then I got in here
and what a difference it's made!
and she's been up to see me
but she's not very good at the walking now

Her neighbour on “the other side” of her house:

she'd been in the [name] in the mental hospital
she was a nice person don't get me wrong
but she had a lot of mental problems in her head
family problems I think
so I really had nobody to confide in

I ask Grace about friends. She tells me “I’ve my [cousin]”. Grace used to live “out of the town”, and “I don’t know so many people now now that I’m in here”, and “I don’t keep up with my neighbours no cos I was too busy working”. Ex-nursing colleagues? “They were all kind of private people”, and “I didn’t really keep in touch”, “but again they don’t want to know you once you’ve retired”. For Grace, “what a difference it’s made” to live in sheltered housing; yet some of the same concerns remain. Grace gets “mixed up”; her new neighbours have “all got problems”; and there are few people here “to confide in”.

“my memory’s so bad”

Grace reveals how extensively, how profoundly, memory loss affects her life. At moments, her memory is split off from herself: “the memory’s rubbish though”. It thwarts her. She berates “the memory” for letting her down, for frustrating and embarrassing her: “you know if you forget things you think oh I should’ve been there! I should’ve been there! I know it’s rubbish rubbish!” She tells me, “if I had my memory I would be perfect”, more flawed than ill. She yearns for her memory, her only privation: “I want for nothing if only I had my memory”. Over and over, Grace explains how the key to how she manages is writing things down and written information: “I live with my diary”. Her master diary, her notebooks, and paper lists are reference points; they help her get her bearings. Writing things down enables her to “manage okay”, worry less, and feel she is “sort of keeping on top of what’s going on”: “I just look up my book and I know where I’m going if I didn’t write everything down I’d be lost”. Coping in this way requires constant toil as “I’ve got to keep checking my wee book”, and depends on “when I remember to write things down”. Twice when we meet, Grace’s diary seems almost an extension of herself so that, as we speak, her voice merges with diary entries:

I always write everything in here
and my [name] taxi’s coming
book for twenty to five
use taxi vouchers
vouchers in my handbag

[name of sheltered housing]
that one's off
and you're Jane

Living with memory loss, even using her diary, limits how far into the future Grace can hold in her mind: "I can only live one day at a time"; "I just take each day as it comes if you start looking away ahead you get mixed up". Even the prospect of a holiday with her daughter: "I don't look forward to it too much until nearer the time". Reflecting on this, I imagined how much harder it would be for Grace, by herself, to make and sustain new friendships outside organised social events.

"if it's not one thing it's another"

As I listen to Grace speaking about her life, no single turning point, or disruption, towers above the rest. She talks to me about living through a series of losses and changes. Many events were, and continued to be, life-altering. Her husband died before she retired. Her brother – her only sibling – was no longer alive. Her daughter – her only child – moved away. She sold her home "and I moved in here so it's been a big change". Her health:

I still go to the hospital
to have the check up on my breast
because I had breast cancer
and they took the breast off
one of them
so they keep an eye on the other one
and the lymph glands
but I'm doing ok

A stroke caused serious, and worsening, memory loss. Getting up from her chair, she winced: "sore back", "wear and tear cos of all the lifting that I've had". Having leukaemia means "I get tired quite easy". There were no tidy transitions:

if it's not one thing it's another
but I don't live my life worrying about things

I try not to worry
but it is quite difficult
when I've got no family here
you know to confide in somebody

“I was always a nurse”

Memory loss was undoing her competence, status and confidence. As a district nurse, “I used to go round all the houses now I’m a patient”. Now, she relies on “untrained” home carers whereas “I used to do it all myself”. Grace tells me “I like to help people that was my nature”, the shift in tense betokening an identity that has expired, and yet survives. Grace still experiences herself as a nurse or helpful person. She describes how she befriended a “nervous lady”. She will “listen” to people “in here” if they want to tell her their problems. She gives her professional opinion on the support she receives. Taking her warfarin at a certain time is something “I know all about”. She shares her nursing stories. She relates to me, as one nurse to another nurse: “being a nurse you could say to people couldn’t you?” Yet memory loss is impairing her skills and, for her, even the semblance of competence: “I used to be a trained nurse you wouldn’t think so”. Grace can no longer – is not permitted – to self-administer her drugs, now kept in a locked box, a metaphor for a sphere becoming closed off to her.

“I gave up my car”

Grace feels the loss of giving up driving acutely. “I miss it terribly”. It is a loss heightened by her lifelong experience of driving as “easy I’ve driven all my days since I was young”. It intensifies the unwelcome feeling of “being dependent on other people”. Grace gave up her car a year after moving to her sheltered flat and the decision reflects further decline in her skills and confidence: “if I did use it I was a bit nervous of you know remembering what was what”. Driving was an automatic, everyday activity. It offered freedom, choice, self-reliance: “I used the car for everything just jump in the car and away you go you can go anywhere you want”. It was a means to lift her spirits “if you were feeling a bit down you could go for a wee run even to the beach”. Not

driving means having to resort to, and rely on, other forms of transport, bringing issues of expense and access. It has terminated long-standing relationships with doctors and nurses at her local health centre, now too far away to attend: “the changeover was very difficult”. For Grace, letting go of her car symbolises the end – the reversal – of progress and achievement over her lifetime. As a district nurse:

I started off on a bicycle
and then I got a scooter
and then I got a car
so I worked my way up
and now I don't have a car

Being there

The next time I see Grace, she is waiting for me in the sheltered housing reception area. To begin with, there is a formal air to our encounter. Grace is composed and takes charge of the meeting, leading me to a table and chairs in an empty communal hall which opens out onto a shared garden. She shows me how she has transferred today's diary entries from her master diary onto a small piece of paper which fits into her handbag, but she seldom looks at it. We talk more about topics that came up last week, and this time Grace says more about her befriending experiences, though is still unsure about her current befriender. In every research visit, Grace repeatedly tells me she does not know, and wants to find out, when her befriender is coming, whether she has left, and whether she needs a new befriender. Again, she asks me – urges me – to find out. My phone call, and a later email to the service manager, confirm Grace has a befriender, but not when she was due to visit. I notice I become imbued with Grace's doubt. We check and check her diary. There is “nothing written down”. We break for coffee. Grace asks me about my family and tells me about hers. We talk for a long time about nursing: our experiences of community nursing, changes in nurse training. Grace belongs to the same generation of nurses as my late mother and expresses a similar sense of vocation. Her stories of her nursing days evoked my memories of my mother's nursing stories. In that moment, I feel a strong connection with my mother and her professional values.

“in here”

For Grace, living in sheltered housing – “in here” – has many benefits. She appreciates the presence of support staff in the building during the day who arrange social events, and provide information and assistance: “you can ask them anything”. Telephone calls each morning from the coordinator are reassuring as “I forget things”: “the people in here care for you they phone you up and tell you you’ve got this on this on this on”. Grace finds that weekly lunch clubs and coffee mornings are “a good way of getting together” with other residents: “I’ve got to know quite a few of the neighbours you know people that go down for the meals”. Unlike her former neighbours, unable to help her due to their own health difficulties, Grace’s new “immediate” next-door neighbour is “very nice”, someone she can approach with queries, “and I would say to her ‘What’s on today?’” Grace likes the “wee garden” which “you can sit out in if you want to sit out the door’s open” as well as her “nice and cheerful” flat. Living “in the centre of the town” is also “quite handy”, bringing shops within walking distance. “In here” is an institution of sorts, but Grace can still “please myself”: “you’ve got your own life”, “nobody bothers you”, and you “don’t need to do anything they wanted you to”. But living in a block of sheltered housing flats means that Grace is now in “a communal situation”; in a place where “everybody’s got something wrong with them”. Generally speaking, “I feel comfortable here”, on polite nodding terms or maintaining friendly contact with “everybody that comes in and out if they speak and most of them do they’re very friendly”.

But, as we talk, a more varied picture of social relations “in here” emerges. In a “communal situation” where “they’ve all got problems”, Grace encounters “people you wouldnae want to mix with”. Some residents are “a wee bit funny but the funny ones don’t always go to the meals”. Others, who are “older”, can sometimes “annoy” or “be hurtful” though Grace makes allowances: “everybody’s got their own way of speaking haven’t they?” and “they don’t mean to be hurtful er but sometimes they can be”. Grace tells me that, when ill or afraid, a person can change, become

“horrible”. She thinks that “a lot of people are mixed up when they come in here”, and that some have been “abandoned” by their families. She does not “have any worries about being in here”, but now locks her door, having once been frightened when a man with dementia mistakenly entered her flat.

“everybody’ll have a history”

“In here”, everyone has “problems” or “history”. “History”, for Grace, has assorted, conflated, meanings: biography, medical details, social problems, family background, life events, and private, personal stories. Having a “history” is why “they” are all “in here”: “I think everybody’ll have a history because it’s sheltered housing”. This means that “in here” is potentially an accepting social space:

but they’re nice people in here
and nobody would condemn you or
you know what I mean
they would accept who you are
they’re nice people
and everybody’s got something wrong with them
there’s nobody perfect in here
they’ve all got problems
I don’t want to know their problems
if they tell me fine
I’ll listen very listen
but er if they don’t tell me I don’t listen
if they don’t confide in you
[J: no ah you’re not you don’t pry]
no that’s it I don’t pry no

Yet Grace’s sense of acceptance is deferred by the conditional “would”. She uses “they” not “we” suggesting she does not necessarily feel one of ‘them’, or a sense of group belonging, even though her memory loss means that she, like ‘them’, is not “perfect”. Grace sees herself as someone in whom others could confide. Over several meetings, Grace tells the story of how she befriended “a very nervous lady”, temporarily placed in sheltered housing as “I think someone was hitting her”, who “didn’t have the courage to start a new church or wanted to go so she comes with me on a Sunday”. Her story

suggests she has taken on a supportive role rather than entered a mutually confiding relationship: “I don’t ask her questions if she wants to tell me anything she’ll tell me”. At lunch club, Grace cannot be sure she will see people she knows and likes. She sometimes meets her next-door neighbour and a “very nervous lady”, but, otherwise, “there’s nobody really that you would”. She is conscious of residents who have “family in the town”. When regulars at social events are missing, for Grace, this means they are probably with their “big family” or their daughter, which throws into relief the smallness of her own family, and the remoteness of her own daughter.

Grace is willing to listen but refrains from prying. For Grace, “everybody’s got their private things about them” – perhaps more so in a place where also “everybody’s got something wrong with them” – which makes it harder to get to know people, due to their reticence to “tell you things”, and because of Grace’s respect for privacy: “you don’t want to be too nosy”. For Grace, not disclosing her history helps her protect her private life in a “communal situation” where “it’s better if they don’t know your history”. Choosing not to reveal personal information, “why you’re here why you’re in sheltered accommodation”, enables her to hide private aspects of herself which might attract social judgement. In some ways, the fact that “they don’t know your history” means that an institution where everyone has “something wrong with them” can be experienced as more like an ordinary home: “it’s called sheltered accommodation it’s just a house”. But Grace feels she lacks closer personal relationships. She wants someone – someone suitable – to confide in, where ‘confide’ is disclosing intimate experiences, revealing worries, feeling able to ask for assistance, and sharing life stories. Grace misses others confiding in her: “if people tell you things well you know them”. “In here”, there are “some you wouldn’t tell too much of your history but others you could confide in”. Here again, “could” signals the hypothetical; in practice, Grace spoke of finding it hard to really get to know someone: “I get to know all the people that lives in the flats I sort of get to know them”. Whereas “I knew my neighbours where I lived before”, she does “not know many folk in here and I’ve been in quite a while”, leaving her wondering whether she is “not very outwardly”, and feeling “a wee bit lonely”.

Being there

The last time Grace and I meet, we go out for afternoon tea. On our return, we join three residents in the reception area, a man (M) in a wheelchair and two women sitting quietly together. I often saw these residents in this space. I speculated that they came there to not feel alone in their flats, to keep each other company, to be near a member of staff in the office, to watch people coming and going, or to wait for someone. Grace (G) introduces me (J) and brightly tells them about our outing. The women hesitate to respond; one especially seems reserved and stares at the floor. But everyone joins in a conversation about a well-known local figure, and Grace tells the story of how she met her husband. Then (from field notes, not verbatim):

G: I don't know who I would meet in here though

M: we're all past our sell by date

G: what age is a sell by date?

M: about seventy nobody wants to buy you after that

J: I'm not so sure about that

M: I wouldn't like to buy me

J: somebody else might want to buy you

G: I would buy my mother even if she was a hundred I wouldn't have bought my father because he was too bossy

J: you'd have left him on the shelf would you? [laughs]

G: oh yes! [laughs]

The marketplace metaphor generates a witty exchange, but also plays with ideas about social value in later life. For Grace, personal qualities, irrespective of age, confer worth: Grace's mother was "a kind soul". For the man, ageing leads to social expiry, to the state of being undesirable, even to himself, obsolete and out of circulation.

"you go there and you mix"

Grace goes to a third sector day centre twice weekly from morning until mid-afternoon. She is charged for this service, which includes lunch and transport, but thinks that the price is "very reasonable", "I like it very much": "you go there and you mix with all

the other people and it's just really very nice". She has not got to know people there "an awful lot", but, unlike sheltered housing where she wishes she knew people better, at the day centre, what matters is meeting new people, "people who maybe don't know all your history". Whether "people tell you about themselves" is less important than mixing with a variety of individuals, joining in, the sense of easy togetherness. In this setting, looser ties are not superficial ties because Grace values the feeling of belonging.

"whoever comes"

Grace shows me a printed schedule of home carer names and visit times. She has transferred this information to her master diary and a smaller portable notebook although she "can't get used to" the twenty-four hour clock format. Morning and teatime visits last thirty minutes while lunchtime and evening visits last fifteen minutes, "checking visits" as Grace calls them. Lots of different home carers come because, Grace explains, "it's a big company er so they'll send in whoever they can". She tells me that they remind her to take her medication and check on her. Having to stay in for home care visits can be a "big nuisance" because "you're sort of tied to them you know to be there". Relying on home carers for essential services – timely assistance with medication, for instance – is worrying: "if they didn't come for some reason or other". Home carers can also, but do not always, help Grace cope with her memory loss: answer questions, find things, check her diary with her. Some are "very nice", do "a good job reminding me to take my medication", and "they know where everything is kept you know they'll find things out". Others, particularly male home carers, are "very very quick". One, "he doesn't say very much just comes in and gives me the medication he doesn't speak very much at all":

it's a man that comes in
they are never so nice as the women
[J: are they not?]
no
I mean they do their job
don't get me wrong but em

[J: what's different about them?]
I don't know
they're they're just in and out
they don't have any conversation
they don't say
"How are you feeling today Grace?"
or "Have you any problems today Grace?"
"Have you had your breakfast Grace?"
"Have you had your lunch Grace?"
"Have you had this Grace?"

One home carer:

he looks quite old
but his wife's just had a baby
so he's maybe worrying about the baby
and I always ask him
"How's the baby?"
but he doesn't say

Grace thinks that "people don't have the same time you know to care for you that they did when I was there". She knows that home carers primarily visit to do a "job", and appreciates good care, but, within the time constraints, feels there is scope for some form of non-instrumental contact: "it's nice to have somebody to talk to".

"if there is a God"

Grace is a life-long church goer. She attends a nearby church on Sundays with the "nervous lady" she has befriended and another male resident. In times of personal crisis, Grace has questioned her faith and her perception of God. Passing her church on our way to a café, she tells me that, after her husband died, "I nearly stopped going". Now, in the midst of struggles with her health, she feels angry with a persecuting God who has caused undeserved suffering and betrayed her idea of a just world:

I think we change though don't we?
and we question if there is a God
why is he doing this to me?

because I've been a good person all my life
being a nurse I helped everybody
and then I think
well why is he doing this to me?!
why am I suffering
the way I'm suffering mentally
and physically [sigh]
but er
you just have to take what comes along, haven't you?
and get on with it

Her relationship with God is ambivalent. She cannot with certainty rely on her faith or God for spiritual and emotional support. Her sense of congregational belonging is marred by "cliques" and "hypocrites" among worshipers. God is a constant and an inconstant presence in her life; loving and attacking; there and perhaps not there.

"I couldn't say much to her"

Grace tells me that her cousin and her cousin's husband are "lovely people and they wouldn't do you a bad turn and they are helpful if you needed them". Sharing a meal together was a weekly fixture before Grace moved to her new flat, an arrangement which has carried on. Her cousin is someone "who looks after me she's very good" but is also "a bit of a gossip" who "likes to know everything about everybody", and not a person Grace feels she can confide in. Grace is "happy to go for my tea but anything else":

I couldn't say much to her
cus it would be all over [town]
if I did say anything
if I worried about something

Until recently, Grace drove to her cousin's house, but now goes by taxi, and relies on her cousin to take her home again. Sometimes they walk, and Grace, though tired, feels unable to request a ride in the car:

when it comes to about half past seven

I'm getting tired
and I'll say to her
"I think I should maybe get ready to go now
I'll get ready"
she says "We'll just walk home"
and I think oh!
walking away from [road name]
to where I live
is quite a long walk

For Grace, it is her cousin's lower level training that makes her insensitive to Grace's fatigue: "she forgets that I get tired quite easy but she's not a nurse she was an auxiliary nurse". I wonder why Grace does not feel she can ask for a lift. She rehearses out loud imaginary dialogues – "well I could maybe say to her, 'Could you run me home? I'm tired'" – in which her wishes are flatly refused or overridden: "she might say 'No'"; "she maybe would say 'Oh the walking's good for you'". Grace's cousin, her only "family in the town", is on hand, 'there' if needed; and weekly meals involve Grace in family life. But they do not have the kind of confiding relationship that Grace feels is missing in her life.

"she phones every night"

Before we go out for tea, Grace proudly shows me family photographs, and flowers her daughter recently brought her. Her daughter lives a two-hour drive away, works full-time, and has school and college age children. She is usually only free to visit her mother at weekends which she does regularly though not every weekend. In the school holidays, Grace goes to stay with her daughter and grandchildren for a week. Grace's daughter sometimes accompanies her to appointments, and helps organise her master diary, writing entries weeks in advance for recurring events such as lunch club. Grace receives a telephone call from her "very kind" daughter every night when "it's wonderful to hear their voices", and she writes things down to tell her. Even on occasions when her daughter goes out in the evening, "she'll delegate who's to phone" to ensure Grace has someone to talk to. Grace, though, also describes tensions in their relationship, as she continues to experience herself as a mother while accommodating

her daughter's growing involvement in her life; and as she acknowledges her increasing desire for contact and support while recognising the impact on her daughter of her declining health. Even though she misses her daughter, Grace understands that she has a full and busy life, "a life besides mother". She wonders whether the physical distance which separates them in some ways shields her daughter from her own longing for closeness: "she just lives so far away but maybe if she lived too near I would maybe never be away from her". Grace communicates her feeling that, despite daily contact with a range of people, she is on her own, an aloneness linked to the scarcity of nearby, close family members: "I've no one local". Her conversation is peppered with "only", "just one", "no one", "nobody".

In Grace's stories, her daughter's influence in her mother's decision-making is apparent, and, perhaps, too, a sense of her level of concern:

my daughter kept saying
"I think you should move out of the house"
"I think you should move out of the house"
so that's how I came in here

Grace appreciates her daughter's support, and helpful intentions, but also pointed to a diminishment of her own authority in their relationship:

but my daughter's nice
but she's quite bossy
most daughters are [laughs]
she means well though
and she phones every night

I ask whether Grace can confide in her daughter:

oh I confide
I confide
my daughter keeps asking me
"Have you any problems?"
"What did you do today?"

Grace imitates how her daughter responds when she does 'confide':

and she'll say
"You're getting all your medication
and you're taking it
and you're doing this
and you're getting out and about
and you're doing things" [laughs]
but she does phone every night

Grace reproduces her daughter's reassurances in direct speech intoned in a manner which reaccents her daughter's words, subtly conveying a disparity between their intention and their effects. The position of 'but' also suggests that the reassurances in some way fall short of being reassuring. Grace reflects on how she has taken, and still takes, care of her daughter and grandchildren. She tells me that moving to sheltered housing puts her daughter's mind at rest: "my daughter feels safe that I'm in here". She feels she has contributed to her family materially by giving her car and some of her furniture to her grandson, and wanting the money from the sale of her house to be used both by her and her daughter "if she needs it".

Grace cherishes her daughter and also feels ambivalent about their relationship. She welcomes, and counts on, her daughter's help but sometimes finds her "bossy". Despite her daughter's committed, diligent support, Grace, in some ways, feels abandoned. She wishes her daughter lived nearer but respects her separate life. Her daughter's presence in her life is crucial, but, such is Grace's everyday "suffering", that the many ways in which her daughter, and others, are 'there' for her, do not entirely dispel her feeling that she is coping on her own. On the face of it, relocating to sheltered housing has brought about a beneficial enlargement of Grace's personal network. Care workers and support staff play a greater role in her life, and she now comes into contact with many more people through organised social events within sheltered housing, as well as at her day centre, and through casually meeting residents in communal areas of the building. Yet merely having more people in her life does not, in itself, meet all Grace's relational needs. What she misses is someone she can really get to know, someone compatible, someone to confide in.

“I didn’t know much about it when I started”

At the time we met, Grace had known her current befriender, Shona, for about a year. Prior to this, she had a relationship with another volunteer which lasted two years and came to an end when the befriender moved out of the area. While we were together, Grace did not recall particular befriending occasions, nor was she sure she still had a befriender, but she fully understood the role of befriender and the benefits of this kind of service. Quite often Grace ‘showed me’ what she did with her befriender or, rather, together, we ‘performed’ aspects of befriending: getting to know one another, going out, practical assistance for Grace, having things in common. Grace spoke of the kinds of things she had done, and would like to do, with her – or a – befriender. The mixture of tenses in her befriending stories – past, present, future and conditional – reflected a mix of memories of past events, current uncertainties about her service, and wished for experiences that a befriender could and would make possible.

“wonderful if I knew who it was”

Grace spoke of missing her befriender, who seemed to have vanished or “left me in the lurch”, and wondered if she would ever return. Without a written record of Shona’s continuing presence in her life, Grace could not look forward to seeing her, or feel sure she was there. The situation was complicated by Grace’s memory of her first befriender leaving.

Appreciative comments about her befriender were almost always followed by expressions of confusion and abandonment:

but I was quite friendly with Shona
and we we we got on well together
but she just suddenly disappeared
and I don’t know where she is
or why she’s not coming

The value Grace placed on befriending intensified her feeling of loss at the departure or disappearance of her befriender, but also her resolve, if need be, to find “a new one”.

“the befriender”

For Grace, befriending combined the formal and the personal.

she was very nice
but I thought she was leaving
but I like the befriender
because they're nice
they're nice people
and they're good
and they
they take me wherever you want to go

A befriender is a particular, likeable person – “she was very nice” – and a role – “the befriender” – which is undertaken by individuals working for an organisation – a generic “they”. The service is person-centred – “wherever you want to go” – and provided to others – “you”. This seamless interweaving of professional-like and friend-like features is everywhere in Grace’s accounts of befriending.

“it’s your private life”

Grace has “no family here you know to confide in somebody”, and has found it hard to establish a confiding relationship with anyone in sheltered housing. But her befriender is “absolutely” someone she feels she could confide in, and someone from “without” sheltered housing, protecting her privacy in a “communal situation”:

[J: but it sounds like you would like a befriender?]
oh I’d like a befriender yes
it’s somebody you can talk to
without in here
you know what I mean
you don’t want all your neighbours
to know all your business

Befriending differs from the social contact Grace has with home carers, support

staff and day centre attenders because, with her befriender, she can share personal information in a safe social space, within a more intimate, kindred kind of relationship: “it’s totally different because it’s your private life you know you’re going out with your friend”.

While Grace does not want to confide in her cousin due to concerns about “gossip”, with her befriender, “you can tell them anything because the you know it’s confidential”. She trusts in a formal aspect of the befriending, the duty of confidentiality, to safeguard her private life. Although Grace has a close, confiding relationship with her daughter, she feels she is “so far away”, and does not want to encroach on her life even while wishing she lived nearer. Grace can confide in her befriender who is both nearby and separate from her family.

“she knew what I was like”

It matters to Grace that people are aware of the ways in which memory loss and other health conditions affect her life, and what they can do to support her. With a befriender, “it would be nice to have if she knew what was wrong with me my memory loss”. She recalls that “I think the girl that used to come she knew what I was like you know what I mean?” I ask Grace what she would want her befriender to know about her:

just that I don’t have a very good memory
I have to write everything down
so that they know if they’re coming
or they’re not coming
um
and that’s really all
if we kind of meet up
and we like the same things

One of the best things, for Grace, about having a befriender “is making appointments to go out and doing things that we want to do”. “Making appointments” is a joint activity, and written in her diary, preventing clashes with prior engagements: “how would you know what day she was coming? I might go out”. A befriender who knew

“what was wrong with me” would make sure visits were arranged like this.

“they take me wherever you want to go”

Grace misses driving “terribly”: the loss of freedom, the narrowing of choices, the erosion of self-reliance. She finds it hard to ask her cousin to drive her home. With a befriender, however:

they take me wherever you want to go
if I wanted to shop
I could go maybe in their car to the shops
because I had a car
but I gave it up
because I wasn't using it in here
and as soon as I gave it up
I missed it

Grace's understanding of befriending as a person-centred service, together with the resources of her particular befriender, gives her more scope to choose where she wants to go and what she wants to do. Having access to her befriender's car and someone who puts her wishes first expands her choices and her ability to direct her life. But it also matters to Grace that going out is a shared activity, something that both she and her befriender want to do:

well you've got something that you both like
like if I wanted to go for a walk
and it's a nice day
we'll go for a walk
and maybe have a coffee somewhere
and they wouldn't mind having a coffee with you

There is a melding of formal and friend-like elements: a service led by Grace's preferences which also involves mutual enjoyment of time spent together. Grace draws on both to explain what she values in her befriending relationship: “if I wanted to go for a walk [] we'll go for a walk” which is “something that you both like”. With her befriender, Grace can get out and about in the town and surrounding area; reach

favourite but more distant places; and take part in ordinary pleasures, if need be with support: buying plants in a garden centre, sharing a meal, “just a walk round the town”,

or if we go anywhere
and had a nice coffee
or something like that
or we went for a walk in the woods
or you know
it depends what you're doing
if it's a nice day we had
did some shopping
because she was quite good at helping me to shop

“we like the same things”

With her befriender, it matters to Grace that “we like the same things”, and that whatever they do together is “something you both like”. Compatibility comes about by formal and informal processes. Grace explains that what the befriending service does is “match you up with somebody somebody with the same interests”. At one point, she is concerned that if she does need a new befriender, “it might be difficult to match me up”. Once the match is made, the relationship is something that they then create together by getting to know one another through sharing experiences, exchanging ideas, and keeping each other company. When they are with one another:

it's so important
we got on well together
I don't know why she's stopped coming
[J: when you say it's important could you say a little bit more about what makes it important?]
well we had the same sort of ideas
and we could talk about any subject
and I can remember her so well
and she was a very nice person
a very nice befriender
if you could call her that
she was a friend
rather than a befriender

In this way, an arranged pairing comes to feel like an authentic friendship.

“I know them and they know me”

In sheltered housing, Grace has only “sort of” got to know “all the people that lives in the flats”, a situation which has not altered over time. For Grace, getting to know someone is a reciprocal process. Knowing her befriender is as important as being known by her befriender. Using a hypothetical relationship with me as an example, Grace explains that a befriending relationship:

it’s like a friend
like you and I meeting up together
if I knew all your history
you would be a friend
and I would know where you came from

For Grace, ties with befrienders are more symmetrical than ties with care and support staff. There is greater mutuality in the exchange of personal experiences, ideas and interests. Speaking of a befriender, Grace recalls how “I knew her” – her job, her marriage, where she lived. It meant something to Grace that she was entrusted with this information: “she told me all these things”. But, while Grace confides in her befriender, she is also aware that her befriender has learned things about her from the befriending service: “she knows me because [service manager] would tell her”. Grace does not lose sight of the facilitating involvement of the organisation.

“they’re called be--frienders”

For Grace, in befriending, the sphere of friendship – the cultivation of a unique, confiding, mutual relationship – overlapped with the sphere of a client-centred service – the assurance of confidentiality, the expectation of regular contact, an understanding of particular health conditions, and, if needed, the provision of support. Grace was aware of boundaries and rules marking a difference between friendship and befriending. A befriender was a friend within certain limits: “well I couldn’t phone her up because they’re not allowed to give you their phone number”; “I can’t write her address because

I'm not supposed to know where she lives". I wonder whether the rules of befriending detract from her experience of mutuality, or make the relationship feel unequal. Grace gives me the impression that her befriender might bend the rules: "but if Shona tells me where she lives she would give me her phone number". At other times, she made it clear that she abides by the rules, even applying them to me when I give her my telephone number and encourage her to contact me with any questions or concerns about the research: "that's fine well I won't be ringing you but I've got it". Otherwise, Grace did not seem to experience any sense of contradiction or tension in the hybrid nature of befriending as friendship and service. She derived benefit from both. The issue for Grace, with her memory "so bad", was not knowing about her befriender – who she was, if and when she was coming, and when she had been – which was confusing, upsetting and disempowering.

Being there

On my fourth visit, Grace lets me in through the entry system, and, when I reach her flat, I find her slightly flustered and out of breath. She tells me she has been getting ready to meet me but was finding it difficult to put on her support stockings which, remembering I was a nurse, she asks me to help her with. We set about reviewing my summary of the views and experiences Grace had shared with me, but, even though this was a "plain day", again and again, she pauses to look at her diary, and involves me in checking times, dates, the home care schedule, and whether and when her befriender is coming. I let her know that I have not been able to find out anything more about her befriending service.

For our final meeting, a week later, I had invited Grace to go out for morning coffee, partly as a way to thank her for her contribution to the research, and partly so that she could 'show me' what she did with her befriender. Due to train delays, I could not reach Grace until the afternoon, and worried that she would be "all mixed up", but, when we spoke on the telephone, she seemed to take the new arrangement in her stride, telling me she would look forward to afternoon tea instead. When I arrived, Grace was

waiting for me, recognised me, and told me she had skipped dessert at lunchtime to make room for a scone at the café. While we were out, in fact during the entire visit, Grace did not check any diary, notebook or paper notes. On our way to the café, Grace ran into two former neighbours, stopping to talk to them, and introducing me as her friend. At the café, too, Grace spotted a former colleague and spent time catching up with her.

As we walked past places that were part of her “history” – her church, her old school, public buildings – Grace told me stories about her earlier life. As she could with her befriender, we also spoke about “any subject”: the increase in road traffic; children and computer games; changing attitudes to divorce and infants born out of wedlock; unscrupulous car mechanics; public transport; the use of home remedies before the NHS; advances in medical treatments; coping with amputation; opposition to private healthcare. Over tea, we discussed articles in a local newspaper. Grace touched on sensitive health and family matters. She returned to the issue of privacy, pointing out the harms of gossip, gossip in small places, and the need to keep confidences. Grace described the “history” of a sheltered housing resident who had undergone a double leg amputation. While I was preparing this case study, I saw that Grace was formulating case studies of her own. I suggested taking a taxi home, knowing that Grace became tired easily, but she declined so we set off together, arm in arm, and walking in step, reminding Grace of the nursery rhyme, ‘The Grand Old Duke of York’, which we sang together, laughing. Grace said, “What are we like?!” I felt the ‘we-ness’. Aware of the importance, and the necessity, for Grace, of people ‘being there’ for her, in various ways, I was struck by how much Grace was ‘there’ for me. She applied herself to the research, concerned that “I hope you got your answers”, “I mean I hope you got some things”. She imagined what it was like to be me visiting her: “you’ll be thinking where you’re going and what you’re going to say and what you are going to do” – tacit recognition, also, that my visits were ‘work’. She made me feel welcome, inviting me to call in if I was in the area, hugging me before I left, and making appreciative remarks: “it’s nice having you coming”.

Knowing that, for Grace, being ‘confided in’ mattered as much as being able to ‘confide’, I later reflected on what Grace’s willingness to confide in me, in our research conversations, said about and meant to me. Grace was entrusting me with her experiences, making me a ‘confidant’, crediting me with the qualities of being competent, sensitive and trustworthy. I wondered about the extent to which people with memory loss were ‘protected’ from the lives of others – their highs and lows, their ‘suffering’ – denying them the chance to respond, excluding their wisdom, dislodging them from the same ‘plane’.

Confiding involves making decisions about when and what to disclose, and to whom. At one point, I asked Grace about her husband which brought back painful memories of the circumstances of his death: “I don’t like to think about it”. Shortly after this, when Grace talked to me about getting to know people at her day centre, she explained that:

it’s nice if they tell you things about themselves
that’s fine
if they don’t tell you
you don’t bother about it
because everybody’s got history
we’ve all got history
[]
and we don’t want to talk about too many things

My inadvertent ‘prying’ into a painful time in her life seemed to put Grace in mind of a reason she and others might not “want to talk about too many things”, and why she, herself, did not “want to be too nosy”: the risk of the (untimely) exposure of sensitive areas of people’s lives. A comparable situation arose when Grace asked me if I was married. I fudged my response, answering, accurately, that I was not married, but concealing my civil partnership. For Grace, in sheltered housing, to pre-empt social judgement and the spread of gossip, “it’s better if they don’t know your history”. With Grace, I also kept part of my (discreditable) ‘history’ private: were I heterosexually coupled, I would not have hesitated to reply.

Endings

My research relationship with Grace enacted aspects of her befriending relationships, as she described them to me. It also yielded insights into ways of getting to know someone, something Grace was finding difficult. The relative informality of my conversations with Grace, together with occasions when she ‘showed me’ what it was like to have a befriender – all occurring in a ‘professional’ research context – added to my understanding of the merging of formal and informal elements in befriending. That Grace, Shona and I were all former nurses, itself, added another layer to the blurring of the ‘professional’ and the ‘informal’. As with Grace and her befriender, an externally arranged pairing – ‘researcher’ and ‘participant’ – began to develop into a social tie that felt mutual and authentic but, at the same time, was asymmetrical and bound by protocol. Our occupational common ground broadened the notion of ‘peers’, opening out the range of social alignments beyond those based on age or health status or type of support.

For me, getting to know Grace entailed staying open to seeing Grace anew, before, during and after our encounters – revising, expanding, complicating my idea of her. It also entailed staying aware of shifts in how I experienced myself when I was with her, and later on. I became aware of parallel processes between Grace checking her diary – “checking and checking and checking”; her daughter repeatedly checking her mother’s welfare – “she keeps asking me”; and me restlessly rechecking the research material. In different ways, we all wanted to be sure. Paradoxically, it was only when I stopped trying to be certain of what Grace was saying, stopped trying to fold or streamline it into ‘themes’, and, instead, let it all just stand, that the data started to make more sense. Grace was managing and struggling; content and suffering; resourceful and dependent; lonely and connected; getting to know people and only sort of getting to know people; wanting to confide and to keep private; wishing to direct her life and to be looked after; finding her situation both better and worse; seeing herself as no longer, and yet still, a nurse and a helpful person. ‘Getting-to-know’ was a mutual endeavour, and, for me, a process of undoing categories and resisting static knowledge; of coming into contact

with an endlessly changing person as an endlessly changing person.

I felt more than fleeting sadness when meetings with Grace came to an end. I missed her warmth and kindness and company, and the way that, through a generational nursing connection, being with her made me feel closer to my, much missed, mother. It was as if I barely knew Grace yet had somehow always known her.

Chapter 5: Further Interpretation and Discussion

Further Interpretation and Discussion

5.0 Introduction

I move, now, from three unique case studies to look at recurring, cross-case topics and themes. In the last chapter, the words of Tom, Jenny and Grace are foregrounded and no reference is made to other works. In what follows, further interpretations of the case studies are brought into dialogue with wider literature, making use of a selection of theoretical concepts, and incorporating reflexive analysis of the research relationships. The chapter is divided into four thematic domains. The first three – liminality, personal community, and contingent and existential limitations – help contextualise the fourth: befriending. Each domain is further divided into sections in which I discuss a range of subthemes and issues. At the end of the chapter, I draw the threads of my discussion together and set out the study's core messages.

5.1 From Cases to Commonalities

First of all, though, I explain how the domains and subthemes were developed. Like Braun and Clarke (2006), I do not take the view that 'themes' reside in, or simply emerge from, research data. I acknowledge the active part I played in identifying underlying "patterns of meaning" (Braun & Clarke, 2006, p. 86), which involved what I 'brought to' the data, as well as my intuitive (Ryan & Bernard, 2003) and creative responses (Vaismoradi, Jones, Hannele Turunen & Snelgrove, 2016). I recognise that other researchers may well have seen different patterns. Nevertheless, while themes might not inhere in data, in reader-response theory terms, they arise from a transaction (see Section 3.2) between researcher and research data.

To re-cap, using a voice-centred relational method of data analysis, I systematically laid out every utterance spoken by participants about self and others in the order in which they were said. This enabled me to trace each person's various co-existing

voices, views and experiences across the data as these shifted and fluctuated, *before* identifying recurring or prominent themes and issues. I then compared individual case studies looking for thematic similarities and differences. Many common themes and issues were evident, and I grouped these into four major thematic areas. Grace, Tom and Jenny all spoke about themselves, their health, and changes in their lives in ways that conveyed in between and ‘both/and’ experiences or permanent states of uncertainty and unresolved transition. I clustered these experiences together in the theme ‘liminality’. A significant issue for all participants was the limits and barriers they encountered in their lives, those that had to be ‘suffered’ and those that could be overcome. I placed these experiences in the theme ‘contingent and existential limitations’. So much of what participants had to say concerned their relationships, and multiple relational experiences fell into the theme ‘personal community’. Finally, as a primary focus of the study, ‘befriending’ was a major theme on its own.

5.2 Liminality and Multiple Transitions

Earlier, I provided a critique of post-diagnostic ‘dementia journey’ models which are based on the capacity of individuals to pass through, and ultimately resolve, states of disorientation, instability or uncertainty in order to ‘live well’ with dementia (see Sections 2.10.4 & 2.10.5). These transition models tend to treat dementia as a single life change disconnected from other events, experiences and situations, and successful ‘journeys’ often rely on the choices that people with dementia are considered able to make, irrespective of constraints in their lives. An advantage of using narrative methods in health studies is that a person’s illness stories are embedded within a biographical context, “weaving the threads of illness events into the fabric of our personal lives” (Hydén, 1997, p. 53). The three multi-focal case studies in this thesis make it clear that – for Tom, Grace and Jenny, at least – the ‘biographical disruption’ (Bury, 1982) of illness, including health conditions other than dementia, was one of several turning points and critical events both in recent years and further back in time. Their narratives do not conform with dominant models of pre- and post-diagnostic transitions (Grenier, 2012).

Tom painted a picture of failing health over a long period of time prior to physically collapsing and being hospitalised with cognitive impairment being one of many symptoms. Jenny recalled receiving a diagnosis of Parkinson's disease but not the onset of memory difficulties. For Grace, memory loss was a sudden occurrence, the result of a stroke. She also spoke of a further major diagnosis of cancer as well as arthritic pain. Illness stories were interspersed with accounts of other major losses and change-events: divorce, bereavement, retirement, the break-up of a friendship, travel and mobility restrictions, relocation, the changing dynamics of relationships, and the introduction of formal services.

In the study, I use the concept of liminality to highlight multiple ongoing transitions in the lives of participants, and the ways these were subjectively experienced. As I go on to discuss, these were the conditions in which befriending relationships took place. I start with transitional experiences of health and self.

5.2.1 Liminality and Health

I maintain that the 'dementia journey', as a universal transition or series of transitions, is, in many respects, a misleading construct. In this section, I focus on Tom, Grace and Jenny's subjective accounts of their health. These cannot be understood with reference to dementia alone as each had co-existing health conditions. Liminality proved a useful concept with which to explore and make sense of each person's experiences since individual stories collapsed the binaries of 'ill' and 'well', 'acute' and 'chronic', conveying in-between states of being neither one nor the other, or simultaneously both.

5.2.1.1 Re-Placing Memory Loss

I purposely left it to each person to decide whether they spoke about cognitive difficulties. I did not want to assume that befriending was meaningful to them in relation to their dementia. I wanted Tom, Jenny and Grace to feel free to talk about what befriending meant to them on their own terms. In the absence of direct questions about

cognitive impairment, the place of dementia in their accounts varied significantly. For Grace, the severity of her short-term memory loss presented a considerable challenge to managing everyday life. This was apparent during many of our conversations and in how we went about arranging to meet. As a retired nurse, Grace understood the pathology of her post-stroke dementia and the use of anti-coagulants in the prevention of strokes and vascular dementia. However, Tom's explanations of his memory loss were changeable, and his sense of its seriousness fluctuated. He mentioned needing help with taking his tablets and washing his clothes. Memory difficulties affected his life "not really" but were also "getting worse" and one of the reasons he needed to be "looked after". For Tom, problems with his memory were the result of a medical condition but also due to old age and an effect of being institutionalised. Memory loss was one of a number of health changes over the past decade, and 'bad legs', fatigue, and "being doon in the dumps" were also prominent concerns. Jenny, who took drugs prescribed for the treatment of dementia, did not refer to memory difficulties at all. In fact, she recalled doing well on a memory test and brain scan results being "all right" for her age. Her experience of ill-health was dominated by dizziness, unpleasant sensations and movement disorders linked to Parkinson's disease.

In the literature on people living alone with dementia, only two studies – Frazer et al. (2011) and Duane et al. (2011) – reported the presence of concurrent health conditions. As indicated, this was somewhat surprising since, in the UK, fewer than 10% of people living with dementia have no comorbidities (Browne et al., 2017). However, dementia with comorbidity has received little attention in qualitative dementia research (Bunn et al., 2014). Bunn et al. (2014) noted the tendency of researchers to focus on "living with dementia as a single disease" (p. 11), and the paucity of studies on the experiences of people living with dementia and coexisting health conditions. Understanding the lived experience of (multiple) impairments is important as part of a renewed social model (Crow, 1996), or a multifactorial (Shakespeare & Watson, 2010) model of disability.

For Grace, Jenny and Tom, memory loss coincided with other debilitating conditions both associated with, and independent of, their type of dementia, each with their own

set of symptoms. These included cancer, stroke, Parkinson's disease, arthritis, and a range of health problems linked to long-term heavy drinking. The side-effects of pharmacological treatments also caused difficulties: the sudden urge to urinate after taking diuretics; involuntary movements and distressing 'wearing off' symptoms related to taking Parkinson's disease medication over time. One compelling source of research data was my witnessing at first hand some of the physical, emotional and cognitive impacts of each person's health conditions, and how these hindered participation in everyday life, and gave rise to a struggle to 'get by', to 'keep going'. Jenny, Grace and Tom reported felt "disruptions to the habitual body" (Lloyd, Calnan, Cameron, Seymour & Smith, 2014, p. 13): irresistible fatigue, alarming sensations, loss of balance, a "rubbish" memory, movement restrictions, spirits and energy "goin doon an doon an doon". There were times when they were *taken over* by their illness experiences, for instance, seized by dizziness, blacking out, or caught up in repetitive checking.

Jenny, Grace and Tom's accounts blurred the demarcations between chronic and acute ill-health, and between illness and wellness. In common with the literature on liminal experiences of living with chronic or life-threatening illness described earlier, their stories were indicative of lives lived in persistent liminality. This was characterised by – often paradoxical – states of 'betweenness', and continuing uncertainty. Jenny did not know when a bout of dizziness would strike, or whether she would ever be able to recover from her dizziness. Much of the time, Grace was unsure of her memory; and she could not know whether her cancer would return. Tom lived in an ongoing limbo, forever wishing, yet doubting his capacity – and also not wanting – to go out again by himself. In different ways, each person experienced themselves as both (potentially) ill and (potentially) well. Sometimes, for Grace, parts of herself were well and parts were ill: "if I had my memory I would be perfect". Then again, her well body might become ill again through cancer recurrence, and she described, in general, "suffering mentally and physically". Jenny knew she was ill as a result of Parkinson's disease but hoped she would become relatively well, again, if her dizziness could be treated. The ontological status of Tom's 'illness' was always at issue for him. His experience of illness and

ill-being was intensely liminal. For Tom, fatigue and malaise were attributable to illness, *and* symptomatic of loss of motivation which he felt he might – and should – be able to overcome, *and* the result of a stultifying environment. He knew he was ill but chose to push it out of his mind; and at the same time he felt he had been mistaken for an ill person. Tom occupied a no man’s land of living with, and dying from, alcohol. Like those with chronic pain (Jackson, 2005), his health status was ambiguous in terms of the legitimacy of his illness. His ill-health was the result of long-term heavy drinking: his memory loss was not innocent. Unlike Jenny who used to attend “the keep fit”, Tom transgressed the ‘optimise me’ culture of healthy lifestyles and self-management. His assessment of his health embraced concern and optimism. For example, in his view, matters were getting worse: having more seizures; and also better: having fewer seizures in recent years. Furthermore, as Thomassen (2009) describes, complete ‘rites of passage’, taking a person through stages of separation, liminality and re-entry, can take place *within* liminal states. This was the case for Tom, Jenny and Grace who experienced acute episodes of ill-health, or health-related difficulties, within the liminality of their long-term conditions, often at frequent intervals, each with their own cycles of disorientation and recovery. These disruptions included seizures, falls, “black outs”, escalations of dizziness and anxiety, nightmares, and heightened memory loss.

Each person was both ‘active’ and ‘passive’ with regard to their health problems, acting and ‘suffering’, taking control within an overall experience of loss of control (Bruce et al., 2014). Grace devised measures to keep “on top” of daily life, and though the strategies she used to cope with memory loss were helpful – writing things down, using a diary, keeping routines, seeking help, having her own ‘personal systems’ in place (Harris, 2006) – insecurity, self-doubt and uncertainty persisted. Jenny, too, found ways to take control within loss of control, doing what she could on ‘good’ days; sitting quietly or lying down on ‘bad’ days; accepting and mobilising help; using a calendar; sharing ‘feel good’ stories; and having contingency plans. Yet Jenny continually felt dizzy and remained at the mercy of sudden exacerbations of dizziness, “horrible” sensations, and falls. Tom found it difficult to gain any traction in his “doon

an doon” slide, but exercised some control over his life by trying to limit how much he drank, choosing which room to sleep in and which television channel to watch, sticking to routines, negotiating assistance from staff, and attempting to influence his home care and cleaning services. Routines, for Tom, provided a degree of structure to his day but were also the antithesis of life, stripping it of novelty and meaning.

The notion of an impermanent liminal phase in a rite of passage (Thomassen, 2009; Turner, 1964, 1977) may not hold up in transitions for older people with long-term impairments for whom liminality may be an enduring experience (Grenier, 2012). In these circumstances, while liminality is ultimately resolved in death, Grenier (2012) suggests that other ‘exits’ from liminal states, even if short-lived, might be possible through reminiscence, acceptance and wellbeing. In the case studies, in the context of ever-present anxiety, uncertainty or malaise, wellbeing could co-exist with ill-being; pleasure and relief could occur amid suffering. There were meaningful ‘micro-resolutions’ to liminal states such as, for Jenny, being able to get on with household tasks, sitting in the sun, enjoying day centre outings, family visits and reminiscing; for Grace, feeling secure in – able to be in – the present, going out shopping or for a meal or a walk in the woods, and getting together with other people; and, for Tom, having someone to talk to and something to do to break-up the day.

In Section 5.5.3, I discuss in detail how, for Tom, Grace and Jenny, befriending relationships could bring about temporary ‘exits’ from liminality. Next, though, I look at liminal experiences of self.

5.2.2 Liminality and Self

In this section, I focus on the ‘liminal selves’ that emerged in Jenny, Tom and Grace’s ‘self-talk’, and what these say about, and, indeed, how they challenge the idea of ‘lost’ and ‘maintained’ self in dementia. This sets the scene for a fuller discussion, in Sections 5.5.2 and 5.5.3, on how befrienders ‘met’ each person as an individual living through, and being altered by, ongoing transitions. In what follows, with reference to

dementia studies on losing and maintaining self, I examine the fluid ways in which Tom, Jenny and Grace talked about themselves as changing and unchanging, and about their potential, lost and indeterminate identities.

For Turner (1964), transition involves “a process, a becoming” (p. 46). Individuals in a liminal phase of transition are ‘betwixt and between’ one status and a new status. As they talked to me, Tom, Grace and Jenny moved between past, present, possible and future identities, reflected in the grammar of their stories. For each person, many versions of self circulated, linked with shifts in self-concept and self-feeling (McLeod, 1997). Grace “*was* always” a nurse but “now I’m a patient”: in the past she “never forgot anything”; once capable of nursing, “you wouldn’t think so now”. Yet Grace also spoke *as* a nurse in ‘collegial’ conversations with me. She asserted her identity as a trained nurse in dealing with difficult situations in sheltered housing, when “*being* a nurse” was an advantage, and in evaluating the support she received: some carers were not “trained”; her cousin was only “an auxiliary nurse”. Grace told me that helping people “*was* my nature” and, at the same time, described, in the present, helping – befriending – a “timid” co-tenant. Jenny “*was* very active”: she had volunteered in a charity shop and gone dancing, to keep fit classes and out with her befriender. She also remained active – “up and *doing* things” – albeit with increasing difficulty, tackling jobs around the house, entertaining visitors and attending her day centre. And she both hoped and doubted she might, in the future, be able to resume activities, including going out with her befriender, if her dizziness abated. Tom presented himself, and his preferred way of being, as having changed utterly *and* also in some sense surviving. At heart, he remained a travelling man, now stationary; and he yearned to travel again if only through organised group outings. In his stories, going “oot” by himself, as he used to, was something he no longer did *and* yet could still do, *and* also did not want to do.

For Turner (1964), liminal or transitional-beings (p. 95) had neither a pre-transition nor a post-transition identity, and yet both. In the unfolding circumstances of their lives, Grace, Jenny and Tom had a fluid sense of who they felt they had been, who they continued to be, and who they were becoming or might become. Past identities

were lost *and* persisted: they contributed to a sense of self in the present, but were also unavailable and mourned. Future identities were seen as conditionally possible, uncertain or harder to enact, and, for Tom, included ceasing to be. Each person's stories, taken together, captured simultaneous processes of holding onto *and* letting go of aspects of self-identity. A continuing, a lost, a changing and an uncertain sense of self co-existed. However, I want to avoid suggesting that feelings of loss and frustration related to altered identities, physical states and personal abilities were somehow 'diluted' or 'evened out' in 'betwixt and between' and 'both/and' states. Experiencing a continuing sense of self did not simply offset or compensate for the experience of a discontinuous sense of self which was often intensely felt: "suffering mentally and physically"; "it's rubbish when you forget" (Grace); "I'm goin doon an doon an doon an doon" (Tom); "how can you go about your life like that?!" (Jenny). Equally, though, the experience of losing aspects of self did not destroy retained or hoped for aspects of self.

Given the cultural dominance of the 'tragic loss of self' narrative, and the social devaluation of people living with dementia (e.g., Bartlett and O'Connor, 2010), there has been an intense research focus on the ways individuals are able to, and can be supported to, maintain 'self' and 'positive' identities (e.g., Wolverson, Clarke & Moniz-Cook, 2016). A recent information booklet on 'living well' with dementia after diagnosis advises readers that "you're still the same person" (NHS Health Scotland, 2017, p. 20). However, as Phinney (2011) suggests:

with the eagerness to show how the self is not lost, less attention has been paid to *shifting narratives* that show how self-understanding may indeed change for those living with dementia, even in the earlier stages of the disease. (p. 266, emphasis in original)

Caddell and Clare (2011) found that individuals with, in their research, early-stage dementia simultaneously experienced both continuity and change in their sense of identity. They argue that, while the onset and progression of dementia may bring changes to sense of self, individuals tried to maintain their identity as much as they could and to carry on with their everyday life as usual. They emphasise the importance

of relationships, activities, emotional support and the environment in strengthening identity and coping with the difficulties dementia presents. Phinney's (2011) position, which my thesis aligns with, is subtly but significantly different. Her emphasis is less on 'maintaining' identity and more on understanding how people with dementia are "living both retained and shifting narratives" (p. 267) and how others "might meet people in that space [...] where they can be both who they are, and who they are becoming" (p. 267).

Caddell and Clare (2011) rightly draw attention to the impact of "external circumstances" (p. 385) on the identity of individuals with dementia. However, my argument differs from theirs in two main ways: first, in not automatically situating 'dementia' at the epicentre of changing identity and self-experience; and second, in not regarding 'external circumstances' as relevant to individuals chiefly in terms of mitigating or aggravating the impact of dementia. Tom, Grace and Jenny each described various events and situations which influenced their sense of self and identity, some of which related to memory loss and other health conditions, and some of which did not. These life changes did not just affect them as people experiencing dementia: they affected them as complex individuals whose identities, and whose diverse feelings about themselves and others, were borne out of, and enmeshed with, their biographies. The deaths of Tom's best mates and the transformation of his home town shook his sense of belonging as 'one of the gang' and a 'native' citizen. The death of Jenny's daughter was a profound event touching all areas of her life. This is not to deny or minimise the effects of dementia on sense of self and identity: severe memory loss had a major impact on Grace's feelings of competence and self-esteem. However, her doubts about her faith and her unwelcoming, 'cliquey' church, for example, were meaningful to her as a lifelong churchgoer and Christian, not just as a person, to use her word, "suffering" with memory loss. So often, it seems, dementia research aims to 'see the person beyond the disease' only then to regard that person exclusively through the lens of dementia.

The case studies support the view that people with dementia experience a fluid,

liminal self-understanding; and that, for Tom, Grace and Jenny, acknowledging loss, change and uncertainty as well as that they were ‘still’ – or could be – themselves was important. Shifts in identity and self-feeling were not solely bound up with the impact of dementia but affected by other events and situations, and to a significant extent shaped by the kinds of relationships they participated in. To a significant extent, each person’s self-experience and identity were shaped by the kinds of relationships they participated in. I go on to make the case that, for Jenny, Grace and Tom, in their befriending relationships, they could be both who they were and who they were becoming. Next, though, I focus on other people in their social networks. This provides insights into the relational contexts of befriending which, in turn, feed into an understanding of the meanings of befriending relationships for those in the study.

5.3 Personal Community

It was not at all the aim of this study to comprehensively map and analyse Jenny, Grace and Tom’s social networks. However, because relationship stories were so prominent, it has been possible to assemble detailed pictures of other people in their lives, past and present; to chart broad changes in their social circumstances; and to situate befriending within these contexts. In this section, I draw on Spencer and Pahl’s (2006) concept of ‘personal community’ to discuss the ways in which Tom, Jenny and Grace experienced past and present relationships. This enabled me to identify a number of liminal and segregated social spaces, as well as unmet relational needs and wishes. I use Bakhtin’s (Bakhtin, 1984; Morson & Emerson, 1990) ideas of ‘surplus knowledge’, addressivity and dialogicality, to explain different modes of knowing and interacting with others. Throughout the section I point to how befriending functions within individual ‘personal communities’ but develop this line of thinking further in my section (Section 5.5) on befriending.

5.3.1 Picturing Change

In Spencer and Pahl’s (2006) study, someone’s personal community consists of all the

people they identify as important to them now, rather than everyone they know. In my study, I took ‘personal community’ to be all the people Tom, Jenny and Grace talked about, and, hence, I included relationships which were formal as well as informal, positive as well as negative. Of particular interest to me was Spencer and Pahl’s (2006) recognition of people in their participants’ lives who were absent or rarely in contact but who, nevertheless, had a continuing psychological presence. As will become clear, their distinction between ‘communities of the mind’ and ‘communities on the ground’ was especially relevant.

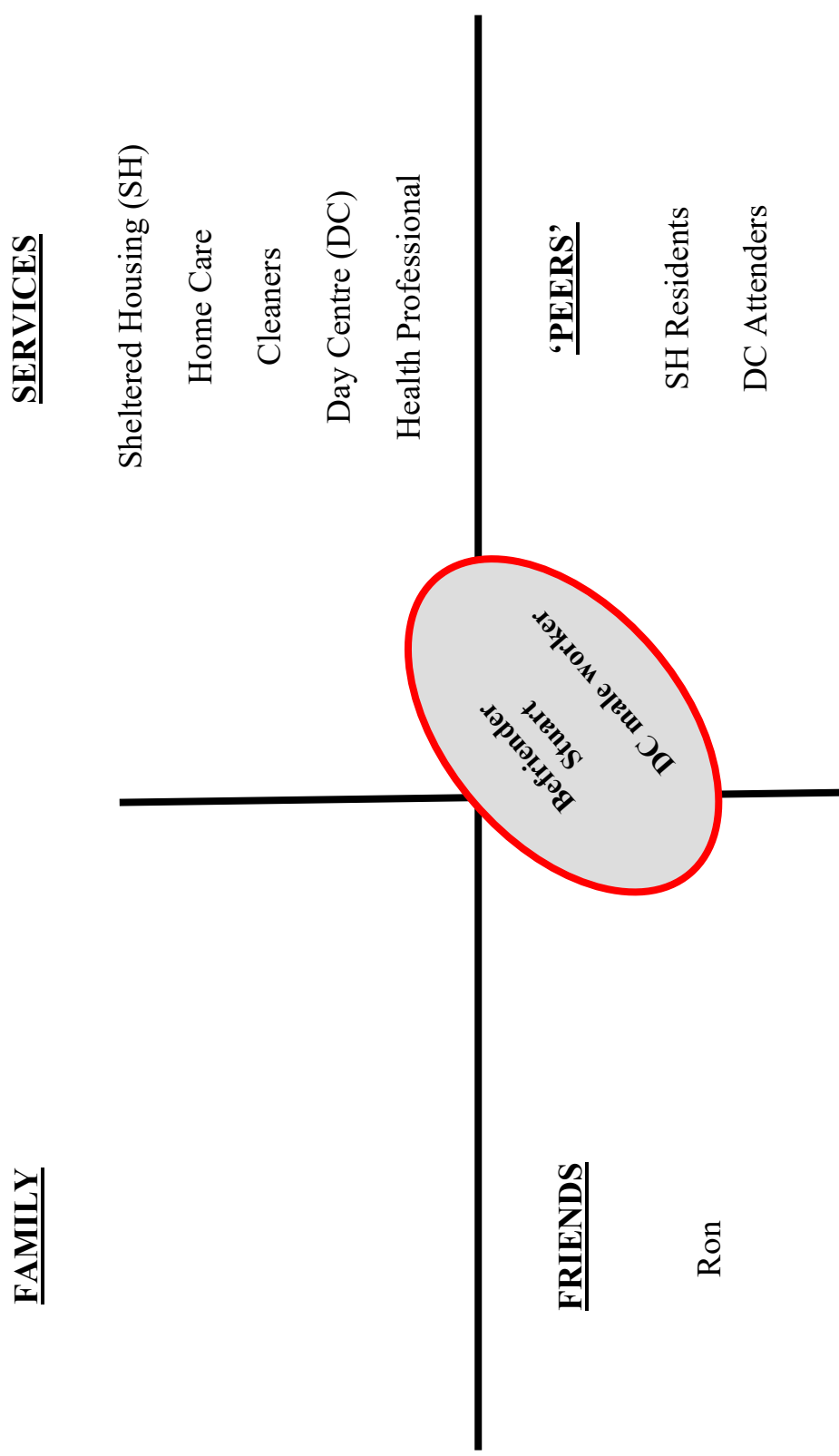
Based on the relationships Grace, Tom and Jenny spoke of in our conversations, I devised, for each of them, a personal community map (Maps 1-3) and a diagram of their ‘on the ground’ relationships (Diagrams 1-3). These convey, in a visual form, information on various facets of individuals’ relationships and access to other people. As I described in Chapter 3 (Section 3.6), I intended the maps and diagrams to be an additional way of representing my findings. However, once formulated, they also served an analytic function in revealing striking features of each personal community which contributed to my interpretive work, such as the degree of age segregation, and, in Tom’s case, the extent to which his social ties existed ‘in the mind’. Readers are invited to consult the maps and diagrams as I discuss aspects of Grace, Tom and Jenny’s befriending and other relationships.

The personal community maps show the presence of communities ‘of the mind’ as well as ‘on the ground’. They identify people considered friends and friend-like ties among current relationships. They indicate how far individuals are able to go out – on foot or using transport – and where they (can) go to. They capture the direction of travel – who visits who – of social contact. Lastly, they make visible the often restricted social spheres in which Tom, Jenny and Grace meet other people. The relationship diagrams display the current involvement, or absence, in a person’s life of four main kinds of relationship: family, friends, services, and ‘peers’. In a simple format, each diagram shows the result of shifts in sources of social contact, and the ‘liminal’ status of befrienders (and other individuals) as straddling different types of tie. For the purpose

of this study, 'peers' refers to people brought together through 'solidarity shaping' (6, 2004) interventions and/or age-based housing, and/or private arrangements, with whom Jenny might have close, loose or non-existent ties.

Maps and Diagrams

Diagram 1: Tom 'On The Ground' Relationships



Map 1: Tom's Personal Community

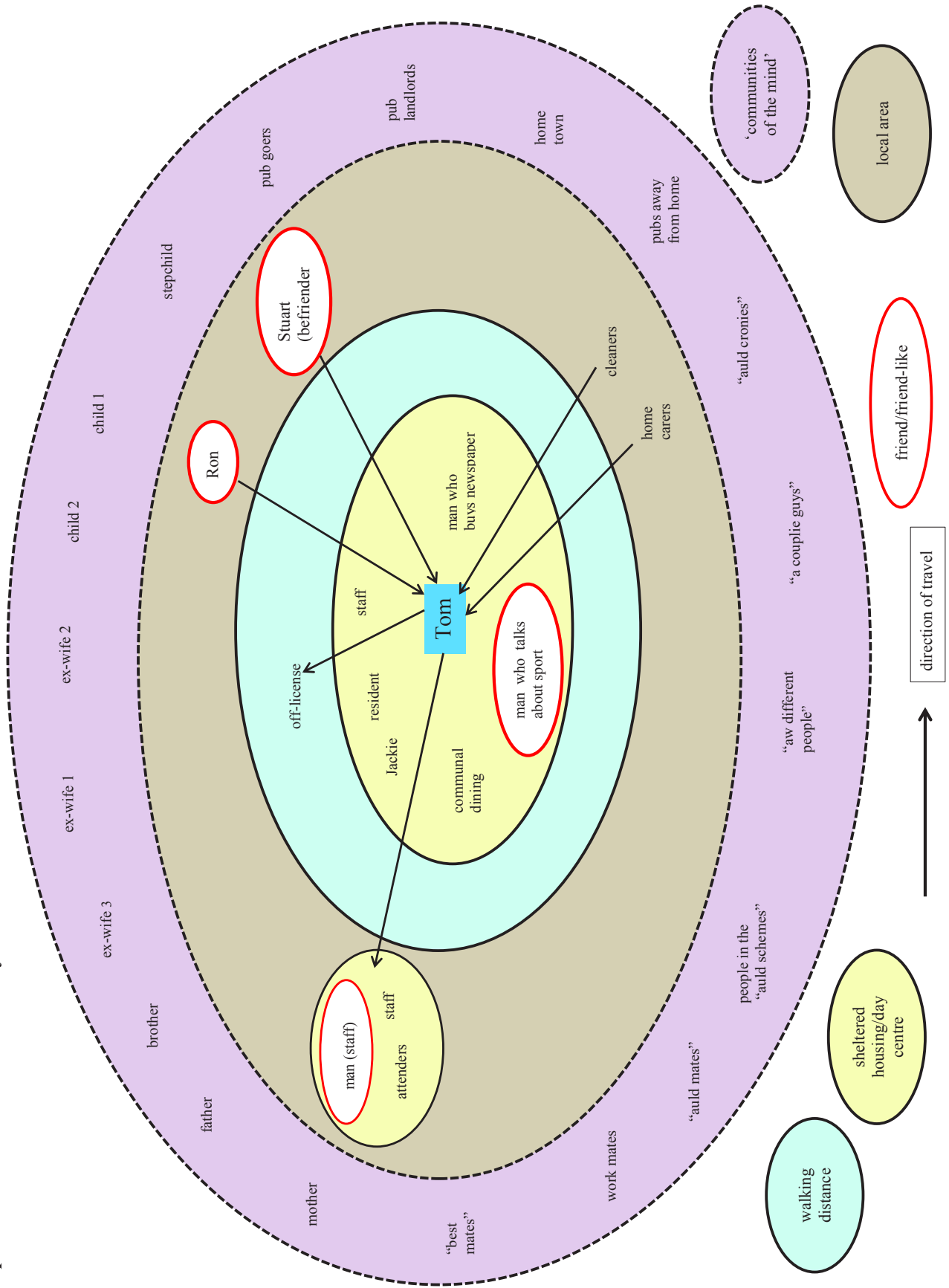
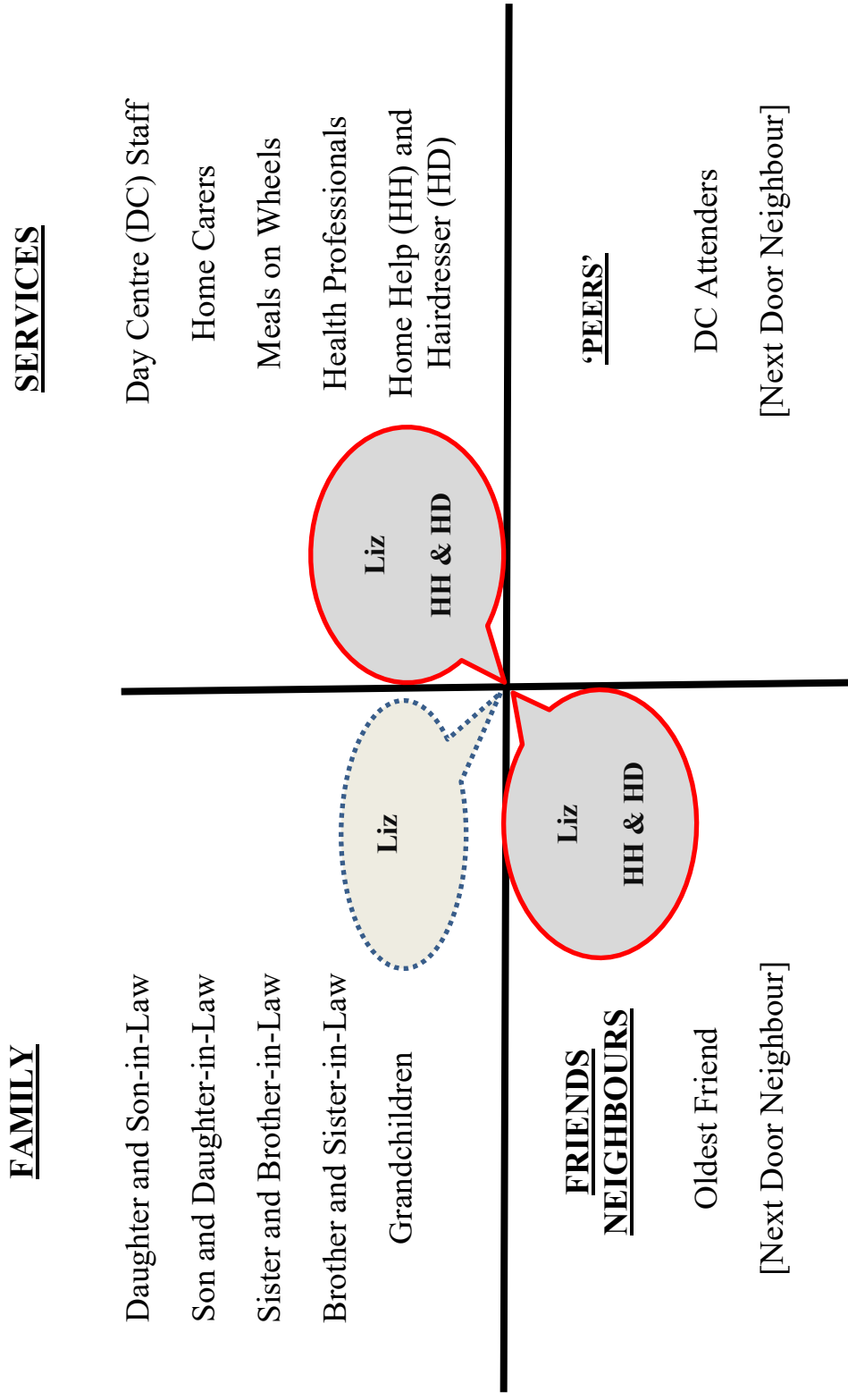


Diagram 2: Jenny ‘On The Ground’ Relationships



Map 2: Jenny's Personal Community

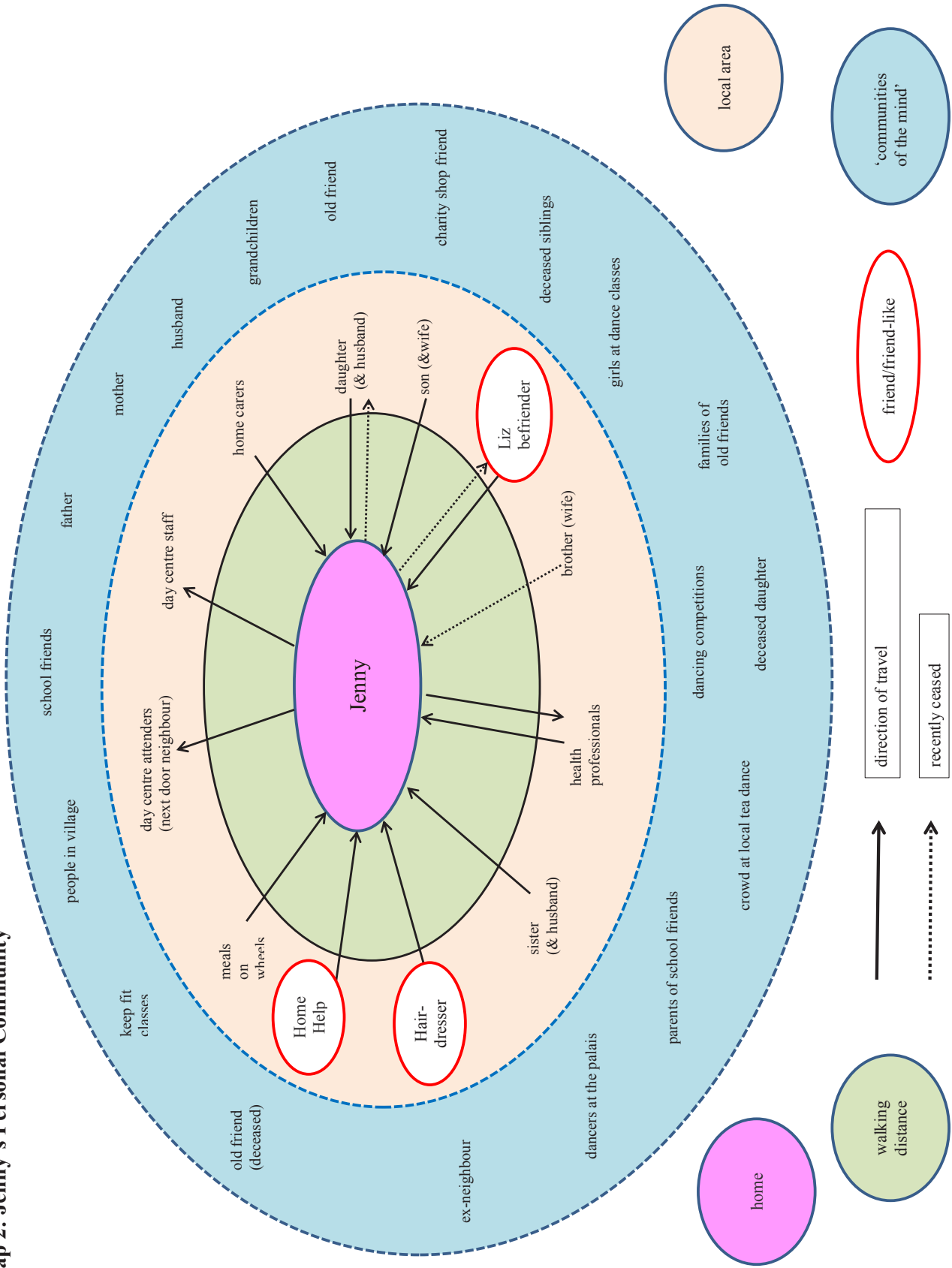
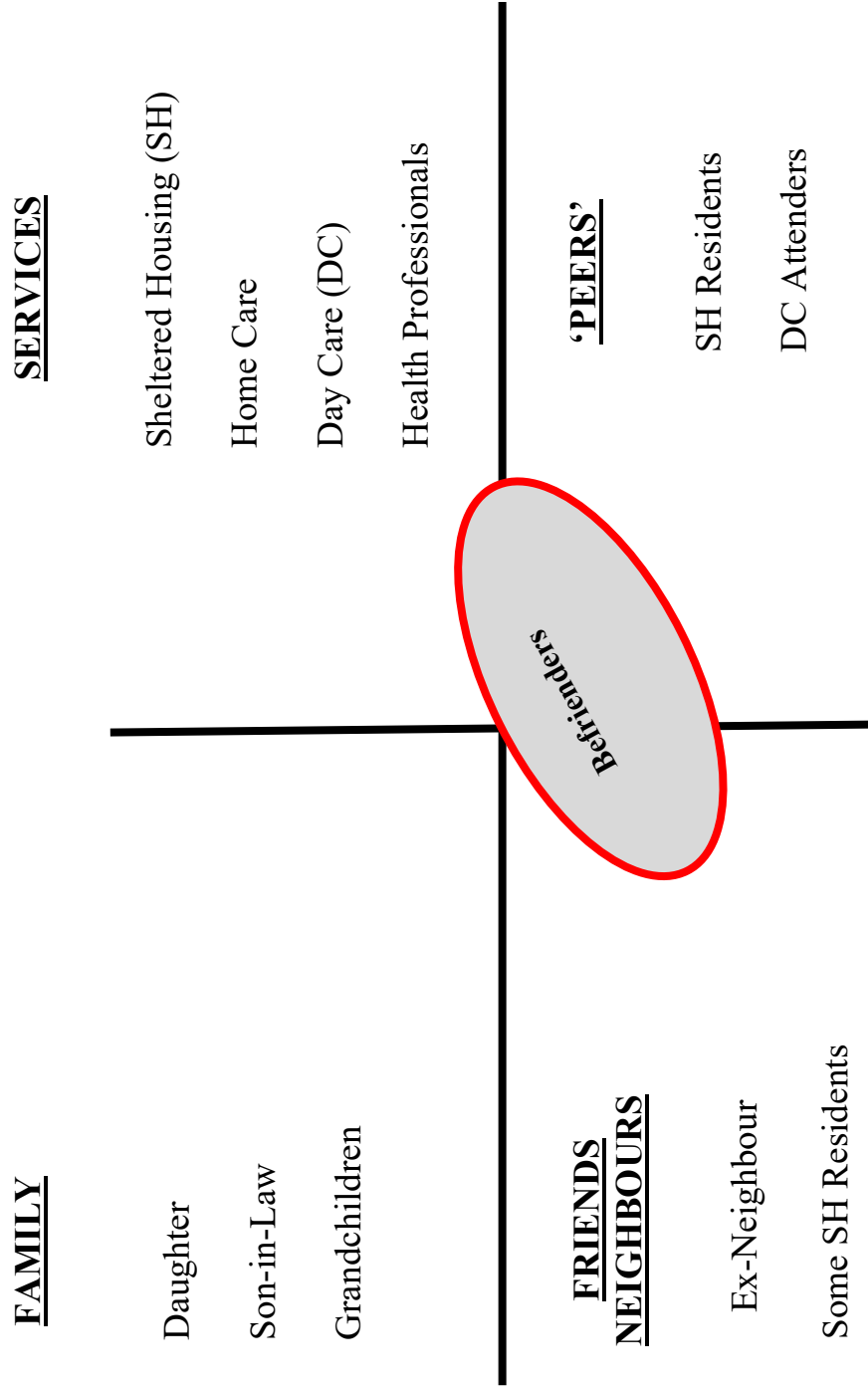
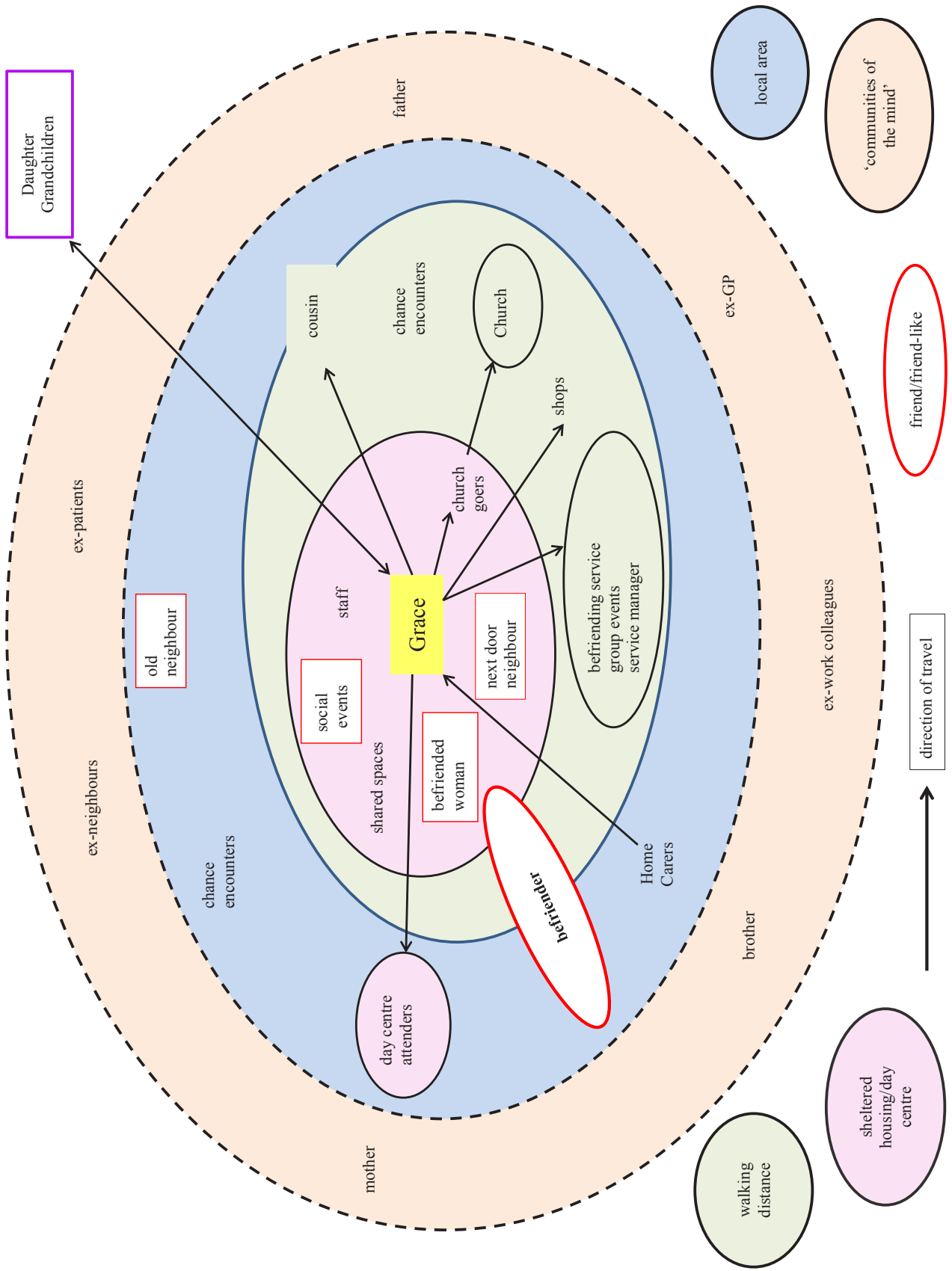


Diagram 3: Grace 'On the Ground' Relationships



Map 3: Grace's Personal Community



It can be seen from the maps and diagrams that there was considerable diversity in the social circumstances of just three participants. However, some broad commonalities were apparent (not all of which are represented in the maps and diagrams). All personal communities had been subject to shrinkage due to loss of contact, for a range of reasons, with friends, family and local networks. There was a growing professional and institutional involvement in each person's life. As in much of the 'living alone' literature, homes and housing had become liminal spaces: private yet communal; homely and more institution-like; places of comfort and confinement; permanent dwellings and yet interim bases from which moving to alternative accommodation was a real possibility (Frank, 2001; Leibing et al., 2016). The size and role of family in day-to-day life varied greatly: very involved and comparatively large for Jenny; highly attentive but small for Grace; and absent altogether for Tom. For each person, independently maintaining existing relationships with family members and/or friends was limited by mobility problems, physical distances, lack of transport and ill-health. While Tom and Grace could reach places in their immediate locale within walking distance – for both, around five hundred metres – Jenny, at the time we met, was unable to go out by herself at all. To sustain a social life, each of them, largely or wholly, depended on people visiting them and being taken to visit other people – to day centres or occasionally to the homes of family members. Grace and Tom took part in communal meals or social events within their sheltered housing but this did not necessarily lead to desired relationships. Outside befriending, opportunities for Tom, Grace and Jenny to make new social connections were almost entirely limited to age- and client-segregated spaces. Many important relationships only survived in 'communities of the mind' (Spencer and Pahl, 2006), strikingly apparent in Tom's map (Map 1) as the most populated area of his personal community. It was in these changing personal networks that befriending relationships occurred.

The stories Jenny, Tom and Grace shared with me, as well as shedding light on broad social change in their lives, also conveyed rich information on their subjective experiences of their relationships, formal and informal, past and present. These stories, many of which were habitual narratives (Riessman, 2008), gave a flavour of ongoing

relational environments (Josselson, 1992), and revealed the nuanced distinctions each person made between different kinds of social contact. This helped to generate an understanding of the distinctive qualities of befriending in individual personal communities. The case studies highlight the importance of seeking to understand how relationships are actually experienced in particular contexts, rather than in terms of social categories (Brownlie, 2014; Spencer and Pahl, 2006).

I go on, now, to provide an analysis of a number of aspects of Grace, Tom and Jenny's subjective experiences of their non-befriending relationships under the heading, 'presence and absence'.

5.3.2 Presence and Absence

Although they all lived alone, given that Jenny, Tom and Grace saw or spoke to at least one person – and usually several people – every day, including, for Grace and Jenny, close family members, a notable finding was that each of them described feeling lonely some or much of the time. The following section captures different ways in which people in their lives were experienced as both present *and* absent, leading to intermittent or near constant loneliness, and, for Jenny and Grace, the feeling that, well supported as they appeared to be, they were having to manage on their own. I focus on psychological as well as physical presence and absence; on perceptions of the 'thereness' of others (Brownlie, 2014; Josselson, 1992); on geographical and emotional closeness and distance (e.g., Bondi, 2008; Spencer and Pahl, 2006); and on the effects of memory loss.

5.3.2.1 'Communities of the Mind'

As their personal community maps show, as well as visible 'on the ground' social contacts, people absent from Grace, Tom and Jenny's lives had a continuing psychological presence in less apparent 'communities of the mind'. For Spencer and Pahl (2006), the immediacy of the psychological presence of friendships is strongest

when friends are in regular, frequent contact. However, this was not necessarily the case for Jenny, Tom and Grace for whom past relationships remained vivid even when direct contact was no longer possible. As discussed in Chapter 2 (Section 2.8.5), research on living alone with dementia describes ways that individuals experienced connections with people who were not physically there which could help ease feelings of loneliness. My study, likewise, illustrates how Grace, Jenny and Tom continued to feel socially and emotionally connected to those, temporarily or permanently, absent from their lives.

Jenny and Grace voluntarily showed me family photographs and gifts – flowers, ornaments – from their daughters, symbols of ongoing relationships (Jamieson & Simpson, 2013). Having no photographs at all, and no obvious personal memorabilia in his flat, Tom relied on his memories and opportunities to share stories to keep alive his links with people and communities now absent from his life. To differing degrees, each person vicariously extended, or maintained, their social circle by taking an interest in people their visitors talked to them about, or by keeping up with friends and family through third parties. For instance, Grace and Jenny’s befrienders shared information about their own families; Jenny heard about her brother’s state of health from her home help; and Tom’s friend, Ron, gave him “all the gen” about the crowd still drinking in the pubs of his home town.

During our conversations, each person spontaneously engaged in reminiscing, both in the sense of talking about their past lives, and of nostalgic reminiscing or sharing ‘feel good’ memories. Both forms of storytelling brought individuals into psychological contact with past relationships or earlier times in existing relationships. These could be positive. Tom, for example, spoke of “good times” travelling; Grace talked to me about the patients she gave “all your love to”; and Jenny shared her recollections of growing up in a village, dancing, and close friendships. Jenny explicitly described her memories as stores of “happier times” that were ‘there’ to revisit.

There has been increasing interest in nostalgia as a psychosocial resource with

the potential to contribute to self-continuity, social connectedness, belonging, self-esteem, and meaning in life (Cheung et al., 2013; Dempsey et al., 2014; May, 2017; Routledge, Wildschut, Sedikides, Juhl & Arndt, 2011, 2012), particularly for those living in adverse circumstances (May, 2017), including people with dementia (Cheston, Christopher & Ismail, 2015). For Jenny, Tom and Grace, nostalgic storytelling could evoke ‘virtual’ friendships; rekindle memories of affirming relationships, or affirming moments within problematic relationships; and bring warmth and vitality into the here and now. Positive life stories also made visible ‘frameworks of belonging’, initially not obvious as these were “provided by the individual’s biography rather than by his or her membership of a particular, readily identifiable social grouping” (Spencer and Pahl, 2006, p. 45). These included home towns, neighbourhoods, occupational groups, family, pub-goers, dance clubs, being ‘one of the guys’. Such contexts of belonging had often been lost through, for example, for Grace, retirement; for Jenny, her inability to dance and take part in community activities; and for Tom, the deaths of friends and the transformation of his local pubs and home town. Often, alternative social groups and settings – day centres, sheltered housing – seemed to provide only a partial or minimal new sense of belonging.

As we conversed, nostalgic reminiscences were interspersed with non-nostalgic stories and memories of troubling, sad or unresolved events and situations. These did not feature in research on living alone with dementia which focused on the social and emotional benefits of the ‘social world’ of memory. In my study, psychological contact with absent people fluctuated, and was linked with the pain and sadness of their absence as well as positive associations. For example, on the one hand, Grace did not like to think about her husband due to the distressing circumstances of his death, but on the other hand “it’s nice to think about him because he was alive”. However, visiting his grave was, these days, a “waste of time” because “there’s nobody there”. Jenny’s positive memories of a more recent friendship were overlaid with hurt and bewilderment at its sudden termination. For Tom, nostalgic remembering had both a vital and a dysphoric character. As someone who had lost ties with contemporaries, and who felt he had lost his place in society, Tom’s nostalgia was frequently what May (2007) calls “reluctant”

(p. 407): an expression of “profound social dislocation” (p. 407) and a critique of his current situation. He inhabited a “nostalgic limbo” (p. 408), mourning while holding onto his lost past, and exiled from the present. In so many of his accounts, Tom was socially, spatially and temporally stranded. In his storytelling, the past contained all that he felt was lacking from conditions now. For him, the plenitude of his former life, as he recalled it, was an indictment of his hollowed out present. Tom’s situation was intensely liminal. He remembered lost friends, recounted their exploits, recited their names, enacted their dialogues, recalled them hailing him. His evocation of fraternal togetherness was palpable even as he lamented its disappearance from his life. Not wanting to return to his “auld haunts” and still wanting to go, he was caught up in nostalgia for a place which existed only in his memory of it. In his memories, again and again, absent friends offered quasi solidarity and affirmed his “ane self”. They had a lasting *and* an ephemeral quality: tantalisingly there and yet not there.

In the case studies, while nostalgic storytelling could create a sense of belonging ‘from afar’ (May, 2017), it could also reflect present-day alienation and dissatisfaction. ‘Communities of the mind’ added a further, and liminal, layer of complexity to each person’s social network. For Grace, Jenny and Tom, reminiscence could foster a beneficial sense of social and emotional connection with historic or distant relationships. As I discuss later in this chapter, each of them valued opportunities to talk with their befriender about “happier times” (Jenny), the “guid times” (Tom) and “a good life” (Grace). In each of the case studies, Grenier’s (2012) suggestion that, for some older people, reminiscence may provide temporary ‘exits’ from persistent liminality appeared to be borne out, at least some of the time. Nostalgic storytelling seemed to move individuals out of ‘betwixt and between’ states, if only temporarily: their stories fashioned stable self-identities based on wellness, activity, autonomy, and mutual ties with others. However, ‘feel good’ accounts did not neutralise bleak or challenging circumstances: “guid times” and “bad times” co-existed. In Tom, Grace and Jenny’s accounts, important relationships had a lingering and often vivid presence in ‘communities of the mind’, engendering a sense of belonging in the present, and shoring up self-identity; yet these relationships were also unreachable and missing

from the here and now.

In their ‘on the ground’ networks, too, people were ‘there’ and ‘not there’.

5.3.2.2 ‘Thereness’

For Grace, Jenny and Tom, the perception that people were ‘there’ for them mattered hugely – for instance, Jenny’s adult children; Grace’s daughter and cousin; Tom’s friend, Ron, and his sheltered housing manager; and, for all of them, their befriender. The ‘thereness’ of others can refer to the way we experience people as ‘there for us’, even when we are apart from them, providing a taken for granted, background feeling of support (Brownlie, 2014; Josselson, 1992). Josselson (1992) explains that the ‘thereness’ of people, although derived from actual relationships, “exists between fantasy and reality” (p. 34). For Brownlie (2014), though, the experience of others ‘being there’ consists of ‘real’ as well as ‘fantasy’ elements: actual or imagined availability; practical support and caregiving; the feeling that someone is ‘on our side’; and the sense of people being, or doing things, alongside us. This was the case for Jenny, Grace and Tom whose health conditions had changed the ways they needed other people. As well as *knowing* others were there, actually *having* others there was as necessary as it was desirable. Josselson (1992) describes how the ‘thereness’ of others provides a psychological ‘ground’ without which individuals ‘fall’. However, although Grace, Tom and Jenny were symbolically supported or ‘held’ by members of their social network, sometimes being literally able to hold onto someone, or something, could be as important: both Jenny and Tom had physically fallen. Grace held on to my arm as we walked to a café; Jenny liked to “link into” people when she went out; and Tom steadied himself on his shopping trolley on his way to the off-licence. Each of them stressed the importance of having someone to talk to *in person*, and, for Jenny and Grace, to provide assistance.

Yet, just as others could be both present and absent, so, too, they could be ‘there’ and ‘not there’, close and distant. Variations of physical and emotional closeness and

distance – ‘paradoxical geographies’ (Bondi, 2008) – can produce situations in which the sense of others being close *and* distant are experienced in the same relationship (e.g., Spencer and Pahl, 2006). Daily telephone calls from her daughter were reassuring for Grace, reinforcing her ‘thereness’, but Grace also experienced her daughter as “so far away”. Grace felt emotionally closer to her out of town daughter than she did to her nearby cousin. Jenny did not feel she had got to know day centre attenders despite all ‘mucking in’ together. Tom lived in close proximity to people who “aw keep to theirselves”. And, for each of them, intimate care could be delivered through an impersonal service.

Members of Grace and Jenny’s families were reliably ‘there’ for them in numerous ways, doing things with and for them: telephoning, visiting, shopping, filling in diaries, liaising with services, going along to appointments. But there were times when family members were unavailable, when they could not be contacted, when they could not come, due to their work commitments and wider responsibilities, and living ‘so far away’. What constituted ‘too far’ to go, for participants, was markedly altered as a result of changes in their health, mobility, and means of transport. Nearby family, friends, and neighbours – and for Grace, her preferred GP surgery – were now, without assistance, out of bounds. Mobility problems separated Jenny from her neighbour although they lived mere feet apart. Distances, both geographical and temporal, severed Tom’s relationship with the pubs of his home town which, though they were still physically there, available to visit, and relatively near, were, for Tom, too far to reach by bus, and not the same places as before. For Grace and Jenny, the ‘not thereness’ of others added to their sense that they were, despite assistance, coping on their own. Even with consistent formal and informal support, everyday struggles with ill-health and ill-being could give rise to feelings of “aleness within connection” (Molzahn et al., 2008, p. 18).

Memory loss, too, had an impact on ‘thereness’.

5.3.2.3 Remember Me?

A sometimes overlooked reason why people with dementia may feel lonely, especially those living alone, is that they may not be able to remember visitors (Alzheimer's Society, 2013), or bring to mind significant others in their absence (Svanström & Sundler, 2015). The part that memory loss might have played in Grace, Tom and Jenny's experience of loneliness cannot really be established from my research data. However, to varying degrees, memory loss did affect each person's ability to recall their befriender – whether they had visited that week, or even whether they still had a befriender. This suggests that cognitive impairment – perhaps, more for Grace and Tom than Jenny – lay behind another way in which other people could be both present and absent in their lives. The value of face-to-face contact with people with dementia is that it provides “visual and sensory clues” (Alzheimer's Society, 2013, p. 30). As Grace told me about a neighbour she was trying to remember, “I'll know her when I see her”. I noticed that, even over the five-week period of the research visits, Tom, Jenny and Grace became better able to remember me, either when they saw me, or in Jenny's case, over the telephone. Regular contact and visits seemed to foster familiarity. This highlights an important aspect of continuity of home carers and other workers for people living with dementia, something all those taking part in the study said they would like. Individually tailored memory aids could also strengthen the ‘thereness’ of others. Conversely, the omission of diary or calendar entries on befriender visits, for Grace and Tom, meant they did not know when, or whether, they would see, or had seen, their befriender.

In this section, I have looked at various ways in which people in Jenny, Grace and Tom's lives were present and absent, there and not there, giving rise to both connection and gaps in their personal communities. Gaps also existed in respect of the kinds of relationships each person wished for but did not have. In the following section I focus on how individuals distinguished between different ties in their social networks. This gives an idea of the relational environments in which, in this study, befriending functioned.

5.3.3 Distinctions

I referred earlier to research on dementia sector voluntary workers (McCall et al., 2017) which reported that individuals with dementia did not discern category differences between volunteers, staff, family members and others with dementia – all of whom were ‘simply’ people in their social networks they could interact with, and sometimes might dislike, and who supported them. However, those taking part in my study were discriminating in their relationships, and identified what others did, and did not, offer them practically, socially and emotionally. This applied not just at the level of categories such as family, home carers, neighbours, and befrienders, but also within categories – for instance, some of Grace’s carers were ‘nicer’ than others – and within individual relationships – for Tom, his “all right” sheltered housing manager ‘checked’ on him in supportive and supervisory ways.

Although, on the one hand, Tom, Grace and Jenny’s ‘on the ground’ informal social networks were shrinking, on the other hand, as a result of increasing contact with services and ‘solidarity shaping’ interventions, each of them was coming into contact with more people. It has been argued that diversity of social ties, rather than any particular type of relationship, is key to various indices of wellbeing (Allan, 1989; Spencer and Pahl, 2006) such as social integration, belonging and self-esteem. While it is often suggested that quality over quantity of relationships is critical, Frazer et al. (2011) point out that quantity as well as quality of social ties may be important. Tom had ‘quality’ relationships with his friend, Ron, his sheltered housing manager, a support worker at his day centre, and his befriender. However, from his point of view, contact with them was more seldom than his past experience of being with others: used to being in company, at work and in pubs, he now found himself “maist o the time” on his own. Not only this, as indicated above, diverse ties, from the passing and superficial to the regular and close, can be deemed ‘quality’ in the sense of having some degree of positive meaning. Jenny, Tom and Grace all talked about having various types of satisfying contact, even if short-lived, in everyday life. These included relatively brief, friendly, non-intimate encounters with particular home carers, other service users,

members of staff at day centres and sheltered housing, and, for Grace, “everybody that comes in and out” of her building, and chance meetings with people she knew in the town. It was not, in itself, the increasing appearance of fleeting, formal or less intimate social contacts which impoverished Grace, Tom and Jenny’s personal communities provided these were in some way rewarding (e.g., Allan, 1989; Spencer and Pahl, 2006). The crucial point, for each of them, was the absence, or shortage, of certain kinds of relationship: “Who is there in our life affects who else we need and how we need them” (Josselson, 1992, p. 27). One type of social tie that everyone identified as missing from their lives was compatible, mutual relationships in which each person could get to know the other. I say more about this below.

In terms of ‘quality’ of social contact, a further point is that Jenny, Grace and Tom’s relationships, including those they valued, were not straightforwardly ‘good’ or ‘poor’. This argument has been made by Tolhurst, Weicht and Kingston (2017) who identify a trend in academic discourse on dementia which tends to allocate relationships to positive and negative types, rather than recognise relational complexity. Jenny, Grace and Tom each spoke in nuanced ways of ambivalent feelings towards individuals in their lives, particularly around areas of dependence, decision-making, and control. Grace loved and appreciated her daughter and found her “bossy”; she wanted her daughter to be nearer but not to take over her daughter’s life. Her cousin was “helpful” and “looks after me”, but Grace did not trust her enough to confide in. Tom experienced sheltered housing as a place where “ye die” and a place where “I’m gettin looked efter”, where care was combined with scrutiny. Ron was his only surviving ‘best’ friend but Tom was angered when he did not understand his – Tom’s – wish to find “digs” of his own. Jenny was glad of the support of her children, and frustrated that she had to rely on them, and wanted to shield them from her worries, and enjoyed being part of a close family circle. As Bondi (2008) puts it, care – both for those who provide it and those who receive it – is “double-edged and deeply paradoxical” (p. 250). The same relationships were not only experienced in multiple ways, they were interactive and negotiated – vividly evident in the dialogues Tom performed in his storytelling. Recognising the two-way nature of the relationships of people with dementia matters

because, so often, they are seen as merely passive receivers of support (e.g., Bartlett and O'Connor, 2010). Grace, Tom and Jenny were never only 'passive' in their contact with other people including their befrienders. However, neither were they only 'active'. This is the subject of the next section.

5.3.4 Negotiation

Grace, Jenny and Tom's relationships were negotiated and had both active, or agentic, and passive, or patiential, aspects (Reader, 2007). Jenny 'suffered' having to rely on her family but made decisions about what she wanted them to do, and if and when she would contact them (see Ward-Griffin, Bol & Oudshoorn, 2007). Tom negotiated with "one o their bosses" to have "one carer at a time" but 'suffered' nothing changing: "'Aye Tom aye' but that was it like ken that was it". Grace tried initiating conversations with a home carer and 'suffered' his lack of response. As Wray (2004) points out, it is possible to be empowered and disempowered at the same time.

Negotiating with others takes place at the level of direct, verbal interpersonal exchange but it also occurs 'in the mind' and linguistically. According to Bakhtin's (Morson & Emerson, 1990) concept of 'addressivity', even if a speaker is unaware of it, or does not talk out loud, all speech is always addressed to an 'other' – a particular person or an ideal listener – and anticipates a response. An obvious example of this is Grace's imagined exchanges with her cousin in which she asks for, and is refused, a lift home. But communication or negotiation can also take place in a more concealed, linguistic way. Bakhtin (1984) advanced the theory of 'dialogicality' whereby, for example, a person's speech contains 'hidden dialogues' in which the words of an invisible second speaker are absent but leave "deep traces" and "have a determining influence" on the words of the first speaker (Bakhtin, 1984, p. 197). For instance, when Grace talks about moving to sheltered housing, she tells me, "no it's a nice place to live". The word "no" seems to counteract a contrary view which does not appear in the surrounding talk and with which Grace weighs up the soundness of her decision to move. Another form of dialogicality is the way a speaker engages with, responds to,

and perhaps criticises, the speech of another by ‘reaccenting’ their utterances, as Grace does when she imitates her daughter’s reaction to her – Grace’s – ‘confiding’ (see p. 203). Tom’s many dialogue-based stories illustrate addressivity and dialogicality in a particularly compelling manner. In these performances, Tom is constantly interacting and negotiating with others – his parents, home carers, old friends, the sheltered housing manager – justifying, talking back, explaining, arguing, resisting, agreeing, arranging, ‘reaccenting’ – his words shaping, and being shaped by, their words.

At multiple levels, Tom, Jenny and Grace negotiated their relationships, ‘acting’ and ‘suffering’, always within the constraints of their situation and from a position of greater or lesser equality. Next, I explore dimensions of what ‘getting to know’ someone meant to participants since each of them spoke of wanting, but finding it hard, to do so, and each felt this had been possible with their befrienders.

5.3.5 Knowing You Knowing Me

Jenny, Tom and Grace felt that, for all their efforts, they were not really getting to know people in the social spaces they now spent time in, and, in Tom and Grace’s case, lived in. In sheltered housing, despite living in close proximity to co-tenants and being part of regular group events – coffee mornings, communal mealtimes – neither Tom nor Grace had been able to forge the sorts of compatible, closer relationships they felt were missing from their lives. For Tom, apart from brief exchanges with other tenants and contact with staff, there was “naebody tae talk to”. Grace had got to know “all the people that lives in the flats” but only “sort of”. At her day centre, Jenny, too, described “not getting to know anybody” as “they don’t speak about their life”. Each of them understood getting to know someone as a mutual process in which they learned about the other person as well as shared something of themselves. Both these aspects of relationship building were important. As Grace put it, with her befriender, “I knew her and she knew me”. In this section, I discuss different ways in which Jenny, Tom and Grace talked of being known, wanting to be known and wanting to know others. These were important dimensions of their befriending relationships.

5.3.5.1 Being Known

All three participants wanted to be known; to be known as individuals and to be known on a more intimate level. This was not straightforward. In my literature review, I referred to a study by Frazer et al. (2011) who found that women living alone with dementia experienced tensions between ‘wanting-to-be-known’ deeply as complex and capable, and ‘not-wanting-to-be-known’, or perceived, as ‘demented’, ‘dotty’ ‘silly’ old women. For Frazer et al. (2011), the women’s concerns about self-disclosure related to the risk of being judged or dismissed as a result of others finding out about their memory loss. Fear of disclosing a diagnosis of dementia can have a major impact on relationships. Some people with dementia attempt to conceal their diagnosis from others, or withdraw socially, due to the stigma attached to dementia (e.g., Alzheimer’s Disease International, 2012; Singleton, Mukadam, Livingston & Sommerlad, 2017). With Jenny and Grace, there were other reasons for ‘not wanting to be known’: sensitive issues other than memory loss; worries about privacy; and a wish to shield family members. Both women had concerns about “gossip” and the “spread” of personal information. Disclosing the extent of health problems – as Jenny did to her GP during one research visit – also carried the risk of being viewed as no longer able to manage at home (see de Witt et al., 2009). Grace thought that sheltered housing residents would not judge her for having problems, per se, since they all had “something wrong with them”; but she also felt that it was “better if they don’t know your history” so that they could not judge her.

Like the women in the study by Frazer et al. (2011), Tom, Grace and Jenny wanted to be known not just as people with problems or incapacities, but as complex individuals with particular views, histories, values, interests, experiences and identities (Allan, 1989). As previous social networks were shrinking, fewer people held this kind of personal information about them (Josselson, 1992), knowledge which could bolster their identities. For example, Tom’s friend, Ron, was the only person who knew him when he was younger, knew his background, his friends, and his home town. Each person wanted to find new relationships in which they could share aspects of

themselves and their lives. Jenny, for instance, enjoyed being able to speak about her past life; Tom appreciated the chance to talk about “just life” and “aw different things”; and Grace liked sharing her nursing experiences, and conversing “on any topic”.

Being known in a fuller sense enabled participants to resist being primarily defined as a care recipient. However, ‘being known’ was also essential to good care. Having too many different home carers prevented each person from developing a familiar, trusted relationship with them. Jenny felt she would “relax more” if she knew her carer and they had worked out together a particular way of showering so that Jenny would know “what she expects of me”. Grace was critical of home carers who did not ask her about herself, how she was feeling, whether she had eaten or had any problems. Both Jenny and Grace wanted their befrienders to know “what I’m like” (Grace), “what I can do and what I can’t do” (Jenny), and appreciated it when they did.

While being known, and degrees of being known in different social situations, were important, those who took part in the study also stressed their wish to get to know other people.

5.3.5.2 Knowing Others

It is one of the hallmarks of high-quality person-centred dementia care that practitioners get to know the people with dementia they work with: their perspectives, routines, interests and life histories (Brooker, 2007). But for Jenny, Grace and Tom, what mattered, as much as being known, was being able to get to know others on an equal, or more equal, social footing. Each expressed frustration or disappointment that other people did not share their lives with them. Jenny, Tom and Grace all recognised that home carers were there to do a job but, for Grace and Tom, visits from familiar, friendly home carers could provide brief but meaningful opportunities for social contact. However, Tom and Grace both gave accounts of attempts to relate to home carers on the same social level in which they were rebuffed and client-worker roles reasserted. Grace recalled being ignored when she enquired about her home carer’s

new baby. Tom described home carers turning down his invitation to sit down and have a cigarette or watch television: “we cannae dae that we’ve tae work”.

‘Care providers’ and ‘care receivers’ have different access to knowledge. Formal caregivers and professionals may elicit the histories of their clients but, bound by codes of conduct, may share little of their own lives. To adapt one of Bakhtin’s (1984) literary concepts, professional knowledge can be characterised as ‘monologic’. In ‘monologic’ novels, dominated by a single authorial perspective, authors enjoy a huge ‘surplus of knowledge’ of the characters they have created and therefore ‘know’ completely. Author and characters do not exist on a single ‘plane’. By contrast, mutual relationships can be viewed as ‘polyphonic’. Bakhtin (1984) argues that, in polyphonic novels, an author’s knowledge of his characters is restricted to that which enables the story to progress. Author and characters meet on the same ‘plane’, only partially known to each other, and “enter into dialogue as equals” (Morson & Emerson, 1990, p. 241). From the perspective of services, support is typically unilateral, provided to, and received by, people with dementia (e.g., Bartlett & O’Connor, 2010; Blood, 2013). Where personal communities become more professional-based (Spencer & Pahl, 2006), there is a corresponding reduction in relationships where knowledge exchange is mutual. For each person in the study, particularly for Grace and Tom, the increasingly formal nature of their social networks meant that there were fewer relationships in which they were entrusted with the stuff of other people’s lives. However, this situation also applied to Jenny, Tom and Grace’s informal relationships when other people did not talk about “their lives” (Jenny), did not “sit down with you” (Tom); and when “the private things about them” stayed private (Grace).

Frequently unrecognised are the ways that individuals with dementia take part in reciprocal relationships, and contribute to the lives of others (Bartlett & O’Connor, 2010). As Baldwin (2009) describes, “all too often the narrative flow is one-way [...] We focus on what ‘we’ can do in ‘their’ lives and fail to appreciate what ‘they’ do in ours” (p. 31). Bakhtin (Morson & Emerson, 1990) held that each of us has a ‘surplus of vision’, or ‘surplus of knowledge’, with respect to each other. We can see what

another cannot: the ‘back of their head’; the ‘blue sky’ background of their suffering – just as others can see ours. With regard to people with dementia, the ‘surplus’ that formal and informal caregivers have is accepted as normal and necessary: their risks, their needs, their histories. But the ‘surplus’ that people with dementia have in relation to others receives much less attention. However, there were many instances of Grace, Jenny and Tom empathising with those in their personal communities, understanding their perspectives, seeing the ‘background’ of their ‘suffering’. Jenny was aware of multiple strains on family members and the impact on her neighbour of a stroke. Tom was sympathetic to home carers’ adverse work conditions. Grace, a former nurse and midwife – a professional confidante – was sensitive and willing to listen to the experiences of “mixed up”, “nervous” tenants, and concerned about a home carer who might be “worrying about the baby”. Grace also empathised with me. Seeing similarities between my ‘job’ as a researcher, and hers as a district nurse, she reflected: “you’ll be thinking where you’re going and what you’re going to say and what you’re going to do”.

Being able to get to know people, to have the experience of someone sharing personal information with them, and the chance to respond to their experiences, views and interests, was an indication of each person’s competence and social worth (Allan, 1989). It also betokened greater relationship equality. However, although individuals wanted to get to know people better, to have mutual, closer, if not confiding, relationships outside their families and institutions, most of their former routes to making friends and acquaintances – pubs, paid and voluntary work, tea dances, neighbourhoods, and so on – were no longer available to them. Josselson (1992) argues that a person’s ability “to find and attract necessary others” (p. 28) lessens their reliance on people who are frustrating or disappointing in some way. I later argue that befriending, as a facilitated relationship, was one way that each person could secure a ‘necessary other’.

Jenny, Grace and Tom lived their lives in increasingly restricted social settings which narrowed the range of people they could forge new connections with. I discuss this next.

5.3.6 Social Segregation

As Allan (1989) points out, while the defining feature of friendship is often seen as its freely chosen nature, making and keeping friends is always, to some extent, constrained by a person's circumstances. The social spaces in which Jenny, Grace and Tom could form new friendships were largely, or entirely, confined to age-segregated and client-segregated housing and day centres where "everybody's got something wrong with them" (Grace), "they've no got any up and go" (Tom), and "there's some of them a lot older than me like" (Tom). Goffman (1963) wrote of the "informing character of the 'with' relationships in our society" (p. 64), the assumption that a person shares the same identity as the company he or she keeps. Sheltered housing and day centres can be viewed as 'mirroring environments' (Goffman, 1963; Josselson, 1992) reflecting back to Jenny, Grace and Tom images of who they had become or how others might see them, which did not always accord with how they saw themselves. There was a degree to which sheltered housing and day centres signalled their recategorisation as 'old people with problems'. All of them were ambivalent about, or resisted, this version of themselves.

Tom experienced co-tenants as inert and self-secluding, as having capitulated to routines, as completely unlike him, and yet with the power to 'infect' him: "and I'm getting like it mase". Tom longed for ways to rejuvenate (West, Shaw, Hagger & Holland, 2017). Grace's experiences of segregated spaces were mixed. She enjoyed the sociable togetherness of her day centre, and opportunities to get to know other residents at social events in sheltered housing. However, Grace was aware that sheltered housing was a place where "everybody's got something wrong with them" and "they've all got problems". This made it both an institution – "in here" – and a private home – "just a house" (see Percival, 2001). Grace oscillated between seeing herself as like and unlike other tenants. Jenny did not refer directly to the age of day centre attenders but hinted at the infantilising age-inappropriateness of some of the activities. For each of them, attendance at day centres had not led to new friendships, though Grace was happy to be in the company of others, Tom enjoyed contact with a male worker at his day centre,

and Jenny liked the staff at hers.

Services designed to enhance the social connectedness of older people and people with dementia, including housing, typically “reinforce their networks with others classed as similar to themselves” (6, 2004, p. 90), making it harder for them to develop relationships within different social groups (Allan, 1989). In age-segregated spheres, older people are treated as homogenous and ‘clumped’ together, giving rise to stereotyping and ageism (Abrams, Swift, Lamont & Drury, 2015; Bytheway, 1995). This is not the same as homophily, the tendency of individuals to form ties with people who are like them in some way, for instance, in terms of shared life experiences and values. Old age and dementia, or other health or social problem, may not be sufficient, or any, grounds for similarity between people, nor what generates bonds between them. Older people living with dementia are a highly diverse population; and, as Allan (1989) contends, the old may have the past in common but the legacy of that past on their lives differs widely.

A common background, life experiences and interests may be important to friendship formation but a prerequisite element is that individuals like, show interest in, and are responsive to one another (Fehr, 1996). Tom connected with people through shared experience of his home town and a mutual interest in sport, but he also liked “meeting aw different people” and talking about “different things”. Grace had nursing in common with her befriender and they could also “talk on any subject”, had the “same sort of ideas”, and “got on so well”. Jenny was interested in the lives of other people and enjoyed occasions when she could talk about her life experiences. No one spoke of developing, or wishing to develop, friendships on the basis of shared age or health problem. Bringing older individuals together on the grounds of their client status, for instance in sheltered housing or day centres, tends to concentrate those with “something wrong with them” in one space. In supported housing, for example, “something wrong” can include mobility difficulties, sensory impairments, progressive and long-term illness, mental health problems, substance misuse, and the need for protection from harm from others (Pannell & Blood, 2012). Many of these issues

applied to Jenny, Tom and Grace, themselves, as well as to other residents and day centre attenders, and, for all of them, could present barriers to social connection. This meant that making and sustaining mutual, compatible relationships in these spaces was difficult; a situation which befriending aimed to address.

5.3.7 Summary

In this section I have looked at multiple aspects of each person's current and historical relationships. Gaining a better overall, and detailed, understanding of individual personal communities brought to light relational gaps and gaps in support. Some of these were created by the deaths of, and lost contact with, significant others who were irreplaceable. Some gaps, for a number of reasons, occurred even in personal communities where support, both informal and formal, appeared to be reliable and robust. For Tom, Jenny and Grace, the presence of 'quality' relationships did not fulfil all their relational needs and desires. Each person talked about wanting to come into contact with people with whom they could form closer, mutual relationships based on getting to know one another. Jenny and Grace also mentioned their wish for a confiding relationship. The concept of 'communities of the mind' provided a means to recognise the continuing presence of people now absent from participants' lives which could be – but was not always or straightforwardly – a beneficial source of social connection. The case studies also indicate the value of looking at the networks of individuals living with dementia, not in terms of 'support', but in terms of negotiated 'relationships'. The close examination of Jenny, Grace and Tom's personal communities provided a relational context for their befriending relationships, discussed in Section 5.5.

Next, I look at solvable and unavoidable limits in each person's life. This was especially relevant to the understanding of befriending, in this study, as a distinctive response to a complex set of circumstances.

5.4 Contingent and Existential Limitations

At the close of my literature review, I drew attention to the distinction between socially imposed and insoluble limitations in people's lives. In this section, I focus on the ways in which Tom, Grace and Jenny spoke about their experiences of different kinds of limits. Tom, for example, situated himself at a kind of 'event horizon' endeavouring to resist the gravitational pull of malaise, institutional aging and oblivion – to not go "doon", to stay "alive". His characterisation of "whits's the matter wi us" was bound up with a situation that did not have to be that way (life in an institution); with illness that, in part, might be overcome (by motivating himself out of his malaise); and with loneliness and the prospect of death. This intricate picture exemplifies key strands running through my thesis: the need to attend to both agency and 'patiency' (Reader, 2007; see Section 2.13) in human experience; and the need for recognition of, and a response to, both 'contingent' and 'existential' constraints that individuals encounter (Baars & Phillipson, 2013) in all their complexity. I now discuss these ideas in relation to the case studies.

5.4.1 Complexities

Tom's experiences of various day-to-day constraints often seemed to merge making it hard to separate what could and could not be altered, taking into account what he actually wanted to change. His health was getting worse, and death ever closer, hastened by continued alcohol consumption. Going out was limited by alcohol-related walking difficulties and fatigue, by a lack of organised outings, by compatibility issues on groups trips with "OAPs" and at a day centre, and by him often not wishing to go. His desire for home and belonging was frustrated by the deaths of close friends and feelings of alienation from his now gentrified home town. Sheltered housing both removed and created barriers to participation in life. On the one hand, supported accommodation enabled him to maintain relative health and autonomy, keep in contact with an old friend, and establish some friendly, supportive relationships; but, on the other hand, it also created a situation in which he felt socially isolated and deprived of

activity and self-care roles, becoming, in his words, “a vegetable”. The constraints in Tom’s life were the result of a complex interplay of factors and included limits that lay beyond issues of impairment and disability (Shakespeare, 2006). For Jenny and Grace, limitations in daily life were similarly due to a convergence of potentially rectifiable sources of disablement, irreversible social change, and ‘impairment effects’, that is, non-socially imposed restrictions related to their health conditions (Thomas, 2004). For example, for Grace, giving up driving, due to memory loss, meant relinquishing her long-held identity as a driver and curtailed her movements; while, Jenny, unable to walk outside alone or, nowadays, feel safe even going out with someone, felt trapped in her home. Their lives might be improved by the provision of transport, familiar home carers, more personal assistance, a choice of meaningful activities, and companionship and support outside their families. However, major difficulties such as memory loss and Parkinson’s disease – each with social, emotional and physical impacts – were an inescapable part of their lives. On top of this were other events and situations which the women did not choose and could not reverse or control, for instance, the death of one of Jenny’s daughters, and the geographical remoteness of Grace’s daughter.

Philosophically speaking, the complexities of each person’s circumstances can also be understood in terms of agency and patiency (Reader, 2007).

5.4.2 Patiency

All the way through this chapter, I have drawn attention to the passive or ‘patiential’ (Reader, 2007), as well as the active or agential, in Tom, Jenny and Grace’s experiences of living with dementia and other health conditions; of enduring and coping with life events and challenging situations; and of negotiating their relationships. However, as McParland et al. (2017) contend, in contemporary discourse on dementia, ‘suffering’, or ‘tragedy’, is often counterposed with ‘living well’, the latter understood as maintaining, or even extending, independence, health and wellbeing, and previous activities and lifestyles.

In policy and research, there is often a focus on what people with dementia can still accomplish, on their strengths, retained abilities, and expressions of agency. For example, as I reported in my literature review, government policies envisage a key role for befriending in enabling people with dementia to remain active and to continue to participate and be visible in their local communities. This is vitally important given a widely held view of dementia as terminal loss of self. For individuals with dementia, this ‘social imaginary’, or “common understanding that makes possible common practices and a widely shared sense of legitimacy” (Taylor, 2004, p. 23), has resulted in deprivation of “choice, autonomy, self-expression and pleasure” (Gilleard & Higgs, 2010, p. 123).

The argument has been made that older people with high support needs, including individuals with dementia, are not passive recipients of care but actively engage in living their lives, and contribute to the lives of others (e.g., Bartlett & O’Connor, 2010; Blood, 2013; Bowers et al., 2011) The case studies amply support this view. Yet what they also show is ‘the other side of agency’. Grace, Jenny and Tom’s accounts of day-to-day life expressed co-existing agential and patiential experiences. These included being able to take some control within a loss of control of their health, and being simultaneously vulnerable and resourceful. As Jenny put it, “what I can’t do” was as much a part of her experience as “what I can do”. Not all of what she could not do and the limits she encountered were resolvable. From their points of view, this applied just as much to Tom and Grace. In other words, even with unlimited resources and the removal of social barriers, for those taking part in the study, impairment and other circumstances which restricted living, or made life hard to bear, could not be remedied (Crow, 1996) and were ‘suffered’ (Reader, 2007).

In drawing attention to insoluble aspects of adversity and suffering, and to the complexities of each person’s unfolding situation, I am not arguing that nothing can be done. On the contrary, I am suggesting that these different kinds of concerns call for different kinds of response which, I will argue, befrienders have the capacity to offer. Based on the case studies, I contend that, in their befriending relationships, individuals

were met as ‘agents’ and ‘patients’. I argue, too, that befrienders played a part in ‘fixing’ avoidable, socially generated, constraints in their lives, and also responded to, and remained ‘alongside’ them in their experiences of insoluble and inherent limits. In the following section on befriending, these points, among others, are illustrated and discussed in more detail.

5.5 Befriending

5.5.1 Introduction

In order to give weight to the importance placed by Tom, Grace and Jenny on other areas of their lives, earlier parts of this chapter focused on transitions, health, self and personal community, highlighting liminal experiences, unmet relational needs, and contingent and existential limitations. These were the contexts and conditions in which befriending relationships were embedded and meaningful. Each study provides an individual picture of Jenny, Tom and Grace’s particular experiences of befriending as shaped by their current circumstances, life histories and changing social networks. However, commonalities were identified. In this section, drawing on case study material, I argue that, for the people in this study, befriending offered a distinct kind of relationship, one with the capacity to go beyond, and cut across, the reach of traditional health and social care services. I discuss the ways that individuals taking part in the research perceived befriending, and what made it stand out as a service. Parts of each case study were given over to my reflections on how the research process ‘performed’ elements of befriending and making new social ties. I revisit and expand on these reflections showing how they enhanced my understanding of not only befriending but of what it might mean to come to know someone. I start with evidence that befriending took place in situations of continuing, rather than completed or completable, transitions.

5.5.2 Ongoing Transitions

In line with Grenier (2012), I have suggested that, due to their ongoing health problems

and changing social situations, Tom, Grace and Jenny lived on many levels in persistently liminal states. Rather than pass through a well-defined phase of transition following a diagnosis of dementia, often conceived as a period of ‘adjustment’, each person had experienced, and was experiencing, multiple transitions over a protracted period. Individuals faced the progression of their dementia and comorbid health conditions, and the real possibility of further change-events such as moving to alternative accommodation, and the onset of new health problems. For people with long-term conditions, the importance of continuity of emotional and psychological support has been recognised, as has the potential of third-sector services to provide “a level of person-centred, in-depth support that statutory agencies often cannot offer” (Long-Term Conditions Alliance Scotland & Scottish Government, 2011, p. 35). Jenny, Tom and Grace’s befrienders were reliable companions, alongside them and ‘on their side’ (Brownlie, 2014), through the vicissitudes of their lives. By the time I sent out a research newsletter with interim findings (Appendix F), around eighteen months after my fieldwork was completed, Grace had broken her hip and moved to a care home where her befriender continued to spend time with her; Tom had died but Stuart had been seeing him regularly until then; and Liz was still visiting Jenny at home. The befriending relationships in this study had endured in time and, in Grace’s case, across services, providing relational continuity. Weekly – sometimes more often for Jenny – visits from befrienders over a long period helped strengthen befriending relationships and reinforce each person’s memory of them. This contrasted with home care visits which were regular, if not always timely, but often brief and delivered by “that many” carers”, not the “same ones” as Tom, Jenny and Grace wanted, making getting to know them harder. Regular, face-to-face visits, of ample duration, from the same person helped Tom, Grace and Jenny to remember their befriender; to hold onto, if not memories of particular visits, then a sense of the presence of, and the qualities of, their befriender and how they spent their time together, always vulnerable as memory loss progressed, as shown in Grace’s stories.

5.5.3 Temporary ‘Exits’

Among their ‘betwixt and between’ experiences, participants described feelings of uncertainty, loneliness, ennui, homelessness, alienation, suffering, insecurity, loss, confinement and ‘dying’. These states were not necessarily experienced continually, or by everyone, but were part of the emotional texture of everyday life, sometimes overwhelmingly so. I referred earlier to Grenier’s (2012) contention that, for older people with impairment and long-term illness, the resolution of liminal periods, or ‘exits’ from transition, might be unrealisable. I suggested that each of the case studies showed ways in which ‘temporary exits’ or ‘micro-resolutions’ were possible through the actions of Jenny, Grace and Tom, themselves, or in concert with others. In their study on existential loneliness in frail older people, Sjöberg, Beck, Rasmussen and Edberg (2017) found that participants’ overall sense of ‘disconnection from life’ could be reversed, for a time, during out of the ordinary occurrences, such as visits from family members, which momentarily restored meaning and interest in life. Not dissimilarly, for Grace, Tom and Jenny, befriending enabled movements out of liminal states, if impermanently, making life more bearable, meaningful and enjoyable.

This can be better understood through an application of an existential view of wellbeing developed by Dahlberg et al. (2009). This view avoids falling into binary thinking around illness and wellness, and is attentive to both agential and patiential aspects of personhood. Dahlberg and colleagues (2009) use an existential conception of persons as always to some extent free and always to some extent constrained and vulnerable. For them, wellbeing or ‘vitality’ means an existence which “encompasses the possibilities of movement and the possibilities of peace” (p. 267). Wellbeing as ‘movement’ relates to the “sense of being able to move into possibilities of engagement that connect us with others, other spaces, other times and other moods” (p. 267). Wellbeing as ‘peace’ relates to the experience of feeling settled and ‘at home’ with the way things are or ‘welcoming’ the present moment; a ‘letting-be’ or coming to terms with ‘what has been’ and ‘what might happen’ (p. 268). ‘Peace’ and ‘movement’ are not opposites since movement can originate from peace and peace can originate from movement.

Viewing befriending from this perspective illuminates how, in this study, co-created befriending relationships, fostered wellbeing from within illness and ill-being.

In Jenny, Tom and Grace's accounts, befriending created possibilities for 'connecting with others' in various ways. First and foremost, befriending relationships, as facilitated friendships, were significant social connections in themselves, given each person's shrinking social networks and the challenges they faced in making new friends and maintaining old ones. Compared to sheltered housing residents and day centre attenders, with their befrienders, Grace, Tom and Jenny had formed deeper, mutual ties. There was a sense of belonging in, and to, a relationship, a connection which existed – even if fragily, for Grace – in their befriender's absence, for example, in Jenny's awareness that Liz "while she's in her own home she's thoughtful for me", and in Tom looking forward to Stuart coming. Through their befriending relationships, social connection also took place via 'imaginative co-presence' (see Section 2.8.5) where psychological contact with others was made by sharing photographs, reminiscing, or hearing about people in befrienders' lives. Grace also briefly connected with others when we went out together, during chance encounters with former neighbours and an ex-colleague.

With regard to 'connecting with spaces', most obviously for both Jenny and Grace, befriending offered a means to go out – both their befrienders had cars – helping to overcome movement restrictions and feelings of confinement, the result of transport and mobility issues. Going out with their befrienders expanded the 'spaces' they had access to: shops, the woods, the park, places to eat, a garden centre, community venues, the wider local area. For Tom, who did not want to go out with his befriender, and for Jenny, who had recently not felt well enough to go out with hers, as well as for Grace, 'spaces' could be re-experienced through sharing memories of journeys, travelling, holidays, outdoor life, previous homes, places of work, towns, cities, villages, and other countries.

In recalling other people and other spaces, Jenny, Tom and Grace were also 'connecting with other times'. Tom talked to Stuart about "memories" and "the good times"; Jenny

could share “lovely memories” with Liz who was “interested in them”. Grace did not mention reminiscing with Shona, although there were times when Grace and I spoke of our pasts and changes in nursing and healthcare. It is at least possible that she shared her “history” with her befriender given, as Grace told me, they had a lot in common as retired nurses. As I discussed earlier, connecting with past times, though this might give rise to dysphoric, double-edged or painful experiences, could also contribute – in the moment, at least – to feelings of self-continuity, self-esteem, social connectedness and belonging. Connecting with future time included, for Tom and Jenny, the anticipation of befriender visits, being able to look forward to seeing someone. For Grace, due to memory loss, this was problematic if visits were not entered in her diary. Tom connected with ‘other time’ within the present. In Stuart’s company, his experience of the deadening oppressiveness of time shifted to an experience of time becoming ‘quick’ in both its modern sense of fast, and its archaic sense of alive: “the time just flies”.

Another benefit of having the opportunity to share life stories with their befrienders is that Tom, Jenny and Grace could convey, and have witnessed and affirmed, meaningful parts of their past selves. Bakhtin (Morson & Emerson, 1990) argued that autobiography is closer to biography in that stories do not flow from a person’s ‘whole identity’ but are told by an imagined narrator, or ‘potential other’, who may be loving. This ‘potential other’ may remember and narrate ideal life stories which the person agrees with, and hence has a special authority. For Bakhtin, ideal biography presents the “valued other in me” (Morson & Emerson, 1990, p. 217). Alongside narratives of selves diminished by ill-health and adverse situations, Tom, Grace and Jenny’s ‘ideal’ biographical stories communicated cherished aspects of themselves, for example Grace’s commitment to her patients; Tom’s spirit of adventure; Jenny’s capacity to be a good and loyal friend.

Connecting with other times could also lead to ‘connecting with other moods’ as, too, could present time activities with befrienders. Often the presence of befrienders was linked with a lifting or easing of mood. For Jenny, Liz is “a comic”, “full of life”, “easy

to get on with”, interested in her, thoughtful, indulgent, playful: she “helps you feel good”. Just talking about Liz could make Jenny smile. In her nearness and availability – “only a phone call away” – Liz was reassuringly ‘there’ for Jenny at times when she felt especially unwell and anxious. Similarly, Cattán et al. (2009, 2011) found that a telephone befriending service made older people feel less anxious as well as less lonely. As Josselson (1992) points out, someone else just knowing about a person’s difficulties can be supportive and a relief. Like Jenny, Grace spoke of valuing being able to confide in her befriender – “without my befriender I would be lost” – as well as her enjoyment of the time they spent together, both ‘mood-altering’ through feelings of relief and pleasure. For Tom, a visit from Stuart “breaks the day up”, alleviating his boredom, and injecting vitality into the interminable sameness of his days. During research visits, I became aware of each person connecting with ‘other moods’: Tom becoming brighter, reflective and occasionally tearful while reminiscing; Grace moving from anxious checking to relaxing in, and enjoying, the present, but also becoming sad or wistful at the return of particular memories; Jenny’s pleasure in storytelling, and my ‘being there’ easing her alarm due to ‘dizziness’.

As well as playing a part in creating ‘wellbeing as movement’, befrienders also helped bring about ‘wellbeing as peace’, the feeling of being ‘at home’, even momentarily, with the way things are, have been or might become. This applied even when a person’s overall experience was feeling not ‘at home’ in body, place and time. Watching sport and talking ‘about aw different things’ with Stuart, Tom felt ‘at home’ in his flat, in himself, and in his relationship with Stuart. Although I cannot infer that Tom had similar conversations with Stuart, when, for example, Tom talked to me about his divorces, or leaving his wives and his parents ‘behind’, it sometimes seemed as if he was trying to ‘make peace’ with his past. Equally, I cannot assume that the time I spent with Grace mirrored what took place in her befriending relationship. I can say, though, that there were moments, and longer periods, of ‘peace’, while we were talking, reminiscing, or going out, when, as mentioned, Grace ‘let go’ of being caught up in checking. This may have been part of her experience of befriending given how much she described enjoying the company of her befriender. With Liz, Jenny experienced ‘peace’ – as both

the origins of, and originating from, ‘movement’ – in their ritual ‘tea and a biscuit’, at once in a ‘settled’ place from which to connect with other people, spaces, times and moods through their conversations, and, at the same time, coming to feel ‘settled’ by doing so.

Other parts of this chapter describe how people, settings and events outside befriending generated wellbeing as conceived in the existential model outlined above. But, befriending, as both a service and friendship, was able to create possibilities for wellbeing in an especially flexible way (the subject of the next section). Dahlberg et al. (2009) concede that their existential view of wellbeing could be considered idealist in that it may be realised only briefly or for limited periods. However, this fits with the idea of temporary ‘exits’ – in Tom’s words, “a break” – from liminality captured in the case studies. It also fits with the argument that, for some people with long-term health conditions, including the individuals in this study, a restorative approach, whether in terms of regaining health or lifestyles, or ‘post-liminality’, is limited. Grace, Jenny and Tom all identified barriers, restrictions, impairments and losses which impinged on the quality of their lives. Some had, or could have, solutions while others were ‘suffered’. In these circumstances, the experience of wellbeing was fleeting or fluctuated. Befriending played a part in enabling each person to overcome ‘contingent limitations’ and provided a response to ‘existential limitations’. Possibilities for ‘movement’ and ‘peace’ were generated within both kinds of limitation. In this study, each befriender engaged with their befriending partner’s strengths, capacities and freedoms – their ‘agency’ – as well as their vulnerabilities, losses, and constraints – their ‘patience’ (Dahlberg et al., 2009; Nicholson, Meyerb, Flatley, Holman, & Lowton, 2012).

I turn now to the distinctiveness and benefits of befriending as both service and friendship.

5.5.4 A Liminal Relationship

Being both friend and worker gave befrienders role flexibility, making them

well-placed to be able to ‘meet’ Jenny, Grace and Tom in the liminal spaces they occupied. One of the surprises for me in the research was that, while each person described or saw their befriender as a friend, each, implicitly or explicitly, continued to understand befriending as a service. These features held true without any sense of tension or contradiction. Conversely, Greenwood et al. (2016) found that volunteer befrienders of people with dementia could experience uncomfortable tensions between personal and professional elements of their role. And research on befriending for older people (Andrews et al., 2003; Pennington & Knight, 2008) identified a potential for conflict if expectations of friendship on the part of clients clashed with the relationship befrienders were able to offer within the boundaries of a formal service. For Jenny, Tom and Grace, however, informal and formal aspects of befriending seemed to seamlessly co-exist or be melded together. Despite – perhaps because – befriending relationships blurred the boundaries between the formal and the informal, for the individuals in this study at least, they did not seem to attract ambivalent feelings, unlike many other relationships in their personal communities.

In this study, I was interested less in placing befriending within a spectrum of relationships, and more in Tom, Jenny and Grace’s particular experiences of befriending. Even so, their accounts are in line with Befriending Networks’ (2014) definition of befriending as a person-centred service combined with elements of friendship. However, that Jenny, Tom and Grace understood befriending as a kind of service did not cast doubt on the authenticity of the relationship (Brownlie, 2014, see below), nor lessen the ways in which befrienders were experienced as actual friends. Tom and Grace saw their befrienders as ‘real’ friends: Stuart was “a friend an that”, and Grace’s befriender “was a friend more than a befriender”. I asked Jenny whether she thought of Liz as a friend – both Grace and Tom volunteered this information – and she nodded her agreement. However, I partly regretted doing so, reflecting later that just posing the question might have raised questions in her own mind about the status of their relationship. It had not seemed important to Jenny to try to categorise her relationship with Liz which, her accounts suggest, was fluidly daughter-like, friend-like, carer-like, nurse-like, neighbour-like, even hairdresser-like.

In Chapter 1, I referred to the Someone To Talk To study (eg, Brownlie, 2014) which suggested that current generations of older people might prefer to receive emotional support via relationships in which the formal and informal were blurred. The Someone To Talk To study also found that, in general, people often turned to informal social relationships for emotional support in ways which “cannot be easily replicated by professionals, or would call for relationships with professionals which are more kin-like or friend-like” (Brownlie, 2014, p. 148). In Tom, Grace and Jenny’s accounts, befrienders provided emotional support in just these kinds of ways, responding from both sides of a formal/informal divide, as friend-like and/or kin-like ‘professionals’. Brownlie (2014) found that, for some, professionals were experienced as ‘doing a job’ rather than genuinely on their side; while, for others, professionals were seen as “safe” because they were “outside the informal sphere” (p. 148). Grace and Jenny’s befrienders were not just ‘doing a job’ but individuals with whom they had formed genuine, close relationships. Yet, as well as part of, their befrienders were also, in some ways, separate from each person’s social network – ‘outside’ their families, and, for Grace and Tom, ‘outside’ sheltered housing: “without in here”, non-residents. Befrienders were trusted figures in whom Jenny and Grace could confide without the worry of gossip, judgment or being a burden. Tom could be with Stuart without the fear of premature aging, growing “old before your age”.

Although Tom did not want practical help from Stuart, all three befrienders in this study were in a position to offer practical, social and emotional support which, in practice, were inseparable, and which cut across the territories of conventional services. Liz’s assistance with Jenny’s mid-week shopping is one example. Assisting Jenny with a household task according to her wishes and way of running her household supported her identity (Christiansen, 1999), and gave her back some control over her affairs. Jenny experienced relief in obtaining needed food items; the feeling of support in Liz being there to help her; and the feeling of being comfortable with this arrangement, not “terrible” as she did in having to rely on her family. Liz was flexibly able to shop on Jenny’s behalf or accompany her to the shops as her health permitted. For Jenny, practical support was experienced as part of a trusted, mutual relationship in which she

felt cared for, cherished and understood. The task of shopping took up only part of the visit: there was still time to talk together, to “chat about what we’ve been doing”, to reminisce, and to enjoy one another’s company.

Important to Grace, Jenny and Tom was being able to engage in many kinds of talk with their befrienders: to “talk about aw different things”, to “converse on any topic”. Befriending was not a specialist conduit for ‘emotions talk’ but each person did talk about their feelings: Jenny and Grace confided; Tom talked about good and bad times. But, other kinds of talk – sharing everyday experiences, nostalgic storytelling, reminiscing, “whit ye gettin up to”, exchanging “the same ideas”, interests, and opinions – also carried, expressed and altered feelings, creating possibilities for wellbeing (Dahlberg et al., 2009). This diversity of talk could include, but was not limited to, worries and problems, unlike problem-focused conversations with professionals (Andrews et al., 2003; Cattan et al., 2009, 2011), and was a feature of befriending that made it friend-like (Allan, 1989; Spencer & Pahl, 2006). And, as described above, ‘emotional support’ was not restricted to talking about emotions, or even talk at all (Brownlie, 2014), but could be a consequence of practical assistance, and included the actual or imaginary presence or ‘thereness’ of befrienders.

Returning to Phinney’s (2011) work on retained and shifting narratives in dementia, discussed previously (Section 5.2.2), Jenny, Grace and Tom’s befrienders met them in a space where they could be “both who they are, and who they are becoming” (p. 267). More than ‘maintaining’ identity, befrienders connected with the people Grace, Tom and Jenny felt they had been, still were, were becoming, and might become. They continued to visit as each person’s health, capacities and situations changed, providing opportunities in which this could be acknowledged, and adapting how they engaged with individuals, as well as supporting their identities in various ways. There was a hidden flexibility in Tom’s befriending service in that Tom could decide what he wanted from his relationship with Stuart – for Stuart to “come up” to see him in his flat – rather than having to meet goals or change his behaviour in some way: to “cut doon yer drinkin” or “go oot”. Because befriending is primarily a relationship – its

task *is* the relationship – Tom was eligible for, and did not forfeit, his befriending service whether or not he became sober or more active, motivated or ‘visible’ in his community. Stuart’s relationship with Tom was unconditional, based on the person he was, not on what he did or might do (Josselson, 1992).

Multiple impairments, aging, and social network change exposed Grace, Jenny and Tom to contingent limitations, avoidable disability, including ‘psycho-emotional harms’ (Thomas, 1999), created by social barriers both external and internal. By providing access to transport, personal assistance, and, most of all, companionship, befriending played a part in helping each person overcome obstacles to ordinary pleasures, activities and meaningful relationships. Befrienders also helped counteract psychological and emotional harms, the result of ageism, poor treatment, objectification, and the devaluing of people with dementia and other impairments. These harms were manifest in Tom, Jenny and Grace’s accounts. For example, placed in age- and client-segregated housing, Tom felt he was aging before his time, and, removed from society, atrophying. Memory loss made Grace feel incompetent, likely to be unfavourably judged, and an added responsibility for her daughter. Jenny perceived herself as a burden on her already strained children, and felt she was not always taken seriously by professionals. And, for all of them, their dependence on formal care, and their powerlessness to influence who provided it, and how, left them vulnerable to poor treatment. By contrast, in their befriending relationships, each person felt liked, respected, appreciated, or even cherished; and each was recognised as a unique individual and a reciprocating befriending partner. In these relationships, while some of their problems could be addressed, they, themselves, were not a problem or burden.

Befriending relationships were experienced as mutual, and perceived as mutually enjoyable. In Bakhtin’s (Morson & Emerson, 1990) terms, they were ‘same plane’ ties in which both they and their befriender became known to each other, and part of each other’s lives: “I knew her and she knew me”. Stuart ‘sat down’ with Tom: they were literally – spatially – on the ‘same plane’. There was a strong sense of individual relationships as always unfolding, of mutual discovery. Jenny and Liz caught up with

one another each week. Tom and Stuart talked together about “whit ye getting up tae”. In addition, as shown in the examples provided earlier, by creating potential for ‘movement’ and ‘peace’ from *within* existential limitations, befrienders also responded to what could not be changed: impairment effects, irreversible losses, life’s limits. Hence, befriending was able to embrace agential *and* potential aspects of personhood: (in)dependence, (in)capacity, (in)efficacy, (un)freedom. Tom, Grace and Jenny valued being able to count on their befrienders for companionship and activity – and, for Grace and Jenny, practical help – but they were not passive in their befriending – or any other – relationships. Each of them was discerning in their choice of company, experienced at forming friendships, and wanted to, and did, contribute to relationships: befrienders did not simply rescue them.

Further insights into the formal/informal nature of befriending, and the process of getting to know someone, were generated reflexively as my relationships with participants developed over time. I will say more about this next.

5.6 Reflexivity: Insights

5.6.1 Brief Encounters

Throughout the case studies and this chapter, I have critically reflected on the ways in which my research relationships with Tom, Jenny and Grace enacted elements of befriending and getting to know another person, enriching my understanding of both. Just as, in this study, befriending fluidly and flexibly moved between being a service and being a friendship – not exactly either and yet both – so, too, in our research relationships the formal and the informal blurred and shifted. I was struck by how Tom, Jenny and Grace each described my visits as like their befriender’s visits, directly, or using similar language: “breaks up the day”, “it’s like having Liz here”, “someone to talk to”, “it’s nice having you coming”. Equally, in their company, I felt welcomed, trusted, entertained, and a focus of genuine interest. Though my day-to-day solitariness was bound up with doctoral studies, and easily rectified, nonetheless, it felt

good to be with people. Being there with each person weekly over a five-week period (there was a two week gap before my final meeting with Tom), paralleling weekly befriending visits, amounted to more than consecutive data generation visits. In effect, regular contact with individuals across that span of time – being there, being together – constituted brief relationships with introductions, endings, processes of coming to know each other, the amassing of a short, shared history, and the intertwining of lives. In this section, I bring together earlier and further reflections on my experience of getting to know Tom, Grace and Jenny, and on the endings of our research relationships.

5.6.2 Knowing Me Knowing You

Goffman (1959) describes how our initial impressions of someone unknown to us may be shaped by their appearance and behaviour, by our “previous experience with individuals roughly similar” and possibly by “untested stereotypes” (p. 13). Included in the case studies are my thoughts on how getting to know Jenny, Grace and Tom involved continual revisions of a fantasy or imaginary person. Brownlie (2014) points out that both researchers and participants imagine each other and what their lives are like. In my case, I noticed that such imaginings were often subliminal, coming into conscious awareness only when disaffirmed, for instance, as mentioned, in my surprise that Tom liked dancing. Greenwood et al. (2016) found that many volunteers acknowledged that befriending had challenged their preconceptions about people with dementia. Having worked in the field of dementia care for almost twenty years, I believed that I had long ago rejected stereotypes of people with dementia. Yet, during research conversations, I came to recognise that I held expectations and assumptions, if not stereotypical ideas, if not so much about ‘dementia’, then about the lives and identities of those who took part. Through an ongoing process of coming to know Grace, Jenny and Tom, these ideas and assumptions were continuously tested and revised, constantly revealing each person as particular, exceptional, non-categorical, and reshaping my sense of both them and myself. Writing on the need to breakdown the sharp divisions between disabled and non-disabled people, Shakespeare (2000) argues that a “realistic aim would involve diverse individuals working together to

continually renegotiate their otherness in a condition of reciprocity” (p. 82). This idea of an ongoing renegotiation of otherness within a reciprocal relationship captures well my experience of encountering and getting to know Jenny, Grace and Tom. In the case studies, there are numerous examples of how, in our relationships, I and those taking part were changing in the moment, and over time, ourselves, and in relation to each other. As Josselson (1992) describes, “whatever happens between us will create some emotional response in me [...] a change in my image of you and my image of myself” (p. 19). Or, following Bakhtin, Frank (2004), explains that:

Since people exist on the boundary with others, who-am-I is always changing in response to who-are-you; our identities can never be stable. Identification with anyone means, paradoxically, recognizing that they are perpetually not identical to what I believed them to be. (pp. 99-100)

My experience of being in each research relationship resonated with the experiences of volunteer befrienders of people with mental health problems (Mitchell & Pistrang, 2011) and people with dementia (Greenwood et al., 2016). For them, befriending not only challenged their assumptions about the individuals they formed relationships with, but was also a source of learning about their own lives and circumstances, and, for Greenwood’s volunteers, “profound reflection on love, life” (p. 15) and “what it means to be human and alive” (p. 10). But, like these volunteers, I also, at times, experienced tensions and discomfort in the dual ‘professional’ and ‘friend-like’ aspects of my research role.

5.6.3 The Sense of an Ending

Ethical consideration was given to the possible adverse effects on those taking part of having, and then losing, social contact through the research process, and to ways to mitigate this. However, I did not foresee the impact of the endings of research relationships on me: my sadness on leaving each person at the end of the final visit, and on realising, then, that I was, despite everything that had transpired between us, only a researcher. I hoped I would be able to see Tom, Jenny and Grace again, as we

had arranged, to share my research findings with them, aware, though, that changes in their health or situation might make this inappropriate or impossible. As it turned out, problems with my own health delayed the preparation of a research findings newsletter (Appendix F) by several months, adding another example to the ways in which, in this study, illness hindered relationships. Tom died just days before the newsletter was completed, and, by then, Grace and Jenny's gatekeepers indicated, directly or by default, that return visits would not be appropriate, or possible, due to health (Grace) or unspecified reasons (Jenny). I fully respected these decisions but nevertheless felt sad again, almost as if I had been prevented from seeing people I was close to.

Tom's death was half-anticipated, half-shocking. I felt slightly wrong-footed by my reactions to it, as if responding to the death of someone much closer, on the one hand, and, on the other, continuing to work as if his death was more remote from my life: a feeling of loss both intense and transient. In one way, this seemed emotionally congruent with my experience of research work, in this study, as involving a mix of the informal and the formal, and of conducting myself in friend-like and professional-like ways. In another way, my sense of loss was tempered by not having known Tom for long, but surprising for this very reason. I saw that time spent with Tom, Grace and Jenny's words and stories, in recordings and transcripts – far longer than the period we were actually in contact – extended my relationships with them. Now, I think that my somewhat unexpected reaction to Tom's death, and my feeling that I was 'more than' a researcher, in certain respects, reflects the distinctiveness of the befriending role and befriending relationships, described as both like and unlike other social ties, 'comparable but indescribable' (Greenwood et al., 2016). My 'formal' research activity became inseparable from 'informal' affective connections with people who were also participants.

The process worked both ways. Frank (2010) refers to a story by Portelli (p. 103), an oral historian, in which a 'source', a labour organiser, asks him for help with his daughter's schooling. Portelli comes to see this request, not as a breach of their agreed research relationship, but as a moment in which both he and his source

truly recognised each other as people whose lives extend beyond the research and their respective work. Each has needs and can call on the other for assistance. (p. 103)

Jenny, Tom and Grace all saw me – as I saw them – not just as a professional, or study participant, but as a person with a life ‘beyond the research’. They took part in the study, contributing their stories to advance knowledge on befriending; and they also asked me about my life, and, sometimes, for help. I hung out washing for Jenny, and helped Grace put her support stockings on. Equally, Grace invited me to call in if I was in the area; and Jenny offered to put me up for the night if ever I was in the area and could not get home.

Following Bakhtin, Frank (2005) describes how one story “calls forth” another, both for the storyteller and the recipient of the story (p. 967). The stories Grace, Tom and Jenny shared in our conversations ‘called forth’ stories and memories in me, some of which I, in turn, shared with them. Many were unspoken, though, but through them, as the case studies attest, I found myself re-experiencing and reviewing my past, connecting with, and coming to see that past, and the people who were part of it, in a changed light. In this way, at least as I saw it, though our encounters were brief, our stories – our lives – became intertwined; each person’s life, or a small fragment of it, became part of my own, changing it, and at times connecting deeply with it.

We touched each other, literally. At the end of all but introductory and first visits, Jenny and Grace moved to embraced me, and I reciprocated, in a mutual physical expression of affection and human connection. Tom and I, though we usually sat together on his sofa, physically touched each other only once, although after a visit when he had seemed particularly low and exhausted, I imagined cupping his cheek in my hand, a soothing gesture, my hand being cool and his cheek hot. The urge to physically connect, to close the space between us, came from me. The last time I saw him, I proffered my hand, which he took, and we shook hands to say goodbye.

* * *

5.7 Summary

For those taking part in the project, befriending was a liminal relationship, straddling or blurring the boundary between formal and informal support. It was this characteristic that gave befriending its flexibility, its capacity to continue to ‘meet’ individuals as their health, their identities and self-experience, and their personal communities continuously changed. Befrienders engaged with each person as they ‘acted’ and ‘suffered’. The application of an existential model of wellbeing showed how befrienders were able to respond to ‘contingent’ and ‘existential’ limits in individual lives, and to foster feelings of wellbeing within a continuing experience of ill-being. Friend-like, mutual and reciprocal aspects of befriending were, from the points of view of those taking part, very important. However, while befrienders were experienced as ‘friends’, each person was aware of the facilitated nature of befriending, of befriending as a service. They derived benefit from both, seemingly unproblematically. My reflections on the ways each research relationship enacted aspects of befriending support an understanding of befriending as a distinctive, mutually affecting relationship.

5.8 Conclusions and Key Findings

In this study, I aimed to explore and learn more about the experiences and meanings of befriending from the perspective of people living with dementia. I was interested in individual befriending relationships and the contexts in which they took place. Over five visits, in our largely unstructured conversations, Grace, Tom and Jenny spoke extensively about themselves and their lives. Each of them made sense of their experiences of befriending, and what befriending meant to them, with reference to their changing circumstances, their biographies, and their other relationships. The disruption of illness, including non-dementia health conditions, was one of many turning points and events within recent years and earlier in their lives

The risk of looking in-depth at multiple contexts of befriending – health, self, personal community – was that, since each is a substantial topic in its own right, without a concept,

framework and/or storyline to contain them and hold them together, my thesis would lose coherence or fall apart. One such conceptual thread, emerging from data analysis, was the idea of ‘transition’, more particularly, ‘in-between’ experiences. Individuals taking part in the study talked about various aspects of their lives as being in persistently liminal states. As they described it, these were the conditions – personal and situational – in which their befriending relationships occurred. In this chapter, I paid attention to individuals’ subjective experiences of liminality; and to the ways that – through the eyes of Jenny, Tom and Grace – their befrienders responded to these experiences, and the ways that each person wanted them to respond. A ‘containing’ framework was that of ‘personal community’. All three individuals told me a lot about their past and present relationships, and I was able to map their personal communities, and get a sense of the qualities and dynamics of the relationships within them. Befriending was seen as one of a number of social ties, both ‘on the ground’ and ‘in the mind’. This shed light on what made befrienders distinct among other people in participants’ lives; and on unmet relational needs and desires which befriending relationships, in significant part, satisfied. Lastly, a storyline capable of holding and integrating the material was my self-reflexive story of the research process. My critical reflections on taking part in each unfolding research relationship added an extra dimension of insight, presenting these relationships as ‘performances’ of informal and formal elements of befriending: its liminal character. I highlighted the intricacies and mutual processes of getting to know someone: what this might mean to each party; and what might make doing so delicate, difficult or risky, but worthwhile. And I foregrounded the reciprocal nature of the research relationships, capturing different ways we each contributed to, and received something from, our encounters. For me, part of this experience was my appreciation of how individual stories connected with, and became a meaningful part of, my own. My self-reflexive work had significance beyond being an account of a one-off, idiosyncratic personal experience in that it added to understanding of the ‘befriender’ side of befriending, resonating with previous work in this field.

While the research touched on many areas of academic interest, ultimately, this was a study on befriending, in the community, for people living alone with dementia, from

their perspectives. Jenny, Grace and Tom all experienced (or remembered experiencing) their befriending relationships as rewarding and meaningful, and as having made an appreciable difference to their lives. Based on the case studies, three key messages emerged.

1) Befriending was a liminal relationship.

Befriending was a relationship in which a formal/informal divide was blurred or straddled. Befriending was understood as friend-like and at the same time recognised as a kind of service. Befriending relationships were experienced as genuine, close, and life-enhancing – actually as friendships; *and* they were viewed as an organised resource. Informal and formal aspects of the relationship did not appear to be in tension. In fact, the combination of friendship with person-centred support was seen as especially advantageous: various forms of support were provided, and could be requested, within a mutual, more egalitarian – yet confidential – companionship. It was the liminal nature of befriending that gave it its flexibility and versatility.

2) Befriending satisfied unmet needs and wishes for certain kinds of relationship.

Befriending fulfilled a wish for closer, mutual, reciprocal relationships which individuals felt they lacked. Mapping personal communities and changes within them, and exploring the qualities of each person's social ties, and the ways these ties were actually experienced, exposed relational gaps, and the extent of loneliness. Participants wished to make new relationships, but opportunities to get to know other people, as well as be known by them, were limited. Outside contact with family members and health, housing and social care workers, occasions for meeting people were mainly, or entirely, confined to age- and client-segregated spaces, which, though enjoyable to some extent, did not lead to the kinds of closer, compatible, confiding relationships that

individuals missed, and may have made it more difficult. Befriending, as a facilitated, ‘matched’ relationship, was able to provide – to be – this kind of social tie. The mutual process of getting to know someone within a befriending relationship, over time, created opportunities for sharing life experiences, interests and activities, which enhanced feelings of self-worth, and enriched everyday life, even if only in the moment. To different degrees, memory loss affected what each person could remember about their befriender’s visits but everyone knew what being in a befriending relationship was like and what was valuable about it.

3) Befriending was a human response to contingent and existential limitations.

Befrienders engaged with individuals in their ‘between’ states of being neither one thing nor another or simultaneously both: well and ill; capable and incapable; who they were and who they were becoming. Befriending was thus a non-binary approach to human encounter, capable of connecting with individuals in both their agency and their patiency. This made it especially suited to responding to both socially imposed and unavoidable constraints in a person’s life, and generating ‘movement’ within both. In befriending relationships, wellbeing – from within ill-being – could result from the removal of social and material barriers, and from human connection that enabled different ways of experiencing self and lifeworld.

In my final chapter, I indicate what these messages, and the study as a whole, contribute to the wider literature, and their implications for policy and practice.

Chapter 6: Conclusion

Conclusion

6.0 Introduction

Taking a holistic case study approach, this project explored the meanings and experiences of befriending relationships from the perspectives of three people living alone with dementia in the contexts of their everyday lives, wider social networks and life histories. Drawing on a combination of methodologies, rich and wide-ranging data were generated, allowing me to embed the meanings of befriending in each person's changing circumstances, focusing on their health, their identities and self-experience, and their personal communities. Reflexive accounts of 'being there' and unfolding research relationships were also sources of knowledge on aspects of befriending and on the mutual process of getting to know someone. Research findings were presented as three in-depth, evocative case studies which prioritised the words and stories of participants.

In my interpretive work, together with Bakhtinian theory, I used the concepts of liminality, personal community, and patiency to attend to different facets of an individual's experiences, relationships and situation; and hence to develop an understanding of the lifeworlds in which befriending took place. I applied an existential quality of life framework to show how befriending had an impact on wellbeing from within ill-being. Three key messages were identified. First, befriending blurred the boundary between person-centred service and friendship which participants both recognised and valued: their needs came first in a relationship that was *for them* but also experienced as mutual and two-way. Second, befriending facilitated the kind of closer, reciprocal relationship which all three participants identified as missing from their lives. Third, befrienders connected with individuals who were living in persistently liminal states: experiencing wellness *and* illness, coping *and* struggling, a continuing *and* a changing sense of self. Befriending responded to participants in their capacities and incapacities, and to surmountable and inherent constraints in their lives.

In this concluding chapter, I identify the contribution my project makes to other literature. I highlight the methodological strengths of the study in the context of dementia research. I discuss the implications of the study as well as its limitations. I suggest areas for future research, and I finish with some closing remarks.

6.1 Contribution to Literature

My research contributes to the literature on befriending for people with dementia and to the literature on living alone with dementia. There was overlap between these areas in the study.

6.1.1 Literature on Befriending for People with Dementia

Research literature on the experience of befriending for people with dementia, living in their own homes, from their perspectives, is currently, to the best of my knowledge, non-existent, so, in this respect, my study is a first. It is also, to date, the only research on befriending and dementia which focuses exclusively on the views and experiences of people living with dementia (though my own experiences as a researcher-participant were also a significant part of the study). Evaluations of pilot projects and research studies on befriending for individuals with dementia in different settings – care homes, hospitals and walking in the city – all include, and to a large extent, if not wholly, rely on the observations, opinions and experiences of other parties: befrienders, professionals, family members and researchers. This may be, at least partly, because participants in these studies and projects had more advanced dementia. In my own research, individuals were able to recall and talk about their befriending relationships, and I have been able to quote them extensively. Unlike other befriending studies, my work provides considerable contextual detail enabling the experiences and meanings of befriending, for individual participants, to be understood in a wider matrix of biography, personal community, everyday life, impairment and disability, and experiences of change.

In keeping with definitions of befriending as a person-centred service combined with

elements of friendships, in my study, based on participant perspectives, befriending was a liminal relationship, straddling or blurring an informal/formal divide. All participants understood befriending as facilitated companionship, a (confidential) service focused on their wishes and preferences, and a relationship experienced as an authentic friendship. Each person described benefiting from both formal and informal aspects and did not refer to any tension or friction arising from this dual character. Again, in line with research on older people's befriending and voluntary sector reports, my work affirmed the importance for participants of compatibility, reciprocity, reliability and mutuality in their befriending relationships. In particular, participants valued the opportunity to get to know their befrienders – as well as be known – on the same social level, something each person was finding difficult to do with many of the people they came into contact with.

Some studies (e.g., Preston & Burch, 2018; Hill, 2016) found that individuals with dementia benefited from befriending even when they could not recall or recognise their befriender. In my study, a notable finding was that befriending relationships had a positive presence in participants' lives despite their memory loss which, to some extent, limited their ability to remember specific visits, including, for two people, very recent visits, and, for one, even whether she still had a befriender. In the context of long-term befriending relationships, befrienders, in the study, continued to be 'there' for individuals in different ways. Two participants trusted that their befriender would visit, and looked forward to these occasions. For the other participant, in the absence of written reminders, while she found it hard to remember her current befriender, she was fully aware of the *role* of befriender, and the benefits of befriending. All three individuals had a strong sense of what their befriender – or a past befriender – was like, and the positive relational environment of their visits.

Josselson (1992) points out that relationships “always occur in existing systems” (p. 27) and that studying “individual relationships abstracted from their larger relational contexts [...] gives us very narrow information” (p. 27). Using a personal community framework allowed me to look at befriending as one of many relationships in each

person's social network, showing the distinctive place it had, and also revealing the qualities and impacts of other relationships, and the ways individuals negotiated them. This study also contributes to an understanding of befriending in relation to co-existing measures to increase social contact and reduce loneliness. 6 (2004) advocates that the effects of such interventions should be considered as a whole rather than singly. All participants took part in other 'solidarity shaping' interventions: day centres, and communal activities and organised social events in sheltered housing. Befriending was the only one-to-one, as opposed to group, service, and the only service not by design – though possibly by choice – based on age. Neither was it based on shared 'client' characteristics. Participants' views on group services and activities were mixed. Each person identified benefits and positive experiences. One person, in particular, enjoyed attending a day centre and going along to social events in sheltered housing. However, for two participants, the rewards of day centre attendance were limited due to difficulties with getting to know people, or finding the experience repetitive or sometimes infantilising, and other 'old' attenders to lack vitality. In comparison, befriending offered something different: the chance to get to know someone – someone compatible – and to build a closer, lasting, mutual relationship; and, for two participants, assistance to go out.

Greenwood et al. (2016) found that volunteer befrienders of people with dementia were conscious of the combination of formal and informal elements in their role, which could feel uncomfortable, but also were part of providing a person-centred service. However, how people with dementia experienced, or whether they even recognised, the formal and the informal in their befriending relationships was unknown. In my study, all three participants were aware that their befrienders were a kind of service as well as a kind of friend. For participants, this meld of features was beneficial and what made befriending distinct in their personal communities. Individuals appreciated having a friend-like relationship which was mutually enjoyable and, at the same time, put their needs and wishes first.

The particular impact of the endings of befriending relationships for people with

dementia, given memory loss, has not been explored. In my research, for one participant, the ending of a long-term befriending relationship and the introduction of a new befriender was a source of confusion, uncertainty and continuing feelings of loss. As befriender visits were not marked in her diary, she was unsure whether this was because her (previous) befriender had left the service or whether her (current) befriender had stopped coming. This suggests that, for people with dementia, memory loss needs to be taken into account in the management of relationship endings (and, if relevant, the introduction of a new befriender).

My research indicates that the meaning of befriending for individuals with dementia to some extent coincides with the policy interest in befriending as a means to reduce loneliness and to enable individuals to become more active and visible in their communities. However, the policy emphasis on the instrumental value of befriending as a type of ‘low level’, preventive health care was not identified by participants as a major benefit – indeed, each had progressive health conditions and described worsening ill-health. Befriending was meaningful not only in helping each person overcome barriers to accomplishing everyday activities, pursuing particular interests and taking part in community life. Importantly, befriending held meaning for participants as a response to the existential ‘other side’ of an active, healthy, independent life: loss, insecurity, loneliness, constraint, alienation, suffering, meaninglessness and ‘dying’. Befrienders remained ‘alongside’ participants, and could be confided in. In situations of insoluble and inherent limitation, befrienders kept turning up, kept being there, kept listening, kept talking, kept sharing.

Finally, what was also different about my research was the level of reflexivity used to explore formal and informal aspects of befriending enacted in the research relationships; and the pleasures, intricacies and mutual process of getting to know someone. My reflections on the impact of research relationships on me echoed research by Greenwood et al. (2016) who found that volunteer befrienders of people with dementia experienced their befriending relationships as fluidly informal and formal; and both “deeply meaningful and emotionally powerful” (p. 16), and, at times,

uncomfortably unequal – an inequality that was at least partly bound up with feelings of ‘professional’ responsibility and a commitment to person-centred support.

6.1.2 Literature on People Living Alone with Dementia

An unintended feature of the study was that all participants lived on their own, and, as a result, the case studies add to a small but growing body of qualitative research on living alone with dementia. As with current literature in this field, in my research, there was marked variability in individuals’ social and living situations, feelings of loneliness, and experiences of organised social groups and activities. In my study, too, participants faced a number of barriers to taking part in community life and to forming rewarding relationships. The main contribution that my work makes to the ‘living alone’ literature is that it provides a more comprehensive picture of the particular personal community in which each participant lived alone. Even in a sample of just three people with dementia, social networks and relational experiences were diverse and complex.

It was not my intention to systematically map individual social networks. Although I indicated in my participant information leaflet that relationships other than befriending might be something we could speak about, no one was expected to. Participants, often voluntarily, talked a lot about their formal and informal relationships with various people. Existing studies on living alone with dementia do provide information on participants’ social networks, identifying supportive and rewarding ties and contacts and others which were less so. However, they often focus on particular types of relationship, with little – or no – attention paid to others. Because I was able to form a detailed impression of the qualities of individuals’ ‘on the ground’ and ‘in the mind’ relationships, it was possible to chart the changing composition, dynamics and underlying basis of individual personal communities; and to identify relational gaps: what current social ties and encounters did and did not offer participants, and the kinds of relationship they missed.

The use of a ‘personal community’ lens also shifted attention from categories of relationship to the qualities and experiences of actual relationships: for example, one participant had a close relationship with her home help. A significant finding was that loneliness could arise even in apparently well-populated personal communities. In part, as other ‘living alone’ studies suggest, this was a result of a lack of closer, mutual, compatible relationships, and an increase in social contacts – formal and informal – that were unrewarding or unwelcome. However, even when the make-up of personal communities included some or several ‘quality’ relationships, such as good relationships with family members or care workers, participants still experienced loneliness. Whereas other studies focus on the presence *or* absence of people in the lives of those living alone with dementia, my work looked at the ways in which others were both present *and* absent, there *and* not there, close *and* distant. I was also able to explore the interstices of participants’ social networks – what it was like when nobody was there – and the different and fluctuating degrees to which each person felt a sense of background support and connection, or had the feeling that they were alone, lonely, or having to manage on their own.

My study moved away from the tendency in ‘living alone’ research to see relationships as either supportive or unsupportive, and to focus on the support provided to people with dementia by others. In my research, individuals experienced ambivalence in their relationships, meaning that, for example, social ties might be perceived as helpful *and* unhelpful, welcome *and* unwelcome. Also, participants referred to the ways that they supported or sympathised with or contributed to the lives of others. As well as support, each person wished for mutual relationships in which they were not – or not only – the focus of care. The study showed that individuals were highly discriminating in their relationships, and resisted objectification in their social ties and encounters with other people. Participants actively engaged in and negotiated their relationships, if not in person, then in their minds (in memories and through addressivity) or in language (through dialogicality). This applied even, or especially, in situations of loss of control and influence. However, the ‘patiential’ side of this dynamic was also manifest: disempowerment, contention, and the objectifying gaze of others, however

much resisted, were also ‘suffered’. Other ‘living alone’ studies describe the benefits of the ‘social world of memory’ or ‘imaginative co-presence’ whereby the presence of others could be brought to mind in ways which were consoling or lessened loneliness. This was richly evident in my work, but what emerged, too, were mixed or negative experiences of ‘communities of the mind’. Individuals consciously or involuntarily recalled, and replayed, memories of people and social scenarios which were double-edged, for instance, positive feelings of connection and affection could be accompanied by sadness and yearning, or were also a source of dysphoria, guilt or distress.

6.2 Methodological Features

In Chapter 3, I suggested that the combination of methodologies I used in my study – narrative, longitudinal, ethnographic and reflexive – were an especially fruitful way of ‘getting inside’ phenomena of interest. Chapter 3 provides a full explanation of my evolving research strategy which I will not repeat here. Drawing on this range of methodological resources enabled me to generate complex, detailed, multifaceted case studies in which befriending was shown as embedded, and meaningful, in multiple contexts of each participant’s life. Unknown elements at the start of the research – the number of participants; the number and frequency of visits; the presence, or not, of a supportive person during meetings; the fieldwork location; the kinds of research relationships that would develop – meant that an emergent, rather than a predetermined, research design was as necessary as it was advantageous.

As indicated, flexibility and willingness to ‘follow’ participants with dementia is argued to maximise the inclusion of people with dementia in research (Nygård, 2006); and giving people with dementia the scope to talk round research topics in an open-ended way can enable individuals to highlight experiences and issues of salience to them (Surr, 2006). In these respects, researchers are in a similar position to those who provide ‘help’. From a disability studies perspective, Shakespeare (2000) writes that in ‘helping’, people “need a lot of confidence in order not to take control. It takes strength

of character to relax and let go, distinguishing between things getting out of hand and things getting out of your hand” (p. 80). As an experienced dementia care worker, I felt comfortable ‘letting go’ but, as someone new to doing research, especially to begin with, I worried about ‘things getting out of hand’ or, at least, crossing a boundary and becoming, possibly inappropriate, non-research activity. I reflect on the ethical edge of providing support and supporting an individual with dementia to take part in research in Chapter 3. However, I came to see that what transpired in our research relationships were enactments of aspects of befriending relationships – in effect, participants ‘showing me’ what they did with their befrienders – and, as such, a source of learning. I was influenced by Brownlie’s (2014) concept of ‘being there’, in terms of generating both ethnographic and reflexive data on what it was like to ‘be there’ with, and for, each participant, and to ‘be there’ in a developing research relationship.

Lastly, my study is an addition to dementia research using a voice-centred relational method of data analysis (others are referenced in Chapter 3). The voice-centred method made me slow down, and allowed me to ‘hold’ and really pay attention to the various ‘voices’ of each participant. By integrating self-reflexivity, it also promoted a high level of critical reflection on my experience of evolving research relationships, adding another layer of understanding to befriending in the context of the project.

6.3 Implications

With the caveat that my findings were based on a small number of cases, I now point to the study’s implications. It is clear from the research, firstly, that the one-size-fits-all provision of age- and client-based day centres, and group events and communal activities in sheltered housing, had limitations in terms of relationship building; and, secondly, that no one ‘solidarity shaping’ intervention met all relational needs and wishes. There is thus a need to counteract the tendency of service providers to assume, rather than ask, what older people with dementia want (Weicht, 2013). The research suggests that, ideally, individuals with dementia who wish to make new relationships, experience rewarding human contact, pursue ordinary pleasures,

and/or maintain or extend their interests should be able choose from and access a range of services and social spaces. These could include but also offer something other than age-specific or client-specific (or segregated) relational environments, such as befriending and intergenerational projects.

For participants in the study, befrienders had, or could have, a positive presence both during face-to-face visits and in their minds when they were not actually together. However, psychological presence, and being able to look forward to seeing befrienders, was affected by memory loss, and diminished when there were no reminders of past and forthcoming visits or a change of befriender. This could cause confusion, uncertainty, sadness and worry. The research points to the usefulness of finding tailored means to reinforce the psychological presence of befrienders. This would involve discovering the most helpful and acceptable ways of reminding individuals about their befriending relationship and arranging befriending visits and activities. Examples from the case studies include calendar and diary entries and reminders from care workers, and, as when arranging my visits, confirmatory telephone calls. The use of photographs as *aides memoire* might also be considered. However, as stated, measures to enhance the ‘thereness’ of befrienders would have to be devised according to individual preferences, and possibly adapted over time. There were some indications in the research that long-term befriending for people with dementia, as well as deepening relationships, might help individuals to ‘hold onto’ their befrienders, mentally and emotionally, as their memory loss progressed, but more research is required in this area.

Another implication of the study for practitioners is the value of a holistic understanding of the experiential qualities of the gamut of formal and informal relationships in the lives of individuals with dementia. This would involve a more focused awareness that each person will have a range of relational needs and wishes, some of which may be being met though existing social networks, and some of which – not least mutual, reciprocal relationships – may not. This applies in situations of obvious social isolation, but it also applies when individuals appear to be well-connected and well-supported, bearing in mind that memory loss and other health conditions will have an impact on

social connection in both scenarios. The study's findings that other people, including close relatives and friends, may be present *and* absent, there *and* not there, close *and* distant, welcome *and* unwelcome, supportive *and* unsupportive, invites practitioners to seek a more nuanced appreciation of the social situation of a person with dementia when thinking about their relationships and need for human contact.

Finally, for policy-makers and investors in befriending, evidence from the case studies supports the need to move towards, conceptually and in practice, non-binary approaches to supporting people living alone with dementia, and often other health problems, which – socially, practically and emotionally – can embrace their capacities *and* incapacities, and existential aspects of their experience. In my study, befriending was one such approach, creating *time* for relationships, and as much about being there as about overcoming socially imposed barriers: both helped to meet human needs for connection, belonging, identity, security, and meaning in life. Current instrumental understandings of the befriending role, as a so-called 'low level' intervention, include crisis prevention, improved health outcomes, recovery, reduced dependency (and, as a result, cost savings), which may lack relevance for older people living alone with dementia and other long-term health conditions. This study, however, suggests that there would be value in explicitly re-envisaging the purpose of befriending in this context as a response to both contingent and existential limitations without emphasising one above the other (Dahlberg et al., 2009). This would include the need to accept, against the grain of cost-utility thinking, that individuals in conditions of increasing constraint, though they welcome and benefit from befriending, may in the overall context of their lives feel better off and worse off at the same time (Molzahn et al., 2008). This may be a reason for continuing befriending rather than evidence of its inefficacy.

6.4 Limitations

The project had a number of limitations. By chance, individuals recruited to the study were, or had been, in befriending relationships lasting between two and four years (one person had been seeing her current befriender for one year). Post-study, all

relationships continued. Evidence from some befriending organisations suggests that, while long-term befriending does occur, this might not be the norm. People with dementia who had been, or had the experience of being, in short-term befriending relationships did not take part in the research. Again, not by design, all participants lived alone. While reducing loneliness is a common objective of many befriending organisations, some services for people with dementia offer befriending to anyone with dementia, including those who live with someone, sometimes with the additional aim of providing a break for informal caregivers. The experiences of people with dementia who did not live alone were not represented in the study. It is possible that, because participants were recruited through volunteer coordinators, especially successful befriending partnerships were selected. One volunteer coordinator felt that, ‘for balance’, it was important to include someone who had had problems with their befriending relationship but was unable to recruit a person with that experience. That the study, intentionally, focused on a small number of participants, greatly limited the composition of recruits in terms of socioeconomic status, ethnicity (including people who did not speak English), sexual orientation, younger onset dementia, and gender reassignment (see Section 6.6). The research criteria excluded people with dementia with more advanced dementia who did not have capacity to take part, although studies involving such participants do exist in the literature on befriending for people with dementia in non-community settings, and in the literature on living alone with dementia (see Chapter 2). Data generated in research conversations were co-constructed, were what emerged as salient at that time, in that place, and in a specific relationship, and were, therefore, inevitably partial and unfinalised.

6.5 The ‘Limitations’ of Case Studies: a Defence

Numerous arguments and counter-arguments have been made about what are seen as the particular limitations of qualitative case study research, some of which, in relation to my own study, I discuss here. Because case study research focuses on one, or a few, cases, the findings it generates are deemed not to be generalisable. While it is true that my case study findings, like much qualitative research, cannot be generalised to a

wider population, they can be added to the existing cache, or portfolio, of case studies on befriending in general, and for people with dementia in particular. As Flyvbjerg (2006) puts it, they can “enter the collective processes of knowledge” (p. 10) in this field. A different argument is that case studies are ‘generalised’ tacitly in the minds of readers (Stake 1978/2000) who integrate new case material into their existing knowledge in that area. Lincoln and Guba (2000) suggest that knowledge generated by a particular case study can be transferred to other similar cases. This requires the researcher to provide enough contextual information for readers to make decisions about ‘transferability’ (Lincoln & Guba, 2000; Wieviorka, 1992, as cited in Thomas, 2011). In my thesis, these contexts were provided in the case studies themselves, in my literature review, and in my later discussion of the contribution to literature this study makes. Meier and Pugh (1986) argue that case study research is well-suited to bridging the knowledge/practice divide, and it is my hope that the transferability of my findings will apply as much to the befriending movement as to a body of academic knowledge.

Case study research can generate ‘experiential understanding’ (Flyvbjerg, 2006; Simons, 1996; Stake, 1978/2000), and can permit readers ‘virtual’, ‘inside’ access to situations (Moriarty, 2011), which was my intention in endeavouring to create richly described, evocative cases studies. However, inescapably, the cases studies represent not ‘reality’ but particular renditions of ‘reality’ which readers, themselves, then interpret: meaning arises in the relationship between the reader and the text, the outcome of what readers bring to the ‘fiction’ of cases as much as what is ‘there’ in them (e.g., McLeod & Balamoutsou, 1996). As Frank (2005) puts it, the meaning of a story depends on the stories it generates. This, arguably, destabilises knowledge, but, in my view, a strength of case studies – my own being no exception – is that they can stimulate thinking, and give rise to ‘new ways of seeing’ (Simons, 1996), to learning not proof (Flyvbjerg, 2006). Reality is “incorrigibly plural” (MacNeice, 1935/1979, p. 30) and exceeds models and certainties. In one way, my case studies are anti-model focusing on particularity and resisting categories. At the same time, though, they draw implicitly and eclectically on sense-making models (Hughes, 2011). Other sense-making models could be used, generating different stories.

A further criticism is that case study researchers are prone to ‘verification bias’ (Flyvbjerg, 2006), using their data to confirm their own preconceptions about their subject of interest (Moriarty, 2011). However, as Flyvbjerg (2006) points out, on the contrary, since case study research requires intense attention to detail, complexity and contexts, ‘falsification bias’ is as, or more, likely. Certainly, at the outset of the research, without fully realising it, and at least partly based on befriending literature, I expected befriending to have an impact on agential features of personhood, that is, to enable or enhance independence, choice and activity, and to overcome barriers to social participation. It was as a result of a detailed, in-depth focus on the complexities and ambiguities of each case, using different methods, that I came to understand the ways in which befriending was also a response to individuals’ potential experiences of dependence, incapacity, and insoluble constraints. And, as I reflect, part of getting to know each participant involved ‘falsification’, that is, a disconfirmation of prejudices that were out of my awareness.

6.6 Areas for Future Research

There is a virtual absence of research on the experiences of befriending for people with dementia living in their own homes, and, consequently, many gaps in the literature, some of which I identify here. Grace’s experience suggests that the ending of a befriending relationship – and, in her case, the introduction of a new befriender – could cause uncertainty and confusion. The particular effect on people with cognitive impairment of the loss of a befriending relationship warrants further investigation. There is a need to increase understanding of the impact on those with dementia of short-term befriending where a service lasts for a few months rather than years. The potentially different experiences and meanings of befriending for individuals with dementia who live with someone is an area for future exploration. As research on older people’s befriending also indicates, little is known about befriending relationships which are problematic or discontinued or declined by individuals with dementia, from their points of view. Lastly, it would be helpful to know more about the befriending

experiences of people with dementia, in specialist or generic services, with protected characteristics covered by the Equality Act 2010 (see Moriarty & Manthorpe, 2017) including age (some people have young-onset dementia); ethnicity; sexual orientation; gender reassignment; and religion.

Coda

This is an unashamedly heartfelt thesis.

It was my hope at the start of the study that I would be able to explore what it was like for people living with dementia to have a befriender, a hope, in part, inspired by some of my own relationships with individuals with dementia, over the years, which have left such a mark on me. These relationships were professional arrangements, and not befriending, but many, it seemed to me, had a strong element of mutuality. For Josselson (1992), mutuality is:

a joint creation [which] always occurs in the space between people, as a product of both of them, with each individual contributing to, participating in, and taking from it. In mutuality, then, it is the *we* that is centrally important. (pp. 148-149, emphasis in original)

I wanted to learn more about how, in befriending, this kind of formal/informal social tie might be experienced by those on the ‘other side’ of the relationship, taking into account the circumstances in which befriending took place. In this respect, my hopes for the project were exceeded. The contributions made by Tom, Jenny and Grace in sharing their experiences, views and stories; in inviting me into their homes; in being willing to meet up on several occasions and spend a lot of time with me was something I neither expected nor predicted – and it made all the difference to the richness of the study and its wider messages. I was interested to find out that no person in the study seemed to have any difficulty accepting – and actually valued – befriending as both a service and a friendship; that authenticity outweighed asymmetry. For others, this might not be so. As our research relationships developed, I was also presented with an

opportunity to reflect on my own experience, in this particular relational context, of formality and informality, finding there a fluid, liminal and hard to articulate sense of equality and imbalance; ease and tension; affection and responsibility. And also finding moving, stimulating and often deeply meaningful human connection.

I stated in Chapter 1 that this was not a study *about* dementia. For me, the research came to be about the subjective experience of living in liminal spaces of which memory loss was a part; the felt realities of imposed and inescapable limits; and relationships – befriending relationships, in particular – which took place in these conditions. I have argued that befriending, through human acts and bonds, was a response to constraints both moveable and immutable. For Baars and Phillipson (2013), it is the immutable that modern culture has difficulty accepting. Yet, as they put it:

Even conditions that we cannot change or did not choose do not have to *remain* meaningless. They should at least be *dignified* and, if possible, meaningfully integrated in our lives and in society.
(p. 12, emphasis in original)

Returning to Phillipson's (2015) non-commodified 'new forms of solidarity', it seems to me, now, at the completion of my research, that befriending is, or has the potential to be, not only one such form of solidarity, but also a relationship with the capacity to dignify and integrate existential limitations into human life and community. It is an ambition of Befriending Networks (2014) that "high quality befriending support is available to everyone who wants it – for as long as they need it" (p. 57). I hope that my research will contribute to the realisation of this ambition by showing what befriending meant to Tom, Jenny and Grace, and by sparking further research.

References

- Abrams, D., Swift, H.J., Lamont, R.A., & Drury, L. (2015). *The barriers to and enablers of positive attitudes to ageing and older people, at the societal and individual level. Future of an ageing population: evidence review*. London: Government Office for Science.
- Adults with Incapacity (Scotland) Act (2000) Act (asp 4)*. Retrieved from http://www.legislation.gov.uk/asp/2000/4/pdfs/asp_20000004_en.pdf
- Age UK (2017). *Promising approaches to living well with dementia*. London: Age UK.
- Alzheimer's Society (n.d.) *Global dementia-friendly movement*. Retrieved March 4, 2019, from <https://www.alzheimers.org.uk/about-us/policy-and-influencing/global-dementia-friendly-movement>
- Alzheimer Scotland (2019). *What is a Dementia-friendly Community?* Retrieved June 27, 2019, from https://www.alzscot.org/dementia_friendly_communities
- Alzheimer's Society. (n.d.). *Volunteer with Side by Side*. Retrieved November 9, 2018, from <https://www.alzheimers.org.uk/get-involved/volunteering/ways-volunteer/volunteer-side-by-side>
- Alzheimer's Society (2013). *Dementia 2013: the hidden voice of loneliness*. London: Alzheimer's Society.
- Allan, G. (1989). *Friendship: developing a sociological perspective*. Hemel Hempstead: Harvester Wheatsheaf
- Anderson, S., & Brownlie, J. (2011). Build it and they will come? Understanding public views of 'emotions talk' and the talking therapies. *British Journal of Guidance & Counselling*, 39(1), 53-66. doi: 0.1080/03069885.2010.531385
- Anderson S., Brownlie J., & Given, L. (2009). Therapy Culture. Attitudes towards emotional support in Britain. In A. Park, J. Curtice, K. Thomson, M. Phillips & E. Clery (Eds.), *British Social Attitudes Survey: The 25th Report*. London: Sage.
- Andrews, G.J., Gavin, N., Begley, S., & Brodie, D. (2003). Assisting friendships, combating loneliness: Users' views on a 'befriending' scheme. *Ageing and Society*, 23(3), 349-362. doi: 10.1017/S0144686X03001156
- Association of Volunteer Managers (2012). *Volunteering demands a new kind of professionalism*. Retrieved from <https://volunteermanagers.org.uk/tag/professionalisation/>

- Baars, J., & Phillipson, C. (2013). Connecting meaning with social structure: Theoretical foundations. In J. Baars, J. Dohmen, A. Grenier & C. Phillipson (Eds.), *Ageing, meaning and social structure: Connecting critical and humanistic gerontology*. Bristol: Policy Press.
- Bakhtin, M. (1984). *Problems of Dostoevsky's Poetics* (C. Emerson, Ed. & Trans.). Minneapolis, MN: University of Minnesota Press.
- Balaam, M.-C. (2015). A concept analysis of befriending. *Journal of Advanced Nursing*, 71(1), 24-34. doi: 10.1111/jan.12553
- Baldwin, C. (2006). The narrative dispossession of people living with dementia: Thinking about the theory and method of narrative. In K. Milnes, C. Horrocks, N. Kelly, B. Roberts, & D. Robinson (Eds.), *Narrative, memory and knowledge: Representations, aesthetics and contexts*. Huddersfield: University of Huddersfield Press.
- Baldwin, C. (2009). Narrative and decision-making. In D. O'Connor and B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface*. London: Jessica Kingsley.
- Barrett, P., Hale, B., & Gauld, R (2012). Social inclusion through ageing in place with care? *Ageing & Society*, 32, 361-378. doi: 10.1017/S0144686X11000341
- Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: towards social citizenship*. Bristol: The Policy Press.
- Batsch, N.L., & Mittelman, M.S. (2012). *Overcoming the stigma of dementia*. Retrieved from Alzheimer's Disease International website, <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>
- Befriending Networks (2014). *Befriending in Scotland in 2014: An overview with case studies*. Edinburgh: Befriending Networks.
- Befriending NetworkScotland (2010) *The Befriender*, 25 May. Edinburgh: Befriending NetworkScotland.
- Befriending NetworkScotland & Alzheimer Scotland (2010). *Working 1:1 with people with dementia. Good practice guidelines*. Edinburgh: Befriending NetworkScotland & Alzheimer Scotland.
- Bell, J. (1975). *The Samaritan concept of befriending*. *British Journal of Social Work*, 5(4), 413-422.

- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199 -211. doi: 0.1111/1467-9566.12530
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13), 1802–1811. doi: 10.1177/1049732316654870
- Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia*, 16(1), 67-78. doi: 10.1177/1471301215581081
- Blood, I. (2013). *A better life: Valuing our later years*. York: Joseph Rowntree Foundation.
- Boddy, J., Neumann, T., Jennings, S., Morrow, V., Alderson, P., Rees, R., & Gibson, W. (2010). *The research ethics guidebook: A resource for social scientists*. Retrieved from <http://www.ethicsguidebook.ac.uk>
- Bondi, L. (2005). The place of emotions in research. In J. Davidson, L. Bondi & M. Smith (Eds.), *Emotional geographies*. Aldershot: Ashgate.
- Bondi, L. (2008). On the relational dynamics of caring: A psychotherapeutic approach to emotional and power dimensions of women’s care work. *Gender, Place and Culture*, 15(3), 249-265. doi: 10.1080/09663690801996262
- Bowers, H., Mordey, M., Runnicles, D., Barker, S., Thomas, N., Wilkins, A., Lockwood, S., Catley, A. (2011). *Not a one-way street: Research into older people’s experiences of support based on mutuality and reciprocity. Interim findings*. York: Joseph Rowntree Foundation.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Brewer, J.D. (2000). *Ethnography*. Buckingham: Open University Press
- Brinkmann, S., & Kvale, S. (2005) Confronting the ethics of qualitative research. *Journal of Constructivist Psychology*, 18, 157 181. doi: 10.1080/10720530590914789
- Brooker, D. (2007). *Person-centred dementia care: Making services better*. London: Jessica Kingsley.
- Brooker, D., Dröes, R.-M. & Evans, S. (2017). Framing outcomes of post-diagnostic psychosocial interventions in dementia: The Adaptation-Coping Model and adjusting to change. *Working with Older People*, 21(1), 13-21. doi: 10.1108/WWOP-12-2016-0039

- Brown, L.M., & Gilligan, C. (1992). Meeting at the crossroads: *Women's psychology and girls' development*. Cambridge, MA: Harvard University Press.
- Brown, L.M., Debold, E., Tappan, M., & Gilligan, C. (1991). Reading narratives of conflict and choice for self and moral voices: A relational method. In W.M. Kurtines & J.L. Gewirtz (Eds.), *Handbook of moral behaviour and development: Volume 2: Research*. New Jersey: Lawrence Erlbaum Associates.
- Browne J., Edwards, D.A., Rhodes K.M., Brimicombe, D.J., & Payne, R.A. (2017). Association of comorbidity and health service usage among patients with dementia in the UK: A population-based study. *BMJ Open*. doi:10.1136/bmjopen-2016-012546
- Brownlie, J. (2011). Not 'going there': Limits to the professionalization of our emotional lives. *Sociology of Health and Illness*, 33(1), 130-144. doi: 10.1111/j.1467 9566.2010.01269.x
- Brownlie, J. (2014). *Ordinary relationships: A sociological study of emotions, reflexivity and culture*. Basingstoke Hampshire: Palgrave Macmillan.
- Bruce, A., Sheilds, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., & Shermak, S. (2014). Stories of liminality: living with life-threatening illness. *Journal of Holistic Nursing*, 32(1), 35-43. doi: 10.1177/0898010113498823
- Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry*, 18, 1-21.
- Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., & Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, 12(192). doi: 10.1186/s12916-014-0192-4
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4(2), 167-182. doi:10.1111/1467-9566.ep11339939
- Butler, J. (2012). Can one lead a good life in a bad life? Adorno Prize Lecture. *Radical Philosophy*, 176, Nov/Dec.
- Byrne, A., Canavan, J., & Millar, M. (2009). Participatory research and the voice-centred relational method of data analysis: Is it worth it? *International Journal of Social Research Methodology*, 12(1), 67-77. doi: 10.1080/13645570701606044
- Bytheway, B. (1995). *Ageism*. Buckingham: Open University Press.
- British Sociological Association (2004) *Statement of Ethical Practice March 2002 (Appendix updated May 04)*. Durham: the British Sociological Association.
- Caddell, L.S., & Clare, L. (2011). I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, 10(3), 379-398. doi: 10.1177/1471301211408255

- Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: Lessons learned and recommendations for health services research. *BMC Medical Research Methodology*, 13(14). doi: 10.1186/1471-2288-13-14
- Campaign to End Loneliness (n.d.). *The facts on loneliness*. Retrieved May 16, 2019, from <https://www.campaigntoendloneliness.org/the-facts-on-loneliness/>
- Campaign to End Loneliness (2014). *Understanding loneliness workshop: the future of befriending*. Retrieved March 24, 2016, from <http://www.campaigntoendloneliness.org/wp-content/uploads/Befriending-Workshop-Report.pdf>
- Cantley, C., & Smith, M (2007). *Getting on with living: A guide to developing early dementia support services*. London: The Mental Health Foundation
- Cattan, M., Kime, N., & Bagnall, A.-M. (2009). *Low-level support for socially isolated older people: An evaluation of telephone befriending*. London: Help the Aged.
- Cattan, M., Kime, N., & Bagnall, A.-M. (2011). The use of telephone befriending in low level support for socially isolated older people: An evaluation. *Health and Social Care in the Community*, 19(2), 198-206. doi: 10.1111/j.1365-2524.2010.00967.x
- Chal, J. (2004). *An evaluation of befriending services in New Zealand*. Final Report. Retrieved April, 5, 2015 from <https://www.health.govt.nz/system/files/documents/pages/an-evaluation-of-befriending-services.pdf>
- Cheston, R. (2004). Top dogs and under dogs: Marginalizing problematic voices. In A. Innes, C. Archibald & C. Murphy (Eds.), *Dementia and Social Inclusion*. London: Jessica Kingsley.
- Cheston, R., Christopher, G., & Ismail, S. (2015). Dementia as an existential threat: The importance of self-esteem, social connectedness and meaning in life. *Science Progress*, 98(4), 416-419. doi: 10.3184/003685015X14467423210693
- Cheung, W. Y., Wildschut, T., Sedikides, C., G. Hepper, E.G., Arndt, J., & Vingerhoets, Ad J. J. M. (2013). Back to the future: Nostalgia increases optimism. *Personality and Social Psychology Bulletin*, 39(11), 1484-1496. doi: 10.1177/0146167213499187
- Christ, R., Kandel, R., Robbins, J., & Stewart, R. (2013). Harvard College Alzheimer's Buddies Program: Extending the intergenerational model. *Alzheimer's & Dementia*, 9(4), Supplement, 649. doi: 10.1016/j.jalz.2013.05.1327
- Christiansen, C.H. (1999). Defining lives: Occupation as identity: An essay on competence, coherence, and the creation of meaning, 1999 Eleanor Clarke Slagle lecture. *American Journal of Occupational Therapy*, 53, 547-558. doi:10.5014/ajot.53.6.547

- Clandinin, D.J. (2006). Narrative inquiry: A method for studying lived experience. *Research Studies in Music Education*, 27, 44-54. doi: 10.1177/1321103X060270010301
- Clare, L., & Shakespeare, P. (2004). Negotiating the impact of forgetting: Dimensions of resistance in task oriented conversations between people with early-stage dementia and their partners. *Dementia*, 3(2), 211-232. doi: 10.1177/1471301204042338
- Clarke, C.L., & Keady, J. (2002). Getting down to brass tacks: A discussion of data collection with people with dementia. In H. Wilkinson (Ed.), *The Perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley.
- Clough, R., Manthorpe, J., Green, B., Fox, D., Raymond, G., Wilson, P., Raymond, V., Sumner, K., Bright, L., & Hay, J. (2007). *The support older people want and the services they need*. York: Joseph Rowntree Foundation.
- Cousin, G. (2013). Reflexivity: The new reflexive practice. *International Journal of Practice based Learning in Health and Social Care*, 1(2), 3-7. doi:10.11120/pblh.2013.00011
- Cridland, E.K., Phillipson, L., Brennan Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research*, 26(13) 1774-1786. doi: 10.1177/1049732316637065
- Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In C. Barnes & G. Mercer (Eds.) *Exploring the Divide*. Leeds: The Disability Press.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London: Sage.
- Dahlberg, K., Todres, L. & Galvin, K. (2009). Lifeworld led healthcare is more than patient led care: An existential view of well being. *Medicine, Healthcare and Philosophy*, 12, 265-271. doi: 10.1007/s11019-008-9174-7
- Danermark, B., Ekström, M., Jakobsen, L., & Karlsson, J. Ch. (2002). *Explaining society: Critical realism in the social sciences*. London: Routledge.
- Davidson, S., & Roassall, P. (2014) *Evidence review: loneliness in later life*. London: Age UK. Retrieved from https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/rb_june15_lonelines_in_later_life_evidence_review.pdf
- Davies, K., & Heaphy, B. (2011). Interactions that matter: Researching critical associations. *Methodological Innovations Online*, 6(3), 5-16. doi: 10.4256/mio.2011.002

Dean, J., & Goodlad, R. (1998). Supporting community participation: *The role and impact of befriending*. Brighton: Pavilion Publishing & Joseph Rowntree Foundation.

Department of Health (2015). *Prime Minister's Challenge on Dementia 2020*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf

Department of Health (2011) *Commissioning framework for dementia*. Retrieved from www.dh.gov.uk/publications

de Witt, L., Ploeg, J., & Black, M. (2009). Living on the threshold: The spatial experience of living alone with dementia. *Dementia*, 8(2), 263 -291.
doi: 10.1177/1471301209103273

de Witt, L., Ploeg, J., & Black, M. (2010). Living alone with dementia: An interpretive phenomenological study with older women. *Journal of Advanced Nursing*, 66(8), 1698-1707. doi: 10.1111/j.1365-2648.2010.05295.x

de Witt, L., & Ploeg, J. (2016). Caring for older people living alone with dementia: Healthcare professionals' experiences. *Dementia*, 15(2), 221-238.
doi: 10.1177/1471301214523280

Dempsey, L., Murphy, K., Cooney, A., Casey, D., O'Shea, E., Devane, D., Jordan, F., & Hunter, A. (2014). Reminiscence in dementia: A concept analysis. *Dementia*, 13(2), 176-192. doi: 10.1177/1471301212456277

Dewing, J. (2007). Participatory research: A method for process consent with persons who have Dementia. *Dementia*, 6(1), 11-25. doi: 10.1177/1471301207075625

Dewing J (2008). Process consent and research with older persons living with dementia. *Association of Research Ethics Journal*, 4(2), 59-64.
doi: 10.1177/174701610800400205

Dewing, J., & Dijk, S. (2016). What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia*, 15(1), 106-124.
doi: 10.1177/1471301213520172

Digby, R., Lee S., & Williams A. (2018). The liminality of the patient with dementia in hospital. *Journal of Clinical Nursing*, 27, 70-79. doi:10.1111/jocn.13869

Doucet, A. (2008). "From her side of the gossamer wall(s)": Reflexivity and relational knowing. *Qualitative Sociology*, 31, 73-87.
doi: 10.1007/s11133-007-9090-9

Doucet, A., & Mauthner, N.S. (2008). What can be known and how? Narrated subjects and the Listening Guide. *Qualitative Research*, 8(3), 399-409.
doi: 10.1177/1468794106093636

- Downey, J. (2011). Befriending in care homes: The results of a pilot study. *Nursing & Residential Care*, 13(8), 395-397.
- Dröes, R.M., van Mierlo, L.D., van der Roest, H.G., & Meiland, F.J.M. (2010). Focus and effectiveness of psychosocial interventions for people with dementia in institutional care settings from the perspective of coping with the disease. *Non-pharmacological Therapies in Dementia*, 1(2), 139-161.
- Duane, F., Brasher, K., & Koch, S. (2011). Living alone with dementia. *Dementia*, 12(1), 123-136. doi: 10.1177/1471301211420331
- Duncombe, J., & Jessop, J. (2002). 'Doing rapport' and the ethics of 'faking friendship'. In M. Mauthner, M. Birch, J. Jessop & T. Miller (Eds), *Ethics in Qualitative Research*. London: Sage.
- Economic and Social Research Council (2015) *Framework for research ethics (Updated January 2015)*. Retrieved April 6, 2016, from <http://www.esrc.ac.uk/files/funding/guidance-for-applicants/esrc-framework-for-research-ethics-2015/>
- Education Scotland: Foghlam Alba (n.d.). *History of Scots from the Middle Ages to the present day*. Livingstone: Author. Retrieved from <https://education.gov.scot/improvement/documents/historyofscotsmar17.pdf>
- Edwards, R., & Weller, S. (2012). Shifting analytic ontology: Using I-poems in qualitative longitudinal research. *Qualitative Research*, 12(2), 202-217. doi: 10.1177/1468794111422040
- Elliott, J. (2005). *Using Narrative in Social Research: Qualitative and Quantitative Approaches*. London: Sage.
- Evans, D., Price, K., & Meyer, J. (2016). Home alone with dementia. *SAGE Open*, July-Sept, 1-13. doi: 10.1177/2158244016664954
- Ezzy, D. (2010). Qualitative interviewing as an embodied emotional performance. *Qualitative Inquiry*, 16(3), 163-170. doi: 10.1177/1077800409351970
- Fearnley, K. (2017). *Living well with dementia* [Brochure]. Edinburgh: NHS Health Scotland.
- Fehr, B. (1996). *Friendship Processes*. London: Sage.
- Ferguson, I. (2012). Personalisation, social justice and social work: A reply to Simon Duffy. *Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community*, 26(1), 55-73. doi: 10.1080/02650533.2011.623771
- Ferrie, J., & Watson, N. (2015). The psycho social impact of impairment: The case of motor neurone disease. In T. Shakespeare (Ed.), *Disability Research Today*. Oxon: Routledge

- Finlay, L. (2002). Negotiating the swamp: the opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230. doi: 10.1177/146879410200200205
- Finlay, L. (2003). The reflexive journey: Mapping multiple routes. In L. Finlay & B. Gough (Eds.), *Reflexivity: A practical guide for researchers in health and social sciences*. Oxford: Blackwell Science.
- Flyvbjerg, B. (2006). Five misunderstandings about case study research. *Qualitative Inquiry*, 12(2), 219-245. doi: 10.1177/1077800405284363
- Fortinsky, R.H., & Downs, M. (2014). Optimizing person-centered transitions in the dementia journey: A comparison of national dementia strategies. *Health Affairs*, 33(4), 566-573. doi: 10.1377/hlthaff.2013.1304
- Fox, M. (2011). Dementia diagnosis and beyond: A counsellor's view. *Journal of Dementia Care*, 19(2), 30-31.
- Frank, A.W. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Frank, A.W. (2000). The Standpoint of Storyteller. *Qualitative Health Research*, 10(3), 354-365. doi: 10.1177/104973200129118499
- Frank, A.W. (2004). *The renewal of generosity: Illness, medicine and how to live*. Chicago: University of Chicago Press.
- Frank, A.W. (2005). What is dialogical research, and why should we do it? *Qualitative Health Research*, 15(7), 964-974. doi: 10.1177/1049732305279078
- Frank, A.W. (2010). *Letting stories breathe: A socio narratology*. Chicago: University of Chicago Press.
- Frank, J.F. (2001). Chapter 1: How long can I stay? *Journal of Housing for the Elderly*, 15(1 2), 5-30. doi: 10.1300/J081v15n01_02
- Frazer, S.M., Oyebode, J.R., & Cleary, A. (2011). How older women who live alone with dementia make sense of their experiences: An interpretative phenomenological analysis. *Dementia*, 11(5), 677-693. doi: 10.1177/1471301211419018
- Gabriel, M., Stirling, C., Faulkner, D., & Lloyd, B. (2014). *Future housing and support needs of people with dementia*, AHURI Positioning Paper No.159. Melbourne: Australian Housing and Urban Research Institute. Retrieved from <https://www.ahuri.edu.au/research/position-papers/159>

Gee, J.P. (1986). Units in the production of narrative discourse. *Discourse Processes*, 9(4), 391-422. doi: 10.1080/01638538609544650

Gergen, K.J. (2009). *An invitation to social construction* (2nd ed.). London: Sage.

Gillett, K., & Dixon, M. (2009). VitalLinks: Nurturing emotional well being in older people through one-to-one communication. *Working with Older People*, 13(4), 20-23. doi: 10.1108/13663666200900066

Gilleard, C., & Higgs, P. (2010). Aging without agency: Theorizing the fourth age. *Aging & Mental Health*, 14(2), 121-128. doi: 10.1080/13607860903228762

Gilliard, J., Means, R., Beattie, A., & Daker White, G. (2005). Dementia care in England and the social model of disability: Lessons and issues. *Dementia*, 4(4), 571-586. doi: 10.1177/1471301205058312

Gilligan, C., Spencer, R., Weinberg, M.K., & Bertsch, T. (2003). On the listening guide: A voice-centered relational method. In P.M. Camic, J.E. Rhodes & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design*. Washington, DC: American Psychological Association Press.

Gilmour, H., Gibson, F., & Campbell, F. (2003). Living alone with dementia: A case study approach to understanding risk. *Dementia*, 2(3), 403-420.

Godwin, B., & Poland, F. (2015). Bedlam or bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care. *Quality in Ageing and Older Adults*, 16(4), 235-248. doi: 10.1108/QAOA-08-2015-0038

Goffman, E. (1959). *The presentation of self in everyday life*. London: Penguin Books.

Goffman, E. (1963). *Stigma: Notes of the management of a spoiled identity*. London: Penguin Books.

Greenwood, D.E., Gordon, C., Pavlou, C., & Bolton, J.V. (2016). Paradoxical and powerful: Volunteers' experiences of befriending people with dementia. *Dementia*. Advanced online publication. doi: 10.1177/1471301216654848

Grenier, A. (2012). *Transitions and the lifecourse: Challenging the constructions of 'growing old'*. University of Bristol: The Policy Press.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry*, 10(2), 261-280. doi: 10.1177/1077800403262360

Halperin, S., & Heath, O. (2012). *Political Research: Methods and Practical Skills*. Oxford: Oxford University Press.

Hanisch, H. (2014). Psycho-emotional disablism: A differentiated process. *Scandinavian Journal of Disability Research*, 16(3), 211-228.
doi: 10.1080/15017419.2013.795911

Harjunen, H. (2003, August 20-24) *Obesity as a liminal and marginalized experience*. Paper presented at Gender and Power in New Europe. The 5th European Feminist Research Conference, Lund University, Sweden. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.535.5497&rep=rep1&type=pdf>

Harris, P.B. (2006). The experience of living alone with early-stage Alzheimer's disease: What are the person's concerns? *Alzheimer's Care Quarterly*, April/June, 84- 94.

Harrison, A.K. (2018). *Ethnography*. Oxford: Oxford University Press.

Heslop, P. (2005). Good practice in befriending services for people with learning difficulties. *British Journal of Learning Disabilities*, 33, 27-3.
doi: 10.1111/j.1468-3156.2004.00310.x

Hill, M. (2016). *Evaluation of the volunteering in care homes project summary report*. Institute for Volunteering Research. Retrieved from https://knowhow.ncvo.org.uk/your-team/volunteers-and-your-organisation/volunteering-in-care-homes-1/copy_of_ViCH_final_report_March_2016.pdf

Hillman, A., & Latimer, J. (2017). Cultural representations of dementia. *PLoS Med*, 14(3): e1002274. doi: 10.1371/journal.pmed.1002274

HM Government. (2018). *A connected society: A strategy for tackling loneliness: Laying the foundations for change*. Retrieved from <https://www.gov.uk/government/publications/a-connected-society-a-strategy-for-tackling-loneliness>

Howard, A. (2014). *Cotswold Befrienders evaluation survey 2014 (year 1)*. Gloucester: Cotswold Befrienders Partnership.

Howard, S. (n.d.). *'Better than pills': Evidence of the benefits of volunteering*. Edinburgh Evaluation Support Scotland. Retrieved November 9, 2015, from http://evaluationsupportscotland.org.uk/media/uploads/resources/stitch_in_time_-_evidence_of_the_benefits_of_volunteering_with_covers.pdf

Hubbard, G., Downs, M.G., & Tester, S. (2003). Including older people with dementia in research: Challenges and strategies. *Aging & Mental Health*, 7(5), 351-362. doi: 10.1080/1360786031000150685

- Hughes, J.C. (2011). *Thinking through dementia*. Oxford: Oxford University Press.
- Hydén, L. C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19(1), 48-69.
- Hydén, L.-C. (2013). Storytelling in dementia: Embodiment as a resource. *Dementia*, 12(3), 359-367. doi: 10.1177/1471301213476290
- Innes, A. (2009). *Dementia Studies*. London: Sage.
- Innes, A., & Manthorpe, J. (2012). Developing theoretical understandings of dementia and their application to dementia care policy in the UK. *Dementia*, 12(6), 682-696. doi: 10.1177/1471301212442583
- Innovations in Dementia (2011). *Dementia capable communities: The views of people with dementia and their supporters*. Exeter: Innovations in Dementia. Retrieved from https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/DementiaCapableCommunities_fullreportFeb2011.pdf
- Innovations in Dementia Care (2014). *Dementia words matter: Guidelines on language about dementia*. Retrieved from <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>
- Irvine, M. (n.d.). *Mikhail Bakhtin: Main theories*. Retrieved August 8, 2018, from <http://faculty.georgetown.edu/irvinem/theory/Bakhtin-MainTheory.html>
- Jackson, J.E. (2005). Stigma, liminality, and chronic pain: Mind body borderlands. *American Ethnologist*, 32(3), 332-353. doi: 10.1525/ae.2005.32.3.332
- Jamieson, L. (2008). *Friendship and befriending*. Presentation given at the Befriending Network Scotland Conference, Edinburgh, Scotland.
- Jamieson, L., & Simpson, R. (2013). *Living alone: Globalization, identity and belonging*. Basingstoke: Palgrave Macmillan.
- Jankowska, M. (2014). Voice-centred relational method: Focussing on the voice, the relationship and socio-cultural context in narratives of personal development. *SAGE Research Methods Cases*. doi: 10.4135/978144627305013512946
- Johannessen, A., Möller, A., Haugen, P.K., & Biong, S. (2014). A shifting sense of being: A secondary analysis and comparison of two qualitative studies on young-onset dementia. *International Journal of Qualitative Studies on Health and Well being*, 9(1). doi: 10.3402/qhw.v9.24756
- Jopling, K. (2015). *Promising approaches to reducing loneliness and isolation in later life*. London: Age UK & Campaign to End Loneliness.

- Josselson, R. (1992). *The space between us: Exploring the dimensions of human relationships*. San Francisco: Jossey-Bass Publishers.
- Keady, J., Williams, S., & Hughes Roberts, J. (2009). Analysing decision-making: Bridging and balancing. In D. O'Connor & B. Purves (Eds.), *Decision-making, personhood and dementia: Exploring the interface*. London: Jessica Kingsley.
- Kelly, A. (2008). Living loss: An exploration of the internal space of liminality. *Mortality*, 13(4), 335-350. doi: 10.1080/13576270802383915
- Kelly, M. (2016, December 12). *Dementia sufferers in Gateshead to benefit from new befriending service*. The Evening Chronicle. Retrieved from <https://www.chroniclelive.co.uk/news/north-east-news/dementia-sufferers-gateshead-benefit-new-12295529>
- Keyes, S.E., Clarke, C.L., & Catherine E. Gibb (2019). Living with dementia, interdependence and citizenship: Narratives of everyday decision-making. *Disability & Society*, 34(2), 296-319. doi: 10.1080/09687599.2018.1528970
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. London: Sage.
- Labov, W., & Waletzky, J. (1967). Narrative analysis: Oral versions of personal experience. In J. Helm (Ed.), *Essays on the verbal and visual arts*. Seattle, WA: University of Washington.
- Lahey, L. (2009). *Counting the cost: Caring for people with dementia on hospital wards*. London: Alzheimer's Society.
- Lavis, V. (2010). Multiple researcher identities: Highlighting tensions and implications for ethical practice in qualitative interviewing. *Qualitative Research in Psychology*, 7, 316-331. doi: 10.1080/14780880902929506
- Leibing, A., Guberman, N., & Wiles, J. (2016). Liminal homes: Older people, loss of capacities, and the present future of living spaces. *Journal of Aging Studies*, 37, 10-19. doi: 10.1016/j.jaging.2015.12.002
- Lester, H., Mead, N., Graham, C., Gask, L., & Reilly, S. (2012). An exploration of the value and mechanisms of befriending for older adults in England. *Ageing & Society*, 32(2), 307-328. doi: 10.1017/S0144686X11000353
- Lewis, J. (2003). Design Issues. In J. Ritchie and J. Lewis (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.

Life Changes Trust (n.d.). *Befriending projects. Report 1 - the first year, October 2015 to September 2016*. Glasgow: Life Changes Trust. Retrieved July 12, 2019, from <https://www.lifechangestrust.org.uk/sites/default/files/publications/Befriending%20Projects%20First%20Year.pdf>

Lincoln, Y.S. & Guba, E.G. (2000). The only generalization is: there is no generalization. In R. Gomm, Hammersley, M. & P. Foster (Eds.), *Case study method*. London: Sage.

Lingard, J., & Milne, A (2004.) *First signs. Celebrating the achievements of the Dementia Advice and Support Service: A project for people in the early stages of dementia*. London: The Mental Health Foundation.

Lishman, E., Cheston, R., & Smithson, J. (2016). The paradox of dementia: Changes in assimilation after receiving a diagnosis of dementia. *Dementia*, 15(2), 181-203. doi: 10.1177/1471301214520781

Lloyd, B.T., & Stirling, C (2015). The will to mobility: Life-space satisfaction and distress in people with dementia who live alone. *Ageing and Society*, 35, 1801-1820. doi:10.1017/S0144686X14000683

Lloyd, L., Calnan, M., Cameron, A., Seymour, J., & Smith, R. (2014). Identity in the fourth age: Perseverance, adaptation and maintaining dignity. *Ageing & Society*, 34, 1-19. doi:10.1017/S0144686X12000761

Local Government Association (2015). *Dementia-friendly communities: Guidance for Councils*. London: Local Government Association.

Lodge, D. (1990). *After Bakhtin: Essays on Fiction and Criticism*. London: Routledge.

Long-Term Conditions Alliance Scotland & Scottish Government (2011). *Emotional Support Matters: Emotional and psychological support needs of people with long-term conditions*. Retrieved from https://www.nes.scot.nhs.uk/media/3223415/alliance_scotland_emotional_support_matters_report_final.pdf

Lyman, K.A. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist*, 29(5), 597-605.

MacColl, E. (1981). *The Radio Ballads: How they were made, when and by whom* (P. Seeger, Ed.). Retrieved on January 17, 2016, from <http://www.peggyseeger.com/discography/ballads/how-the-radio-ballads-were-made>

Madill, A. (2008). Realism. In L.M. Given (Ed.), *The Sage encyclopedia of qualitative research methods*. Thousand Oaks, CA: Sage.

- MacNeice, L. (1979). Snow. In E.R. Dodds (Ed.), *Louis MacNeice collected poems*. London: Faber & Faber. (original work published 1935)
- Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., Watts, S., Robinson, L., Gemski, A., Warner, J., Goodman, C., Drennan, V., & Iliffe, S. (2011). *The transition from cognitive impairment to dementia: Older people's experiences*. National Institute for Health Research: Service Delivery and Organisation programme.
- Mason, J. (2002). *Qualitative Researching* (2nd ed.). London: Sage.
- Mason, A., & Wilkinson, H. (2002). Don't leave me hanging on the telephone. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations*. London: Jessica Kingsley.
- Mauthner, N.S., & Doucet, A. (1998). Reflections on a voice-centred relational method of data analysis: Analysing maternal and domestic voices. In J. Ribbens & R. Edwards (Eds.), *Feminist dilemmas in qualitative research: Private lives and public texts*. London: Sage.
- May, V. (2017). Belonging from afar: Nostalgia, time and memory. *The Sociological Review*, 65(2), 401-415. doi: 10.1111/1467-954X.12402
- McCall, V., McCabe, L., Rutherford, A., Bu, F., Woolvin, M., Wilson, M., and Law, S. (2017). *The Role of volunteering in dementia care*. University of Stirling, Stirling, Scotland. Retrieved July 4, 2019, available on request from https://www.researchgate.net/publication/320042320_The_Role_of_Volunteers_in_Dementia_Care
- McCorkle, B. H., Dunn, E. C., Mui, Y., & Gagne, C. (2009). Compeer friends: A qualitative study of a volunteer friendship programme for people with serious mental illness. *International Journal of Social Psychiatry*, 55(4), 291-305. doi: 10.1177/0020764008097090
- McDonnell, A., McKeown, J., Keen, C., Palfreyman, J., & Bennett, N. (2014). Introducing on-ward volunteers to work with patients with dementia. *Nursing Older People*, 26(4), 28-33.
- McLeod, J. (1997). *Narrative and Psychotherapy*. London: Sage.
- McLeod, J. (2001). *Qualitative Research in Counselling and Psychotherapy*. London: Sage.
- McLeod, J. (2010). *Case Study Research in Counselling and Psychotherapy*. London: Sage.
- McLeod, J. (2011). *Qualitative Research in Counselling and Psychotherapy* (2nd ed.). London: Sage.

- McLeod, J. (2013). *An Introduction to Research in Counselling and Psychotherapy*. London: Sage.
- McLeod, J., & Balamoutsou, S. (1996). Representing narrative process in therapy: Qualitative analysis of a single case. *Counselling Psychology Quarterly*, 9(1), 61-76. doi: 10.1080/09515079608256353
- McLeod, J., & McLeod, J. (2011). *Counselling Skills: A Practical Guide for Counsellors and Helping Professionals* (2nd ed.). Maidenhead: Oxford University Press.
- McLeod, J., & Thomson, R. (2009) *Researching social change*. London: Sage. doi: 10.4135/9780857029010
- McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, 39, 258-269. doi: 10.1111/1467-9566.12438
- Meier, P., & Pugh, E.J. (1986). The case study: A viable approach to clinical research. *Research in Nursing and Health*, 9(3), 195-202. doi: 10.1002/nur.4770090303
- Mental Health Foundation (2015). *Dementia, rights, and the social Model of disability: A new direction for policy and practice?* London: Mental Health Foundation.
- Mental Welfare Commission for Scotland (2010). *Consent to Treatment: A Guide for Mental Health Practitioners*. Edinburgh: Mental Welfare Commission for Scotland.
- Mentoring and Befriending Foundation (2010). *Befriending works: Building resilience in local communities*. Manchester: Mentoring and Befriending Foundation.
- Minghella, E., & Schneider, K. (2012). Rethinking a framework for dementia 1: A journey. *Working with Older People*, 16(3), 122-131. doi: 10.1108/13663661211260943
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2010). People with dementia living alone: What are their needs and what kind of support are they receiving? *International Psychogeriatrics*, 22(4), 607-617. doi: 10.1017/S104161021000013X
- Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: A cross-sectional survey. *BMC Health Services Research*, 13(43). doi: 10.1186/1472-6963-13-43
- Mitchell, G., & Pistrang, N. (2011). Befriending for mental health problems: processes of helping. *Psychology and Psychotherapy: Theory, Research and Practice*, 84: 151-169. doi: 10.1348/147608310X508566

Molzhan, A.E., Bruce, A., & Sheilds, L. (2008). Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal*, 35(1), 13-20.

Moriarty, J. (2011). *Qualitative methods overview*. Methods review (1). NIHR School for Social Care Research, London. Retrieved from <http://eprints.lse.ac.uk/id/eprint/41199>

Moriarty, J., & Manthorpe, J. (2012). *Diversity in older people and access to services: An evidence review*. London: Age UK.

Moriarty, J., & Manthorpe, J. (2017). The diversity of befriending by, and of, older people. *Working with Older People*, 21(2), 63-71.
doi: 10.1108/WWOP-07-2016-0017

Morson, G.S., & Emerson, C. (1990). *Mikhail Bakhtin: Creation of a Prosaics*. Stanford, CA: Stanford University Press.

Mulvihill, J. (2011a). Personalised befriending support for older people. *Quality in Ageing and Older Adults*, 12(3), 180-3. doi: 10.1108/14717791111163613

Mulvihill, J. (2011b). The unique and valuable support provided by mentoring and befriending. *Working with Older People*, 15(1), 34-37. doi: 10.5042/wwop.2011.0118

Murphy, K., Jordan, F., Hunter, A., Cooney, A., & Casey, D. (2015). Articulating the strategies for maximising the inclusion of people with dementia in qualitative research studies. *Dementia*, 14(6), 800-824. doi: 10.1177/1471301213512489

Murphy, R.F., Scheer, J., Murphy, Y., & Mack, R. (1988). Physical liminality and social disability: A study in the rituals of adversity. *Social Science & Medicine*, 26(2), 235-242. doi: 10.1016/0277-9536(88)90244-4

National Alzheimer Buddies (2018) *Our stories*. Retrieved November 19, 2018, from <http://www.alzbuddies.org/stories>

Neale, B., Henwood, K., & Holland, J. (2012). Researching lives through time: An introduction to the Timescapes approach. *Qualitative Research*, 12(1), 4-15.
doi: 10.1177/1468794111426229

Newhouse, B.J., Niebuhr, L., Stroud, T., & Newhouse, E. (2001). Living alone with dementia: Innovative support programmes. *Alzheimer's Care Quarterly*, 2(2), 53-61.

Nicholson, C., Meyerb, J., Flatley, M., Holman, C., & Lowton, K. (2012). Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social Science & Medicine*, 75, 1426-1432. doi: 10.1016/j.socscimed.2012.06.011

Nourhashemi, F., Amouyal-Barkate, K., Gillette-Guyonnet S., Cantet, C., & Vellas, B. (2005). Living alone with Alzheimer's disease: Cross sectional and longitudinal analysis in the REAL.FR Study. *Journal of Nutrition, Health and Aging*, 9(2), 117-120.

Nuffield Council on Bioethics (2009). *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics.

Nygård, L. (2006). How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, 13, 101-112. doi: 10.1080/11038120600723190

Nygård, L., & Starkhammar, S. (2003). Telephone use among noninstitutionalized persons with dementia living alone: Mapping out difficulties and response strategies. *Scandinavian Journal of Caring Sciences*, 17, 239-249. doi: 10.1046/j.1471-6712.2003.00177.x

Nygård, L., & Starkhammar, S. (2007). The use of everyday technology by people with dementia living alone: Mapping out the difficulties. *Aging & Mental Health*, 11, 144-155. doi: 10.1080/13607860600844168

Ohtonen, I., & Olofsson, S. (2017). *Att leva ensam med en demenssjukdom: En litteraturöversikt* [To live alone with dementia: a literature review]. (Dissertation). Retrieved from <http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-35842>

Older People's Commissioner for Wales: Comisiynydd Pobl Hŷn Cymru (2018). *Rethinking Respite for People Affected by Dementia*. Cardiff: Author.

Oliver, M. (2004). If I had a hammer: The social model in action. In J. Swain, S. French, C. Barnes & C. Thomas (Eds), *Disabling Barriers: Enabling Environments* (2nd ed.). London: Sage.

Ortner, S.B. (2006). *Anthropology and social theory: Culture, power, and the acting subject*. Durham, N.C.: Duke University Press.

Pannell, J., & Blood, I. (2012). *Supported housing for older people in the UK: An evidence review*. York: Joseph Rowntree Foundation.

Patrick, H. (2006). *Mental Health, Incapacity and the Law in Scotland*. Haywards Heath: Tottel Publishing.

Peel, E. (2014). 'The living death of Alzheimer's' versus 'Take a walk to keep dementia at bay': Representations of dementia in print media and carer discourse. *Sociology of Health & Illness* 36(6), 885-901. doi: 10.1111/1467-9566.12122

- Pennington, J., & Knight, T. (2008). Staying connected: the lived experiences of volunteers and older adults. *Ageing International*, 32, 298-311.
doi: 10.1007/s12126-008-9020-5
- Percival, J. (2001). Self-esteem and social motivation in age-segregated settings. *Housing Studies*, 16(6), 827-840. doi: 10.1080/02673030120090566
- Phillips, R., & Evans, B. (2016). Friendship, curiosity and the city: Dementia friends and memory walks in Liverpool. *Urban Studies*, 55(3), 639-654.
doi: 10.1177/0042098016632699
- Phillipson, C. (2015). The political economy of longevity: Developing new forms of solidarity for later life. *The Sociological Quarterly*, 56, 80-100.
doi: 10.1111/tsq.12082
- Phinney, A. (2002). Fluctuating awareness and the breakdown of the illness narrative in dementia. *Dementia*, 1(3), 329-344. doi: 10.1177/147130120200100305
- Phinney, A. (2011). Horizons of meaning in dementia: Retained and shifting narratives. *Journal of Religion, Spirituality & Aging*, 23(3), 254-268.
doi: 10.1080/15528030.2011.563210
- Phinney, A. (2014). As the body speaks: Creative expression in dementia. In L.C. Hydén, H. Lindemann & J. Brockmeier (Eds.), *Beyond loss: Dementia, identity, personhood*. Oxford: Oxford University Press.
- Polkinghorne, D.E. (1991). Narrative and self-concept. *Journal of Narrative and Life History*, 1(2&3), 135-153.
- Ponce, A.M.D., & Gove, D. (2016). A comparative analysis of national care pathways for people with dementia living at home in Europe. *International Journal of Integrated Care*, 16(6), 1-8. doi: 10.5334/ijic.2644
- Pratt, R. (2002). 'Nobody's ever asked how I felt'. In H. Wilkinson (Ed.), *The Perspectives of People with Dementia: Research Methods and Motivations*. London: Jessica Kingsley.
- Pratt, R., & Wilkinson, H. (2001). *"Tell me the truth": The effect of being told the diagnosis of dementia from the perspective of the person with dementia*. London: The Mental Health Foundation.
- Preston, C., & Burch, S. (2018). Dementia buddying as a vehicle for person-centred care? The performance of a volunteer led pilot on two hospital wards. *Journal of Health Services Research & Policy*, 23(3), 139-147.
doi: 10.1177/1355819618767944

- Preston, L., Marshall, A., & Bucks, R.S. (2007). Investigating the ways that older people cope with dementia: A qualitative study. *Aging and Mental Health*, 11(2), 131-143. doi: 10.1080/13607860600844572
- Proctor, G. (2001). Listening to older women with dementia: Relationships, voices and power. *Disability and Society*, 16(3), 361-376. doi: 10.1080/09687590120045932
- Ragin, C.C. (1992). Cases of "What is a case?" In C.C. Ragin & H.S. Becker (Eds.), *What is a case? Exploring the foundations of social inquiry*. Cambridge: Cambridge University Press.
- Reader, S. (2007). The other side of agency. *Philosophy*, 82, 579-604. doi: 10.1017/S0031819107000162
- Reinhartz, S (1997). Who am I? The need for a variety of selves in the field. In R. Hertz, *Reflexivity and Voice*. Thousand Oaks, CA: Sage.
- The Relatives & Residents Association (2010). *Together but alone: Isolated older people in care*. London: The Relatives & Residents Association.
- Riessman, C.K. (1990). Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine*, 30(2), 1195-1200. doi: 10.1016/0277-9536(90)90259-U
- Riessman, C.K. (2008). *Narrative Methods for the Human Sciences*. Thousand Oaks, CA: Sage.
- Rose, K.M., & Lopez, R.P. (2012). Transitions in dementia care: Theoretical support for nursing roles. *Online Journal of Issues in Nursing*, 17(2), Manuscript 4. *Online Journal of Issues in Nursing*, 17(2), Manuscript 4. doi: 10.3912/OJIN.Vol17No02Man04
- Routledge, C., Arndt, J., Wildschut, T., Sedikides, C., Hart, C.M., Juhl, J., Vingerhoets, Ad J.J M., & Schlotz, W. (2011). The past makes the present meaningful: Nostalgia as an existential resource. *Journal of Personality and Social Psychology*, 101(3), 638-652. doi: 10.1037/a0024292
- Routledge, C., Wildschut, T., Sedikides, C., Juhl, J. and Arndt, J. (2012). The power of the past: Nostalgia as a meaning making resource, *Memory*. 20(5), 452-460. doi: 10.1080/09658211.2012.677452
- Ryan, G.W., & Bernard, H.R. (2003). Techniques to identify themes. *Field Methods*, 15(1), 85-109. doi: 10.1177/1525822X02239569
- Sabat, S. (2002). Surviving manifestations of selfhood in Alzheimer's disease: A case

- study. *Dementia*, 1(1), 25-36. doi: 10.1177/147130120200100101
- Saldaña, J. (2003). *Longitudinal qualitative research: Analysing change through time*. Walnut Creek, CA: Altamira Press.
- Samsi, K., & Manthorpe, J. (2014). Care pathways for dementia: Current perspectives. *Clinical Interventions in Aging*, 9, 2055-2063. doi: 10.2147/CIA.S70628
- Scottish Dementia Working Group Research Sub Group (2014). Core principles for involving people with dementia in research: Innovative practice. *Dementia*, 13(5), 680-685. doi: 10.1177/1471301214533255
- Scottish Government (2008a) *Adults with Incapacity (Scotland) Act 2000 Code of Practice for Local Authorities Exercising Functions under the 2000 Act*. Edinburgh: Author.
- Scottish Government (2008b) *Adults with Incapacity (Scotland) Act 2000 Communication and Assessing Capacity: A Guide For Social Work and Health Care Staff*. Edinburgh: Author.
- Scottish Government (2013). *National dementia strategy 2013-2016*. Edinburgh: Author.
- Scottish Government (2017). *National dementia strategy 2017-2020*. Edinburgh: Author.
- Scottish Government (2018). *A connected Scotland: Our strategy for tackling social isolation and loneliness and building stronger social connections*. Edinburgh: The Scottish Government. Retrieved from <https://www.gov.scot/publications/connected-scotland-strategy-tackling-social-isolation-loneliness-building-stronger-social-connections/>
- Shakespeare, T. (2000). *Help*. Birmingham: Venture Press.
- Shakespeare, T. (2006). *Disability rights and wrongs*. Oxon: Routledge.
- Shakespeare, T., & Watson, N. (2002). The social model of disability: An outdated ideology? *Research in Social Science and Disability*, 2, 9-28.
- Shakespeare, T., & Watson, N. (2010). Beyond models: Understanding the complexity of disabled people's lives. In G. Scambler & S. Scambler (Eds.), *New directions in the sociology of chronic and disabling conditions: Assaults on the lifeworld*. Basingstoke: Palgrave: Macmillan.
- Shakespeare, T., Zeilig, H., & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia*. Advanced online publication. doi: 10.1177/1471301217701506

- Shomaker, D.J. (1989). Age disorientation, liminality and reality: The case of the Alzheimer's patient. *Medical Anthropology*, 12(1), 91-101.
doi: 10.1080/01459740.1989.9966013
- Simons, H. (1996). The paradox of case study. *Cambridge Journal of Education*, 26(2), 225-240. doi: 10.1080/0305764960260206
- Simons, H. (2009). *Case study research in practice*. London: Sage.
- Singleton D., Mukadam N., Livingston G., & Sommerlad, A. (2017). How people with dementia and carers understand and react to social functioning changes in mild dementia: a UK-based qualitative study. *BMJ Open* 2017;7:e016740.
doi: 10.1136/bmjopen-2017-016740
- Sjöberg, M., Beck, I., Rasmussen, B.H., & Edberg, A.-K. (2017). Being disconnected from life: Meanings of existential loneliness as narrated by frail older people. *Aging & Mental Health*. Advanced online publication.
doi: 10.1080/13607863.2017.1348481
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: theory, method and research*. London: Sage.
- Social Research Association (2003). *Social Research Association Ethical Guidelines*. Retrieved on May 9, 2015, from <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf>
- Somers, M. (1994). The Narrative constitution of identity: A relational and network approach. *Theory and Society*, 23(5), 605-649. Retrieved from <http://www.jstor.org.ezproxy.is.ed.ac.uk/stable/658090>
- Soniat, B.A. (2004). Dementia patients who live alone: Research and clinical challenges. *Journal of American Geriatric Society*, 52, 1576-1577.
doi: 10.1111/j.1532-5415.2004.52427.x
- Spencer, L., & Pahl, R. (2006). *Rethinking friendship: Hidden solidarities today*. Princeton, NJ: Princeton University Press.
- Stake, R.E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage
- Stake, R.E. (2000). The case study method in social inquiry. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case study method*. London: Sage. (original work published in 1978)
- Sterin, G.J. (2002). Essay on a word: A lived experience of Alzheimer's disease. *Dementia*, 1(1), 7-10. doi: 10.1177/147130120200100103

- Stiles, W.B. (2001). Assimilation of problematic experiences. *Psychotherapy*, 38(4), 462-465. doi: 10.1037/0033-3204.38.4.462
- Surr, C. (2006). The role of interpretive biographical methodology in dementia research. *Dementia*, 5(2), 284-290. doi: 10.1177/147130120600500210
- Svanström, R., & Sundler, A.J. (2015). Gradually losing one's foothold: A fragmented existence when living alone with dementia. *Dementia*, 14(2), 145-63. doi: 10.1177/1471301213494510
- Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, 19(1), 93-117. doi:10.1111/j.1467-9566.1997.tb00017.x
- Taylor, B.E. (2014.) *Loitering in a liminal space: Enactments of differing realities of hallucinations in dementia* (Unpublished PhD thesis). University of Edinburgh, Edinburgh, Scotland.
- Taylor, C. (2004). *Modern Social Imaginaries*. Durham, NC: Duke University Press.
- Thomas, C. (1999). *Female forms: experiencing and understanding disability*. Buckingham: Open University Press.
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569-583. doi: 10.1080/0968759042000252506
- Thomas, C., & Milligan, C. (2015). *How can and should UK society adjust to dementia?* York: Joseph Rowntree Foundation.
- Thomas, C., & Milligan, C. (2018). Dementia, disability rights and disablism: Understanding the social position of people living with dementia. *Disability & Society*, 33(1), 115-131. doi: 10.1080/09687599.2017.1379952
- Thomas, G. (2011). *How to do Your Case Study: A Guide for Students and Researchers*. London: Sage.
- Thomassen, B. (2009). The Uses and Meanings of Liminality. *International Political Anthropology*, 2(1), 5-27.
- Thompson, R., Valenti, E., Siette, J., & Priebe, S. (2016). To befriend or to be a friend: A systematic review of the meaning and practice of "befriending" in mental health care. *Journal of Mental Health*, 25(1), 71-77. doi: 10.3109/09638237.2015.1021901

- Thomson, R. (2007). The qualitative longitudinal case history: Practical, methodological and ethical reflections. *Social Policy & Society*, 6(4), 571-582. doi:10.1017/S1474746407003909
- Thomson, R., & McLeod, J (2015). New frontiers in qualitative longitudinal research: An agenda for research. *International Journal of Social Research*, 18(3), 243-250. doi: 10.1080/13645579.2015.1017900
- Todres, L., & Galvin, K. (2005.) Pursuing both breadth and depth in qualitative research: Illustrated by a study of the experience of intimate caring for a loved one with Alzheimer's disease. *International Journal of Qualitative Methods*, 4(2), 20-31. doi: 10.1177/160940690500400202
- Tolhurst, E., Weicht, B., & Kingston, P. (2017). Narrative collisions, sociocultural pressures and dementia: The relational basis of personhood reconsidered. *Sociology of Health & Illness*, 39, (2), 212-226. doi: 10.1111/1467-9566.12523
- Tower Hamlets Friends and Neighbours (2012). *More than just tea and a chat: Our experience of befriending*. London: Tower Hamlets Friends and Neighbours.
- Turner, V.W. (1964). Betwixt and between: The liminal period in *rites de passage*. In The Proceedings of the American Ethnological Society Symposium on New Approaches to the Study of Religion, pp. 4-20. Pittsburgh: University of Pittsburgh.
- Turner, V.W. (1977). Variations on a theme of liminality. In S.F. Moore & B.G. Myerhoff (Eds.), *Secular Ritual*. Assen, Netherlands: Van Gorcum.
- Tyson, L. (2015). *Critical theory today: A user friendly guide* (3rd ed.). Oxon: Routledge
- UK Data Archive (n.d.). *Anonymisation*. Retrieved August 5, 2015, from <https://www.ukdataservice.ac.uk>
- Vaismoradi, M., Jones, J., Turunen, H., & Snelgrove, S. (2016). Theme development in qualitative content analysis and thematic analysis. *Journal of Nursing Education and Practice*, 6(5), 100-10. doi: 10.5430/jnep.v6n5p100
- van Gennep, A. (1960). *The rites of passage* (M.B. Vizedom & G.L. Caffee, Trans.). London: Routledge & Kegan Paul. (original work published 1909)
- Vintage Vibes (n.d.). *Our services*. Retrieved July 4, 2019, from <https://vintagevibes.org.uk/>
- Wall, S. (2015) Focused ethnography: A methodological adaptation for social research in emerging contexts [40 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 16(1), Art. 1. Retrieved from <http://nbn-resolving.de/urn:nbn:de:0114-fqs150111>

Ward, R., Howorth, M., Wilkinson, H., Campbell, S., & Keady, J. (2011). Supporting the friendships of people with dementia. *Dementia*, 11(3), 287-303. doi: 10.1177/1471301211421064

Ward Griffin, C., Bol, N., & Oudshoorn, A. (2006). Perspectives of women with dementia receiving care from their adult daughters. *Canadian Journal of Nursing Research*, 38(1), 120-146.

Warner, J., McCarney, R., Griffin, M., Hill, K., & Fisher, P. (2008). Participation in dementia research: Rates and correlates of capacity to give informed consent. *Journal of Medical Ethics*, 34, 167-170. doi: 10.1136/jme.2006.019786

Weicht, B. (2013). The making of 'the elderly': Constructing the subject of care. *Journal of Aging Studies*, 27, 188-197. doi: 10.1016/j.jaging.2013.03.001

Weir, M., Goode, R., & McDonald, A. (2010). Midlothian Befrienders' cross generational networking across the school community divide to build social capital. *Journal of Intergenerational Relationships*, 8(1), 69-78. doi: 10.1080/15350770903520684

West, K., Shaw, K., Hagger, B., & Holland, C. (2017). Enjoying the third age! Discourse, identity and liminality in extra care communities. *Ageing & Society*, 37, 1874-189797. doi: 10.1017/S0144686X16000556

Windle, K., Francis, J., & Coomber, C (2011). *Preventing loneliness and social isolation: Interventions and outcomes* (Research briefing 39). London: Social Care Institute for Excellence.

Wolverson, E.L., Clarke, C., & Moniz-Cook, E.D. (2016). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Ageing & Mental Health*, 20(7), 676-699. doi: 10.1080/13607863.2015.1052777

Wray, S. (2004). What constitutes agency and empowerment for women in later life? Toward the development of a culturally sensitive theoretical framework to examine ageing. *Sociological Review*, 52(1), 22-38. doi: 10.1111/j.1467-954x.2004.00440.x

Yale, R. (2013). *Counseling people with early-stage Alzheimer's disease: A powerful process of transformation*. Baltimore: Health Professions Press.

Zeilig, H (2015). What do we mean when we talk about dementia? Exploring cultural representations of "dementia". *Working with Older People*, 19(1), 12-20. doi: 10.1108/WWOP-10-2014-0032

6, P. (2004). Can government influence our friendships? The range and limits of tools for trying to shape solidarities. In C. Phillipson, G. Allan & D. Morgans (Eds.), *Social networks and social exclusion: Sociological and policy perspectives*.

Aldershot: Ashgate.

APPENDICES

APPENDIX A



Jane Andrew



THE UNIVERSITY
of EDINBURGH

Participant Information Leaflet About me

My name is Jane Andrew. I'm a research student at Edinburgh University. I'm interested in what it's like to have a befriender if you have memory difficulties or dementia.

About the research

I would like to find out about your experiences of befriending and your day to day life. I will use the information to build a picture of what befriending means to people who have memory difficulties or dementia. This may play a part in helping people in a similar situation in the future.

What's it like to have a befriender?

Research Project: The Meanings and Experiences of Befriending for People who have Memory Difficulties or Dementia

About taking part

If you're interested, I'd like to come and see you, and we can talk about the research, and get to know each other a bit better. You can decide after this what you want to do.

If you agree to take part, I would like to visit you a few times at home or another place where you feel at ease – you can choose. I would like us to talk about what it's like to have a befriender and about your day to day life.

What sort of things do I want to find out?

I am interested in what you want to tell me about having a befriender and day to day life. This might be things like:



What it's like to have a befriender?

- the kinds of things you do together
- how you get on
- the difference it makes to you



Your day to day life.

- what a usual day is like for you
- what you do on different days
- other people you see



About you

- tell me a bit about yourself
- changes in your life
- things it's important your befriender knows about you

How we can do the research

- ★ by talking together and having a conversation
- ★ by looking at and talking about photographs or things that are special to you
- ★ by you showing me what you do with your befriender, eg, going out somewhere, playing a game, having a chat

Important things to know

To help me, I will want to record what we say using a recorder. This will stay private.

I'm only interested in what you want to tell me. You don't have to talk about anything you don't want to.

I will check to make sure you're feeling okay. We can stop at any time. It's all right to have someone with you. You can ask me questions.

You do not have to take part in the research. If you don't want to, you will still get the same services. You can also change your mind about

taking part at any time. You don't have to say why.
Your services will stay the same.

What will happen to the things you tell me?

At the end of the research, I will write a report or thesis for my research degree. This will be about what you and other people have told me about your experience of befriending.

I will give you a short copy of the research report. I will also share what I learn with other people interested in befriending services. I may publish articles about the research.

I might want to quote what you say. I will not use your name or other personal information so that you and anyone you talk about can't be identified. Information about you will be stored safely and kept confidential.

What if you have questions or concerns?

If you would like to know more, or have questions or concerns, you can talk to:

Me (Jane Andrew): (01738) 447188

or

[.....]

If you would like to talk to someone independent of the research, please contact:

Dr Colin Chandler (Postgraduate Research Coordinator):

Tel 0131-6515168

Email: Colin.Chandler@ed.ac.uk

School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG

What to do if you are interested in taking part

Please let know, or contact me:

Jane Andrew

Tel: (01738) 447188

Email: s1459490@sms.ed.ac.uk

School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG

Thank you for taking time to read this.

APPENDIX B



THE UNIVERSITY
of EDINBURGH

Jane Andrew

What's it like to have a befriender?

Research Project: The Meanings and Experiences of Befriending for People who have Memory Difficulties or Dementia

Information Leaflet for Family Members, Friends, Volunteers and Professionals

About me

I am a research student at the University of Edinburgh. Before this, for many years, I worked with people with dementia as a mental health nurse and as a community support worker. In this research project, I want to learn more about the experience of befriending for people who have memory difficulties or dementia.

About the research

Research has shown that befriending relationships can be valued by both volunteer befrienders and their befriending partners. However, there has been little research about the experience of befriending from the point of view of people with memory difficulties or dementia.

I am interested in what it's like for a person with memory difficulties or dementia to have a volunteer befriender, and what having a befriender means to them in their everyday life.

The aim of the research is to contribute to knowledge about services for people with memory difficulties or dementia which offer informal social and emotional support.

Who can take part?

Anyone known to have memory difficulties or dementia, who has a volunteer befriender, lives in the community, and is able to give informed consent to take part, can be in the research.

The study recognises that different people have different understandings and experiences of memory difficulties or

dementia. The person does not have to talk about memory difficulties or dementia but they can if they wish to.

What will taking part involve?

I hope to visit each person who agrees to take part in the project two or three times or so. The visits will take place at the person's home or another place of their choice, and will usually last from thirty minutes to an hour. The person can have someone with them if they wish.

I plan to talk to each person about what it's like to have a befriender, and about their day to day life. The visits will be very informal. The person can choose what they want to say about their experiences, and won't be expected to talk about anything they don't wish to.

I will want to record the conversations using a digital voice recorder.

Who else will be involved?

It is important that anyone considering taking part is enabled to make an informed decision. It is also important that each person who does join the project feels properly supported.

At the start of the study, someone (or more than one person) who knows the person well, eg, befriending service staff, family member, health or social care worker, will be identified to: approach a person they think might be interested, check whether they are able to give informed consent; introduce me; and provide ongoing support if needed.

What will happen to the information participants share with me?

The information will be used to write my doctoral thesis at the University of Edinburgh. With the consent of participants, personal accounts will form part of the thesis, but great care will be taken to ensure that each person and anyone they talk about cannot be identified. A person's name and their personal details will not be used. Personal information will be stored securely and kept confidential.

A summary of the research findings will be given to participants. The findings will be shared with befriending organisations and other interested groups, and may also be shared through publishing articles.

What if I have any questions?

If you have any questions about the research, please don't hesitate to contact me:

Jane Andrew

Tel: (01738) 447188

Email: s1459490@sms.ed.ac.uk

School of Health in Social Science, University of Edinburgh,
Teviot Place, Edinburgh, EH8 9AG

If you have questions or concerns that you wish to discuss with someone independent of the research, please contact:

Dr Colin Chandler (Postgraduate Research Coordinator)

Tel: 01316515168

Email: Colin.Chandler@ed.ac.uk

School of Health in Social Science, University of Edinburgh,
Teviot Place, Edinburgh, EH8 9AG

Thank you for taking time to read this.

APPENDIX C



Research Project: The Meanings and Experiences of Befriending for People with Memory Difficulties or Dementia

What's it like to have a befriender?

Information for Befriending Organisation/Health and Social Care Professionals

Gaining Consent for Research

This information sheet is to be used alongside the Information Leaflet for Participants and the Information Leaflet for Family Members, Friends, Volunteers and Professionals.

There are three key parts to deciding whether a person is able to give consent to take part in the research.

A Potential Participant Needs to:	
Be informed	Be given enough information about the research in a way the person can understand.
Choose freely	Agree to take part willingly without persuasion or influence.
Have capacity	Be able to understand what the research is about, what taking part will involve, and what will happen to the information they share. Be aware of the pros and cons of taking part. Be able to remember information about the research for long enough to decide about taking part, or continue to agree to participate each time the research is explained to them.

Be Informed

Please invite the person to read the information leaflet or, if the person finds it easier, talk to them about the research, explaining what the project is about and what will happen if they take part. I am also happy to be in contact to discuss the research and answer any questions.

Choose Freely

Taking part is completely voluntary. It's important to support and enable the person to become involved in the research if they wish to, but it's also very important that the person isn't influenced or persuaded to agree to take part. If a person says they don't want to take part or shows in some other way that they are not happy to take part, eg, they seem anxious or uninterested, then this should be accepted as the person choosing not to participate.

Have Capacity

The person needs to understand what the research is about, what it will involve, and what will happen to the information they share. The person needs to be aware of the pros and cons of getting involved, eg, what it might be like to talk about their experiences with a researcher. The person needs to understand that they do not have to take part or can stop taking part at any time without giving a reason; and that not taking part or withdrawing will not affect any services they receive. The person needs to be able to remember information about the research for long enough to decide about taking part. If a person can't remember agreeing to take part they can still participate as long as, when reminded about the research, they continue to agree to take part.

What happens next?

If you think a person is able to give informed consent and the person is willing to take part in the study, please contact me (my contact details are below).

I would then like to arrange to meet with the person to introduce myself, talk about the research and answer any questions. The person can have someone with them if they wish. After the meeting, the person will have time to think things over, and I will arrange to contact them (or a nominated person) in a week (or longer if they wish) to find out their decision. At the first research visit, the person will be asked to sign a consent form (or if need be their verbal consent can be recorded or witnessed). The person's willingness and ability to consent to take part will be explored at each research visit.

If the person seems interested in taking part but you're not sure whether they are able to give informed consent, or if you have any other queries or things you would like to discuss, please contact me.

Jane Andrew

Tel: (01738) 447188 Email: s1459490@sms.ed.ac.uk

School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG

APPENDIX D



Research Project:

The Meanings and Experiences of Befriending for People with Memory Difficulties or Dementia

What's it like to have a befriender?

Consent Form

Please circle YES or NO for each statement below:

- | | |
|---|----------|
| I have had a chance to look at the information leaflet and ask questions | YES / NO |
| I have talked to Jane Andrew about the research | YES / NO |
| I understand what the research is about and what taking part will involve | YES/ NO |
| I know that I don't have to take part and don't have to give a reason why | YES / NO |
| I know that I can stop taking part at any time without giving a reason | YES / NO |
| I know that if I don't take part or stop taking part my support and services won't be affected at all at any time | YES / NO |
| I agree that Jane can record what what we talk about | YES / NO |
| I agree that Jane can write about and quote what I say | YES / NO |
| I know that my name and other personal information will not be used so that I and anyone I talk about will not be identified. | YES / NO |
| I understand that everything I tell Jane will stay private unless she is concerned I might come to harm | YES / NO |
| I agree to take part in the study | |

Your name.....

Signed.....

Today's date.....

APPENDIX E



Research Project:

The Meanings and Experiences of Befriending for People with Memory Difficulties or Dementia

What's it like to have a befriender?

Consent Form

I have talked to Jane Andrew about the research and asked questions

I understand what the research is about and what taking part involves

I know that I don't have to take part - and can stop taking part - and I don't have to give a reason why; my services won't change at all

I agree that Jane can record what we talk about

I agree that Jane can write about and quote what I say

I know that my name and other personal information will not be used so that I and anyone I talk about will not be identified.

I agree to take part in the study

Your name.....

Signed.....

Today's date.....

APPENDIX F



Jane Andrew



THE UNIVERSITY
of EDINBURGH

What's it like to have a befriender?

Research Newsletter

Findings So Far

Research Project: The Meanings and Experiences of Befriending for People who have Memory Difficulties

October 2017

★ News on the Research

I want to let you know about the befriending research you took part in last year.

What you and other people told me has helped me build a picture of what befriending means to people who have memory difficulties and other health problems.

The research is not finished yet. It takes a long time. I can share some of the main findings so far.

★ Life Changes

People talked about ways their lives had changed:

- having more health problems
- the loss of close relationships
- having to rely on other people
- moving to sheltered housing
- not being able to get out much
- being less active than before
- losing contact with people
- needing help from services
- feeling lonely or bored
- spending more time alone



★ Everyday Life

People said that day to day life could be hard. They managed but sometimes it was a struggle.

People often felt unwell or not themselves. This could be feeling down, dizzy, tired, worried, forgetful or muddled up; or having falls, aches and pains, seizures or difficulty walking.

Memory loss and other health problems stopped people from doing what they used to be able to do. They missed getting out and about. They felt stuck at home. They depended on other people to visit them and take them out, and do practical things for them.

Everyone who took part lived on their own, and sometimes felt bored or lonely. They missed people who had died or moved away or become unwell or were taking care of someone else or lived elsewhere.



★ New Friends

People kept in touch with old friends if they could but also wanted to make new friends. This was hard due to life changes and having few chances to meet the right people. Everyone wanted to have friends and also to be a friend.

★ Other People

Every day, everyone saw or spoke to at least one person, and usually several people, such as family members, home carers, a home help, a hairdresser, cleaners, staff and members of day clubs, and sheltered housing staff and residents. People talked about good sides and difficult sides to their relationships. For example:



As well as loving and caring about family members, some people felt bad having to rely on them, didn't want to worry them, or thought they could sometimes be a bit bossy or insensitive.

As well as being happy with friendly, helpful home carers, everyone said they had too many different carers who made quick visits so they couldn't get to know them.

As well as appreciating some things about going to a day centre or living in sheltered housing, people felt they weren't really getting to know anyone, or didn't have much in common with them.

People felt lonely not just because they were on their own a lot, or because they had nobody in their life, but because they missed certain kinds of relationship.

★ What's good about having a befriender?

Befrienders mattered to people in different ways depending on their present situation and their life stories. Many good points about having a befriender were mentioned by everyone.



With a befriender:

- you get to know them and they get to know you
- you both enjoy being together and doing things together
- you are part of their life and they are part of yours



A befriender:

- treats you as a person and not just someone who needs help
- knows about problems you have with your health
- helps you do the things you want to do
- goes out with you if you wish and can give you a lift
- assists you with practical things



A befriender is:

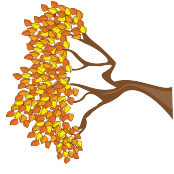
- someone you can share things with such as memories, interests, opinions, ideas, everyday experiences, and keeping up with each other's lives
- someone you can talk to outside your family and care services
- someone you can confide in and who will keep what you say private
- someone you look forward to seeing
- someone you feel is nearby
- someone you think of, and who thinks of you, when you are not together
- someone who keeps you company and gives you a break from feeling lonely or bored
- someone to enjoy doing ordinary things with such as watching sport on television; going shopping or out for coffee, a walk, or an ice cream; having fun.



A befriender is a friend and also a kind of service

★ **Things people said about their befriender:**

“I know she’s there and it’s a good feeling”



“she took me out a lot”

“means I can talk to somebody”

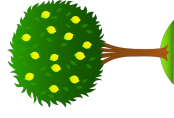
“I know them and they know me”

“she was a friend rather than a befriender”

“I look forward to him coming”

“you can tell them anything because it’s confidential”

“a man-tae-man thing”



“it gies me a break”

“it’s so important”

“we had the same sort of ideas we could talk about any subject”

“it’s totally different because it’s your private life”

“while she’s in her own house she’s thoughtful for me”

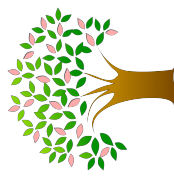
“she knows what I can do and what I can’t do”

“he’s guid a friend and that”

“since he’s been away like ken I quite miss him”

“I think he quite enjoys hiself an aw”

“we like the same things”



“full of life”

“she’s a comic at times”

“she just pops up!”

“I wish I could see more of her”

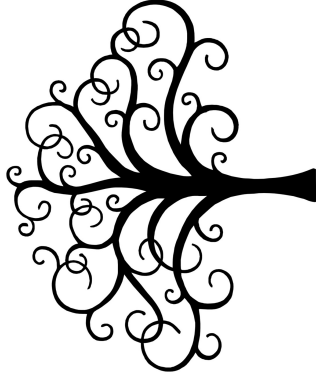
“she was quite good at helping me to shop”

“she helps you feel good”

“you need somebody like that”

Thank you very much for helping me and other people understand why befriending matters.

I will keep you posted about the research.



Thank You

If you have any questions or concerns you can talk to me or ask someone else to contact me on your behalf:

Jane Andrew

Tel: 01738 - 447188

Email: s1459490@sms.ed.ac.uk

School of Health in Social Science, University of Edinburgh, Teviot Place, Edinburgh, EH8 9AG



If you would like to talk to someone independent of the research, please contact:

Postgraduate Research Coordinator:

Dr Colin Chandler: 0131- 6515168 (until 31/10/17)

Email: Colin.Chandler@ed.ac.uk

Dr Ken MacMahon: 0131- 6513960 (from 1/11/17)

Email: ken.macmahon@ed.ac.uk

School of Health in Social Science, Teviot Place, Edinburgh, EH8 9AG

APPENDIX G

Appendix G: Example of Data Analysis Process

Extract from first recorded conversation with Tom (May 2016).

T = Tom

J = Jane

T: nothing here really even this place is ssssfff aye

J: do you know people ye yer neighbours do you know your neighbours?

T: they aw keep to theirself

J: oh do they? Do they?

T: aye

J: oh

T: och there's

J: [sheltered housing manager] was saying you have um like there's a dining room downstairs

T: aye there there was er ah it used to be all right a couple o years ago but [] and that was it it just aw dried up like ken I was doon the other [] "Why do we no go away any more?" "Nae one wants to go Tom" so there we go ach it's usually a couple o bob tae go ken?

J: yeah

T: [aye there was times there was the long boat on the canal like with the OAPs but once was enough like ken?]

J: oh right

T: once was enough even er I go tae a club on a Monday and that's a bit dodgy noo

J: oh aye is that the [name of organisation] one?

T: aye aye

J: that's dodgy?

T: aye it's getting a bit thingammy noo I enjoyed myself last week like ken but

J: did you?

T: aye

J: so it's a bit hit and miss?

T: aye aye aye

J: sometimes it's all right

T: but it's a fuckin some of them used to have a clue down there like ye ken? But there's only four or five take it noo ye ken ach

J: mmm right when it's good what makes it good?

T: ah well ye go oot ken? And things like that ken

J: oh the you you go out from the

T: aye but nowadays nobody wants to go anywhere naebody wants to go anywhere it's like in here this place is crap [laughs!]

J: [laughing] so nobody here wants to go out with you?

T: naebody wants to go anywhere!

J: nobody wants to go anywhere
T: that's what I was saying to ye "When are we goin oot?" "Tom nobody wants to go anywhere"
J: ohh so they all stay indoors?
T: they aw stay indoors aye
J: that's what it sounds like it sounds like you're itching to get out and go somewhere
T: [] [laughing]
J: [laughing]
T: uh ach aye it used to be guid but no now yaaach
J: what would make it better?
T: goin oot!
J: going out where would you go?
T: [burps] anywhere!
J: anywhere yeah
T: that's that's we used to go oot fer eh away for the weekend I said "When are we going away for the weekend?" "Nae one wants to go anywhere Tom"
J: oh right
T: ken things like that
J: did you used to go away for a weekend from here?
T: aye
J: oh right like an outing like a few of you go out away for somewhere
T: aye quite a few of us used to go out like nowadays errr this is a place where you die if I tell you the truth that's the honest truth
J: is that how you feel about this place?
T: aye
J: a place where you die?
T: aye that's what I said to [manager] "I'm going I'm going doon I wannae go doon [] the morn hm pff see if I can find somewhere else to live" ken? this place is a tip ken?
J: mmmm
T: aw I do aw day aw I do nowadays is go doon there and get a cerry oot and come back and watch television I've tried that pub, I've tried that pub ach!
J: mmm
T: [has a mouthful of beer] it's er it's a bit er it's under the weather put it that way [laughs]
J: right
T: if tss ken naebody wants tae dae anything at aw noo ken?
J: no? what about [befriender] does he
T: oh he's awright aye
J: how about would that would you go out with him?
T: [befriender's] awright aye
J: what about do you go out with [befriender]?
T: oh naw no really I cannae go it'd be awright if I had a car or something like ken? It'd be nae bother like ken? But
J: yeah
T: I cannae walk that far anyway

J: right right

T: and if you go on a bus you'll go away ages on a bus and then you've got to come away the way back like

J: so you want a motor you need a kinda transport?

T: ach! to tell you the truth I'm not that bothered noo actually to tell you the truth I'm not that bothered noo

J: no?

T: to tell you I'm not that bothered [befriender] comes down to see me and that's fine for me ken? Makes a wee change means I can talk to somebody and things like that ken

J: yeah

T: we talk about we only talk about life and fitba and things like that ken [] I dinnae go in for fitba very much noo like ken but still it aw gies me a break ken you need somebody like that

J: yeah

T: cos er the carers they come in like ken?

J: yeah

T: they're only here for ten minutes an "There's your pills Tom bye bye" an there's three drugs in here supposed to spend half an oor wi ye daein what like? ["Ah well who's] tidying things?" [wrang] I dae it aw myself "But we're supposed to dae it" ken?

J: oh right, yeah

T: [they] came in this morning "We're gonnae polish an that". I says "Wha are ye wantin daein? "Make your bed" "I can make my ane bed" "Clean sheets" "Dae that masel" [] They says er "Washing" "Dae it masel" [] [turned roond] [] "Have smoke or what if you want" er och yer "I thought I'd told yous I dinnae want yous here anyway" They say "We've got to come Tom that's it" [manager] old them like ken?

J: mmm

Appendix G: Example of Data Analysis Process

Second Reading ('I-voice') underlined in green (where 'I' reading coincides with 'reading for relationships', I have highlighted relevant text in green).

Third Reading ('relationships') underlined in red.

T: nothing here really even this place is ssssfff aye

J: do you know people ye yer neighbours do you know your neighbours?

T: they aw keep to theirself

J: oh do they? Do they?

T: aye

J: oh

T: och there's

J: [sheltered housing manager] was saying you have um like there's a dining room downstairs

T: aye there there was er ah it used to be all right a couple o years ago but [] and that was it it just aw dried up like ken I was doon the other [] "Why do we no go away any more?" "Nae one wants to go Tom" so there we go ach it's usually a couple o bob tae go ken?

J: yeah

T: [aye there was times there was the long boat on the canal like with the OAPs but once was enough like ken?]

J: oh right

T: once was enough even er I go tae a club on a Monday and that's a bit dodgy noo

J: oh aye is that the [name of organisation] one?

T: aye aye

J: that's dodgy?

T: aye it's getting a bit thingammy noo I enjoyed myself last week like ken but

J: did you?

T: aye

J: so it's a bit hit and miss?

T: aye aye aye

J: sometimes it's all right

T: but it's a fuckin some of them used to have a clue down there like ye ken? But there's only four or five take it noo ye ken ach

J: mmm right when it's good what makes it good?

T: ah well ye go oot ken? And things like that ken

J: oh the you you go out from the

T: aye but nowadays nobody wants to go anywhere naebody wants to go anywhere it's like in here this place is crap [laughs!]

J: [laughing] so nobody here wants to go out with you?

T: naebody wants to go anywhere!

J: nobody wants to go anywhere
T: that's what I was saying to ye "When are we goin oot?" "Tom nobody wants to go anywhere"
J: ohh so they all stay indoors?
T: they aw stay indoors aye
J: that's what it sounds like it sounds like you're itching to get out and go somewhere
T: [] [laughing]
J: [laughing]
T: uh ach aye it used to be guid but no now yaaach
J: what would make it better?
T: goin oot!
J: going out where would you go?
T: [burps] anywhere!
J: anywhere yeah
T: that's that's we used to go oot fer eh away for the weekend I said "When are we going away for the weekend?" "Nae one wants to go anywhere Tom"
J: oh right
T: ken things like that
J: did you used to go away for a weekend from here?
T: aye
J: oh right like an outing like a few of you go out away for somewhere
T: aye quite a few of us used to go out like nowadays errr this is a place where you die if I tell you the truth that's the honest truth
J: is that how you feel about this place?
T: aye
J: a place where you die?
T: aye that's what I said to [manager] "I'm going I'm going doon I wannae go doon [] the morn hm pff see if I can find somewhere else to live" ken? this place is a tip ken?
J: mmmm
T: aw I do aw day aw I do nowadays is go doon there and get a cerry oot and come back and watch television I've tried that pub, I've tried that pub ach!
J: mmm
T: [has a mouthful of beer] it's er it's a bit er it's under the weather put it that way [laughs]
J: right
T: if tss ken naebody wants tae dae anything at aw noo ken?
J: no? what about [befriender] does he
T: oh he's awright aye
J: how about would that would you go out with him?
T: [befriender's] awright aye
J: what about do you go out with [befriender]?
T: oh naw no really I cannae go it'd be awright if I had a car or something like ken? It'd be nae bother like ken? But
J: yeah
T: I cannae walk that far anyway

J: right right

T: and if you go on a bus you'll go away ages on a bus and then you've go tae come aw the way back like

J: so you want a motor you need a kinda transport?

T: ach! to tell you the truth I'm no that bothered noo actually to tell you the truth I'm no that bothered noo

J: no?

T: to tell you I'm no that bothered [befriender] comes doon to see me and that's fine for me ken? Makes a wee change means I can talk to somebody and things like that ken

J: yeah

T: we talk about we only talk about life and fitba and things like that ken [] I dinnae go in for fitba very much noo like ken but still it aw gies me a break ken you need somebody like that

J: yeah

T: cos er the carers they come in like ken?

J: yeah

T: they're only here for ten minutes an "There's your pills Tom bye bye" an there's three drugs in here supposed to spend half an oor wi ye daein what like? ["Ah well who's] tidying things?" [wrang] I dae it aw myself "But we're supposed to dae it" ken?

J: oh right, yeah

T: [they] came in this morning "We're gonnae polish an that". I says "Wha are ye wantin daein?" "Make your bed" "I can make my ane bed" "Clean sheets" "Dae that masel" [] They says er "Washing" "Dae it masel" [] [turned roond] [] "Have smoke or what if you want" er och yer "I thought I'd told yous I dinnae want yous here anyway" They say "We've got to come Tom that's it" [manager] old them like ken?

J: mmm

Appendix G: Example of Data Analysis Process

‘I-voice’ and ‘relationship’ readings copied and pasted in sequence.

Relationship utterances (in original sequence) grouped together according to which person, people or institution they refer to.

Second Reading: I-Voice

I was doon the other []

I go tae a club on a Monday
I enjoyed myself last week

ye go oot

that’s what I was saying to ye

I said “When are we going away for the weekend?”

if I tell you the truth

that’s what I said to [manager]
“I’m going
I’m going doon
I wannae go doon []
see if I can find somewhere else to live”

aw I do aw day
aw I do nowadays
is go doon there
and get a cerry oot
and come back
and watch television
I’ve tried that pub
I’ve tried that pub ach!

I cannae go
it’d be awright if I had a car or something
I cannae walk that far anyway
if you go on a bus
you’ll go away ages on a bus
and then you’ve go tae come aw the way back

I'm no that bothered noo actually
to tell you the truth
I'm no that bothered noo
to tell you
I'm no that bothered noo
[befriender] comes doon tae see me
and that's fine for me
means I can talk tae somebody
I dinnae go in for fitba very much noo
still it aw gies me a break ken
you need somebody like that

"I dae it aw myself"
I says "Wha are ye wantin daein?"
"I can make my ane bed"
"Dae that masel"
"Dae it masel"

"I thought I'd told yous
I dinnae want yous here anyway"

Third Reading: Relationships

Sheltered Housing

nothing here really

even this place is sssfff

they aw keep to theirself

it used to be all right a couple o years ago
it just aw dried up like ken

"Why do we no go away any more?"
"Nae one wants to go Tom"
so there we go
it's usually a couple o bob tae go ken?

[there was the long boat on the canal like
with the OAPs
but once was enough like ken?]
once was enough

Day Centre

I go tae a club on a Monday
and that's a bit dodgy noo

it's getting a bit thingammy noo
I enjoyed myself last week
but it's a fuckin
some of them used to have a clue down there
but there's only four or five take it noo

but nowadays nobody wants to go anywhere
naebody wants to go anywhere

Sheltered Housing

it's like in here
this place is crap [laughs!]

naebody wants to go anywhere!

that's what I was saying to ye
"When are we goin oot?"
"Tom nobody wants to go anywhere"

they aw stay indoors aye

it used to be guid but no now yaaach

we used to go oot
away for the weekend
I said "When are we going away for the weekend?"
"Nae one wants to go anywhere Tom"

quite a few of us used to go out
nowadays errr
this is a place where you die

this place is a tip

it's er it's a bit er it's under the weather put it that way [laughs]

if tss ken naebody wants tae dae anything at aw noo ken?

Befriender

oh he's awright aye

awright aye

comes doon to see me
and that's fine for me
Makes a wee change
means I can talk to somebody

we talk about
we only talk about life and fitba
and things like that ken

it aw gies me a break ken
you need somebody like that

Carers

the carers they come in like ken?
they're only here for ten minutes an
"There's your pills Tom bye bye"
supposed to spend half an oor wi ye
daein what like?
["Ah well who's] tidying things?"
"I dae it aw myself"
"But we're supposed to dae it" ken?
[they] came in this morning
"We're gonnae polish an that"
I says "Wha are ye wantin daein?"
"Make your bed"
"I can make my ane bed"
"Clean sheets"
"Dae that masel"
They says er "Washing"
"Dae it masel"
[]
["Have smoke or what if you want"]
I thought I'd told yous
I dinnae want yous here anyway"
They say "We've got to come Tom that's it"
[manager] told them like ken?

Appendix G: Example of Data Analysis Process

First Reading: 1) narrative aspects; 2) researcher responses (to narratives and arising in interviews). My early thoughts, feelings and ideas on reading this section of transcript (narrative aspects) and on my actual experience of this part of our conversation (researcher response).

Narrative Aspects

aw I do aw day
aw I do nowadays
is go doon there
and get a cerry oot
and come back
and watch television
I've tried that pub
I've tried that pub ach!

- strikingly concise
- elsewhere describes other things that happen in his day, so this is an artful account emphasising the contraction of his present life
- so few words used, also communicating how much his life has shrunk
- short, compact story but contains all the elements of Labov and Waletzky's (1967) story grammar: 'orientation' information: "aw I do nowadays"; a complicating action: "go doon there and get a cerry oot and come back and watch television"; a 'resolution' - in his story, a failure to resolve: I've tried that pub, I've tried that pub"; "ach!" is both evaluation and coda.
- simultaneously a habitual narrative and a narrative which breaches the habitual: Tom's unvarying daily routine is remarkable, a radical departure from his previous way of life.
- often performs dialogues; mimesis (showing) over diegesis (telling) (Lodge, 1990)
- re-accent words/speech of others - a way of engaging in dialogue with them (Bakhtin)
- dialogues - although reproduced by Tom - to an extent acknowledges/includes perspectives of others
- dialogues seem habitual, the sort of exchanges Tom typical has with different people - creates impression of 'relational environments' (Josselson, 1992)
- dialogues examples of negotiation and resistance in relationships and limits of influence
- contrast between emptiness of Tom's life and liveliness of his storytelling
- binaries emerging: then/now; movement/confinement; going out/staying in

Personal Responses

- worry I am mishearing; Tom hard to understand - no teeth etc
- notice I am invested in the 'active', in wanting to overcome obstacles to Tom going out; takes me a while to 'get'/accept that he wants to stay in; that he wants to want to go out
- a "place where you die" I find powerful, 'dying' seems to be on so many levels
- secretly pleased he argues back, asserts himself, but connect with his lack of influence
- overwhelming sense of 'stuckness', inertia, dysphoria but animated/emotional storytelling

