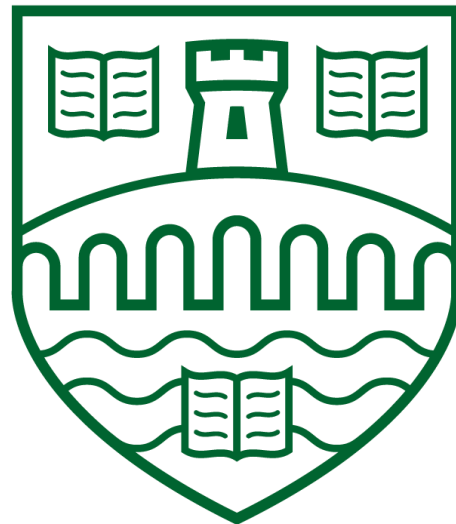


*DEMENTIA AT THE THRESHOLD:
A QUALITATIVE INVESTIGATION OF
NEGOTIATING THRESHOLD SPACES
WITH DEMENTIA*



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For Nana

“I need you to know what I know: to be rendered powerless does not destroy your humanity. Your resilience is your humanity.”

The only people who lose their humanity are those who believe they have the right to render another human being powerless. They are the weak.

“To yield and not break, that is incredible strength.”

(Gadsby, Olb and Parry, 2018)

ABSTRACT

This thesis argues for a profound shift in the way in which we understand dementia, advocating from a move away from the rhetoric of loss and decay, and towards an acknowledgement of people with dementia as whole and undiminished by the progress of their disease. It highlights the role of the narratives of decay in oppressing and disabling people with dementia, and contends that it is the meaning attributed to dementia, rather than the dementia itself, which limits both what people with dementia can do and who they can be.

This research uses an ethnographic approach to explore key areas where the physical, social and temporal spaces controlled by people with dementia meet those controlled by others, and elucidates the complex relationality of these threshold spaces. Through drawing on 78 hours of audio interviews with 11 people living with dementia in Scotland, this research highlights key physical, social, and temporal thresholds that participants encountered as part of their day-to-day lives.

This thesis highlights the weaknesses in approaches that construct people with dementia as passive victims of biological tragedy. It offers instead a theoretical perspective that is rooted, in the understanding that a person cannot be 'unmade' by cognitive impairment. This perspective is grounded in Heideggerian philosophy, and allows for a deeper exploration of how people with dementia experience the physical, social, and temporal world as undiminished Dasein living with cognitive impairment. These experiences are contextualised through the lens provided by 'Thomas' social relational approach to disability, which emphasises the role of society in disabling and oppressing people with dementia. These findings emphasise the need for a profound shift in both how dementia is represented as a

reductive and tragic process and the ways in which barriers to social inclusion are constructed as the result of medical rather than social processes.

CONTENTS

ACKNOWLEDGEMENTS	3
ABSTRACT	7
CONTENTS	9
1: INTRODUCTION	13
Overview	13
Key Concepts	17
Thesis Structure	21
2 : DEMENTIA, DISABLEMENT, & DISABILITY	25
Introduction.....	25
Civilised Oppression	26
People with Dementia as Targets of Civilised Oppression.....	29
The Medical Model as a Mechanism of Oppression.....	32
Opposing the Medical Model: Learning from Disability Studies.....	36
Disability and the Lived Experience of Impairment.....	38
The Importance of Threshold Spaces	42
Summary.....	44
3 : A SELF BEYOND PERSONHOOD: DASEIN, DWELLING, AND BEING-WITH-OTHERS	45
Introduction.....	45
Considering Personhood.....	46
The Limitations of Dementia Reconsidered	47
The Danger in Dualism	49
Heidegger’s Dasein.....	51
Being-in-the-World.....	53
Dwelling	54
Being-with-Others, Near-Dwellers and Neighbours	58
Summary.....	60
4: METHODOLOGY, METHODS AND ANALYSIS.	61
Introduction.....	61
Research Questions	62
Taking an Ethnographic Approach	62
Recruiting Participants with Dementia.....	67
Research Design and Methods	69
Ethical Considerations	76
Passages in to and out of the Field	82
Analysis.....	85
Summary.....	89
5: MANAGING THRESHOLDS IN PHYSICAL SPACE: THE ART OF DWELLING WITH DEMENTIA	91
Introduction.....	91
Separating the dwelling from ‘Elsewhere’	92

Material Objects and Threshold Guardians	92
The Role of Knowledge and Being a Known Visitor	95
Managing Risk and the Potential for Unwanted Passing	100
Windows and Window Ledges.....	107
Thresholds in Vertical Space	123
Navigating Shared Space and the Nachbar	129
Summary	137
6: RELATIONSHIPS, SOCIAL THRESHOLDS, AND BEING-WITH-OTHERS	139
Introduction	139
Social Relationships and Physical Objects	140
Beyond the Written Word.....	148
The Role of the Inner Circle.....	153
Restricting Access to the Inner Circle.....	159
Responding to Violations of the Social Threshold	161
Driving as a Social Threshold.....	165
Guarding the Social Threshold: The Role of Community Engagement	171
Summary	173
7: I HOPE I'M IN THE CROWD THAT DOESN'T GET ON THE SILLY SIDE': MANAGING TEMPORAL THRESHOLDS	175
Objects as Guardians of the Temporal Threshold	176
Making-Present with Dementia	185
Lived Temporalities and the Speed of Elsewhere.....	187
Managing Changes and the Import of Time.....	193
Avoiding the 'Silly Side': Looking Towards the Future with Dementia.....	198
'I don't know where I'm going to end'	204
Telling a Different Story.....	208
Summary	212
8: SYNTHESIS AND DISCUSSION	215
Introduction	215
Dwelling at the Physical Threshold.....	216
Relational Arrangements and Social Thresholds.....	228
Always With-Dementia	228
Being-Towards and Temporal Thresholds with Dementia	236
Limitations.....	243
9: CONCLUSION.....	245
Thresholds	245
The Dasein Perspective.....	246
Dwelling.....	247
What thresholds do people with dementia encounter in the course of their everyday lives?	249
How do people with dementia manage threshold spaces?	250
How does investigating thresholds facilitate greater insight and support better outcomes for people living with dementia?	251
What is the benefit of exploring the experiences of people with dementia as disabled people?.....	252

Future Directions.....	254
Final Thoughts	255
REFERENCES.....	257
APPENDIX A: MENTAL CAPACITY PROTOCOL.....	285
APPENDIX B: INFORMATION SHEET.	293
APPENDIX C: CONSENT FORM.....	304

LIST OF FIGURES

PICTURE 1: THEMES AND SUB THEMES EMERGING IN STAGE THREE	88
PICTURE 2 : ANTI COLD CALLING STICKER	93
PICTURE 3 : NEIGHBOURHOOD WATCH STICKER.....	93
PICTURE 4: ISABEL DEMONSTRATING HER DOOR ALARM.....	102
PICTURE 6 : ONE ORNAMENT IN TWO PARTS	122
PICTURE 5: TWO ORNAMENTS ON A WINDOWSILL	122
PICTURE 7: MARK'S SHOE TECHNIQUE, LEFT FOOT.	128
PICTURE 8: MARK'S SHOE TECHNIQUE, RIGHT FOOT.....	128
PICTURE 9: SIMPLIFIED BUS TIMETABLE & NOTEPAD WITH PENCIL.....	141
PICTURE 10: HAZEL'S PERSONALISED FOOD WASTE BIN.....	144
PICTURE 11: A TALE OF THREE CALENDARS.....	145
PICTURE 12: GEORGE'S VISUAL MEDICATION GUIDE.....	150
PICTURE 13: GEORGE'S VISUALS	152
PICTURE 14: GEORGE'S DAILY PLANNER.....	152
PICTURE 15: MARK'S BEDSIDE POSSESSIONS IN SITU.....	178
PICTURE 16: NIGEL'S READING MATERIAL	195
PICTURE 17: MARK'S ANNOTATED GOD'S GARDEN'.....	205
PICTURE 18: NIGEL SHOWS OFF HIS ELEPHANT'S GRAVEYARD MEMENTO MORI	210

1: INTRODUCTION

“Someone ought to do something”

(Pratchett, 1996, p111).

Overview

The way we talk about dementia has changed. Whether it is within academia, where the discourse casts an increasingly critical eye over the ways in which people with dementia are diagnosed, informed and treated (Millby, Murphy and Windthrop, 2017 and Bonner et al., 2015 respectively), or in a wider societal context, where there are growing tensions between how people without dementia represent people with dementia (Peel, 2014) and how people with dementia themselves wish to be represented (DEEP, 2015). Where these conversations mirror one another, however, is in the scale of the problem, with both academic and public sources presenting dementia as “the greatest global challenge for health and social care in the 21st century” (Kivimaki and Singh-Manoux, 2018, p1574).

It is this growing awareness of dementia as a societal rather than individual problem that has prompted increased efforts to identify risk factors, with an aim of reducing dementia prevalence by up to 35% (Livingston et al., 2017), alongside greater calls for early identification and diagnosis (see Donegan et al., 2017 for a review). What such efforts fail to provide, however, is substantive benefits for people who are already living with a dementia diagnosis. Having moved beyond the stages of prevention or diagnosis, the focus of policy and research increasingly becomes one of mitigation, enabling people to ‘age in place’ (Milligan, 2009; Wiles, Leibing, Guberman, Reeve and Allen, 2011) by creating ‘dementia friendly’ spaces. This is further emphasised by policy, with the Department of Health (2015) aiming to adapt existing communities such over 50% of the 850,000 people who live with dementia in the UK (Alzheimer Society, 2017) live within one by 2020. Despite this increase

in research activity, several key questions remain: what does it mean to be ‘dementia friendly’? How, and by whom, should dementia friendliness be assessed, and upon what scale? How large is one’s community? Indeed, what constitutes community for a person with dementia? Is it sufficient to attend only to the processes of aging in place (and thus geography) or must there also be consideration of an individual’s social and emotional place in aging as argued by Wang, (2019)? In the current socio-political climate, these questions become more than flights of intellectual fancy: they are fundamental to ensuring progress, and they demand answers.

The following doctoral thesis addresses these questions by introducing the concept of thresholds as a theoretical lens through which questions of physical and experiential accessibility, space, place, and temporality can be interrogated. By broadening the definition of the threshold beyond a set of architectural features, this research departs from the work of scholars who view thresholds both physically anchored and socially salient, to ask: how do we know what, and where, thresholds are?

Throughout this text, I shall present an understanding of thresholds as omnipresent. We meet them often, for they stand between where we are and where we wish to go. They mark the point where we meet others in a social relationship in the present moment, even as they separate who we were once from who we are, and who we might become. Despite this, there are few works that sufficiently recognise the importance of threshold spaces to those who might wish to enter, or engage with, dementia friendly initiatives, spaces, and services. Such a gap in the literature challenges the viability of a dementia friendly space that fails to attend to its thresholds, and as a result restricts or excludes people with dementia from the very space designed to enable them?

I present this thesis as the product of four years of intensive research activity, and the culmination of a process that began in my three years as an autism support worker following my undergraduate degree. That this role focused on facilitation, enablement, and person centred practice continues to have a profound impact on both my personal perspective and my research. The concept of physical thresholds as they are presented in this thesis was certainly seeded during these years, where transitional spaces often became the focus when service users experienced difficulty moving between spaces or activities. The concept was further developed during my conversations with people living with dementia at conferences and academic events, some of whom reported feeling at home among the autistic community where challenges related to executive dysfunction and impaired short term memory are common (see Ozonoff, South & Provençal, 2007). The process of working alongside and building relationships with adults with different ways of Being and relating to and within the world made clear to me that any attempt to link cognitive capacity to selfhood are flawed at best at malignant (Kitwood, 1997) at worst. As such, my experiences can be seen throughout this research; in my choice of philosophical grounding, the pivot towards disability studies, and ultimately in my dedication to treating people living with dementia as experts and curators of their own experience.

The work of this thesis is to attend to this gap in the literature. It does so by drawing upon insights from accomplished scholars in a variety of disciplines, including those who align themselves with philosophy, sociology, anthropology, disability studies and dementia studies. It draws great strength from its association with its parent project, the 'Our Places, Our People' research project and situates itself within the broader scope of the Neighbourhoods programme by examining in detail those physical, social, and temporal thresholds which are present but ill elucidated elsewhere in the research package. As such, the results of this thesis serve to deepen the consideration of physical thresholds within the Our Places, Our People project while also forging new avenues into for the consideration of what physical, social,

and temporal thresholds might be important for people living with dementia. This doctoral research further adds to the parent project through its incorporation of the social relational model of disability, and the explicit consideration of people living with dementia as targets of civilized oppression. These insights are further contextualized by reading the research in the context of the other seven working groups within the ESRC, NIHR funded Neighbourhoods and Dementia research programme (Neighbourhoods and Dementia, 2012).

This research is further privileged by the involvement of Alzheimer Scotland, who not only part funded the project, but who acted as key gatekeepers and facilitators throughout. It is through these partnerships that this research has been able to situate itself in a broader context, and glean insights into family life, service use, and the importance of neighbourhood and community spaces to people with dementia (see Ward, Clark and Hargreaves, 2012 and Ward et al., 2017 for a review). It is through attending to the following four research questions that this thesis contributes to this growing literature, and contributes both to the parent project and to the wider body of knowledge:

What thresholds do people with dementia encounter in the course of their everyday lives?

How do people with dementia manage threshold spaces?

How does investigating threshold spaces facilitate greater insight and support better outcomes for people living with dementia?

What is the benefit of exploring the experiences of people with dementia as disabled people?

Key Concepts

Dementia, Disability, and Civilised Oppression

It is necessary, therefore, to provide a brief insight into the key terms and concepts upon which this work is based. The following section is therefore, supplemented by the more in depth discussions of each concept that occur in Chapters Two and Three and are further developed throughout the thesis. As a basis for this process, it is important to note from the outset the meanings that this research ascribes to the word dementia, and what it does not. First, this thesis defines dementia in the following way; as a collection of degenerative neurological diseases that are sufficiently alike in symptomology to be brought together under a single overarching term. While there is an argument for differentiating between participants based on their specific diagnosis, and thus dividing the participants into those diagnosed with Alzheimer's Disease, Dementia with Lewy Bodies, Frontotemporal Dementia or Mixed Dementias and so on, such an approach would not reflect the lived reality of participants. Investigating the experiences of 'people with dementia', allows for an exploration of the participants' experiences in the context of their engagement with a range of social structures and networks for whom 'dementia' is more salient than 'posterior cortical atrophy' or even 'mixed dementias'. That these people are marginalised based on the common construction of them as people with (a) dementia ensures that such an approach is both valid and salient. This work thus joins the growing body of literature that seeks to elucidate the relationship between the person with dementia and the society within which they live through by highlighting the distinction between a person with dementia encountering challenges due to their progressive cognitive impairment, and the person being disabled by an ablest and stigmatizing society (Dorenlot, 2005). To this end, this thesis adopts Carol Thomas' social-relational approach to disability (1999; 2004; 2012) which positions disability as a status imposed upon a person with impairments by the organisation of space, place, and society, and impairment, as it is understood as a biological, pre-social aspect of

one's body (Thomas, 2007). As such, this work is able to acknowledge the biological effects of dementia disease as impairments and their impact upon the embodied experience of the person with dementia as impairment effects, which exist pre-socially and which "no amount of social justice can eliminate". It is the societal imposition of disability upon the person with dementia as a disabled person with an impairment that this work views through the lens of Harvey's (1999; 2015) concept of civilised oppression, thus highlighting the subtle and pervasive ways in which the organisation of society, and the interactions between individuals who are not oppressed and those who are, enforce and recreate oppression at an interpersonal level.

The Narratives of Decay

The 'narratives of decay' are those that dehumanise, devalue and demean people with dementia based on their impairment. These narratives present dementia as a phantom, and a force to be resisted at all cost. They construct the person with dementia as unknowing and unknowable, a "vegetable", (Albinsson & Strang, 2003 p.229) who has been 'unravelling' (Fortana and Smith, 1989) by the disease. Indeed, the power of these constructions is such that it can lead to an understanding of the person with dementia as a 'shell' (Radden and Fordyce, 2006), leading kin to proclaim that "Mom no longer exists even though she's still there" (Albinsson & Strang, 2003 p.230). People with dementia are as such constructed as 'effectively dead' (Luntly, 2005), releasing society of its obligations towards them as they become a 'human non-person' (Singer, 2011). These narratives are reductionist, and persist even where person centred care exists, for arguing that a person with dementia must be treated as a person in deference to their history (Kitwood, 1997) does not necessitate that the person believe in their continued person-ness. These are the narratives of decay, and many of the decisions that have shaped this thesis have been made explicitly with the goal of deposing them in mind.

Heidegger's Work: Dasein and Dwelling

This thesis draws extensively from both Heideggerian philosophical constructs and hermeneutic approaches to analysis and interpretation. As such, it is necessary to outline briefly two theoretical constructions here. The first of these is Dasein. Dasein (or Da-Sein, 'there-being' in German) is at its most foundational level, Heidegger's conceptualization of the self, the I, or the person. The contribution of Dasein to this thesis is as simple as its trappings are complicated: Dasein is not reliant upon cognition. The implications of this are far reaching, for a self that is not reliant upon cognition (as it is in Cartesian models where thought precedes being, 'I think *therefore* I am') cannot be eroded by cognitive impairment or decline. As a result, this work is able to not only discount any suggestion that people with dementia are necessarily lesser than those without, and that, resultantly those with more significant impairments are human 'nonpersons' (Singer, 2011; Hofmann, 2017) and 'shells' (Herskovits, 1995), but to undercut these sentiments altogether. The second Heideggerian concept that places a major role in this work is that of dwelling, which is at its core 'how' Dasein is in the world. Dasein is a dweller, and dwells through creating *things* (both physical, as in buildings, and nonphysical, as in societal systems, norms, mythos and so on) and protecting, preserving, and cherishing those things. It is this concept that provides the contextual lens for many activities at the threshold, as Chapters Five, Six and Seven explore the ways in which the practices of dwelling influence the organisation of threshold spaces.

Thresholds

This thesis uses the terms 'thresholds' and 'threshold spaces' to highlight a complex phenomenon which is both central to this work, and key to the lives of people with dementia. In their most familiar form, these thresholds might be aligned with designated spaces which separate one area from another, as they are at doorways in Latimer (2018) and Buch (2015) and become the focus along fences in Agamben (2005), these works rarely acknowledge the

rich complexity of the threshold space. Thresholds are discrete spaces, in that they are distinct from the phenomena that lies at either side, yet because their ‘thresholdness’ results from their ability to draw together these phenomena, they are both beholden to them and shaped by them. Heidegger presents this notion in the following way:

The threshold [...] bears the doorway as a whole. It sustains the middle in which the two, the outside and the inside, penetrate each other. The threshold bears the inbetween. What goes out and goes in, in the inbetween, is joined in the between's dependability. The dependability of the middle must never yield either way

(Heidegger, 1971, p.201).

This extract gives a clear example as to how thresholds manifest in physical space, as at once beholden to and shaped by the spaces on either side while still being distinct phenomena themselves. This thesis, therefore, treats thresholds in a similar way: as significant and distinct, yet beholden. As stable and dependable, yet responsive to changes on either side. As such, the term ‘threshold space’ is used to capture not only the threshold itself, but those efforts and phenomena that are proximal to it, and from which it most directly draws its character.

The majority of this thesis is, therefore, an exploration of the experiences of people with dementia as they approach, and manage, these relational meeting spaces. Where these thresholds occur in physical space, I find my approach aligned with that of Latimer (2018) and Buch (2015) and their understanding of threshold spaces as tied to physical architecture, particularly at doorways, and staircases. Where the consideration moves to social thresholds, however, the analysis requires a step towards abstraction, while still aligning itself with the way relationships are often communicated in informal speech- that is, spatially, where an individual can both ‘go too far’ and ‘meet someone halfway’. That thresholds can represent intangible ‘spaces’ where two social forces are drawn together, therefore, is easily understood. The thesis also turns its focus towards the consideration of temporal thresholds, which once

again draws upon the tendency to discuss temporalities as related to spatial arrangements: The past is a foreign country, after all (Lowenthal, 1985). The past can feel, and be felt on a profound and emotional level, as distant, and left ‘behind’, while the future is ‘coming towards’(see Rogers, 2017 for a discussion). Thus, much as physical thresholds can draw together two physical spaces, and social thresholds are situated between people, temporal thresholds are those nonphysical spaces where past and present are drawn together, for example, where a past time is made ‘present’ through remembrance, or the future is drawn towards the present through expectation, anticipation or planning. What this means for people with dementia, in the context of being people with impairments who are marginalized and disabled by societal structures, is teased out throughout the body of this thesis, and is at the heart of the first research question; what thresholds do people with dementia encounter in the course of their everyday lives?

Thesis Structure.

This thesis is organised into nine parts, of which this introductory chapter is the first.

Chapter Two begins by exploring the concept of civilised oppression as Harvey (2015) presents it. This leads into the consideration of people with dementia as oppressed by society on the basis of their diagnosis. The chapter then considers the ways in which dementia studies would benefit from drawing from the well-established and politically powerful discipline of disability studies, and particularly the implications of the Social Model of Disability. This is followed by a discussion of the challenges associated with applying the Social Model to dementia and concludes by arguing that Carol Thomas’ (1999; 2003; 2006) Social Relational Approach presents an opportunity to navigate the weaknesses inherent in the social model while still drawing on its strength.

Chapter Three opens with a consideration of Kitwood's work on personhood, and focuses particularly on its grounding in philosophical thinking. The chapter goes on to argue that it is the positioning of personhood as a status, rather than a property that is inherent within the self, that has encouraged debates to continue as to whether people with dementia are whole 'selves' by the end of their lives. The tendency to discuss dementia as a reductive force, which results in a 'hollowing out' or zombification (Kessler, 2007) is parsed together as the narratives of decay. These narratives, the chapter argues, are examples of societal aggression towards a marginalised and vulnerable group, and have profound impacts both upon what people with dementia can do, and what they can be. The Chapter then moves to introduce Dasein as an alternative to the cognition-focused models of selfhood. The rest of the chapter is spent discussing Heidegger's philosophical construction of Dasein, and its nature in relation to being-in-the-world, dwelling and being-with-others.

Chapter Four draws together the theoretical considerations of chapters Two and Three into a single theoretical framework, and discusses the methodology of the study. This begins with a discussion of ethnographic approaches as a way of exploring the experiences of others in-the-world, and the use of observation, interview, digital photography and field notes as methods of data capture. Having outlined the structure of the project, the chapter then discusses participant recruitment and issues of consent, entering the field, and ethical challenges. The final sections of the chapter provide an explicit discussion of the process of data analysis as it was undertaken using Hermeneutic phenomenology, and the process of writing an ethnography.

Chapter Five stands as the first findings chapter, and as such focuses on how participants encountered and experienced physical thresholds during the course of their everyday lives. Stepping off from the familiar concept of thresholds as spatially bound to architectural features, particularly doorways, windows and stairs, this chapter demonstrates the power of

the person with dementia as manager of thresholds and a dweller within their home space. The chapter places a particular emphasis on the ways in which participants could influence threshold spaces to facilitate access for those who were welcome, or restrict or deny access to those who were unwelcome.

Chapter Six introduces the idea of social thresholds. This chapter begins by exploring the significant impact of social thresholds on physical spaces, and highlights the potential for objects around physical thresholds to represent both a means of managing physical thresholds and an ongoing relationship with someone who is not present in the moment of crossing. This discussion extends into a consideration of the role of trusted others and key individuals in the lives of people with dementia, and highlights the social threshold that differentiates between those who are held in confidence as part of the ‘inner circle’ and those who are not. The complexity of the social threshold as it relates both to interpersonal relationships and ongoing rights and citizenship is then explored in relation to driving and maintaining the status associated with being ‘a driver’.

Chapter Seven is the final findings chapter of the thesis and describes the experiences of participants with dementia as they approach and manage their passage over temporal thresholds. This chapter strongly repudiates the narratives of decay, and strongly advocates for an understanding of people with dementia as whole and undiminished Dasein. The chapter begins by highlighting the ways in which participants were able to draw together the past and present through reminiscence and storytelling in order to convey key information about themselves. The focus then shifts towards a consideration of the present as a time which is both subject to contestation where the participants rhythms of life and living differ from the speed and temporality of the outer world, and as the period within which participants must manage changes in impairment. Finally the chapter considers the role of participants as managers of temporal thresholds between the present and the future. This

discussion highlights the tensions inherent within the narratives of decay, and contests that participants remained forward-facing, active agents throughout their lives, regardless of their dementia diagnosis.

Chapter Eight draws the findings of Chapters Five, Six, and Seven, together with the existing literature to demonstrate the impact of adopting a Dasein perspective for dementia and the value of thresholds as an analytical framework. Chapter Eight thus uses the findings of this research to present a sharp critique of the narratives of decay, highlighting the power of the person with dementia at physical, social, and temporal thresholds as a demonstration of their ongoing orientation towards and experience of the world. The chapter goes further, demonstrating both the damaging and ablest assumptions upon which the narratives of decay are based and the value of Thomas' social relational approach to disability as a lens through which participants experiences should be understood as the experiences of disabled people living with cognitive impairment. The chapter closes by emphasising the value of the thresholds as a novel framework that highlights both the power of the person with dementia and the complex relationalities of civilised oppression and structural disablism.

Chapter Nine concludes the thesis by drawing focus back to the research questions. After considering each of these questions in turn and providing a brief insight into the key findings as they relate to the concerns raised, the chapter then details the main contributions to knowledge that are made by this thesis, namely the development of the thresholds framework, the application of the Dasein perspective to dementia, and the use of dwelling as a dualistic concept that provides a nuanced insight into the ways in which people with dementia organise and manage their physical, social, and temporal thresholds as undiminished dwellers.

2 : DEMENTIA, DISABLEMENT, & DISABILITY

Introduction

One of the major contributions of this doctoral thesis is its argument that people living with dementia should be considered as disabled people. While there is a growing tendency for dementia literature more widely to acknowledge either people with dementia as disabled, or dementia as a disability, a systematic adoption of a disability approach is rare. In this chapter I argue that the reticence to align dementia studies with disability theory is predominantly due to the radical linguistic and conceptual shifts involved in such a change. Viewed through the lens of disablement people with dementia are not incidentally marginalised within society; their exclusion from public space is not due to the lack of ‘special’ provision. Instead people with dementia are targets of societal oppression that is enacted through the relationships that they have with other people, organisations, and the state. Throughout this chapter I argue that only by engaging with people with dementia as both individuals with a degenerative brain disease and as targets of oppression that dementia research might meet its emancipatory goals.

This chapter opens by exploring the concept of civilised oppression as it is presented by Harvey (2015). This construction provides an avenue for analysis that recognises marginalised people are oppressed while simultaneously attending to perspectives that consider oppression is both quintessentially violent and knowingly perpetuated. This argument in turn leads into the consideration of people with dementia as an oppressed population and concludes that, while ageist constructions contribute to the stigmatisation of older people, people with dementia are doubly vulnerable due to their position at the intersection of age and disability. From this point the chapter considers the ways in which

sociological investigations of dementia might draw from the well-established and politically powerful discipline of disability studies. Particular attention is paid to the ways in which disability studies has rejected medicalised approaches to disability and advocated for approaches rooted in the Social Model of Disability. This is followed by a discussion of the challenges associated with applying the Social Model to disability and concludes by arguing that Carol Thomas' (1999; 2006) Social Relational Approach presents an opportunity to navigate the weaknesses inherent in the social model while still drawing on its strength.

Civilised Oppression

“When we think of oppression, we think of police abducting people in the middle of the night, people being tortured, lynched, or arbitrarily imprisoned, [...] We think of systematic brutality, terror, and evil on a scale that shocks. [...] the kind of evil that should be recognisable as evil.”

(Harvey, 1999, p1).

One of the primary challenges associated oppression as it occurs in the everyday context, and particularly with citing specific populations as targets of oppression, is the presumption that oppression must be easily identifiable to be present. From such a perspective, the argument that marginalised people in society are oppressed becomes more divisive. Is a forced admission to a care home (Dwyer, 2010) tantamount to abduction? Are care practices that strip people of their dignity and actively humiliate them implements of torture (Barclay, 2016)? Does failing to address suffering perpetuate pain and create ‘torture without a torturer’ (Marino & Marino, 2014, p54)? Such arguments are unlikely to facilitate communication between those constructed as targets of such oppressive measures (or, perhaps, those who construct them as such) and the professionals who are instrumental in these processes and act in line with their best intentions and practices (see Hertog, The, Miesen & Eefsting 2004 for an example of this). It is important to ask too whether oppression must always act along these recognisable contentious pathways. Must each act of

oppression be one of atrocity (Card, 2002) and critically must oppression be enacted interpersonally by evil-doers?

The focus of this research is not however whether people with dementia can be victims of violent oppression. As such, while this work acknowledges that people with dementia *can* be targets of violent abuse and subject to repressive legal precedent (see Behuniak, 2010 for a review), its focus turns instead towards what Harvey (1999; 2015) terms ‘civilised oppression’. Civilised oppression is primarily differentiated from the ‘traditional’ oppressions described above by its nonviolent nature, the seeming triviality of the oppressive practices, and the central role of ‘distorted relationships’ in enabling and perpetuating the oppression.

Importantly:

“There are, by definition, no blatantly violent actions to see, nothing to arouse any deep moral concern in “observers.” Even the agents of the oppression typically do not strike us as immoral, let alone evil. In some cases they are even transparently well intentioned toward the victims they oppress. We can learn about this form of oppression only from the victims themselves.”

(Harvey, 2015 p4)

Using such a framework has a number of advantages, many of them resulting from the critical insight that is provided by considering civilised oppression as a primarily relational, rather than physical, experience. It is therefore possible to consider a range of marginalised identities as potential targets of civilised oppression including those who are overweight, Muslim, living with chronic pain, or ex-prisoners (Holland, Blood, Thomas, Karunaratne, & Lewis, 2010; Ahmed, 2018; Parsons, Dolan & Stuart, 2016; Jarldorn, 2016, respectively). Indeed, by separating traditional (violent) acts of oppression from civilised oppression, it remains possible to unilaterally condemn acts of violent oppression as morally corrupt and unconscionable without necessitating the vilification of those individuals who contribute to civilised oppression. This is particularly important given that Harvey (2015) notes throughout her text that the mechanisms of civilised oppression are so subtle that not only those who

are oppressed might find it difficult to identify individual instances of oppression but those who enact oppressive practices may not recognise their behaviour as such.

It is because acts of civilised oppression are enacted routinely, thoughtlessly, and with an air of triviality they are able to “pass under the social radar” (*ibid*, p82). As such it becomes necessary not only to identify those behaviours that contribute to oppression but to convince those who are not oppressed of the significance and impact of those actions and their role in perpetuating them. Fully recognising oppression, Harvey argues, can only be achieved by inverting the oppressive power structure so that, rather than presuming the primacy of their own knowledge, the non-oppressed person accepts the oppressed person as the authority on being oppressed. Such genuine engagement with those who are targets of oppression is vital as “a privileged person can be thoughtful, well intentioned, and warm-hearted and yet know nothing about what it is like to live a life of [...] exclusion” (*ibid* p44). This highlights a key difference between knowledge and understanding in Harvey’s text. It is possible to gain knowledge of oppression without engaging with the oppressed. Understanding, by contrast, can only be gained by engaging empathetically with the victims of oppression and accepting their place as experts in that experience. Thomas (2006) takes this further arguing that such engagement goes beyond what might elsewhere be called best practice and represents a moral imperative. Indeed to seek understanding in this way is to enter into:

*“a mode of learning **which those who have been oppressed are owed** in the name of eliminating the very state of their oppression. In the absence of such learning, oppression cannot but continue to be part of the fabric of the moral life. Indeed, the absence of such learning, the studied refusal to engage in such learning, is one of the very ways in which oppression manifest itself. Worse, such studied refusal adds insult to injury.”*

(Thomas, 2006 p82, emphasis mine.)

While this arguably provides a strong argument for qualitative research, participatory methods, and ‘user-led’ activism, it is important to note that merely collecting accounts of

oppression is not sufficient. Rather such approaches risk becoming an exercise in generating knowledge without understanding. This is of particular importance because victims of civilised oppression will by definition:

“suffer as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms- in short, the normal processes of everyday life. We cannot eliminate this structural oppression by getting rid of the rulers or making some new laws because oppressions are systematically reproduced in major economic, political, and cultural institutions.”

(Young, 1990, p41)

From this position, not only is there a moral imperative for those who are not oppressed to listen to those who are and to engage with them as experts in their lived experience, but for them to use their new understanding to reassess their own behaviour such that they can contribute to a change in societal norm.

People with Dementia as Targets of Civilised Oppression

It is a relatively noncontroversial insight that people with dementia become the focus of oppressive social regimes. What is interesting to note however is that while there are well documented concerns around the encroachment of technologies intended to both surveil and regulate people with dementia (for example, White & Montgomery, 2014; Fehling & Dassen, 2017) efforts to develop newer more effective versions of these technologies continue unabated. In light of this, it is possible to suggest that the resistance in acknowledging people with dementia as targets of civilised oppression may not be a result of a lack of evidence or the presence of overwhelming evidence to the contrary. Instead this reluctance may be rooted in the realisation that for people with dementia to be oppressed there must be an oppressor. This shift in conceptualisation leads to disquieting conversations as to the occurrence and nature of abuse, particularly as it occurs in long standing

relationships (spousal, domestic or otherwise) where one party develops dementia (see Thomas & Milligan, 2017). It is critical to note therefore, that this thesis argues that one can act in good faith to “respond to the needs of people with dementia with a positive desire to assist and ease anxiety” (*ibid* p126) while still perpetuating disabling and ablest narratives and engaging it civilised oppression. Such a conceptualisation is likely to meet with resistance as non-oppressed persons, Harvey notes, are often “shocked to hear themselves described as oppressors, and yet they are.” (2015 p56). Furthermore, in the case of civilised oppression, those who enact oppression are unaware that they do so. Harvey argues that it is this benign ignorance that characterises most non-oppressed people and that the complexity of human relationships and interactions makes it difficult, if not impossible, to perceive the level of ones privilege and the effects of ones behaviour all of the time, in every situation. There is, I would argue, little to be gained by seeking to portray people with dementia as surrounded on each side by malicious oppression, enacted deliberately and consciously by spouse and diagnostician alike. Instead it is worth noting that:

“None of us is fully and permanently alert to our own behavior, although we can become more self-aware with effort and over time. Empathetic understanding is, I suggest, appropriate in some cases involving agents who contribute, all unknown to themselves, to civilized oppression, especially where those involved are trying to become more self-aware. [...] We are in solidarity with them “against their oppression.” This does not mean “against their oppressors”.

(Harvey, 2015 p57-58)

There are a number of benefits to considering people with dementia as an oppressed group. In the first instance, positioning the use of systematic or relational power to restrict people with dementia as a moral ‘wrong’ both demands focus and prompts a critical review of potentially oppressive practices. Secondly, it highlights the role of knowledge as both a precursor to and distinct from understanding the character of civilised oppression and its effects. Thirdly, because knowledge of the oppression is not guaranteed (“a privileged person can be thoughtful, well intentioned, and warm-hearted and yet know nothing about what it

is like to live a life of [...] exclusion” *ibid* p44), nor does its presence automatically result in understanding, it is necessary for those who would stand in solidarity with the oppressed to do so by learning from them. This is arguably a challenge for Kitwood’s (1997) discussion of moral solidarity as recognition of human unity; a concept he considered central to personhood (*ibid*, p100). For Kitwood, to act in the spirit of moral solidarity necessitates only that one recognise that “we are all [...] in the same boat; and there can be no empirically determined point at which it is justifiable to throw some people into the sea” (1997 p10). Such a metaphor hinges on the understanding of humanity as already united in one ‘boat’ where the choice is between allowing their continued passage and forcibly throwing them into the sea in an act of violent oppression. Civilised oppression, by contrast, may permit people with dementia to be passengers on the same boat but does so in such a manner that makes the upper decks impassable, except during specified hours wherein ‘special’ arrangements are made.

To push this analogy to its limit; civilised oppression is what allows Rose to pride herself on travelling on a vessel that carries the rich and poor to New York without ever realising that she and Jack may have a fundamentally different experience of the voyage. Indeed, booking passage on the Titanic may allow Rose to pride herself on her open-mindedness; she is after all choosing to frequent a space that is ‘lower class friendly’. There is no necessity to question why such a journey might ever *not* be accessible to lower class people particularly as based on her experience leads her to believe that such spaces are accessible by default. Yet being permitted passage on the same ship (or boat, per Kitwood, 1997) does not necessitate an equality of experience or that the same value be placed on all passengers. Plot mechanics notwithstanding, Rose may never have known of the restrictions placed upon lower class characters, or of the barriers that resulted in their lack of access to life boats. She comes to understand these experiences only through engaging with Jack, a process which ultimately highlights not only the flawed premise that lower class passengers are in some manner

inferior people, but the structural mechanisms employed to keep them locked below deck, and it is ultimately her privilege that allows her to speak (albeit ineffectively) against them.

To be truly person centred is to move beyond abstaining from acts of violent oppression (pushing a fellow human into the sea) and engage proactively in challenging the systematic and systemic mechanisms of civilised oppression where they occur (segregation, for example, or locking passengers below decks as in Cameron, 1997), under the guidance and with deference to the experiences of people living with dementia. By viewing people with dementia as both individuals with a degenerative disease and as targets of civilised oppression it is possible to challenge a range of oppressive factors that extend beyond Kitwoods (1997) malignant psychology to consider social, physical and relational structures. This lends itself to the fourth point. It is only through engaging people with dementia as simultaneously a) people with a degenerative illness, b) experts in their own experience, and c) targets of oppression that it is possible to stand in solidarity with them as an oppressed group. I would argue that, while contemporary dementia literature engages frequently with points a and b, it is the engagement with people with dementia as oppressed that is less commonplace. It is this final factor, therefore, that I explore through disability theory.

The Medical Model as a Mechanism of Oppression

It is important to acknowledge, particularly at this point in the thesis, the progress that has been made by dementia research over the last twenty years. It is only through understanding history that a resurgence of old patterns of belief might be avoided in the future. For this reason it is necessary to begin this section, not with Kitwood's (1997) impactful text *Dementia Reconsidered* and the profound changes brought about by the move towards a person-centred

ethos of care, but with an acknowledgement of the biomedical perspectives to which Kitwood's work was reacting. Behuniak (2010) provides a particularly clear insight here:

“Within this [the biomedical] model, AD [Alzheimer's disease] is a neurological disease, its symptoms have biological roots, and the individual who falls victim to it is not an individual with AD but an individual redefined as an AD patient. Given this medical construction, the appropriate response to this neurological assault were medical interventions that attempted to control this out-of-control disease by controlling the body of the patient—in essence meeting force with force.”

(p.232-233)

There are several aspects of this quote that are worth noting: firstly, the positioning of dementia as a solely medical concern with biological roots situates both the problems associated with dementia and any potential solutions within the medical sphere. As a result, literatures approaching dementia from a medical perspective seek to 'fix' the defective body without consideration for the social, economic and spatial structures that disable them (McRuer, 2006). This is the perspective that leads to the forceful approach where the 'battle' is primarily between the physician, armed with the (predominantly pharmaceutical) tools of their trade and the disease (Behuniak 2010). The person with dementia is merely the field upon which doctor and disease meet in battle. Arguably, this is a predictable outcome of a biomedical perspective where the body is “like a machine and can be repaired when it breaks down [...] there is a technological solution for everything” (Bond & Corner, 2001 p98). As such, from a biomedical perspective, dementia is best understood through its symptoms which include but are not limited to; slowed cognition, memory loss, delusions, behavioural changes, mental illnesses such as anxiety and depression, and mental decline (Hugo & Ganguli, 2014; Luntly, 2006; Fauth & Gibbons, 2014; Doctor, Iqbal & Naguib, 2014; Mintzer et al., 2000; Thyrian et al., 2016; and Godfrey et al., 2005 respectively).

When viewed from a medical perspective, within which both dementia itself and the challenges that are associated with living with the disease are tied to physiological changes at the individual level, it is possible to argue that social approaches have little to offer (Lyman, 1989). Dementia patients, therefore, are ‘victims’ to a disease that ‘unravels’ them progressively over time (Fortana & Smith, 1989; Beard, Knauss & Moyer, 2009). This unravelling inevitably results in a ‘loss of self’, leaving ‘effectively dead’ ‘shells’ or ‘zombies’ behind (Milne & Peet, 2008, Luntly, 2005; Radden & Fordyce, 2006; Herskovits, 1995; & Kessler, 2007 respectively). That such a construction provides an opportunity for oppressive practices is clear as they work together to position the person with dementia as a human nonperson towards whom we have few obligations (Singer, 2011; Hofmann, 2017). While the majority of Chapter Three is dedicated to exploring ways in which these claims of degeneration and loss of self might be rejected outright it is necessary to acknowledge such constructions as a continuation of a biomedical understanding of dementia that relegates people with dementia to the role of patient with a terminal degenerative illness.

It is this biomedical narrative that Kitwood (1997) sought to address by defining personhood as a “status that is bestowed upon one human being, by others, in the context of relationship and social being [implying] recognition, respect and trust” (Kitwood, 1997, p.8). This distinction allows personhood to remain intact throughout the dementia journey, as the process is grounded in the relationship that is maintained by others rather than by the individuals cognitive capacity. While the philosophical underpinnings of Personhood are discussed in more detail in Chapter Three, it is nevertheless important to note here the ways in which Personhood and the resultant move towards person centred care fundamentally altered the ways in which dementia was discussed, conceptualised, and communicated both within the UK and internationally. Critically, in presenting Personhood, and advocating for person-centred care, Kitwood provided an opportunity for professionals to adapt their practice without denouncing the core of the biomedical model with which they were aligned.

Critically, in personhood, Kitwood (1997) acknowledged that dementia was at its core a biological process, while drawing attention towards the psychosocial implications of living with the disease. To adopt a 'person centred' approach, therefore, was to move away from the strictly biomedical model and its exclusive focus upon symptom management (Kitwood, 1988) and begin to reflect on how professionals were communicating with, building relationships with, and respecting the relationships of people living with dementia (Kitwood, 1997).

It is important to note that while Kitwood (1997) is particularly influential he was not a lone visionary, but the figurehead for a movement that had been growing for some time which advocated for placing the person with dementia at the centre of their own care (i.e. Rader, 1995; Thomas, 1996, Sabat and Harré, 1992). Indeed this wider movement enjoyed significant success with person centred care entering the National Service Framework in 2001 (Dept of Health for England and Wales, 2001), in part due to its conceptual simplicity. Person centred care can be encapsulated by "V+I+P+S" where:

- 1) Valuing people with dementia and those who care for them (V)*
- 2) Treating people as individuals (I)*
- 3) Looking at the world from the perspective of the person with dementia (P)*
- 4) A positive social environment in which the person living with dementia can experience relative wellbeing (S)"*

(Brooker, 2004 p216).

This model tempers the biomedical approach by acknowledging the impact of social processes and stigmatisation. Person centred care demands that people with dementia should be treated as individuals rather than hosts to a disease or a field of battle between medical professionals and a degenerative illness. Furthermore, positioning healthcare professionals as part of a system of care allowed the person centred framework to challenge practices that

perpetuated patterns of infantilisation, intimidation, stigmatisation and invalidation (Kitwood, 1993) as results of a malignant social psychology without passing moral judgement upon the actor themselves. This is arguably compatible with Harvey's (1999; 2015) notion of civilised oppression, where individual actors might perpetuate systems of oppression without realising that they are doing so or even being aware that such mechanisms are in place. What personhood does not do however is provide a suitably robust framework for challenging the beliefs which underpin such systems on a systematic level.

Opposing the Medical Model: Learning from Disability Studies.

If Kitwood's person-centred approach does not succeed in challenging the structural processes that contribute to the oppression of people with dementia and their marginalisation within society then it is necessary to look elsewhere. Given that people with dementia become targets of oppression on the basis of their dementia, and more specifically on the basis of their existence as embodied carriers of a degenerative health condition linked with both older age and progressive cognitive impairment, it is most appropriate to turn towards the disability literatures in search of an answer. At its core the British strand of disability theory contends that disability is a socially constructed, societally enforced, and fundamentally oppressive status that is imposed upon people with impairments by the organisation and construction of the social world (Oliver, 1996). Grounded in the Union of the Physically Impaired Against Segregation's (UPIAS) Fundamental Principles of Disability (1976) the history and development of disability theory is both complex and culturally sensitive. The following section provides only a limited insight into several influential debates within disability theory and does so exclusively in the context of British disability literature. Deeper explorations are to be found in the writings of the dedicated scholars upon whose work this section is substantially based: Carol Thomas, Tom Shakespeare, Vic Finkelstein, Mike Oliver, and Jenny Morris.

Although the history of UK disability theory and particularly the progress made around and towards a social model is complex, this thesis need only focus on Fundamental Principles of Disability as the impetus for, and the core of, the Social Model of Disability (SMD). Resulting from the activism of disabled people, and the labour of predominantly disabled scholars, the SMD stands in direct opposition to medicalised perspectives on disability. It was created as a replacement for the dominant medical model, arguing that people are disabled not by their impairment, but by social structures which restrict and disable them. Where the medical model placed “undue emphasis on clinical diagnosis” creating a “partial and inhibiting view” of the individual (Brisenden, 1986 p.173), the SMD argues that ‘disability’ is a social construction that “penalises” (Tregaskis, 2002, p 457) people with impairments when they deviate from societal norms (Oliver 1990; Thomas, 1999). Where the medical model constructed people with impairments as deviant “problem people” (Briesenden, 1986 p.175) for whom the ultimate goal should be cure and rehabilitation at any cost (Shakespeare & Watson, 2002), the SMD argues that the ‘fault’, and thus the responsibility to adapt, lies with society rather than with the individual (e.g. Finkelstein, 1980; Oliver, 1990; Thomas, 1999). Indeed the SMD goes further and argues that not only is disability not resident within a person as the medical model suggests, but that it is an unnecessary, additional system of oppression inflicted upon disabled people by the nondisabled. Specifically:

“It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. [...] We define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by contemporary social organisation”

(Oliver, 1996, p.22)

There are several points to note here. Firstly, the positioning of disabled people as targets of oppression, the mechanisms of which include exclusion and isolation and result in

disadvantage and restriction. As such it would be entirely appropriate to consider disabled people in the United Kingdom to be targets of (predominantly) civilised oppression, in line with Harvey (2015). The second is the scope of the concept of impairment or a ‘defective mechanism of the body’. This allows dementia to be framed as an impairment without significant controversy. Indeed, Thomas and Milligan (2015) highlight a myriad of ways in which people with dementia experience similar oppressive barriers including being misunderstood, systematically devalued by society, denied opportunities to express or pursue their needs and desires, and forced to endure the use of chemical restraint via sedation. Nevertheless they note that the collaboration between dementia and disability studies has been forged only “incrementally” (Thomas & Milligan, 2018, p116). This observation speaks more to several core tensions underlying disability theory in the UK than it does the applicability of the disability perspective to the experiences of people with dementia.

Disability and the Lived Experience of Impairment

One of the most influential divides within disability studies centres around the body and its relationship to disability. It is not surprising that the SMD, as a direct reaction to the biomedical model and its exclusive focus upon bodily impairment, did not account for nor make space for a discussion of the embodied experiences of those living with impairment (Oliver, 2013). Attempts to explore these lived realities, where challenges were not merely present in the outer world, but in the “aches and pains and urinary tract infections” (Watson & Shakespeare, 2001, p.12) of disabled people, were actively criticised as perpetuating the same oppressive biomedical perspectives that the SMD had sought to eradicate. The erasure of the body from disability discourse was widely criticised (see Crow, 1996; Thomas 1999), in part because it created an emancipatory model which could attend only to the concerns of the “healthy disabled and permanently and predictably impaired” (Wendell, 2001, p21). Such

a construction, therefore, could not be applied to the lives of those whose impairments were invisible, mental, chronic, unpredictable or painful (see Crow, 1996) who “experience[d] physical or psychological burdens that no amount of social justice [could] eliminate” (Wendell, 2001, p18).

The erasure of the body in the social model introduces two principle challenges for the study of dementia. Firstly, dementia is by its nature both unpredictable and degenerative. This, ultimately, problematizes any attempt to align the experiences of people with dementia with the paradigmatic construct of the disabled person as someone who needs only societal and environmental adaptation to live without disability (*ibid*), as the effectiveness of adaptations will change over time. As such, dementia diagnosis not only challenges the inclusion of people with dementia into the disability literatures but marginalises them within the field of gerontology. At the moment of diagnosis they become incapable of aging ‘well’ or ‘successfully’ or ‘healthily’ (Angus & Reeve, 2006, Minkler & Fadem, 2002 and Koen & Yonelinas, 2014 respectively). They must, at best, aim to live well with dementia (Martyr, Nelis, Quinn & Wu, 2018). This drive towards ‘living well *with dementia*’, (which I would argue would be more accurately parsed as living well *despite* dementia given its focus on maintaining a previous lifestyle rather than adapting to a new embodied experience) follows a similar path to the SMD. It erases any experiences of difficulty, frustration, pain or suffering associated with the experiences of living with dementia lest it reinforce the narrative of people with dementia as suffering (see Bartlett, Windemuth-Wolfson, Oliver and Denning, 2017) rather than targets of civilised oppression. As a result it is necessary to consider the pitfalls of a disembodied SMD as it applies to dementia, and to identify a contemporary approach which incorporates the valuable theoretical, political and social aspects of the SMD while attending to its weaknesses.

The exact placement of the body within disability theory may remain a matter of heated debate within the literature. There is at least some consensus however on the idea that even if the body itself is irrelevant the body as it exists *in situ* is relevant to disability theory (Freund, 2001) and to an extent in the dementia literatures as the aging body in space becomes the focus of architectural design (Buse, Nettleton, Martin & Twigg, 2017). Were this thesis strictly limited to a consideration of dementia and spatiality this would be sufficient, however such restriction would be wholly inappropriate in the context of the complex web of interactions that are made manifest at physical, social, and temporal thresholds. As such this research follows the path laid by phenomenologists, critical realists, and materialists (Goodley, 2012; Watson, 2012 & Thomas, 1999 respectively) among others in considering the body as not only a relevant ‘object’, but a vehicle for the embodied experience of space (Buse et al., 2017), relationships (Buse & Twigg, 2014) and time (Twigg, 2008). It is critical to acknowledge at this juncture that considering impairment and disability as separate-but-interrelated makes it necessary to separate this research from the post-structuralist approaches advocated by Shakespeare (e.g. 1996; 2004) and his colleagues. These approaches do not allow for a body that is ‘real’ or ‘pre-social’. Such ‘essentialist’ approaches are often met with resistance when communicated to those working from within a discipline associated with the biological, medical, or natural sciences where ‘the body’ is the primary subject of study (see Williams, 1999). Given that this research was conceptualised not only as an academic endeavour but a potential vehicle for change and improvement and that managing dementia care requires a holistic approach drawing on a myriad of disciplines and perspectives, adopting such a position would be counterproductive. Instead this research follows both theoretically and ideologically from Thomas’ (1999; 2006; 2009) and uses her social-relational approach. As a result, this thesis uses terminology in the following way:

disability/disablism: *“the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people characterised as ‘impaired’ by those deemed*

*'normal'. Disablism is social-relational in character and constitutes a form of social oppression. [...]
As well as enacted in person-to-person interactions, disablism may manifest itself in institutionalised
and other socio-structural forms"*

(Thomas, 2012 p.211)

*impairment: "A characteristic, feature or attribute within an individual which is long
term and may, or may not, be the result of disease, genetics or injury and may:*

1: Affect that individual's appearance in a way which is not acceptable to society,

And / or

2: Affect the function of that individual's mind or body, either because of or regardless of society,

And / or

3. Cause pain, fatigue, affect communication and reduce consciousness

(Thomas, Gradwell & Markham, 1997)

*impairment effect: The direct and unavoidable impacts that 'impairments' (physical, sensory,
intellectual, emotional) have on individuals' embodied functioning in the social world.
Impairments and impairment effects are always bio-social and culturally constructed in
character, and may occur at any stage in the life course*

(Thomas, 2012 p.211)

While these three concepts encompass the majority of Thomas' work as it applies to this thesis, it is also necessary to acknowledge the contribution and value of what she calls 'psychoemotional disablism' particularly in the context of living with dementia. Psychoemotional disablism, which acts at the individual level to limit not just what disabled people can do (as structural disablism does) but who they can be (Thomas, 2007). In these cases, internalising disabling narratives and beliefs has a profound negative effect on an individuals self esteem, their confidence, and their ontological security (*ibid*, p.72). Such disablism can be explored in the context of both direct relationships (e.g. between the disabled person and others, or between the disabled person and themselves) and indirect interactions (e.g. between the individual and an ableist society) (Reeve, 2008; 2014). Such

insights further emphasise not only the value of viewing people with dementia as disabled, and as such as targets of civilised oppression who are vulnerable to psychoemotional disablism, but of exploring their experiences at the threshold spaces where the individual meets another, where public and private meet.

The Importance of Threshold Spaces

The previous discussion has considered at length the value of considering people with dementia firstly as targets of civilised oppression and, secondly, as people who are disabled by society on the basis of their embodied impairments. There is also a need to more explicitly discuss the value of exploring how these processes are encountered by people with dementia at physical, social, and temporal threshold spaces. This argument is most clearly made in relation to physical thresholds, as both the SMD and the wider Neighbourhoods project are deeply concerned with the organisation of physical space as it impacts the lives of disabled people and, thus, people living with dementia. Indeed, there have been a number of articles published with the intention of highlighting the ease with which physical thresholds can be rendered impassable for people with dementia by, for example, disguising threshold spaces and doorways as other objects (i.e. Kincaid & Peacock, 2003; Vanderhorst & Koenig, 2015). There is also a well established literature that explores various methods of facilitating physical thresholds by, for example, clearly labelling cupboards and drawers (Chard, Liu, & Mulholland, 2009) and using photographs and meaningful objects to help residents in nursing homes differentiate between their rooms and those of others (Gross et al., 2004). Thresholds are paradoxically central to, and absent from, the considerations of these works, despite their focus on spaces where one physical space meets another. Given the presence of such literatures, it is possible to see how physical thresholds might become sites of civilised oppression and disablement (i.e. by blocking passage as per Vanderhorst & Koenig, 2015) or facilitation and enablement (was with labelling in Chard et al., 2009, or increasing visual

access in Namazi & Johnson, 1991). Exploring how people with dementia experience and navigate these thresholds, therefore, provides an opportunity to better understand the experience of disablement and oppression as it occurs on a day-to-day basis.

Living with dementia is an intrinsically spatial experience where people are disabled in and by space and experience their impairments in the context of their environment. Patterson and Hughes (1999) explore this experience in the context of ‘dys-appearance’:

“The disabling and disabling sociospatial environment produces a vivid, but unwanted, consciousness of one’s impaired body. Here the body undergoes a mode of ‘dysappearance’ which is not biological, but social. For example, in the context of the ubiquitous disabling barriers of the spatial environment, one’s impaired body ‘dysappears’- is made present as a thematic focus of attention. When one is confronted by social and physical inaccessibility one is simultaneously confronted by oneself.”

(Patterson & Hughes, 1999, p.603)

In such cases encounters with impassable barriers or threshold spaces not only influence how an individual interacts with the space itself but how they feel both about themselves and about the space (Davidson & Milligan, 2004). This interrelation allows spaces to be, simultaneously, physically accessible and mentally or emotionally oppressive (Freund, 2001). Indeed, such complexities ensure that simply being able to physically access a space does not necessitate an equality of experience or even successful access in a holistic sense. It is possible, therefore, for a space to be physically and architecturally accessible, but experienced as inaccessible due to less-visible factors such as the expectation of speed and the intrinsic timing of the space (c.f. Hoxie & Rubenstein, 1994; Allen, 2004). It is this complexity that necessitates an investigation of nonphysical social and temporal thresholds alongside a consideration of physical threshold spaces. Such an investigation may, for example, highlight where a shared space like a supermarket is considered to be accessible because it has designated hours or check-out lanes that are designed to compensate for some of the

disabling aspects of that space (i.e. Brorsson, Ohman, Lundberg, Cutchin & Nygard 2018). It is important to note, however, that while such interventions may make the physical space accessible under certain circumstances, it fails to address the social or temporal aspects of the space more generally, forcing people with dementia to inhabit different ‘spheres’ even when using the same facility (Imrie, 2000). That these efforts are often parsed as additions to public space rather than intrinsic requirements for public space given the rights of disabled people (Equalities Act, 2010) is indicative of the very civilised oppression Harvey (2015) describes. Focusing on these threshold spaces, therefore, allows for an exploration of the tensions that are made manifest when a person with impairments as a result of their dementia meets, negotiates with, and manages thresholds in a predominantly ableist society (Goodley, 2014).

Summary

This chapter has made a number of important contributions to the thesis in terms of defining its theoretical foundations. First, it introduced the concept of civilised oppression and the value in considering people with dementia as targets of that oppression. It goes on to draw from the discipline of disability studies to highlight how considering people with dementia both disabled and oppressed by society. Positioning the thesis in this way allows not only for an investigation into the lived experiences of people with dementia, but a multi-layered analysis that is capable of capturing the impact of disablism as an extrinsic and intrinsic force that restricts both what people with dementia can do, and who they can be (Thomas, 2007). Finally, the chapter highlights key points where existing literatures in dementia research touch upon, but never fully acknowledge, the importance of threshold spaces in enabling or disabling people with dementia.

3 : A SELF BEYOND PERSONHOOD: DASEIN, DWELLING, AND BEING-WITH- OTHERS.

Introduction

Where the task of Chapter Two was to elucidate the ways in which positioning people with dementia as disabled people and targets of civilised oppression provides an opportunity to challenge ableist and dehumanising narratives, it is the work of this chapter to attend to the philosophical constructs that underpin this research. I argue that an uncritical acceptance of Cartesian mind-body dualism, with its construction of the self as both shaped by and reliant upon cognition, is complicit in the construction of the narratives of decay. Indeed, by challenging the notion that thought is the preeminent component in selfhood (as Descartes does in ‘I think, *therefore* I am’), it is possible to unilaterally dismiss any constructions of the person with dementia as one who is hollowed out or reduced (Luntly, 2005; Radden & Fordyce, 2006; Kessler, 2007) by the effects of their disease.

The chapter opens by acknowledging the impact of Kitwood’s (1997) work on Personhood before shifting focus to consider its philosophical underpinnings. I then contend that Kitwood’s construction of Personhood as a status bestowed by others fails to sufficiently disrupt the narratives of decay, as it demands only that people with dementia be *treated as* individuals with a lived history, rather than engaged with as whole and undiminished individuals navigating the world with progressive cognitive impairment. The body of the chapter builds from this point, as I present Heideggerian philosophy, and specifically the concepts of Dasein, Dwelling, and Being-with-Others as key concepts which at once facilitate exploration of the threshold and preclude any intrusion by the narratives of decay. From this perspective, I argue, it is possible to approach dementia studies and people with

dementia in a way that is sensitive to their experiences and challenges, critical of their oppression, and respectful of their undiminished value.

Considering Personhood

It is impossible to engage with dementia studies as a discipline, or dementia research in a UK context, without acknowledging the impact of Kitwood's seminal text, *Dementia Reconsidered* (1997). The implications of this text are profound, and its reach extends beyond the academic sphere, where it provides a foundation for the contemporary activism surrounding human rights and citizenship for people with dementia (Mansell & Beadle-Brown, 2006; Bailey, Ridley & Greenhill, 2010; Turner, 2001, respectively). *Dementia Reconsidered* is also profoundly important for this work, as it was Kitwood's (1997) reconstruction of dementia that helped lay the groundwork that makes it possible to adopt disability approach for people with dementia. Critically, Kitwood argues that dementia is more than a diagnosis, or the presence of disease, but:

“Neurological Impairment + Personality + Biography (Life History) + Physical Health + Malignant Social Psychology”

(Kitwood, 1997 p.83)

While proposing such a model does not afford Kitwood the status of disability theorist, it certainly aligns dementia studies with the disability literatures discussed in Chapter Two. Indeed, Kitwood's (1997) notion of Personhood draws strength from preexisting work within disability studies, which also presented Personhood as a cultural status. Luborsky (1994), for example, argues:

“Personhood is bestowed by society, and is earned by achieving and maintaining expected social roles and ideals. It is not an intrinsic property of the individual nor can it be seized merely by individual fiat (Fortes 1987; Schiebe 1984). By person I refer to the cultural category of full adulthood or full Personhood. The term individual is used to refer to the concrete biological

organism. Personhood is not an automatic or intrinsic property of the individual nor can it be gained by personal claim—it must be socially legitimated.”

(p.240)

While Luborsky's (1994) concern is primarily with the extent to which people with physical impairments were not afforded full Personhood status, that Kitwood's Personhood draws from this work, gains acclaim and is ultimately reabsorbed into the disability literatures (i.e. in Blain-Moraes et al., 2013) demonstrates the extent to which the core concepts of Personhood are shared between disciplines. Where these concepts differ, however, is in the explicit acknowledgement of the disabled person or person with dementia as oppressed. It is important to note, therefore, that while Kitwood (1997) highlights the importance of social relationships through discussing malignant social psychology, he does not extend his analysis to the systematic cultural and societal aspects of this oppression. For the purposes of this research, such insight is provided by the lens of Thomas' (1999; 2007) social relational approach to disability, and Harvey's (1999; 2015) conceptualisation of civilised oppression.

The Limitations of Dementia Reconsidered

As impactful as Kitwood's 1997 text is, it is vital to consider not only the 'fruit' it bore in terms of institutional and cultural change (Manthorpe and Samsi, 2016), but the roots of Kitwood's theorising. It is important to note, for example, that while *Dementia Reconsidered* (1997) applied the principles of Personhood to dementia care, there is evidence to suggest that Kitwood's interest was not dementia per se, but in how dementia could be used as a case study to uncover underlying philosophical principles. As Dewing (2006) notes:

“[Kitwood's] ultimate project, ontological in nature, is centered on having a moral concern for 'others' to enable forms of moral praxis or empowerment [...] Indeed, 'Moral Concern for Others' is the title of his seminal work, yet rarely referred to within contemporary dementia literature”

(p.8)

Taken in this context, the rationale behind Kitwood's focus upon Personhood as a status bestowed by individuals upon one another becomes clear. From this perspective, his argument that "there can be no empirically determined point at which it is justifiable to throw some people into the sea" (1997 p10) can be applied not only to dementia, but to human relationships more broadly, as a reflection of our moral duty to one another. As a result, malignant psychology becomes more of a reflection upon the negative patterns of thought that allow one to consider 'throwing someone out' in the first place. This distinction is not without import. Indeed, I contend that it is this subtle change in direction results in a model of Personhood that requires only that people with dementia be treated in a way that honours the person that they were. Such a construct therefore only dictates that people with dementia be treated *as if* they were people: it does not demand that they be recognised as whole and undiminished individuals in the now. It is this caveat that, in turn, makes Personhood an ill wrought tool for the fight against the narratives of decay, wherein the person is ultimately reduced and rendered lesser by their disease (Radden and Fordyce, 2006).

There are, arguably, two means by which such an oversight might be remedied: by disregarding Kitwood's work wholesale, much as Shakespeare and Watson (2002) would do with the social model, or by addressing the weaknesses in its foundation. Given the positive impact of Kitwood's (1997) model of Personhood, and the tendency for contemporary caring to be carried out in line with the principles of Personhood, the former option must be rejected out of hand. This, then, requires an examination of the roots of Personhood as presented by Kitwood, particularly in the context of *Dementia Reconsidered* (1997). While it would certainly be possible to delve into extended philosophical discourse here, such analysis would only serve to distract from the broader work of this thesis. As such, I turn to a critical review offered of *Dementia Reconsidered* at the time of its publication, which pinpoints what I consider to be the primary weakness of the work.

“While proposing an alternative theory, [Dementia Reconsidered] is actually premised on an I-It construction, on precisely that which it criticizes in the traditional care culture. The following statement illustrates this: ‘Some glimpses of the way in which the experience of dementia may differ from one person to another can be gained from studies of personality’ (p. 71). Examining personality studies to obtain insights into a subject’s experience is incongruous with I-thou relations. [...] The approach outlined by Kitwood is more about knowing the other in the relation, and not about confronting the other in their otherness.”

(Greenwood, 1998 p155-156)

The distinction between relationships formed in the manner of I-It and those that are conducted as I-Thou draws from Martin Buber’s (1923/2004) text *Ich und Du* – translated as I and You. In his work, Buber argues that it is possible for people to relate to one another in two ways as objects (I-It) and as other people (I-Thou). According to Greenwood’s (1998) reading, therefore, *Dementia Reconsidered* fails to avoid positioning people with dementia as objects of consideration, and thus fails to demand that those without dementia engage with them as other complex beings with needs and desires that extend beyond the interaction of the person without dementia (in this case, the ‘I’). It is by leaving open this potential for people with dementia to be approached either as objects (I-It) or complex individuals (I-Thou) that Kitwood’s work allows the narratives of decay to continue. Those works which build upon Kitwood (1997) thus risk inheriting the weakness, or face engaging with such narratives as potentially valid interpretations.

The Danger in Dualism

When considering philosophical approaches that might serve to undermine and ultimately silence the narratives of decay, it is important to recognise the ways in which such efforts have already been appropriated to reinforce rather than challenge the construction of dementia as a disease that ultimately erodes the self. Radden and Fordyce (2006) provide an apt example here:

“As the disease progresses, almost all hint of the person we knew will likely be eclipsed, leaving only the body—maybe itself barely recognizable—to taunt us with its empty endurance. But breaking from Lockean concepts and instead acknowledging the self ‘as another’ in Ricoeur’s words, has revealed ways to salvage for a little longer a little more, not only of the sameness of the dementia sufferer but also, perhaps, aspects of their ipseity or selfhood”

(p. 85)

Read uncritically, the above abstract might seem to advocate for a move away from Locke’s idea of the self that is tightly bound with cognition as a “conscious thinking thing, [... that is] concerned for itself, as far as that consciousness extends” (Locke, 1690/1836 p230) it does so only as a method of stalling the ultimate decay of the self with dementia: “for a little longer” (Radden and Fordyce, 2006, p.85). Importantly, however, the passage acknowledges, as the narratives of decay do, the on-going existence a living body. The problem, therefore, lies in adopting a dualistic construction of the self wherein mind and body can be ultimately separated. Such separation introduces the potential for erasure, as the presence of a self becomes ultimately reliant upon the ability to convey one’s selfhood in a way that is understood and perceived as valid by others. Such occurrences are discussed at some length by Boyle (2014) who notes that people with dementia are often denied the opportunity to demonstrate their capacity for agency by those who link cognitive, and particularly discursive, capacity with continued agency. As such, people with dementia who attempt to retain and utilise power in situations and relationships through being (*ibid*, p1140) rather than doing or saying may be wrongly presumed to lack agency, and ultimately, selfhood.

It is worth noting, too, that the more contemporary shifts towards rights or citizenship based approaches rarely directly address these underlying assumptions. Bartlett (2014a; 2014b), for example explores the lived experiences of people with dementia who directly and routinely engage in social activism. Yet these people with dementia are constructed as powerful agents precisely because they can perform the role of ‘social activist’ in spite of their dementia (with

some reporting negative consequences precisely because they were able to meet these expectations) (2014a). Such works are immensely valuable for capturing the experiences of people with dementia as they encounter civilised oppression and stigmatisation, but they do not inherently challenge the presumption that selfhood is reliant upon cognition. Instead, they demonstrate that *not all* dementia related cognitive impairment endangers selfhood, as those people with dementia who can no longer leverage power through neurotypical channels and societally validated ways remain unrepresented.

What is required, therefore, is a philosophical framework that does not rely on cognition, and thus is not beholden to the ability of others to intuit and recognise the presence of ‘valid’ thought. This, I argue, can be achieved by shifting away from the dualism of philosophers like Descartes and Locke, and adopting a Heideggerian perspective.

Heidegger’s Dasein

In constructing cognition as the preeminent component of the self, upon which being depends, Descartes allows for the deconstruction of the self with dementia. Thus, if we adhere to the concept that the presence of thought indicates ‘being’, as in ‘I think, therefore I am’ then a decline in cognitive function threatens the reverse ‘I think not, therefore I am not’. Heidegger’s philosophy offers an alternative interpretation, captured neatly in the word he uses to refer (broadly speaking) to the self: Dasein, which when examined in its component parts constructs the self as ‘there’ (*Da*) ‘being’ (*Sein*). Dasein, therefore, is a Being which is perpetually engaged in the activity being (*sein*) there (*da*), where ‘there’ is the world. As a result, Dasein’s Being is dependent not on thought, but on being in the world- on experience. As Heidegger notes:

‘Being-in is not a ‘property’ which Dasein sometimes has and sometimes does not have, and without which it could just be just as well as it could be with it. It is not the case that man ‘is’

and then has, by way of an extra, a relationship-of-Being towards the 'world'- a world with which he provides himself occasionally."

(1954/1993 p84)

Being-in-the-world is both the character of Dasein's experience (Riya, 2006), and how Dasein comes to understand itself "proximally and for the most part in terms of its world" (Heidegger, 1954/1993 p120). Dasein is inseparable from the world, and comes to know itself through its experiences therein. As a result, Dasein is rendered immune to the threat of dissolution or decay based on cognitive decline, setting it apart from concepts borne of Cartesian mind-body dualism (Radden & Fordyce, 2006). People with dementia continue to experience their surroundings throughout their life course, though these views may be rarely captured and recorded in academic research (See Godwin & Waters, 2009 for an exception). As a result, people with dementia, as Dasein with dementia, cannot ever be diminished by any aspect of their impairment for so long as they experience being-in-the-world, which they do until the end of their life (see Bourbonnais & Durcharme's 2010 for an example of this). It is in death, and *only* in death, that Dasein can be extinguished (Heidegger, 1954/1993). Until that moment, the person with dementia as Dasein with dementia, remains whole, and forward facing with an "ability-to-be" (*ibid.* p434) and a future that is coming towards which is of equal value to its past. This perspective even remains if one dismisses the concept of a 'self' as a metaphysical fancy:

"Even if one rejects the 'soul substance' and the Thinghood of consciousness, or denies that a person is an object, one is still positing something whose Being retains the meaning of present-at-hand, whether it does explicitly or not."

(Heidegger, 1954/1993, p114).

Dasein is, as a result, not beholden upon the recognition of its existence by another. It is whole because it is in-the-world, separate from the ability or willingness of others to

recognise and respect that being, a position entirely in step with Boyle's (2014) observation of agency in adults with advanced dementia.

Being-in-the-World

Given the extent to which Dasein is always in-the-world, it is important to clarify what it means to be in-the-world, at least as it relates to the work of this thesis. Firstly, it is important to recognise the impact of Dasein's experience of being-in-the-world, as the way in which Dasein comes to know itself as a Being-in-the-world. The second and third aspects of being-in-the-world that are particularly influential on this work are those which form the heart of Division I and Division II of Heidegger's *Being and Time* (1927/1962): how Dasein interacts with things which are not itself, and how it organizes itself in relation to its finite existence respectively. Importantly, like Buber (1923/1970), upon whose work which Kitwood (1997) built Personhood, Heidegger acknowledges the primary distinction between the way in which people (as Dasein) engage with objects, and the way in which they engage with people as other Dasein. Critically, Dasein engages with objects 'for-the-sake-of' accomplishing a task whereas Dasein exists itself 'in-order-to' (1927/1962 p.86). Dasein is the haver of desire, and the creator of goals for which all objects can be engaged with in the manner of 'for-the-sake-of'. The exact pattern of relations that occur between Dasein, other Dasein, and objects in-the-world is the subject of most of Heidegger's works. It only necessary to note here, however, that Dasein as always in the world is always and inextricably positioned as in relation to both objects, and other Dasein. That it is possible for Dasein to engage with others in a way that is 'for-the-sake-of' achieving an objective does impact upon the substance of either being, but represents a 'deficient' way of being-with one another. As Heidegger (1927/1962) notes:

“passing one another by, not ‘mattering’ to one another – these are the possible ways of solicitude. And it is precisely these last-named deficient and Indifferent modes that characterize everyday, average Being-with-one-another.”

(p158)

While the phrasing is complex, the implication of such a construction is simple: there is no way that Dasein can be-in-the-world as a Being in receipt of experience, that is not valid. There is no cognitive impairment, no deficit in communication, memory, or mood that can rend apart that which Dasein is. Instead, Dasein remains undiminished, (though, arguably, in receipt of different experiences of being-in-the-world), a Being which ‘gathers together’ memories of the past (Heidegger, 1971), experiences the present, and looks ahead to a future which is silenced only in death, and never by impairment.

Dwelling

Given that this thesis proceeds from the acceptance of people with dementia as Dasein who are always in the world, and explores thresholds as they are experienced by people with dementia as they navigate their daily lives as embodied Beings, it is necessary to highlight the spatial aspect of that existence. In Heidegger’s later work (1971) this is explored as in the concept of dwelling. In his piece, *Being, Dwelling, Thinking* (1971) Heidegger argues that the act of dwelling is not interchangeable with the act of residing, because it is possible to reside in a place without dwelling there. Dwelling, Heidegger contends, is instead a fundamental thing that Dasein does, *because* it is Dasein. He notes:

“We do not dwell because we have built, but we build and have built because we dwell, that is, because we are dwellers.”

(1971, p.148)

With this in mind, the exploration of how Dasein with dementia experience and manage threshold spaces might be usefully explored wherever the dwelling space meets a ‘space’

where that Dasein does not dwell. Such an understanding of dwelling is particularly apt for this study given the ongoing trends towards enabling people with dementia to live at home for longer and the emphasis on building dementia friendly communities and neighborhoods (i.e. Department of Health, 2015). To draw on Heidegger's conceptualization of dwelling not just as existing in a space, but as being emotionally bound to it and to the community associated with it, therefore allows for a more nuanced view of what it means to 'dwell', which in turn, allows for a consideration of what it means to dwell within or as part of a community.

There are three main aspects of dwelling that are particularly pertinent to this research. The first is the understanding of dwelling as an ongoing and flexible process that occurs through the medium of time; as such people must continually "learn to dwell" (Heidegger, 1954/1993 p363). This element of temporality is key to understanding not only daily experiences, but experiences of dwelling over time, as one becomes at-home or no-longer-at-home in the context of progressive illnesses and impairments (Ohlen, Ekman, Zingmark, Bolmsjo & Benzein, 2014), the introduction of telecare (Lopez & Sanchez-Criado, 2009), the entry of care into the home space (Andersen, 2008) and the move into residential living (Zingmark, Norbberg & Sandman, 1993) are all of potential concern for people living with dementia. As such, it becomes necessary not only to consider dwelling as a fundamental way in which Dasein is in-the-world, but as something that can be disrupted with profound negative effects. Diprose (2011), for example, uses dwelling in this way to examine the difficulties people experienced in feeling at home in the aftermath of disaster. She notes that the buildings (as shelters) are simultaneously a product of dwelling-as-building, and facilitative of dwelling more broadly.

"[A dwelling] provides an anchor for the building of, first, the inhabitants' desires, aspirations, perceptions, and memories at a pre-reflective level, and, when the building recedes through habituation, it provides the ground for the emergence of more abstract capacities of measuring,

valuing, and thinking. This is why loss of a building and things that have participated in the building of one's dwelling can strike at the core of one's being"

(ibid p.62)

Read in this way, a dwelling, in the Heideggerian sense, encompasses more than spatial physicality, and highlights the intricate relationships that occur between people, their homes, and the objects that they keep within their home. A challenge to dwelling, therefore, creates a challenge to abstract processes such as thinking and valuing, much as has been discussed in the literature regarding the increasing presence of care and caring within the dwelling space (i.e. Surr, 2006; Kontos and Martin, 2013).

This consideration of spatial aspects of dwelling necessitates an acknowledgement of how Dasein dwells as an activity. There are two primary ways in which Dasein dwells that are relevant to this research, namely dwelling-as-building (*bauen*) and dwelling-as-maintaining (*wohnen*). In *Being, Dwelling, Thinking* (1971) Heidegger argued that the tendency to construct 'dwelling' as interchangeable with building (as a noun) led to an impoverished idea of what it is to build. Patra (2006) explains his complaint thus:

"The Old English and High German word for building, bauen, means 'to dwell'. This signifies: to remain, to stay in a place. The real meaning of the verb bauen, namely, to dwell, has been lost to us."

(Patra, 2006 p.210).

If we follow Heidegger's thought- that building is dwelling, that dwelling is how Dasein is in-the-world, and that being-in-the-world is both part of Dasein and how Dasein comes to know itself, then the reason behind his concern at losing the 'real meaning' of building-as-dwelling becomes clear. If we do not know the manner of our dwelling and how we dwell, we cannot know ourselves as Dasein. To recover this, Heidegger proposes two active components to dwelling: building (*bauen*) and protecting and maintaining (*wohnen*). For the

sake of clarity, however, rather than referring to the concepts themselves in their original German, or the recursive building-as-building and building-as-dwelling (where dwelling is itself to build...) the thesis shall use the terms in the following way:

Those aspects of building-as-dwelling that are tied up in the construction, creation, or building of something, which Heidegger calls *bauen* are henceforth referred to as “dwelling-as-building (*bauen*)”.

Those aspects of building-as-dwelling that are concerned with maintaining, protecting and cherishing that which has already been built, which Heidegger calls *wohnen*, is from here out referred to either as “dwelling-as-maintaining (*wohnen*)” or “dwelling-as-protecting (*wohnen*)” as is most appropriate in context.

While defining the *bauen* and *wohnen* in this way limits the extent to which the entirety of Heidegger’s thought on dwelling can be used within the thesis, it is necessary to consider dwelling in some manner that might be applied during analysis if it is to provide insight. To assign *bauen* to creation and *wohnen* to preservation does so, while still allowing for the English word ‘dwelling’ to represent the two aspects intertwined. It is also necessary to note that while considering dwellings (as spaces within which Dasein dwells) rather than ‘houses’, ‘flats’ or ‘bungalows’ as discrete units, would circumvent the need for an a priori assumption about the limits of the home space, it introduces unnecessary levels of confusion when used as such. For example, to use the word dwelling in all of its meanings (including the Heideggerian) would allow for a discussion of how people dwell (as their way of being-in-the-world) through their practices of dwelling (as specific acts of *bauen* and *wohnen*) within their dwelling (the place-in-which-they-dwell). In an attempt to accommodate the complexities that are facilitated by a dwelling-as-a-place-where-Dasein-does-dwelling this research will refer to the place-in-which-Dasein-dwells as ‘home’ where it is best characterized as inside the primary building in which they dwell, and as the home-space where dwelling proceeds beyond these architectural boundaries, for instance into the garden or beyond. Those places where Dasein does not dwell (but may nevertheless access, such as

the dwellings of others, meaningful spaces, doctors offices and so on) are referred to simply as Elsewhere.

Being-with-Others, Near-Dwellers and Neighbours

As noted in the previous section, the fundamental experience of being-in-the-world ensures that Dasein is always surrounded by both objects and other Dasein. This understanding is critical, for the world is a “with-world” that “one that I share with Others” (1954/ 1993 p.155) Such a construction is vital for understanding Dasein as it not only constructs the world as a space which exists beyond individual Dasein, but acknowledges at once the inextricable relationality of being in the world with other Dasein alongside Dasein’s temporality. Dasein exist together in one world, but only for a finite period of time. Dasein is always with others in the with-world, and because it cannot be separated from the world by anything other than death, the question can no longer be ‘how do I relate to this shell that was once by loved one?’ (as in Radden and Fordye, 2006) but how can I, as a person without dementia, continue to communicate with my loved one with dementia, whose experience of being in the world has been transformed by the dementia disease? That this positioning acknowledges the work already undertaken to support carers and family members to ‘learn to listen’ in a way that facilitates new methods of communication (as in Lovett, 1996; Basting 2009, Banner 2014) demonstrates the potential for such a perspective to find resonance within the existing body of dementia literature.

From this perspective, and having explored the ways in which Dasein is always in-the-world, knows itself through its experiences of being in-the-world as a dweller, and is constantly surrounded by and in relationship with both objects and other Dasein, it is necessary now to examine one space in which all of these concepts might be applied- at the threshold. It is the spatial orientation of each of the concepts listed above that make such an example possible; Dasein exists in space, alongside objects and other Dasein; Dasein dwells through building

physical and nonphysical things which are themselves spatially situated either through being constructed physically (as buildings) or socially (as social structures with other embodied Dasein). As a result, the home space as a dwelling within which Dasein enacts their practices of building (*bauen*) and maintenance (*wohnen*) represents a space that is necessarily surrounded by thresholds. Where these thresholds occur remains open, as dwelling can extend beyond the traditional boundaries of the house and into spaces that might otherwise be understood as communal or free of ownership and thus of dwelling. Yet these are the areas where Dasein may dwell together, or where each might dwell but separately alongside one another. Shared, communal spaces such as the gardens associated with a block of flats are examples of this: as each is a space in which the dwelling of multiple Dasein might overlap in harmonious or conflicting ways as each seeks to build (as in *bauen*) and preserve (as in *wohnen*) according to their habits. These Dasein, then, are not just ‘others’ in the sense that they inhabit a shared with-world, but Dwellers who dwell alongside- they are “the *Nachgebauer*, the near-dweller” (Heidegger, 1971 p.349): the neighbour. How people with dementia manage and navigate the thresholds that separate them from their neighbour, and their dwelling space from that of their neighbour, calls upon each of Heidegger’s constructions. That both the person with dementia and the neighbour are necessarily Dasein who are in-the-world as dwellers, that they are each surrounded by other Dasein and objects, and that they comport themselves in a way that reflects their past experience, their lived present, and their oncoming future highlights the complexities that are brought into threshold spaces as it ‘draws together’ both neighbours as Dasein, and neighbours as Near Dwellers. Such complexity is glimpsed in existing research, as people with dementia reflect upon their experience of community (e.g. McMillan & Chavis, 1986; Davis, 2003; Doyle, de Medeiros & Saunders, 2011), and their engagement with neighbourhood spaces (Keady et al., 2012). This thesis draws from Heideggerian thought to provide novel insight into the ways in which people with dementia continue to dwell in the context of their impairment.

Summary

This chapter provided a brief insight into some of the philosophical perspectives that implicitly or explicitly inform key works in dementia research. It argued that the narratives of decay, wherein people with dementia are constructed as being progressively reduced to hollowed, empty versions of themselves by their disease (as in Radden and Fordyce, 2006), continue due to a continued implicit adherence to Cartesian mind-body dualism.

It began with a consideration of the philosophical limitations that undermine Kitwood's (1997) work, arguing that a Dasein perspective supports rather than undermines the conceptualisation of Personhood by attending to its weaknesses without challenging its strengths. From this point, the focus of the chapter focused on providing an insight into Heidegger's philosophy as it applies to this research. The result is a theoretical framework that constructs the person with dementia as Dasein with Dementia, and thus inextricable from their experiences of being-in-the-world, being-with-others and being-towards objects. It argues for an understanding of Dasein as a holistic entity which cannot be separated into distinct components, and thus is not at risk of decay based on impairment. Finally, the chapter draws together these aspects at a potential threshold, highlighting the complexities of dwelling with dementia in the context of a shared spatial world, in which the threshold draws upon not only the expectations and experiences of the Dasein with dementia, but those near-dwellers who dwell proximately and whose practices of dwelling may overlap, harmonise or conflict with those of the person with dementia. It is here, at the point where the literature highlights an increasingly complex web of interconnections between the person with dementia, their environment, other Dasein, and society that I turn to the most pertinent question: how might such relational complexities be captured, analysed, and understood? This is the work of Chapter Four.

4: METHODOLOGY, METHODS AND ANALYSIS.

Introduction

Where the work of Chapters One, Two and Three has been to introduce this doctoral research, it is necessary in this chapter to move away from the broadly theoretical concerns discussed thus far and focus instead upon practical concerns of undertaking research and analysis. The following chapter describes in detail the methodological approach, data collection methods, and analytic techniques in turn, highlighting the ways in which they are at once grounded in the literature and theoretical considerations discussed in previous chapters, and formative for the findings and analysis presented in Chapters Five, Six and Seven.

The chapter begins by presenting the ethnographic approach taken by this research, highlighting the ethnographic principles which make the methodology particularly well suited to research involving people with dementia. The chapter then describes the processes of recruiting participants and obtaining consent. This is followed by engagement with the research design, taking each method used in turn to elaborate on the process of research itself. Following this, the ethical and logistical challenges that resulted from working directly with people with dementia are highlighted by the use of a vignette that draws together my experiences of being in and out of the field to provide an insight into a 'typical' visit with a participant with dementia. Having provided an example of how the data collection methods were used in the field, the chapter then discusses each in turn, beginning with a description of participant observation and ending with a reflection on the use of field notes as an influential tool for both fieldwork and analysis. Finally, the chapter describes its analytic processes, highlighting the value of using hermeneutic phenomenology as a vehicle for

analysis, detailing the different stages of analysis, and reflecting on the process of writing a vital component in the creation of an ethnography, in preparation for the presentation of findings that occurs in Chapter Five, Six and Seven.

Research Questions

Given the literatures presented in Chapters Two and Three, and the commitment of this research to investigate how people with dementia experience and navigate threshold spaces without pre-emptively specifying where such a space might occur, the following research questions were developed to provide direction, shape, and clarity to the data collection and analysis:

- i. What thresholds do people with dementia encounter in the course of their everyday lives?
- ii. How do people with dementia manage threshold spaces?
- iii. How does investigating threshold spaces facilitate greater insight and support better outcomes for people living with dementia?
- iv. What is the benefit of exploring the experiences of people with dementia as disabled people?

Taking an Ethnographic Approach

As this research considers people with dementia as disabled people and targets of civilised oppression, it was vital to adopt a methodological approach that could at once be facilitative of participants and sufficiently robust that its findings could be communicated in a way that might inspire and demand change in a range of academic and practice based contexts. While there are a number of methodologies which might accomplish such a task, there were few that would do so in a way that: a) fore-fronted the participant's experience, b) provided sufficient flexibility to facilitate a range of participants and their needs, c) did not require significant labour on the part of participants, and, d) did not pre-emptively limit the scope of the investigation to those thresholds that I, as a researcher without dementia, might intuit

as significant. Introducing such principles resulted in a move away from participatory action methodologies, where the positive aspects of fore-fronting the experiences of people with dementia must be balanced against the extra labour required of participants in order for them to be ‘fully involved’ (Natasi et al., 2000) and the ethical concerns associated with the need to protect members of a vulnerable community (Morgan, Cuskelly, & Moni, 2014) whose experiences might be shaped by, and expressed through, “unwelcome truths” (Kemmis, 2009 p.463). Adopting an ethnographic approach, by contrast, addressed many of these concerns.

Building upon the traditional, immersive ethnographic method first used broadly within anthropology (Van Maanen, 1988), contemporary variations, or ethnographic approaches, have a number of key strengths that are particularly pertinent to this research. Firstly, ethnographic work positions the participant as the expert in their own experience, and in doing so explicitly seek to address the power imbalances between researcher and participant (Shakespeare, 1996; Berger & Lorenz, 2015). Such measures are vital given my presence in the field as both the architect of the project and as a non-disabled researcher who does not live with dementia (Shakespeare, 1996; Richardson, 2000; Wilkinson, 2002). Indeed, it is only through entering the field as a ‘daft laddie’, or a novice who seeks to learn from participants rather than ‘study’ them (Berger, Feucht & Flad, 2014) that it is possible to gain a meaningful insight into how people with dementia experience and manage threshold spaces. This allows participants to be conceptualised as experts and truth-tellers of their own experience in that moment at the physical, social, or temporal threshold without requiring their experiences to be positioned as reflective of an empirical ‘truth’ (Hammersley, 2017). Adopting an ethnographic approach to interviewing also allows for participants to visit and revisit key events or narratives during the interview, a practice that was particularly facilitative for these participants who were able to clarify and embellish on previous tellings as their memory provided further detail.

Secondly, by adopting a methodology which is broadly nondirective, in a way that encourages participants to control not only the timing, duration, and setting of the research visit but the content of our discussions, an ethnographic approach allows participants with dementia to choose which information they share, and how they share it (Baumbusch, 2011; Petersen, 2011; Berger et al., 2014). This allows not only for a growth of rapport over time, but for the fluctuating impairment effects associated with dementia, and allows the participant to share their experiences at a time when they feel physically and emotionally able to do so.

Thirdly, adopting an ethnographic approach acknowledges the importance of engaging with participants in “naturally occurring” (Brewer, 2000, p.10) environments. Critically, ethnographic methods allows for people with dementia to be asked about their practices of dwelling in the place in which they dwell; allowing the environment itself to become a facilitative factor, a practice which has a long history in dementia research (Namazi, Rosner and Rechlin, 1991). Indeed, the ability to engage with participants in situ allows for greater insight into how people with dementia dwell within a space (as in Hockey’s 1990 study of nursing homes as transitional spaces) as well as into how being within those environments shapes the way in which people with dementia communicate (Bourbonnais and Ducharme, 2010). As a result, participant observation forms a key component of this thesis’ ethnographic approach as it not only allows the voices and experiences of people with dementia to be captured with a sensitivity to the physical, social, and temporal contexts in which they are shared, but removes the overt and potentially disabling reliance on vocal expression that might disable participants if interviews were used in isolation. This was a key component for engaging with participants like Stan, who often found it difficult to articulate his thoughts clearly, and preferred to provide ‘tours’ around key locations, including his home, his neighbourhood, and his local church. Such an approach was also useful in contextualizing discussions with other participants, like Bob and Hazel, who both discussed particular aspects of being in space while demonstrating their use of the spaces (or objects)

in question. In such instances, any attempt to understand and explore the experiences of people with dementia at the threshold without the opportunity to engage with and observe the participant in *in situ* would have led to, at best, an impoverished understanding of their experience as the practices of dwelling and management were enacted routinely, and often demonstrated specifically for the researcher within the dwelling space. Finally, ethnographic approaches require the researcher to engage extensively with the principles of reflexivity throughout the research process, from project conception to analysis and dissemination (Malinowski, 1922; Hammersley & Atkinson, 1983; Draper, 2000; Holloway & Biley, 2011). It is only through engaging with reflexivity as a recursive practice that it is possible to mitigate the risks of producing research which might perpetuate, rather than challenge, the systems of civilised oppression that marginalise and disenfranchise people with dementia (Harvey, 1999; 2015).

For all its strengths, however, adopting an ethnographic approach does open this work to criticism. The most obvious of these is well-documented claim that for research to be considered an ethnography, the researcher must leave their customary environment and immerse themselves in the lives of participants for approximately a year (Pink & Morgan, 2013). Such prolonged contact is thought to provide unique insights into how participants engage with the everyday activities of life (de Laine, 1997; Tedlock, 2000). That this research is described as taking an 'ethnographic approach' rather than as 'an ethnography' is intended to show deference to the on-going discourse around what does and does not constitute an ethnography proper without becoming entrenched in it. As such, this research aligns itself with what might be considered to be works taking an ethnographic approach, which demonstrate that studies of a shorter duration should not be dismissed as "quick and dirty" versions of a true or traditional ethnography (Hughes et al., 1996 p61). Instead rapid (Millen, 2000), focused (Knoblauch 2005; Stephens, Cheston & Gleeson, 2012), and short term (Pink & Morgan, 2013) ethnographic approaches account for a shorter period of fieldwork in a

number of ways, including by using digital technologies to capture of a large amount of data over a shorter period of time. Bourbonnais & Durcharme's (2010) investigation into the ways in which people with advanced dementia used screaming as a communication method is a clear example of this.

It is worth noting, too, that ethnographies which are shorter in duration permit a more intense engagement with the field than might otherwise be possible. As Pink and Morgan (2013) argue:

"It is useful [...] to create short term research engagements that benefit from the production of forms of intensity, empathy and an ongoing ethnographic-analytical- theoretical dialogue. Indeed to achieve this we often need to intervene in peoples lives in new ways, that are intensive, potentially intrusive and involve asking what they might think are irrelevant questions. None of which is sustainable over long periods of time."

(p 3-4)

This ability to enter the field and ask seemingly 'irrelevant' questions is particularly facilitative of research into the threshold, which itself may be considered an irrelevance given its status as an often-travelled, ever-managed space. Most importantly, however, this form of ethnographic approach incorporates flexibility, allowing participants to cancel, shorten, or extend the duration of the research visit depending on their embodied experience as a person with dementia who lives with impairment, and maintains a life and commitments beyond the boundaries of this research. This approach resulted in visits to participants that ranged between twenty minutes and four hours in length, where I could visit their home up to six times over the course of seven months in line with their preferences and in deference to their health and other commitments. By building in flexibility at the outset, it was possible to acknowledge a participant's levels of tiredness, agitation and exhaustion and adjust in future visits without framing it as a failure to participate.

Recruiting Participants with Dementia

Much of the success I experienced in recruiting participants to this research can be linked to the involvement of Alzheimer Scotland as a stakeholder and funding body. Through leveraging this pre-existing connection, I was able to draw upon knowledge and identify avenues of recruitment that might otherwise have remained inaccessible. The benefits of this were particularly evident when navigating the numerous gatekeepers that existed between myself as a researcher, and participants with dementia, a process that is often troublesome without built in stakeholder involvement (Hellstrom et al, 2007). My invitation to speak with the Scottish Dementia Working Group demonstrates the value of such pre-existing connections, as does my ability to contact professionals employed by Alzheimer Scotland who facilitated dementia cafes so that my arrival had been advertised to attendees ahead of time. Undertaking recruitment in these pre-existing contexts allowed me to engage with both people with dementia and gatekeepers in a way that was honest and open. As a result, I was able to explain both the aims of the research and reassure all involved that the research represented a negligible level of risk to the participants, that it would be neither invasive nor restrictive, and that their privacy and anonymity would be assured throughout the process (Mental Capacity Act, 2005). This engagement ensured that both participants and those who supported them understood that as a non-clinical, non-therapeutic research project, there would be no ‘reward’ for participating beyond the experience of having participated (Clarke & Keady, 2002) and aiding in the furtherance of dementia research (McKillop, 2002). Table 1, below, provides a brief insight into each participant including their approximate age at the first visit, the number of times they were visited, their living situation, and their engagement with walking interviews, while the participant profile section which follows provides a brief description of each.

Psydonym	Gender	Approx Age	# Times Visited	First Visited	Last Visited	Audio Hours Recorded	Area Type	Living Situation	Received Care?	Used Sensory/Mobility Aids?	Took Part in Walking Interview?
Flash	Male	90s	3	March	April	6:18	Urban	Sheltered	Yes	Hearing	No
George	Male	70s	4	April	August	10:48	Suburban	Home	No	Hearing, Vision, Mobility	No
Hazel	Female	60s	4	April	July	7:46	Suburban	Home	No	None	Yes
Isobel	Female	70s	5	February	June	7:25	Urban	Home	Yes	Mobility	Yes
Janet	Female	60s	2	April	April	2:35	Suburban	Home	No	None	No
Margaret	Female	80s	2	February	March	4:37	Urban	Sheltered	No	None	No
Mark	Male	80s	5	April	July	14:56	Urban	Home	Yes	Mobility, Vision	Yes
Nigel	Male	50s	6	July	July	10:30	Suburban	Home	No	None	Yes
Stan	Male	70s	4	February	May	4:50	Suburban	Home	No	None	Yes
Sybil	Female	80s	2	April	May	3:40	Suburban	Home	Yes	Hearing, Vision, Mobility	No
Bob	Male	70s	1	March	March	3:25	Urban	Sheltered	Yes	None	Yes

It is important to clarify at this juncture that while approximately half of the participants were recruited through groups associated with Alzheimer Scotland, others were recruited through other organisations that explicitly focused on supporting people with dementia or otherwise advertised their activities as ‘dementia friendly’. While this strategy was effective in facilitating recruitment, it should be noted that by targeting groups that advertised their connection to dementia there is a potential loss of other voices. Milligan (2000; Milligan & Morbey, 2013) notes that gender and class are often ingrained in traditional support spaces in such a way that certain groups, may find them emotionally or mentally inaccessible. This is particularly true of men, who often feel out of place in ‘dementia cafes’ and similar conversational spaces (ibid). Similarly, a strategy that focuses on groups which announce their dementia connection will by extension miss those who do not wish to disclose their diagnosis through attending, or who do not see those spaces as representative of their experience. While I made attempts to challenge the issues of the former by reaching out to groups focused on physical activities or sports reminiscence groups where the membership was exclusively male, the latter remains a limitation of this research which should be tended to in future research. Although some ethical considerations have been highlighted here, these are presented in greater detail after discussion of the research design itself.

Research Design and Methods

Interviews

Interviews often form one core element of the ethnographic research design. This research included two interview styles: unstructured, informal interviews within the house and walking interviews (see Clark & Emmel, 2010; Ward & Campbell, 2013). As this research explicitly positions participants as disabled people and targets of civilised oppression, it was, and is, important to acknowledge and seek to mitigate the extent to which participants might be

disempowered by the research methods themselves. It was through cultivating and maintaining this awareness that I was able to consciously relinquish as much power as possible. Unstructured interviews allowed for greater space for participants to control the direction of our discussions. While unstructured interviews are less pressured, participants were also encouraged to choose whether they would prefer a smaller number of longer visits, or a greater number of visits that were shorter in duration (Pratt, 2002), and they were encouraged to take breaks within that time where needed (Nygard, 2006). I also made a concentrated effort to engage with participants in a manner that was familiar, guided by Weinberg's (1996) observation that there was a fundamental difference between 'talking with' someone, where each member of the conversation is an equal participant, than there were associated with 'interviewing' someone, where the researcher retains a position of authority. This was reinforced by moving away from structured or semi-structured interviewing techniques, and embracing the flexibility offered by unstructured interviews, where there were no pre-determined questions, and thus no correct or incorrect answers (Leech, 2002; Hellstrom, Nolan, Nordenfelt & Lundh, 2007). This was particularly influential for my participants, many of whom went on to recount feeling significant anxiety when faced with structured measures, which they often associated with embarrassment, failure, and the emotional process of their diagnostic journey.

It quickly became clear that informality, rather than the formality associated with the researcher's mantle was facilitative of my participants in an interview setting (see Hammersley and Atkinson, 1983). For example, in my first interviews with Margaret and Isobel (who were among my first participants), I arranged myself with a notepad at my side, intending to make quick notes to remind myself of any particular topics or phrases that I wanted to return to as they occurred in conversation. It was only after Margaret took me around her flat that I realised she spoke more freely when the notepad, itself a material reminder of our roles as researcher and participant, was not present. This impression was

confirmed when I reclaimed the notepad briefly, noticed a change in her demeanour, and returned it to my bag. This pattern was repeated twice more with two different participants before I abandoned the notebook entirely, preferring to take field notes in the car directly following an interview, and to remain present in conversation with only the Dictaphone accompanying me into the interview space as a physical prop. The results of this decision were twofold. Firstly, my participants became easier in my presence and spent less time apologising for not providing 'good' information. Secondly, I found that being stripped of the material objects of research facilitated my own research practice. Left with only the Dictaphone as a physical symbol of my researcher role, I found myself better able to engage with participants. Freed from the task of taking notes, I became a more egalitarian conversational partner (Oakley, 1981). Secure in the knowledge that the Dictaphone would capture our conversation, I could focus instead on engaging with participants in a way that was genuine, nondirective (Leech, 2002) and open (Selltiz 1959). Ultimately, this openness facilitated rapport building, and allowed me to engage with participants in a way that was enabling, thus helping to ensure that it was the participants experience and voice at the heart of this work, rather than my own pre-formed assumptions, a process that was crucial to accomplishing the goals of this work (Barton, 1993).

Walking Interviews

Alongside interviewing participants within their homes, the research also made use of walking interviews as an additional avenue of data collection. In this, this research aligned itself with the methods of its parent project, the Our Places Our People study, which uses walking interviews as a method of exploring the ways in which people with dementia experience and engage with their neighbourhood. The rationale behind the adoption of walking interviews as a data collection method is mirrored in both projects, as walking within the neighbourhood while discussing the neighbourhood, and crossing thresholds while

discussing thresholds both facilitate recall for people with dementia by discussing phenomena in context, rather than separate from it (Clark and Emmel, 2008; Ward and Campbell, 2013).

Using walking interviews encouraged participants to become curators of our time together, as they chose if, when, and where we would walk together. It is important to note, however, that providing this freedom resulted in 5 participants (Flash, George, Janet, Margaret and Sybil) choosing not to walk outside during our time together. When queried on why they chose not to walk, these participants offered a myriad of explanations including preferring not to walk outside, finding the outdoor environment difficult to navigate due to mobility impairments, fearing a fall, feeling tired, and distrusting the weather. Each of these reasons were respected as valid and represented of their habits of dwelling, with potential limitation in data collection being addressed by undertaking walking tours of their home space. Whether inside or out of doors, these walks both changed the dynamics of the interviews themselves, but provided ample opportunities to observe how the person with dementia navigated the physical and social spaces of their neighbourhoods. This facilitated a more nuanced insight into the complex relationships that existed between the person with dementia and the spaces they routinely accessed, as well as how they navigated those public spaces in the context of potential social encounters with others. Insights into these physical threshold crossings and the spatial arrangements that informed them are discussed at length in Chapter Five. Similar methods have also been used to explore the potential impact of context and the environment on healthy behaviours (Garcia et al., 2012), wellbeing (Carpiano, 2008), and continue to become more prevalent within qualitative research as advances in digital technologies make 'walking' or 'go along' interviews a viable method of prompting novel insight without sacrificing audio quality and data capture.

Photographs and Objects

Although it was not my intention to create a visual ethnography, I nevertheless wanted to make visible to the reader the phenomena I encountered in the field (Harper, 2012). In this, my thinking was aligned with scholars like Pink (2009; 2012) and Mason and Davis (2009) who argue that the sensory world represents a fundamental aspect of the experience of being-in-the-world, and as such support the use of multiple data collection methods to capture it. As such, while my field-notes often reflect on my own embodied sensory experiences of being in a place, I use digital photographs both to highlight areas and objects that appeared to become significant during interviews and to exemplify the topic at hand. I do not consider the digital images I captured to have an inherent meaning, but use them to explain, exemplify and communicate meaning uncovered using other methods. The images thus serve a twofold purpose, first in facilitating the process of analysis by providing a visual reference for audio and transcribed data, and second in providing contextual or demonstrative visual information for the reader where they are included in the thesis. As such images, as I use them in the thesis, are intended to enhance rather than replace description by capturing the materiality of often immaterial threshold spaces. It was an unexpected development to have participants supplement this aspect of the data capture themselves through the gifting of objects and tokens. While much has been written elsewhere on the import of mundane objects (for example; Hurdley, 2013) and the practices of hosting, which themselves involve materialities of foods and containers (van den Hoonarrd, 2005) I was surprised at the extent to which I often left participants houses with token objects despite explicitly resisting attempts to do so. This was particularly notable with Bob- who refused all of my attempts to leave the residence without a chamois cloth after I admitted I did not own one nor know of their particular use for glass; Flash, who escorted me to the main road that separated his residence from my car and agreed (at my request) to remain on that side, only to cross moments later with a pink flower he had picked from the bush behind him while he waited to wave me off;

and Mark who made extra copies of the poetry he took to his local club and kept them in an envelope until my next visit. These tendencies towards physical tokens was reversed with female participants, who often baked, purchased or otherwise set aside food for us to share, with Isobel going so far as to suggest I should remain for dinner so as to avoid rush hour traffic. While few of these objects find themselves represented in the thesis, they nevertheless reflect a material relationality of this work that informed data collection and analysis.

Participant Observation

Observation is one of the most powerful tools available to an ethnographer (Van Mannen, 1988; Fetterman, 1998), but it takes on greater significance for this study because participants, people with dementia and thus people living with impairment, may experience difficulties in communicating the wealth of their experiences using only spoken language. Indeed, observation is often used within dementia studies for precisely this reason (e.g. Chao, Chen, Liu & Clark, 2008; Nygard, 2009; Dugmore, Orrell & Spector, 2015; Buse and Twigg, 2016). Observation allows the researcher to capture not only what people say they do, but what they do and how they do it in the context of their day to day lives. This insight, paired with the researcher's ability, as a novice in an unexplored space, to notice and question aspects of these experiences that have become habitualised and taken for granted by participants who routinely navigate the space and enact their practices for dwelling there (Storti 2001). In this way, my position as an ethnographic observer within an unfamiliar space was often one which placed me somewhere between a participant and a nonparticipant, as I was increasingly drawn into relational activities such as taking my turn in making tea, while seeking to observe the way in which participants managed threshold spaces without myself participating. That including me in the tea making routine arguably represents a process wherein I became a participant at a social threshold, however, problematizes this, and it is a critical to note that,

as an individual within the dwelling, I could never wholly engage as a non-participant, for I was always engaged with my participants in some way at a social threshold.

Field Notes

Field notes represent one of the pillars of ethnographic work, with Geertz going so far as to argue that between the creation of field-notes and the written ethnography, an ethnographer must also consider ‘scribe’ to be a facet of their researcher identity (Geertz, 1973). While the way in which field-notes are used vary between researchers and over time (see Van Maanen, 1988) the process of writing in an unpolished way in context is a fundamental aspect of then writing polished ethnography (Richardson, 1990). My decision not to take notes during my conversations with participants, as noted above, is not contrary to this tradition (Emerson, Fretz & Shaw, 1995), as writing field-notes as a reflective practice following a period in the field has equal validity (Jackson, 1990). As such my relationship to field-notes is one of participating-to-write, or where I dictated rather than wrote field-notes, participating-to-speak. As Emerson, Fretz & Shaw observe:

“For the most part, these impressions remain “headnotes” until the researcher sits down at some later point to write full field-notes about these scenes and events. [...] ethnographers should take note of their initial impressions. These impressions may include those things available to the senses—the tastes, smells, and sounds of the physical environment, and the look and feel of the locale and the people in it. Such impressions may include details about the physical setting, including size, space, noise, colors, equipment, and movement, or about people in the setting, such as their number, gender, race, appearance, dress, movement, comportment, and feeling tone. [...]the ethnographer can begin to assimilate strange sights and sounds by attending to and then writing about them.”

(2011, n.p)

From this perspective, my field notes were used as a method to capture not only what I was aware of in the field, but of my own thoughts, feelings and emotions on encountering the field. This writing informed my future visits with participants, as made a note of particulars that required a follow up, as well as forming the first stage in the ‘process of textual

production and reproduction' (Atkinson, 1992 p5). It is important to acknowledge at this point that field-notes are not a complete nor accurate representation of events 'as they happened', they are descriptive in nature and selective in focus (ibid, 17). In undertaking my research, my notes were transformed from mental notes (Lofland & Lofland,1995) to 'full field-notes' by the process of "turning away from the field toward the worlds of research and writing" (Emerson, Fretz & Shaw, 2001 p358). These field-notes were then, in turn, used to provide depth and context to the transcripts of interviews, and the review of visual images (Van Maanen, 1988).

Ethical Considerations

Given the positioning of people with dementia as both vulnerable (Mental Capacity Act, 2005) and at risk (Cooney, Howard, and Lawlor, 2006) the decision to engage directly with participants with dementia introduced a number of additional ethical considerations to the study, particularly in regards to establishing capacity, gaining and maintaining consent, and managing participant stress and distress. While these factors are discussed to some extent throughout the body of this chapter and beyond, the following section will briefly detail the steps taken to account meet the ethical responsibilities of the research. Each of the steps below were detailed in full in my application to the University of Stirling's General University Ethics Panel, and were approved under reference GUEP20 on the 19th December 2016.

Establishing Capacity

As this research is substantively informed by the field of disability studies, it was vital that each potential participant was approached in a way that presumed capacity, rather than incapacity (Dewing, 2002). Such an explicit approach was vital, for presuming that a diagnosis of dementia is mutually exclusive with the capacity to provide informed consent is not only inaccurate but risks perpetuating the very mechanisms of oppression this work seeks to

disrupt (Adults with Incapacity Act, 2000; Mental Capacity Act, 2005; Dewing, 2007; Scottish Government, 2008; Nuffield Council on Bioethics 2009). As a result, this research adopted the Mental Capacity Protocol designed and developed by the Our People, Our Places study, which had been previously approved by ethics committees at both the University of Stirling and the Social Care REC. Presented in Appendix A, this protocol allowed for information to be shared in a conversational manner, and aimed to be facilitative of the different ways in which potential participants could communicate understanding, consent, and assent throughout the consent process (Karlawish, Casarett & James, 2002). This was accomplished by first establishing the person's orientation in time, place, and person, before discussing the details of the research, and their involvement and establishing their comprehension through asking questions about the information they had been provided. The protocol provides an explicit framework for establishing capacity to consent, while still providing an option to leave and return to undertake the process again at a future time if the potential participant is unable to demonstrate capacity where their ability is suspected to have been undermined by illness or other factors. Where participants could not sufficiently evidence capacity to consent, their engagement with the research ended, while those who sufficiently met the criteria proceeded to the consent stage.

Obtaining and Maintaining Consent

As discussed in Chapter Two, people with dementia may experience and manifest vulnerability both as a result of their impairments and as a result of systematic disablement. As such the process of negotiating consent, particularly informed consent, with people with dementia requires a number of decisions to be made at the outset. First and foremost, among these is how consent is understood as a concept, and how the securing of consent is undertaken as a process. It is vital to acknowledge, therefore, that the manner in which informed consent is differentiated from uninformed consent within a research context is

inherently problematic (Wilkinson, 2002). Ultimately, the process of establishing informed consent requires not only that the participant demonstrate the capacity to consent, as described above, but that they are able to convey their ability to be informed participants. This introduces two key issues; the power of the researcher as the shaper and communicator of information and an on-going challenge to what it means to be ‘informed’.

My efforts in mitigating the power imbalance introduced in and perpetuated through the consent process were significantly shaped both by my engagement with the disability literatures, and by my experiences of providing support to adults with cognitive impairment. The result was an effort to shift much of the onus involved in demonstrating ‘informed’ consent from potential participant to myself, embracing the idea that a failure to provide informed consent may just as accurately reflect inaccessible materials and procedures as lack of capacity. This approach closely aligns with those of Brady, Fredrick and Williams (2012), who sought to adapt research materials to be accessible for participants with aphasia- a condition which, like dementia (e.g. Bourbonnais and Ducharme, 2010), can affect speech, language comprehension and writing. They argue:

“Standard approaches to ensuring informed consent are poorly matched to many patients’ information needs [...] Development of ‘accessible’ documentation may also improve all potential participants’ access to the research process [...] Thus, for clinical, legal, and ethical reasons, we should be facilitating the accessibility of information provision and consent processes [...]however...]enabling people[...]extends beyond the development of accessible written materials to support their spoken communication needs. “

(Brady, Fredrick & Williams 2012, p.194)

In the context of this research, the call for a facilitative ethical process was met in two primary ways. Firstly, through the design of a Mental Capacity Protocol (Appendix A, discussed above, and secondly through attending to the design of the study materials. To this end, the information sheet and consent form were written in clear, accessible English, and

supplemented with visual images reinforcing the key message in each section (Appendices B & C). This process of creating accessible materials and approaching the consent process in the spirit of facilitation (Nuffield Council on Bioethics, 2009) created a 'formal' space within which participants were encouraged to seek more information (Clarke & Keady, 1996) and make informed choices (Karlavish, Casarett & James, 2002).

It is this notion of informed choices and informed consent that introduces an additional layer of complexity to the ethical grounding of this work. It is vital to note, for example, that even where participants are capable of providing 'informed' consent at the outset of the study, the degenerative nature of dementia problematizes the assumption that capacity once demonstrated, and consent once given, could be relatively assured throughout the research process (e.g. Wilkinson, 2002). However, because informed consent stands as a bedrock of academic research (see Miller and Boulton, 2007) and because obtaining informed consent means providing "adequate information" (Allred and Gilles, 2012 p.150) and presuming that the potential participant takes this information on board in a way that is congruent with the researcher's intentions, despite being shared by their expectations of research generally, and social research specifically, as well as their personal interests and intensions (Edward and Allred, 1999). The extent to which participants can be 'informed' is therefore problematic, especially where the information given encompasses the potential outcomes of the research and its impact, something the researcher themselves cannot foresee at the point of fieldwork (Miller and Bell, 2012; John 2014).

With this tension in mind, therefore, this research engaged in a process of initial and on-going consent, where participants who demonstrated capacity at the point of recruitment were frequently presented with opportunities to reinforce or withdraw their consent (Dewing, 2007). Critically, through this subtle repetition of the process of establishing capacity and consent I was able to detect where a participants informed consent began to

become more aligned with uninformed consent (Wilkinson, 2002), which ultimately resulted in one participant (Stan) ending his participation as neither his capacity nor his informed consent could be established after my fourth visit.

Managing Stress and Distress

Although undertaking interviews with participants is generally constructed as unproblematic, there are several points that require explicit consideration, particularly when engaging with individuals who are potentially isolated (Cotrell & Schulz, 1993; Holmén, Ericsson & Winblad, 2000) and who live with a cognitive impairment. As such, there were two key aspects of the research encounter that introduced the potential for participants to experience stress or distress: the encounter itself, and their reminiscence upon the encounter. It is important to note that an attempt to censor or avoid topics that might cause unease for participants, while conceptually simple, is not only complicated in practice but undermines the emancipatory and inclusive principles of this work (Dewing, 2002). Indeed, the assumption that there exists a clear distinction between potentially distressing topics, the discussion of previous distress, and the experience of distress in the moment is itself worthy of contestation (Denzin, 2003). My approach in the field was, therefore, to approach each encounter with an awareness of the relationship that existed between myself and the participant (Ellis, 2007; 2016). This position allowed me to respect the participants decision to share their memories of living through times of great distress (such as with Isobel's reflection on the death of her children, Janet's increasing struggle with aggression, and Flash's reflection upon his time in the army) while still reaffirming throughout that they were free to stop at any time, to change the subject, or to take a break if they wished. Acknowledging my place within the research relationship and the conversational dynamic was vital, for these memories were shared between people (Slatterly, and Rapp, 2003) in a way that was shaped and influenced by a wide reaching web of interconnectivities that spanned beyond the direct

relationship between the participant and I in the room (Brooks, 2006). To this end I was often comforted by Frank's (2004) assertion that a researcher couldn't:

“Act on principles that hold for all times. We act as best we can at a particular time, guided by certain stories that speak to that time and other people's dialogical affirmation that we have chosen the right stories. [...] By remaining open to other people's responses [...] we engaged in the unfinalized dialogue of seeking the good.”

(p.191 – 192)

As such, the discussion of distressing topics was something that we navigated relationally, together. While I always made a point of reminding participants that they need not speak on any matter they did not wish to, I was guided by their mood (Field, 2006) as to when and how often such reminders were appropriate. Reassured that participants did wish to share their thoughts, emotions and experiences, I engaged by listening deeply to the stories that participants wished to share (Ellis and Patti 2014), and sought to create a space in which they could feel heard by actively recognising, relating and reacting to their narratives (Way & Tracy, 2012).

In spite of these attempts, however, there was evidence of a participant experiencing distress and regret over her engagement in the research after the fact (Jones (1998; Clarke, 2006). This became evident after I received a phonecall from one of Margaret's family members several days after a visit to inform me that I was no longer welcome, and that she believed our conversation had “made [Margaret]'s dementia worse” (CP Field notes) as she had been distressed the following evening and for several days after. This event proved to be particularly challenging for me as an early career researcher who was “seeking the good” (Frank, 2004, p.192), and resulted in a significant period of reflection wherein I questioned not only my comportment in the field, but the wisdom of allowing participants to set the time and duration of my visits. This period was, ultimately, cut short by other engagements with participants, who made short work of any potential safeguards. This was particularly

true of Hazel, who dismissed my concern about staying beyond 12pm and encroaching upon her lunch, by informing me that she didn't like to eat during the day— a practice which was confirmed, and mirrored by her husband who reinforced my welcome. The final result was, perhaps, an acutely targeted awareness of signs of fatigue in participants, but my dedication to engaging with participants as knowledgeable, powerful, and competent individuals who were capable of directing both the conversation during field work and the shape of the encounter (i.e. Corbin and Morse 2003, Nunkoosing 2005) remained. Indeed, Margaret's data remains within the thesis as a result of her decision to have our time together remain as part of the study rather than removing it entirely following her withdrawal, an instruction I received during that final conversation.

Passages in to and out of the Field

The following vignette has been compiled from the reflections captured both in my field notes, and as part of the transcribed interviews with participants. As such, it represents an amalgam of many passages into and out of the field, and provides an example of the ways in which the study's methodology, methods, and practices were intrinsically linked with one another, and enacted through the research relationship.

“April 31st 2017.

Met with Sue Donym today at her home in Afar. I called ahead before leaving the office and spoke with her husband (Alyas) who confirmed they were both at home and happy for me to visit. The drive was easy, but ended up parked around the corner again- Sue insists I should park on her drive in future. I arrived at 2pm, and Sue waved through the window for me to let myself in and met me at the door. Sue and I sat in the livingroom, Alyas entered briefly with tea for us, but took his upstairs to “let us chat”. I put the Dictaphone on her chair arm

to keep it out of the way of the mug and biscuits. Checked Sue was still happy to chat, and reminded her that she could kick me out whenever.

I asked Sue about their holiday, and she spoke animatedly about the cottage and the nearby farm animals. She was less clear about specific events, but returned to them later in the visit (museum, dinner out, etc). I asked Sue if she wanted to walk today- she agreed, but only to a short walk as she expected it to rain. She went upstairs briefly to tell Alyas, and came down with her coat- this one had a larger lapel, and was easier to clip the walking microphone to, and had an inside pocket to keep the Dictaphone in (no more hands getting tangled in wires!).

We walked a loop around the housing estate- n.b. there's an interesting discussion of relationships between generations about halfway through the walk. Sue noted that she didn't know the names of most of her neighbours, but knew them to wave to, and could describe their cars/whether they had children who played outside etc. Sue spoke about the games her son (deceased) used to play as a child- seemed sad but not distressed (reminded her after she didn't need to tell me things she didn't want to. Sue said she wouldn't- I left it at that). Took a brief stop on the way back as Sue struggled with the incline- Sue very resistant to resting, but I wasn't comfortable continuing until she had her breath.

Returned to the house, my turn to make tea. Returned to the living room to Sue examining the side of her shoe- n.b interesting discussion here about her concerns about falling and her need for good 'grippy' shoes that are still easy to take on and off. Spoke for another hour or so, before setting up next meeting and heading off before the rush hour. Sue says I should bring my husband over for dinner as 'there's always plenty' as she still struggles to work out how to cook for two not more. Old patterns die hard (temporal threshold?). Drove off ASAP after getting in the car- Sue waiting at window as expected as I went past. Parked two streets down to take notes, emailed confirmation of exiting field to supervisors and headed home."

The vignette above combines a number of fieldwork experiences and practices, several of which are particularly important. Firstly, my tendency to call ahead and confirm on the day that the visit was still convenient to participants, Sue's greeting, and my efforts throughout to remind Sue that she could both end the visit and redirect the conversation at any time are examples of engaging with consent as an on-going process. The move from a home based interview, to a walking interview, and back, along with the changes in focus and dynamic which accompanied these movements is broadly representative of my experiences in the field. With the exception of Nigel and Stan, few participants wished to start the visit with a walk, and as such the pattern of sit-walk-sit was more representative of the dataset. It should be noted, however, that some participants never engaged with walking interviews either due to difficulties accessing their outdoor space (George, Sybil) or declining to do so (Flash). The section above also captures the practice of setting the date for future visits before leaving the home, and the presence of another key individual within the home (in this case, Alyas, Sue's husband).

Analysis

Data Management

Fieldwork was conducted between February and August 2017, and resulted in 34 interviews and over 78 hours of audio interview content. These files were initially collected on an Olympus WS-853 Dictaphone, using either the inbuilt or clip-on microphone before being transferred onto a password locked computer at the University of Stirling and removed from the device. The audio files were sent for verbatim transcription and received between September 2017 and June 2018, with commonly used names (those of participants and spouses) replaced with pseudonyms in the resulting text file prior to the first round of analysis. Photographs were initially arranged by participant pseudonym and anonymised through digital blurring (where details like faces, names or house numbers were shown) before being saved alongside the transcripts for that participant. Original audio files, along with non-anonymised transcripts and photographs were saved in a separate folder to allow for reference throughout the analysis process while limiting the chance for them to be accessed or seen by unauthorised parties. Digital media was stored on the University of Stirling mainframe, with paper copies of consent forms and other materials being stored in a locked cabinet. Field-notes were reviewed as part of process of preparing to engage with analysis, with notes taken of potentially useful insights, and key sections

Using Hermeneutic Phenomenology

Although hermeneutic phenomenology used rarely within dementia studies, it has a long history both as a basis for other phenomenological approaches (particularly Interpretative

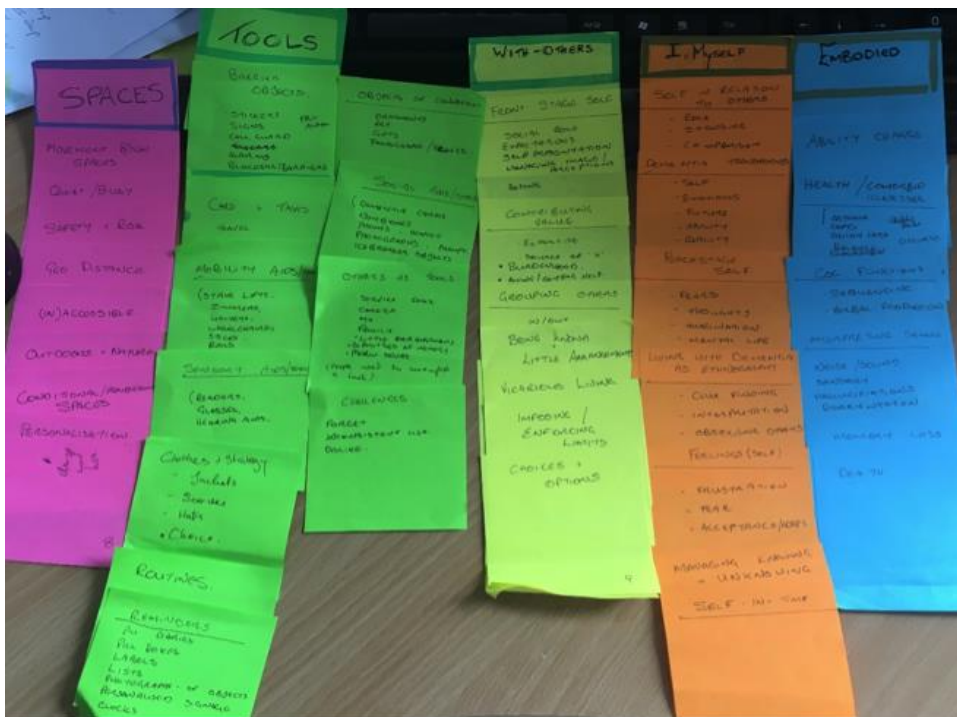
Phenomenological Analysis, see Smith, Flowers and Larkin, 2009) and is used regularly in the contexts of nursing and allied health research (i.e. Annells, 1996; Van der Zalm and Bergum, 2000; Laverty, 2003; Ajjawi & Higgs, 2007; Taylor, 2017). It is important to acknowledge that while there are a number of philosophical distinctions between the phenomenological approaches rooted in Husserl's transcendental philosophical approach and Heidegger's hermeneutic phenomenology there are three key features that are of direct relevance to this research. Firstly, hermeneutics understands engagement with the world to be characterised first by experience, then by contemplation (Bennett, 2013) and as a result removes any grounds for challenging the data, or the experience of participants, on the basis of their cognitive impairment. Secondly, the goal of hermeneutic phenomenology is to facilitate an understanding of what an experience is like, rather than simply provide a description of it (Draucker, 1999). Such understanding is necessary and owed to people with dementia by people without dementia, in line with their status as targets of civilised oppression (Thomas, 2006; Harvey, 2015). Finally, hermeneutic analysis is characterised by its use of the 'hermeneutic circle', wherein analysis is understood to be an iterative process that evolves through engaging with the data, thinking about the data, writing the data, returning to the data repeatedly over time. The result of such a conceptualisation is the recognition that analysis, and understanding, is a dynamic process that evolves over time (Smythe et al., 2007). Critically, like Van Manen (1990), advocates of hermeneutic phenomenology recognise the importance of writing in the process of analysis, rejecting the construction of artificial borders between a stage in which only analysis is undertaken, and a stage where the results of analysis are faithfully transformed into written prose without further engagement (Spence, 2017). As such, 'themes' become indicative of what a researcher

'sees or hears' in the data (Smythe et al., 2007, p.1392) rather than authoritative, exhaustive, and preclusive statements of 'fact'. Instead, the data, in 'conversation' with the researcher, the wider context, and its own composite parts, simultaneously raises and answers its own questions (Bontekoe, 1996).

Stages of Analysis

Given the extent to which hermeneutic analysis differs from other forms of phenomenological analysis primarily in the attitude of the researcher, in that they must seek to analyse and synthesise the data in a way facilitates the emergence of meaning (Crowther, Smythe and Spence, 2014; 2015) and results in a written ethnography that is representative of both the wider body of data collected and the researchers experience in the field. For the purposes of clarity, therefore, I have followed the example laid out by Titchen (1993) and colleagues (Edward & Titchen, 2003) in an attempt to outline my analytic process. The first stage of analysis was characterised by immersion, wherein I was mentally and physically surrounded by physical copies of the interview transcripts, coded directly on paper and created physical notes of the emerging nodes. In this stage, my aims were to both become acquainted with my data in the printed rather than spoken or experiential format, and to outline call 'first order' constructs (Schutz, 1970). It was not until step two that these primarily descriptive constructs became the foundation for my own analysis. This strategy of noting the presence of first order constructs in step one and my interpretations as second order constructs in step two while working on the same physical print-out facilitated my movement within the hermeneutic circle as I was able to more clearly track the links between participant's own statements and my own interpretations. Step three involved spreading

related post-it notes out in such a way that they could all be viewed simultaneously, before arranging them into sub-themes and themes- the result of which can be observed in Picture 1: Themes and Sub Themes Emerging in Stage Three.



Picture 1: Themes and Sub Themes Emerging in Stage Three

Finally, stage four involved moving the analysis from paper into NVivo 11, a process that not only encouraged critical reflection on the analysis as a whole, but further engagement with the hermeneutic circle as I reviewed the framing, naming, and position of each theme in relation to one another as I (re)constructed the data in NVivo. Once all transcripts and coding was transferred to Nvivo, the software was used to explore and visualise the data, confirming the validity and salience of the nodes within the dataset and facilitating constant comparison (Glaser & Strauss, 1967) to ensure that the codes were used consistently throughout.

Writing an Ethnography

Van Manen (1990) argues that a ‘good’ phenomenological work is not just one that describes a phenomena, but one which presents it in such a way that:

“the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way.”

(p. 39)

This quest to capture the significance of an experience while honouring its complexity demands that researchers remain “Janus-faced” (Stanley, 1990 p623) looking at once towards the field and their participants, and yet towards the academe. In this context, the act of writing becomes itself relational, placing the thesis at the threshold as it draws together the academy and the field, and the experiences and voices of participants with dementia. The aim of ethnographic writing is, therefore, to relate not only the words of participants, but in the construction of the written piece to convey the sense of having been ‘there’ (Geertz, 1988). The result should be “evocative in addition to being factual and truthful” (Van Maanen, 1988, p34), a document that keeps one ‘face’ towards my participants and my experiences in the field, and the other towards the academy, the research communities, and the developing discipline of dementia studies.

Summary

While seeking to explore the experiences of people with dementia at the threshold resents a number of logistical, methodological and ethical challenges, each of these provided a unique

opportunity to further refine this research and reflect upon the process as a researcher. This chapter began by presenting a case for adopting an ethnographic approach as an avenue for at once eliciting valuable insight from participants with dementia, while providing sufficient flexibility in method and practice that research encounters could be shaped reflexively to meet the needs and desires of participants over time. This was supplemented by a discussion of the methods of data collection used with participants, principally, interviews, walking interviews, photography, observation and researcher field notes. The closing sections of the chapter then seek to capture the complex and iterative processes of analysis and writing. It has been this process of talking, reading, writing, re-reading, and re-writing that has shaped the three findings chapters to come. The following three chapters each present an insight into how people with dementia navigate particular thresholds, with Chapter Five focusing on physical thresholds, Chapter Six on social thresholds, and Chapter Seven completing the findings section of this thesis with its exploration of participants experiences at temporal thresholds.

5: MANAGING THRESHOLDS IN PHYSICAL SPACE: THE ART OF DWELLING WITH DEMENTIA.

Introduction

As the first chapter in which I present the findings, it is appropriate to consider those aspects of thresholds which are most aligned with how the concept is predominantly encountered in everyday life; their manifestation in physical space. The following discussion draws on the concept of Dasein as both perpetually in-the-world, and continually engaged in activities of dwelling-as-building (*bauen*) and dwelling-as-preserving (*wohnen*). Thomas' (1999; 2007) social-relational approach is used to provide key insights into the relational aspects of disability as it manifests in physical and material practices which can enable and/or disable at different times, in different contexts, and in different relationships. This perspective is key to unpacking the complexities that occur at physical thresholds where the place in which a person with dementia dwells meets the shared spaces of Elsewhere.

The chapter begins by discussing those points where the home-place met Elsewhere, focusing particularly on the importance of doors, doorways and window areas as thresholds that draw together home and Elsewhere. This allows an investigation into how these thresholds could be made manifest as places that simultaneously facilitated passage for the welcome visitor while acting as bulwarks against the unwanted intruder, with particular emphasis on how this relates to dwelling and the use of objects as methods of threshold management. Having considered how thresholds draw together home and Elsewhere, the chapter then turns to focus on troublesome thresholds within the home, drawing out the difficulties associated with both vertical up/down thresholds and those that appear

horizontally as in/out spaces. The fundamental concept of the participant's physical, social and relational experiences as inextricable from one another is introduced in this chapter, and recurs in those that follow as the focus shifts from the physical to the social (Chapter Six), before discussing temporal thresholds in Chapter Seven.

Separating the dwelling from 'Elsewhere'

In the methodology chapter I discussed the importance of explicitly acknowledging and consciously looking beyond preconceived ideas or fore-structures as part of hermeneutic 'looking' and analysis. As such I note here that I entered into the field with a simplistic notion of *where* thresholds might be, but with little expectation around what they were or how they were managed in the everyday. As such the first sections of this chapter are dedicated to those first notions which most clearly align with the language I used throughout my ethics applications and participant recruitment where the ideas of doors and windows as threshold spaces made accessible an otherwise abstracted and at the time unformed concept (as per Weinberg 2006). As a result, many of the discussions which explicitly focused on doorways and windows formed the basis of my early visits with participants, a touch stone which itself facilitated my passage into the field and over the physical and social thresholds managed by my participants.

Material Objects and Threshold Guardians

Doors & Doorways

For participants, the front door provided a forcible bulwark between their dwelling and Elsewhere; between themselves as older people and unknown others in the world. It was the front door that, once secured, could (for the most part) be trusted to fulfil its purpose and be ignored, while also representing (most commonly) the primary mode of physical passage

between the dwelling and elsewhere. That there is a necessity for the parentheses in the previous sentence is key: as relational spaces, thresholds were drawn, redrawn, and encountered both by the participants themselves and by those who dwelled Elsewhere. As such physical thresholds were imbued with activity and tension as an aspect of their being. Nowhere was this as prevalent as at the front door, which was the only threshold space to

host objects directly focused towards those who were unwelcome. Picture 2 and Picture 3 show two stickers in two different residences, the first declaring the presence of a neighbourhood watch initiative, and the second deterring cold callers and doorstep salesmen. Both stickers are themselves placed on the patterned glass that was itself an architectural feature intended to dissuade unwelcome visitors from peering inside the door in a forcible demarcation between public and private spaces (c.f. Kaup, 2011) while still providing sufficient light to enter the home.

As a space which drew together the Elsewhere and the home the front door became a space that was at once its own, and beholden to those spaces on either side of it. Importantly, while pictures Picture 3 and Picture 2 were taken from within the

participants home, I first viewed them from the outside, in the same manner as their intended audience and any person approaching the home. In my first crossings into the field, and into these particular homes, I was consciously aware of the stickers, and their counterparts that I



Picture 2 : Anti Cold Calling Sticker



Picture 3 : Neighbourhood Watch Sticker

observed in numerous other houses. As a researcher, they served as a reminder of the privilege of being allowed inside, subsequently fading from my awareness as my research progressed and I visited each house repeatedly.

This is, arguably, a reflection of their purpose and message, they are not ‘for’ people who are known, expected or welcome, but the unknown, the uninvited, and the unwanted. So strong was this targeting that on one occasion Nigel commented that he no longer noticed the sticker at all, that it had been installed by the previous owners of the house and simply never been removed. It was something he had intended to do, as the sticker was not the “kind of thing” he and his wife would have installed themselves, but it had faded from their awareness in the course of everyday, and thus it remained, a guardian of the threshold that required no maintenance to fulfil its purpose.

It is worth noting that the majority of my first visits were marked by an encounter with some form of ‘guardian’ at the doorway threshold. While in some cases these objects were passive, in others objects became foregrounded in my awareness as they were actively used- first by myself as someone seeking entry, and then by my participants as a method of response. This was particularly notable when visiting Margaret and Mark, who each lived alone and employed an intercom system as a technological mediator between themselves and potential visitors. Others accomplished a similar feat by using social resources to influence the threshold (McKnight, 1987; Warneken, Grafenhain & Tomasello, 2011) - that is, by delegating the task of answering the door to a trusted person, often a family member or spouse (as with Isobel, George and Stan) or through requesting that I be accompanied by a trusted individual on my first visit to Flash and Sybil). This method of using others as a means of managing threshold spaces is explored in depth in the next chapter (Chapter Six). It is meaningful to note that while my experiences of crossing an unfamiliar physical

threshold and entering a participants' home for the first time were often similar, the way in which participants organised their threshold spaces were deeply personal and tightly bound with their practices dwelling-as-building (*bauen*) and dwelling-as-maintaining (*wohnen*). Critically, while the act of crossing often appeared smooth from my perspective as a visitor it was not always so, as the thresholds themselves proved flexible and dynamic, and were reorganised at need in line with the participant's wishes and lived experience.

The Role of Knowledge and Being a Known Visitor

One example of the flexibility and the underlying relationality of threshold spaces themselves came through my visits with Isobel. Isobel was an older woman who lived in a one-floor adapted bungalow which she shared with her adult son, who had sustained a traumatic brain injury in adulthood and now required substantive care. Isobel had a large family network of children and grandchildren who visited regularly, alongside the comings and goings of the care staff who supported her son. On my first visit to her home, I parked in the communal parking bay across the road and spent a moment ensuring I had everything I needed before exiting the car. I knocked at the door, and was greeted by one of Isobel's daughters, who had watched my approach across the street and down the drive through the living room window. I was led through the short hallway into the living room, where Isobel waited along with her second adult daughter, her granddaughter and her infant great-granddaughter. While fieldnotes from this initial visit reflect that the experience was akin to being at once "a source of entertainment, and in the middle of a practical exam" (CP Fieldnotes), I was instructed on how to navigate the doorway-threshold in the future in such a way that I bypassed these measures on a subsequent visit:

"I knocked on Isobel's door and was told to 'let myself in'. Opening the door I found it wasn't Isobel or her daughters who had called, but [Isobel's Son's] support worker who was escorting him to the bathroom. She nodded towards the living room where Isobel sat bundled up on her chair in her pyjamas

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

and dressing gown. It turns out she had a chest infection, but wouldn't consider the idea of me coming back another day. NB: Isobel says knock and enter in future so she doesn't need to get out of her chair.

(CP Fieldnotes, underlining in the original)

In Isobel's case my first crossing had been influenced both by Isobel's experience as an individual with limited mobility and by her family's wish to limit her vulnerability. It is notable therefore that she gave directions on how I was to enter her home on future visits once my identity and intentions had been verified. It was through Isobel's decision to share this information that it became clear that while I would certainly pass over physical thresholds in the course of my leaving and arriving on subsequent visits, I had also crossed an unseen social threshold during the course of our early conversation. It is this social passing that transformed the way in which I was to approach the physical threshold of the doorway in later visits. What this research understands as a social threshold is explored in more detail in Chapter Six.

It was possible to see a similar pattern of influence between social and physical thresholds in my encounters with Mark. Much as with Isobel, my first entry to Mark's home was mediated by a threshold guardian. This time, however, this 'presence' at the threshold was material and digital, rather than human: an intercom system which limited access to the building, subsequently reinforced by the closed door to his flat. Over subsequent visits, I was instructed on how to bypass these elements, first by being told to let myself in at the flat door after using the intercom, and latterly how to bypass the intercom all together. As with Isobel, these practices of dwelling-as-protection and guardianship (*wohnen*) adapted to with our growing rapport and Mark's physical impairments which often made responding to the buzzer effortful. It is interesting to note at this point that throughout fieldwork it was only Isobel and Mark who asked that I follow a 'knock and enter' protocol and that both managed

the movement of care professionals crossing into and out of their home numerous times a day. In the following quote, Mark reflects on the importance of knowledge in navigating the doorway threshold (in indicating the button to push), the impact of temporality (in deciding when the service button would or would not work) and his own process of managing the access of carers:

Mark: When I knew you were there. I shouted come in

I: Yes, you did, yes.

Mark: Yeah. [...] but all the carers walk in. [...] in to me. But I have to let them in at nights. [...] But during the day it's open till 2 o'clock. [...] So you can use that other [button], till 2 o'clock. And so everybody knows, everybody in the block knows that. So they can tell who they want to use that. All my girls know because they know other blocks [...] So they get to know me they can er... at 9 o'clock they come in the morning. [...] And they just walk in.

I: So do you... do you keep your flat door locked, overnight and whatever, then open it...

Mark: [speaking at the same time] Oh yes

I: in the morning?

Mark: As the girl goes out at night I lock the door."

(Mark, Interview Transcript)

Interestingly, Sybil, who was also visited by care workers throughout the day, actively resisted any attempts to open her threshold in this way. Rather than leave the door unlocked, or dispensing privileged knowledge, Sybil managed her threshold directly. This was facilitated both by having a Yale-lock system that would allow her to put the door on the latch when she heard taxi drivers arrive; and by having her living room arranged such that her preferred seat faced the small side window that looked out onto the driveway, rather than the 'main' window which faced the front of the house and the road. Even here, however, some level of concession was necessary, as care workers needed a way to access her home in the event that Sybil could not open it for them, even though in general Sybil preferred to manage her

threshold herself. The solution (which needed to satisfy Sybil, her family, and the company providing her care) was to install a combination outdoor key safe by her front door. Sybil explained that this meant that in order for carers to access her home without her involvement they would need to call their head office to ask for the combination code, then walk from the back door (through which they routinely entered due to the proximity to her drive) to the front door and access the safe. Notable here is the introduction of not just an object as a mechanism for securing the threshold, but the inclusion of a tertiary human element who must themselves be contacted by phone in order to pass on the knowledge necessary to enter the key safe and thus the home 'uninvited'.

Key to these accounts are the practices of dwelling as both aspects of building (*bauen*), and protection (*wohnen*). That the thresholds to Isobel and Mark's homes became passable thresholds during my fieldwork did not detract from their initial status as guarded or troublesome. While neither kept their door habitually locked, as Stan and George did, initial passage required explicit consent sought through either human or digital means through passing family members or ringing the intercom. It was only with gifted knowledge and thus explicit permission that these methods of protection could be effectively bypassed. To enter either residence was to know (the appropriate button, that the door was unlocked and so on) and/or to be known. Uninvited or unexpected persons at either residence who lacked this knowledge would find the threshold difficult if not impossible to pass- a factor upon which Sybil based her own threshold management. For these participants, securing the threshold and protecting their home place was only possible through the integration of objects and strategies was a fundamental part of how they negotiated those aspects of dwelling-as-protection (*wohnen*). The integration of new tools or techniques was often in response to some perceived shift in their ability to protect their dwelling, such as through physical impairment or the introduction of carework to the home-space. Critically, while the above

examples have discussed the giving of privileged knowledge as a method to allow known persons to avoid being impacted by threshold tools and objects, the use of knowledge as a strategy could also inform which threshold was approached in the first place.

While the previous section focused on how objects could be used to influence who entered the home space and when it is necessary to note the secondary level of privileged information which informed the habits of myself, Sybil's family and care workers. Specifically, welcome persons approached the back door, while the unknown and unknowing approached the front door. While in isolation this practice might seem to be a function of the house's orientation in relation to its driveway and the road, Bob and Hazel both employed a similar means of separating the welcome from the unknown or unwelcome visitor. This method of managing the thresholds between the home-place and Elsewhere were so clandestine as to become almost invisible in their simplicity. In my first visits with Bob and Hazel, for example, I drew upon the presence of familiar markers (such as the house number, the garden layout, or the home's orientation in relation to the nearby road) to identify the appropriate door to knock on to announce my arrival, with my participant unlocking the door to allow me to enter. It was only once I was within, once I had become known, that I was instructed to knock at the back door in future- a knowledge I gained directly from Bob, and vicariously through following the trusted person into Sybil's home. In these cases how 'open' a threshold was could be managed not only through adapting the practices of dwelling, but by redefining the meaning of the threshold space itself: in this case, by considering the front door an area where unknown persons arrive, and the rear door as a place for those who are known. George also discussed this, explaining that while he would not generally open his front door, he knew that a knock at his back door meant announced the arrival of his next-door neighbour, whereas "everybody else comes to the front". By introducing this separation between known and unknown, welcome and unwelcome at the moment of announcement,

George, Sybil, Hazel, and Bob were all able to differentiate between visitors who might be safe, and those who may represent a risk before deciding whether they should answer the door. This management strategy worked even when they could not remember whether someone was due to call. A lesser version of this practice also occurred with Isobel, for while the majority of foot traffic came through the front door, those care workers who supported her son and needed a place to park would occasionally enter through the garden gate and rear door. In each case, an invitation to approach through the 'rear' door was given only to those who could be trusted in some manner, with George, Sybil, Hazel and Bob all maintaining the practice of keeping the front door locked as default.

Managing Risk and the Potential for Unwanted Passing

While the discussion to this point has focused on the way in which the threshold at the doorway could be made traversable to those who were welcome, it is equally important to discuss how a threshold might be secured when approached by the unwelcome. As active spaces, thresholds became sites of dwelling both as building (*bauen*) and preserving (*wohnen*). As might be expected of an area that draws two phenomena together, however, these processes were not without their tensions. For example, over the course of my conversations with Mark it became clear that his customary arrangement of having his house keys on the small desk in his hallway with his notebook had been introduced relatively recently. When asked about it, Mark explained that he'd changed his habits to appease the concerns of his close friend and neighbour, who felt that his tendency to leave them hanging in the lock, or on a hook just inside the doorway, represented a safety risk. This tension between Mark's perception of the communal hallway as a safe space, and his neighbour's concerns about intrusion into the hallway leading to intrusion into his flat, are made clear in the following section:

Mark: I used to leave the keys in the door, and the door open you see, because she comes in and [neighbour] across there, she comes in as well. And the lady next door they bring me a paper every day. [...]

I: That's grand, that. So do you not leave the keys in the door now?

Mark: No. No. Jane [my neighbour] – Jane said. [...] Well they're on the desk. [...] Jane said that, you know, I left them in the door, and that was dangerous.

I: Oh right enough cos if they needed to get in...?

Mark: Cos people could open the door [...] and get them.”

(Mark, Interview Transcript)

In this section, the discussion about where the keys are kept is informed by several relationalities. In the first instance, Mark sees no problem with leaving his door unlocked and the keys in the lock, secure in his relationships between Jane and his other neighbour who regularly accessed his home. The second point of note is the relationship between Jane and Mark- that Mark would wish to facilitate her access, that she cares about his safety, and that he cares about her opinion. The final significant factor is that of those unwelcome people who could ‘open the door and get them’. The threat in this instance isn’t immediate, but protracted: whoever took Mark’s keys might not use them immediately, or themselves, but through the loss of those keys the doorway would become ultimately insecure. It is the interaction of those three factors together that prompted Mark to change his habit and stop keeping his keys in the door. This rearrangement, however, had itself caused problems as the keys were no longer where Mark usually kept them, leaving him to rely on his impaired memory to successfully locate his keys in order to leave his home. This, then, necessitated a further step, where the keys were placed between other important objects that connected him to Elsewhere: specifically, his printer and laptop (which he used to copy poetry for his group), and beneath the intercom which announced the arrival of potential visitors.

This shift in where the keys were kept also separated Mark from others, like Stan, George and Isobel all of whom continued to keep their keys near the door. Interestingly, however, a similar concern had indeed been discussed with Isobel, who like Mark maintained a predominantly open threshold with care staff entering and leaving relatively uninhibited. Rather than remove the keys from the door, however, Isobel opted to disguise their location using a small wall mounted clock, the front panel of which opened outwards to reveal a key box. As we discussed the key box, Isobel brought my attention to the small push-button alarm that she could press to summon the police if she felt threatened by someone at her door. Picture 4 shows Isobel demonstrating how she could stand in the doorway, barring entry, while simultaneously using the button to summon aid without it being obvious to a potential intruder. Here we see again the interaction between the methods of threshold management (in this case, blocking the door and the presence and use of the alarm) alongside the importance of curating threshold knowledge (part of Isobel's confidence was based in knowing she could summon help discretely). Critically, both Isobel and Mark engaged with these methods of dwelling through creating a threshold place that could protect their home place, alongside habits of dwelling that became integrated part of their routine- limiting the extent to which memory impairment could impact their ability to dwell.



Picture 4: Isobel demonstrating her door alarm.

The discussion of doorway thresholds as sites of deliberate action and management does not however, imply that all objects and security measures were deliberate acts of dwelling-as-building (*bauen*), that they were welcome, or that they were successful. Nigel's ambivalence

towards the neighbourhood watch sticker on his window (Picture 3) is an example of this. Here the sticker became invisible, eclipsed by the everydayness of dwelling, but may have continued to impact those approaching the house who were unaware of Nigel's disinterest. For George and Anne, however, the difficulties engaging with threshold objects came not from disinterest but through progressive physical impairment. During one conversation Anne noted that the small raised foam dots she had placed on particular buttons of the telephone and television remote to reduce the need for George to attempt to navigate the objects with his macular degeneration had once been applied to the burglar alarm.

George: The only thing is the alarm, I don't...

Anne: Oh, [...] That is a problem that we can't solve. We've got a house alarm and George can't see the numbers now. I did put these dots on it so he could feel where to start and he knew where to go after that, but then that's given a clue to any intruder. [...] Of the numbers. So I can't have the sticky dots on them because the insurance doesn't like that, because it would tell an intruder [...] at least one or four of the numbers. I had it on all four to start off with. So that's a problem.

I: Did you realise that was an issue or did they say to you, you can't have that...

Anne: I realised it was an issue myself because I thought I can't give any indication of what our code is really. Because that limits the...when it's all the nine numbers there's a million choices. But if I've only got four numbers [...] they could try all the different combinations with the alarm, so I don't suppose that's very legal to do that.

George: I don't know, I don't think so. [...]

Anne: Also his problem is remembering the code. So it's not just not seeing it.

(George and Anne, Interview Transcript)

This highlights the importance of acknowledging dwelling, as both protection (*wohnen*) and building (*bauen*), and threshold spaces as eminently changeable. In the first instance, Anne's introduction of a new item to the burglar alarm is indicative of creating a space (*bauen*). That this practice of creation was then the subject of concern, raising the potential for the area to become insecure, demonstrates the potential for conflict between *bauen* and *wohnen* (as

preserving and protecting), with both practices harmonising in the removal of the dots ‘creating’ a clear keypad. As the conversation progressed, George further discussed his unease in relation to using the burglar alarm, as it required not only clear eyesight, but quick access to his memory and swift movement to enter the code in good time while under pressure and listening to the ‘beep’ that warned of intrusion. As such, the alarm system was rendered ineffective as a method of protection any time George and Anne left the home separately, and was as a result only used when they went out together. This particular interaction highlights the potential difficulties of navigating threshold spaces with an impaired memory: if knowledge and knowing facilitates access to the welcome and restricts the unwelcome, what happens in the event of forgetfulness? It is this potential, for George to be marked out as an intruder in his own home, which made him fearful at the thought of using the burglar alarm. That this in turn made it increasingly difficult for him to remember the code, or to manage the gaps in his visual field in such a way as he could enter it, served to compound the problem to the point at which the object initially tasked with protection became itself an impediment to dwelling-within.

While George’s ultimate rejection of an object that had initially served to protect his home highlights one troublesome aspect of dwelling with dementia, it is important to note the multifaceted nature of doors and doorways where they are considered primarily in the context of the threshold they guarded rather than as objects themselves. To this point, the discussion has focused primarily on the manner in which thresholds might be made passable for those who are welcome, and prevent access by those who are not. The following quote from Margaret highlights the potential dangers in confining ideas about what thresholds might be, and how they might be crossed, based on their spatiality and general use. The following conversation resulted from my asking Margaret about a square keyring she had

looped over the handle of her front door, a decision which was tightly bound to her experiences of friendship and cohabitation within her supported accommodation:

Margaret: "And then he started, and I was, [explaining] I don't like the bananas when they get speckled. [...] And I used to keep them for him. And next thing, he was at the door. And one of the days, he asked me to come in, and I went, 'no, don't bother', he was banging against it with his wheelchair. I said, 'no, it's alright, just stay where you are'. Here, this night, I'm sitting, and I went, my keyhole, I went, uh-oh.

I: Never! [...] Was he looking through it?

Margaret: Aye. I nearly died. I went into the toilet for something, and you know how you never, I never go in without doing the hand basin, and the pan, and that. And I just happened to look round, and I said, that looks like somebody. So whenever, I waited, and then I went and started at the back of the door, and he went, 'are you there, Margaret?' I said, 'uh-huh, I'm here'. [...] and I went, 'right, what can I do for you.' 'No, I just wondered how you were.' [...] So I thought, right...

I: I'd be better if you weren't peeping in my keyhole.

Margaret: Exactly. Well I couldn't prove it, but I says, 'no'. So then, I got the key-rings, and I stuck them up against the door. I can't remember, somebody came in later on and went, 'what's all that behind the door?', I said, 'I've got my reasons for that', but I said, 'just leave them there'."

(Margaret, Interview Transcript)

In contrast to other discussions that occurred around doorways and the management of those threshold spaces, this extract introduces the concept of a threshold that is not troublesome, but entirely unwanted. In this case it was not the door or doorway which represents the danger of physical invasion, but the keyhole alone which introduces the potential for visual access to an otherwise private space. This is particularly pertinent as the keyhole in question did not allow for a view into any space other than the bathroom, an area that Margaret had at that point successfully maintained as entirely private. Impactful, too, is the gendered aspect of this incident; that Margaret was viewed in an unwanted way by a

younger male, who attempted to gain access to her home through physical means (by running into the door with his wheelchair).

There are two aspects of Margaret's reaction to this incident that are particularly interesting when considering threshold spaces. The first is in the negotiation between understanding the keyhole as a method of protection, and thus both a product and facilitator of building (*bauen*) and dwelling (*wohnen*) and the need to render it impassable. Here, the door itself continued to act as the impenetrable boundary that she desired- with only the keyhole introducing the potential for visual ingress. By hanging a keyring over the open space Margaret successfully re-secured her doorway, as the actions necessary to push aside the keychain would necessarily fill the keyhole itself. The method in which she did so is also usefully viewed both as an exercise in dwelling-as-protecting, and in demonstrating the importance of understanding Dasein as in-the-world and orientated primarily through action rather than theoretical consideration. The second point of note is Margaret's conscious decision not to disclose the event despite stating elsewhere in the conversation that the man involved was known to staff. Rather than a lack of opportunity, therefore, the decision not to call upon social connections and other people to secure this boundary is worth reviewing. Principally, Margaret cites not being able to 'prove' the incident, but throughout the quote above and the wider conversation it became clear that she was particularly worried both about being embarrassed (which she avoids in the quote above by deflecting 'I've got my reasons') and about being identified as an 'easy mark' to take advantage of. This latter tension, around actively maintaining and managing thresholds and relationships as an older person who is known by others to have dementia, is discussed in more depth in Chapter Six.

Windows and Window Ledges

While only Margaret identified her doorway as an area that allowed visual access into or out of her home, the importance of window areas was evident throughout fieldwork. Contrasted with doors and doorways, windows introduce a number of distinct features which were of particular value to participants- of these the ability to allow visual passage between inner and outer spaces was perhaps the most obvious. Windows provided participants with an opportunity to assess the weather, allowing them to consider what attire would be appropriate in their own time, as well as allowing visual access to other people, animals and spaces without either party physically crossing a threshold. It is important to acknowledge, however, that neither windows nor the spaces that surrounded them existed as a mere 'void' through which the Elsewhere beyond the home space could be accessed visually. Instead, the properties of the glass, the angle of the window, its ability to open or close, and the practice of guarding the threshold against visual intrusion through the use of coverings were all significant. This section focuses on three particular facets of the window space; first, as visual thresholds that draw together the home and Elsewhere, then as a threshold that is visible to the self and others before finally discussing the importance of windows as things of significance in their own right and the practices which surround them

Windows as Visual Thresholds

While ability to see through and maintain the windows as things emerged as important to participants through both observation and discussion. Margaret, for example, had arranged her living room such that she could sit in her armchair facing the television, while seeing out onto the street one floor below. From this vantage point Margaret was able to watch the children across the road play and grow, watch friends leave their homes and return, as well as observe known strangers and unknown people moving up and down the street, while also

watching the program on television and knitting. For Margaret, the organisation of her home space provided a further feeling of safety by assuring her anonymity. Specifically, it was her arrangement of her space in relation to her window that allowed her to view activity on the street below, while ensuring that it was difficult to see into her flat or discern if she was present while approaching either on foot or by car. When she moved to the window to wave me off, however, it became clear that by moving directly to the window she could choose to see, and be seen in return. This allowed Margaret to engage with a silent form of being-with, one which did not require her to engage in conversation (which she sometimes found difficult), but nevertheless built up a sense of relationship between herself and those she observed. She spoke in some depth about the children who lived across the road and their changing play patterns as they aged, as well as which one of them took the dog for a walk, showing a concern for their welfare formed through her experience of being-with them as a near-dweller.

Hazel also engaged with windows as a means of observation, with one notable difference.

Hazel: And the wee birds on the roof over there, I can see them in the cabinet window. [...] I must be sad, I sometimes sit here and count how many birds there are there. Then get up and look out the window to see that I counted the right amount. I thought to myself you're mad.

I: It makes you happy though. I don't see why not.

Hazel: Oh, it keeps me going anyway.

I: Aye.

Hazel: There's two I can see just now anyway but I can't see through the way, the middle bit of the window. Aye, so it's good fun."

(Hazel, Interview Transcript)

Hazel: The people in that house there [...] at the corner, yeab, that blind is never open. And I just sit and I look there and I can see the traffic all going past.

I: Oh aye, it's a reflection.

Hazel: Yeab. And I keep thinking to myself, God if they were standing behind that blind they'll be thinking I'm watching them all the time. But I'm just watching all the traffic all the time. [...] You know, so... I quite enjoy that. I'm weird. [...] I don't look at the traffic at the front. I look at it in somebody else's window."

(Hazel, Interview Transcript)

In these extracts, Hazel explains that she enjoys using windows and glass surfaces to watch the reflections of things rather than the things themselves. Critically, this manner of watching introduces an element of challenge or skill- most notable in the first extract where she uses the reflection to count magpies before moving to the window to count them directly. This simple introduction of a notion of challenge and ability shifts what might otherwise be cast as purposeless (Roach and Drummond, 2014), as a genuinely meaningful activity. The tension between what is perceived by others as purposeful, and what is enjoyed by the individual is acknowledged by Hazel herself when she jokingly posits the idea that she's 'mad' for using windows in this way.

Indeed, Hazel's engagement with windows as things with a purpose other than being for-the-sake-of looking through, or for-the-sake-of keeping weather out and so on, arguably impacted the ways in which she sought to manage her relationships with near-dwellers by actively managing her window spaces. In the following quotes, for example, windows play an important role in how Hazel experiences the effects of her memory impairment, and how she manages that experience.

Hazel: "In fact, there was a day...it was just a couple of days ago and [my husband] was out and I knew there was something I had to do in the house. I looked in the calendar. I looked on my phone and I thought 'what the heck am I meant to do?' Well, I stood over there and I let out a scream and I thought 'oh my god what have I done here' but the back door was shut luckily and all the windows were shut and him next door he's away for a couple of days..."

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

I: *Aye, so that's perfect, he'll...nobody will know.*

Hazel: *Well, I wouldn't have wanted him to come in anyway even if I had of screamed. [...] Well, screamed loud because, I mean, he would have come straight in... [...]*

(Hazel, Interview Transcript)

I: *“What do you do when you feel like screaming if you can't just shut everything down and have a wee scream to yourself?”*

Hazel: *I did one day actually. I shut all the windows and I shut the door and I had a scream but it wasn't really much of a scream but I did, sort of, let it out. [...] A, sort of, growl more than a scream and it did help a bit but I thought to myself 'don't be so blinking stupid'. Well, I swore at myself actually which is very unusual and then it's not been so bad since.”*

(Hazel, Interview Transcript)

These quotes demonstrate a distinct difference in the way that Hazel relates to indirect reflections in windows, and windows themselves. In the earlier quotes, viewing the world through a reflection allowed for a sense of distance and safety. By being separated from the objects of her interest, Hazel expressed a sense of contentment (“that’s good fun”, “I quite enjoy that”). By contrast, her own windows, as discussed in the two quotes above, represent potentially unsecured thresholds, in this case allowing her sounds of frustration to escape and reach the next-door neighbour. In the first quote this is expressed as fear (“Oh my god, what have I done?”) while in the second she takes deliberate action to secure these thresholds against the outside world, creating boundaries that she considers impermeable to sound. Through placing barriers and filters between herself and others, she was able to manage the impressions she made and maintain an air of someone who didn’t yet “have it bad”. For Hazel, exposure was often related to the experience of vulnerability. She feared screaming both in that it would summon her neighbour, triggering an unwanted intrusion into her home, and in that it might indicate she might have crossed some unseen threshold, and have what she called “the bad dementia”. That the tensions around how participants managed

their dementia in relation to others forms the core of Chapter Six, while the idea of the ‘bad dementia’ how it effects the way Dasein relates to itself is considered in Chapter Seven.

Windows as Physical Barriers

While the discussion to this point has focused predominantly on the potential for people with dementia to use the threshold spaces provided by windows as *things* that, it is vital to note that much as with doorways, these thresholds allow movement in both directions, as Flash shows in the following extract:

Flash: I wasn't long in here and I opened the window and I threw bread out to the birds. The next thing they was a chap on the window, you've not to throw bread out to the birds. I said, it's just to give them something. No, no, she says, it encourages the rats and mice. I says, the birds have got it in before they...

I: Aye, right enough.

Flash: So I went out...I'm going stand behind the curtain, open the window and throw it out.

I: Just sneaky, like.

Flash: Yes. So it's not me. [...] It must be somebody...whoever lives up the stair. The lady that lives up the stair.

(Flash, Interview Transcript)

To an extent this movement can be seen in the quote above, where a staff member ‘enters’ visually and audibly by knocking on the window to address Flash’s feeding of the birds. This use of a window as an entry contrasts well against Hazel’s concerns around the window as a potentially unsecured exit, which would allow others to hear her scream of frustration, permitting her distress to cross the threshold between her home, and Elsewhere. The way in which Hazel and Flash managed these events were appreciably different, in part due to whether the potential challenge to the threshold was in something from Elsewhere entering the home, or something from within the home escaping.

As with doorways, however, it is important to acknowledge that instances where a participant's control of the threshold is challenged are not always so neatly navigated. George, who lives with significant visual and physical impairments, managed the complications arising from the interaction between his dementia and his physicality by leaving the task of opening the front door to his wife. On the single instance where I was met by at the door by George, he discussed the confluence of factors that meant he felt able to do so:

George: I don't answer the door anyway. I knew you were coming, that's why, because Anne left the keys in the door. I knew she was up the stair, and it was about time, I think, you were due anyway, but normally I don't answer the door anyway"

(George, Interview Transcript)

While this quote arguably demonstrates both the mobilising of social resources to secure a physical threshold and the impact of calling ahead as a facilitative technique, its role here is primarily contextual. It is important to recognise not only that George doesn't answer the door, but that his decision to do so is sufficiently conscious that it required a specific combination of factors in order to facilitate him breaking that 'rule'. The keys being left in the door, by pre-arrival phone call, his wife's proximity and his awareness of the time that allowed me to be expected, which themselves relate to physical, social and temporal aspects respectively, led George to undertake a different course of action because he felt both safe and enabled. At another point in the conversation, George discussed his experience of not answering the door on other occasions where the living room window (itself proximal to the front door) allowed unwelcome visual access while still maintaining a physical boundary.

George: We've had...is it a Jehovah's Witness or something? I didn't answer, they stood in front of the window and looked in before they went away, aye, so I just looked back. They were stood out there. Oh aye, we've had that, but normally they're not bad"

(George, Interview Transcript)

In this case, while those attempting to gain access could see inside, and made eye contact with George himself, the physical impassability of the window itself allowed George to feel secure in his habits of dwelling- that is, refusing to answer the front door. However, this was not always the case. In the following section George and Anne were discussing the difficulties he experienced in accessing the major city nearby, where the speed of traffic, number of people passing by and noise made George feel ‘drunk’, disorientated and upset. While these experiences are discussed in relation to the embodied experience of Being-in-the-World with Dementia in Chapter Eight, it is the role of the window-threshold that is particularly impactful here.

Anne: The other time [you felt frightened] was in a restaurant with my sister.

George: I was just going to say that because I was facing headlights through the window [...]and the headlights were coming straight towards me because was it the street was going up, [...] I mean, if they were going to the side maybe but they were directly coming at me.

I: So it felt like they were coming towards you more.

George: Yes.

Anne: He feels all that assault. It's like an assault on his senses. When the rest of us just shut that out George can't seem to shut that out anymore.

(George and Anne, Interview Transcript)

In stark contrast to the confidence he expressed in the earlier quotation, where an entity outside the window could be relied upon to stay there, this example demonstrates the ways in which thresholds which are themselves familiar (in this case, windows) can become troublesome when in a different setting. While earlier George felt secure in his home-place, and in the physicality of his dwelling (in its built aspects), the combination of his sight loss, his dementia, the unfamiliar setting and the increased threat of a car in comparison with a person combined to make the experience distressing. It is interesting to note that the option to ‘shut out’ the cars, or the feeling of being under threat was not available in this instance

despite the window still acting as a barrier to other senses, separating George from the sound, smell and feel of the street outside. Nevertheless, through becoming experienced as unmanageable and insecure the window threshold drew the perceived danger of the road and the oncoming cars into the safety of the restaurant, resulting in significant distress. Importantly, this experience of danger was particular to George- with neither his wife nor his sister in-law perceiving the window in this way. This provides an apt example of a moment where a participant's impairment resulted in an impairment effect, but did not become disabling. Critically, while Anne and George's established patterns of communication allowed them to reflect on this experience during the interview, would have been easy to mistake George's reaction as irrational in the moment it occurred; as there was little danger of the cars crashing into the restaurant. This demonstrates the need for those supporting people with dementia to be both empathetic in the moment, and open to considering the individual's experiences as valid to them. To view such episodes from a threshold perspective facilitates this, without necessitating confrontation about whether cars are 'really' going to crash into the window, instead facilitating discussions about how these threshold spaces might be experienced as secure, or at least, as a non-threat.

Physical Thresholds as Sites of Resistance.

The potential to be at once a permeable threshold (to sight, sound and smell) while still representing a physical barrier that prevented others physically entering the home was fundamental to the character of window thresholds. That, with the exception of George's restaurant experience, windows were not understood as points of entry in the same manner that doors were. It is worth noting, however, that despite generally trusting in the physical security offered by the window, participants were often keenly aware of windows as active spaces that required attention and management. In the following section Flash discusses why

his living room window has become a site of tension between himself and the support staff at his assisted living facility.

Flash: I wasn't long in here and I opened the window and I threw bread out to the birds. The next thing they was a chap on the window 'you've not to throw bread out to the birds'. I said, 'it's just to give them something'. 'No, no,' she says, 'it encourages the rats and mice'. I says, 'the birds have got it in before they...'[...] I'm going to stand behind the curtain, open the window and throw it out. [...]. So it's not me. [...] I said, 'it's not me. It must be somebody... whoever lives up the stair. The lady that lives up the stair'."

(Flash, Interview Transcript)

The tension in the above quote is borne of the differing views of Flash and the support staff about appropriate behaviour in shared spaces; specifically the garden outside Flash's window and the wider building which would be affected by vermin. Flash, by contrast, not only disagrees with the complaint on the mundane level, arguing that the birds will eat the bread before it attracts vermin, but on a fundamental level where he has integrated the ground directly outside his window into his dwelling space. As such, the support worker's insistence that he refrain from acting in a particular way is seen as restrictive of his dwelling. As a result, rather than curtailing the behaviour, the intervention of a staff member does little to dissuade Flash from throwing out bread, but rather encourages him to take steps (in this case hiding behind the curtain) to disguise that he is the transgressor. This is particularly pertinent in that Flash then disclosed that he thought the flat above was empty, making the rebellion more focused on staff being unable to 'prove' he had thrown out bread, rather than them being unaware. That it was rebellion, rather than simply a desire to feed birds close by, became particularly clear when Flash pointed out the bird feeder his son had installed two feet away from the window in an attempt to make such actions unnecessary. In this example, therefore, the bread, window-latch and curtain all become tools with which Flash manages his threshold space- the bread bringing his desired company into view, the window latch letting him throw

the bread while still providing a barrier he controls between himself and care staff, and the curtain as a method of eluding detection. Viewed from this perspective- as a reinforcement of his preferred practices of dwelling and a restatement of 'his' space, it would be possible to suggest that no amount of bird feeders would change his behaviour. It is, in short, not about the birds.

For Bob, tensions surround his window-thresholds were less focused on the expansion of his dwelling into shared outdoor space, and more tightly woven with his own sense of having-been and his desire to continue to 'work'. It was this interplay that led Bob to leave his home in the morning and head to the local shopping centre every morning where he would 'check in' and stay until evening- holding hours that mimicked his traditional working hours. This close connection to his past, and particularly his identity as a working man, also led Bob to have a particular appreciation for *properly cleaned* windows, a result of plying his trade as a window cleaner for many years. As a result, a significant proportion of my visit with Bob was spent being tutored on the appropriate method of cleaning glassware, the difference between a chamois and a rough cloth, and the virtues of undiluted ammonia as a cleaning substance. It was through this tutorage that I learnt that Bob not only found his dirt on his own windows annoying, but took offence to the poorly cleaned windows of his neighbours, both as an aesthetic affront, and a factor that reflected poorly on the community. Rather than suffer the sight of a job poorly done, Bob proudly related his strategies for addressing this state of neighbourhood disrepair: he would sneak along the street to clean windows in the dark. Bob's particular bugbear was not just that the windows themselves were insufficiently clean, but that the regular window cleaners did not properly attend to the white PVC window frames, causing them to yellow and become unsightly overtime. It was only as Bob was discussing this habit that it became clear that, like Flash's bird feeding, this was not action for the sake of rebellion. Instead, Bob expressed a deep connection with his neighbourhood and

community, expanding aspects of his dwelling out into his street- and sought to serve them in the same manner he had during his working life. That he had been reprimanded by staff for this behaviour had not diminished this need, so instead of undertaking the cleaning in the daylight hours, Bob now completed it after dark, thus disguising his passage over the contested threshold.

This example highlights an important aspect of dwelling in both of its aspects as both the building and maintaining of nonphysical things as a function of dwelling. In this case, rather than building an object, place or societal structure, he instead constructs a place for himself in the social fabric of his community, as a working man with purpose and value, as a rebel, as a phantom window cleaner. Critically, even within our interactions this work-related expertise allowed Bob to assert a level of status and knowledge that could be balanced against my position as a researcher. This was reinforced by his insistence that I take a rough, dark cloth home to clean my own windows; something he could not be dissuaded from (n.b. to my credit I did escape without a chamois or my own decanted ammonia). Such actions take on particular significance when viewed through the Social-Relational Model of Disability, where Bob's behaviour is that of direct rebellion against a formal care system that seeks to limit his ability. Specifically, because Bob is an older man with dementia, he met with resistance in cleaning his own windows on the basis of both his age and his diagnosis, which was amplified when he attempted to do so for others. In such cases it is possible to argue that a more person-centred approach would have been to create situations where it was acceptable, or indeed desirable, for Bob to continue serving his community in this manner. The extent to which psychoemotional disablism may negatively impact on the dwelling of people with dementia is discussed more explicitly in Chapter Six, but it is notable in this case that rather than internalise the messages about what he could not do, he continued to defy them. It was in this case the windows themselves that both enabled this resistance and

problematized it both in terms of risks of physical harm should he fall, and the social risks associated with an uninvited man cleaning the windows of others after dark and uninvited.

Window Ledges and their Occupants

Considering the significance of the windows—both as things which ‘gather’ the Elsewhere and the home together (Heidegger, 1954/1993) and thresholds which can both admit and resist passage—it is important to stress the importance of the area which surrounds the window itself. For the most part, the objects which adorned window areas fell into two categories: those which acted to communicate with others who approached the threshold, and those which had meaning to the individual, and as such offered passage over a temporal threshold (discussed in detail in Chapter Seven). It is important to note, however, that while the windowsill is at once like many other horizontal surfaces within the home (with sideboards, coffee tables and shelves often hosting meaningful objects) they are unique in their placement between inside and outside, between the home-place and Elsewhere. Items placed on the windowsill could not only be viewed from within the home (as shelves and tables were), but from outside, marking the line between a space which was public, and one that was personalised and private, between outside and inside.

Much as it would be a mistake to restrict the discussion of a participant’s engagement with windows as objects that are for-the-sake-of looking through, it would be an oversimplification to suggest that the management of window ledges as thresholds was characterised by a single instance of arrangement followed by passive viewing. While such acts of dwelling-as-building were certainly present, for many participants windowsills also formed the focus of dwelling-as-maintaining. Margaret, for example, lined the windowsill of her living room with bamboo plants in clear containers, while Hazel grew plants at her kitchen window both of which required different patterns of care. While the use of clear

water beads for hydration had removed much of the processes of nurturing from Margaret, Hazel by contrast had traditional pots with soil. Although this maintenance of traditional methods might appear ideal, the plants themselves became a source of tension between Hazel and her husband John, as activities surrounding their maintenance foregrounded Hazel's memory impairment:

Hazel: "Well, the flowers are lovely, I just watered them all.

John: Oh no, not again.

Hazel: Yes, I've just watered these ones on the table.

John: You haven't touched the ones in the kitchen?

Hazel: Which ones in the kitchen?

John: The ones you keep killing because you're feeding them too much bloody water.

Hazel: Don't know which ones you're talking about.

John: On the windowsill.

I: I'm staying out of this one.

Hazel: On the windowsill, no, they're okay.

John: They're all dying because they're full of water. Put any more water in there and you could use it as a swimming pool."

(Hazel and John, Interview Transcript)

While it would be possible to discuss the pattern of overwatering, and the labour that resulted, or to focus on the tension that such incidents created, it is telling to view such activities as disrupted activities of dwelling. The above extract demonstrates several of the tensions that result from Hazel's attempts to maintain her surrounding. Firstly, it is interesting to note framing of overwatering as a function of poor care; Hazel is cast as "feeding them too much water" rather than forgetting she has watered them. From such a perspective, her behaviour becomes harmful (she waters them too much) rather than being viewed as a mistimed act of maintenance (she waters them when she believes she has not).

While the example at hand is banal in its everydayness, to take a wider view would be to see how it is possible to cast disrupted dwelling as deficient dwelling, rather than an attempt to dwell in the accustomed way that is interrupted by particular impairment effects- in this case, Hazel forgetting that she had watered the plants in the first place. How one might respond to one aspect is quite different to the other, for example, disordered dwelling might become the target of interventions intended to stop the behaviour entirely. By contrast, viewing dwelling practices from a perspective that presumes legitimacy- that is, that they are aligned with Hazel's dwelling and as such are orientated towards dwelling-as-maintenance or preservation – efforts can be made to account for her impaired memory. An example in this case might be the installation of a moisture indicator that provides guidance about when the plant does or does not need water in the moment, removing the requirement for Hazel to successfully access her memory in order to determine if she should, or should not, water the plant. What such efforts may not address, however, is Hazel's continuing desire to dwell actively, by watering the plants herself at the time when she feels they require it.

It is important not to ignore John's ongoing facilitation of Hazel's dwelling. That she is capable of repeatedly overwatering plants to the point of death, this is possible only through John's repeated efforts to replace the dead plants with new specimens. This requirement for others to intervene in threshold practices is discussed more explicitly in Chapter Six, but it is nevertheless important to acknowledge here that Hazel's dwelling- specifically her desire to maintain and care for plants within her home- is only possible through John's repeated intervention. Similar small acts of maintenance were common throughout the fieldwork, emphasising the potential fragility of dwelling for people with dementia. These efforts ensured that the participants were not merely existing in space, but engaged actively in dwelling- fulfilling a role where there was an ability to create and to maintain in a meaningful way. Such opportunities are not without their tensions, however. To embrace a perspective

of maintenance activities as examples of dwelling-as-building, or dwelling-as-maintenance implies that they are undertaken in isolation except where remedial action becomes necessary. This is not always the case. The following quote is drawn from an interview with Mark, where he discussed a problem he was experiencing with having a cleaner come around once a week.

Mark: “I have to move [the ornaments] every week when she has been, she always spreads them like that. And to me, that doesn't do any good at all. I just don't like them there.

I: Where do you like them?

Mark: Well, I like them there.

I: But together?

Mark: But together. [...] You see them now, how they are. [...] This one? These two? [...] They are two, aren't they?

I: They are two.

Mark: But they should be acting like one. So they've got to be together.

I: . [...]. Do you have to change that every time she's been round?

Mark: Yeah.

I: Have you told her?

Mark: No.

I: [Laughs] Bless her, she comes round and she wipes and she thinks she's putting them back in the right place and you've got to go round after her.

Mark: No, she puts them back where she thinks they should go! And she's wrong. [...] They... um, my wife used to buy these things.”

(Mark, Interview Transcript)

This subtle conflict appears inconsequential on the surface. In Mark's case the tension wasn't due to *his* practices of dwelling as maintaining and preserving, but in the building- or rather the building and rebuilding of the window ledge space after each visit by his cleaner. Critically, he casts the cleaner's behaviour as an act of deliberate choice, while Mark's own rearrangement of the ornaments on his windowsill is setting things 'right'. It's possible to argue that the exact placement of objects in relation to one another on a windowsill is of relatively low importance when an individual is living with cataracts, poor balance and dementia (as Mark is), however it is clear that for Mark this is not the case. Picture 6 and Picture 5 show the difference in how the ornaments are placed by the cleaner as two distinct figures and when Mark places them together as 'one', respectively.



Picture 6: Two ornaments on a windowsill



Picture 5 : One ornament in two parts

The relationship between how objects were displayed by a window, and who had purchased or placed them there was important to a number of other participants. Critically, these objects

drew meaning not only by (usually) being visually pleasing, but by marking the visual ‘beginning’ of the home place. As such, where these objects were not bought explicitly by others they often invoked them in other ways- through housing meaningful photographs, acting as mementos for journeys together and so on. For these participants it became a matter not just of whether the windowsills were populated by objects and plants but who had done so, and why. A windowsill full of objects thus became a visual barrier, where the memory of friends and family was made concrete through their gifts which ‘guarded’ the boundary of the window space itself.

Thresholds in Vertical Space

During fieldwork it became clear that while doors and windows were threshold sites that required active management, there was another aspect of the home space which presented particular challenges for the participants, specifically the organisation of high or low spaces. I first noticed this in my discussions with Sybil, as we were talking about which household chores she liked to do herself, and which carers participated in. She explained:

Sybil: [The care workers] do the cleaning when I allow them to do it. [...] I've never asked them to wash the windows. So they just don't... we used to have a man come round, but he stopped coming and I don't think there's anybody taken his place. I clean the bottom half of them but I wouldn't stand on the steps to [...] do the top, no. [...] No it's not worth it. [...] It's bad enough when I'm walking."

(Sybil, Interview Transcript)

Like Bob, Sybil's focus in this extract is less upon the windows as they exist for-the-sake-of looking through, than it is on windows parts of her home that need to be maintained. As such, the act of cleaning the bottom portion of her windows becomes more explicitly an act of dwelling-as-preserving (*wohnen*), that is, as a practice of care and maintenance. As the quote demonstrates, she considers the windows as part of her cleaning routine, which she will

‘allow’ care workers to participate in but resists surrendering completely. The latter half of the quote highlights the tensions present in this action, however, as Sybil sought to balance her dwelling with the impairments associated with her aging body. Critically, her perception of cleaning the upper half of the windows as a separate and risky activity, demonstrates again the shifting thresholds- in this case, not just between inside and outside, but between up and down. For Sybil this concern was tied to her embodied experience of poor balance, and the pivotal role that a fall had played in triggering her journey towards diagnosis when she broke her ankle. In this context, the potential to fall from a height takes on even greater risk than the dwelling and maintaining she carried out at ground-level, and was as such regarded with extra caution.

The Role of Vertical Spaces: “Out of Sight, Out of Mind”

Far from being confined to window spaces, vertical thresholds occurred in the houses of many participants, influenced by a range of different experiences and impairments. The pervasiveness of this particular theme became clear on the morning that Margaret escorted me to her kitchen cupboards and explained that while the design was standard for her supported housing block, it rendered half of the contents inaccessible to her as they were far beyond her reach. She then walked me to her wardrobe where items she didn’t use were often stowed above her head, and complained that the only way she could have a ‘proper clear out’ was if she could ask her niece to lift things down for her. Similar issues emerged when I accompanied Mark to his local shop, as he avoided using his lower cupboards due to physical difficulty, something he had sought to utilise by dedicating two of his lower cupboards for his cleaner’s supplies. Having noted and discussed these experiences, I maintained a more active watch for them in the field going forward, leading to a realisation that while these vertical thresholds were more subtle than those that appeared horizontally between the home-space and elsewhere, they were similarly relational. Hazel’s husband John,

for example, organised her medication each week, placing the weekly pill bible on the shelf at her eye line while boxes for following weeks were stored higher. Having been present during one medication delivery, I listened to John reinforcing that the medications ‘weren’t hers’ and ‘not her problem’ until they’d been set up in the weekly dispenser. While this was a strategy that had been introduced after Hazel had mis-ordered medication on a number of occasions, it nevertheless capitalised on vertical thresholds to restrict the extent to access to potentially harmful substances in her home, while other items were kept where they could be easily identified and accessed. The effectiveness of such a technique was further supported when I watched Nigel search the kitchen for a coffee pot he had misplaced- a process that excluded all shelves above and below his eyeline (with the exception of the kitchen counter). Rather than search each shelf, Nigel searched from left to right around the kitchen, including in the oven (‘in case’). This pattern was repeated again when Mark asked if our walking interview could incorporate his need buy some necessities for his flat. As we navigated the store he reflected that without help, he could only shop for items within a certain mid-range of the shelves, thus restricting both his engagement with that space, and how he interacted with his home space when he returned with items to put away.

While it might be argued that these issues might allow for subtle ‘management’ of people with dementia that causes less distress (something I shall specifically debate as part of the discussions in Chapter Nine), it should be noted that vertical thresholds did not only affect what participants could interact with when stood in a stable position on the floor. Both George and Hazel had experienced significant difficulty navigating their way up and down the stairs in their home and elsewhere, a process that profoundly impacted their processes of dwelling. For George, passage between his upstairs and downstairs rooms was facilitated by using a collapsible stair-lift upon which he would sit. Whether this process was considered risky in itself was a matter of debate however, as Anne playfully ‘nagged’ him to fasten his

seatbelt before setting his chair in motion on several occasions during my visits. When he wished to access outside spaces, however, George and Anne had to employ different tactics—some of which they undertook themselves, some of which required inviting the state into their home to install hardware. The result of this dualistic approach was that George could secure his balance as he stepped down the step into the garden by holding onto a standardised white hand rail, but could only see the step below and discern the difference in depth because Anne had painted it red. Importantly, while they had been given support (in regards to the provision and installation of the rail) to allow George into and out of the house, this did not extend to providing support to help him climb the stairs into the higher back portion of their garden— which he preferred. As a result they had paid privately to have a long metal hand rail installed to facilitate his continued access. Anne had subsequently gone further, painting the bottom edge of the first grey concrete step with a strip of white paint to indicate the final edge between stair and flat paving below. It is interesting, and noteworthy in the context of the everydayness of dwelling, that it was only as Anne was showing me her efforts that she realised she had only painted the bottom step. It was a realisation prompted by my asking about why she'd chosen to paint it in such a way, presuming it to be a conscious decision. When I returned again, the steps had all been painted and George noted that while having one stair painted had been 'good', having the entire staircase outlined was 'far better'. It is clear, therefore, that as ubiquitous as the threshold might be, Heidegger's notion of habit as a force that can distract from and 'cover over' the detail of often-encountered experiences has a place here. As such, it becomes necessary to examine physical thresholds as they occur at one moment of time, but repeatedly and with a fresh awareness as peoples embodied experience and impairment effects change.

It is worth noting that the design of the home-space—particularly the presence or absence of troublesome vertical thresholds—necessitates viewing these experiences through a lens

informed by the Social Relational Model of Disability (Thomas, 1999). Through changes in their embodied experience, and the shifting landscape of the participant's impairments, a great deal of their vertical space was experienced as inaccessible. In this case, the positioning of objects outside the visual field, and thus facilitating forgetting, or simply placing them in a space that is too 'risky' for the person with dementia to access accomplishes the same effect - disablement. To limit the examination of physical thresholds to invisible 'lines' which exist in a space, and as such may be identified through implementation of a cursory checklist would be a mistake. Instead, physical thresholds were made manifest as relational spaces that drew together the person with dementia and those around them, their dwelling spaces and elsewhere, and the complexities of their bodies *in situ* in various ways and at various times. These thresholds were made manifest through dwelling in its complete sense, encompassing not only the construction of space and the practices of maintenance, but the way in which the participant moved within it as they dwelled.

Mark provided a clear insight into the tensions that can occur around threshold crossings when pointed out that he needed to put his shoes before undertaking a walking interview. It is worth noting that I, as a nondisabled person who does not often consciously reflect on the physical process of putting on shoes, did not register Mark's announcement as unusual in the moment he made it, despite his mentioning in an early visit that he could no longer go swimming because he could not re-dress himself without support. This was nevertheless a difficulty Mark was keenly aware of, and he was keen to show his solution exclaiming "Here's something for you". Asking me to follow him to his bedroom, he proceeded to retrieve a litter-picker and a long-handled shoehorn from their places, sit on the end of the bed, and demonstrate his technique for manipulating the Velcro fastenings of his shoes in such a way that he could change his footwear independently. Interestingly, what I had taken to be the items of interest (the litter picker and shoehorn) were not what Mark had wanted to

demonstrate. Rather, his excitement focused around a new pair of shoes that had thick, straight Velcro straps that he could easily manipulate, where his older pair could not be closed securely. For Mark, the tool that he felt most expedited his crossing of this particular vertical threshold- the one that separated him from his shoe fastenings- was the modified design of the closing flap. The litter picker and shoehorn combination, by contrast, he almost dismissed saying; “I have been doing that for the whole time [...] I have to do something don’t I?”. Picture 7 demonstrates Mark’s method of closing his left shoe by leaning across with his dominant right hand and using the angle to his advantage, while Picture 8 shows the modified technique for his right shoe, which requires the shoehorn to close the flap.

This too introduces a difficulty in providing a comprehensive account of thresholds in a home space- that the process is relational, that it is changeable and that it is embodied all impact on the accessibility of different thresholds to an observer. Following the conversation, and Mark’s demonstration, I asked specifically about his older shoes and how he would



Picture 7: Mark’s shoe technique, left foot.



Picture 8: Mark’s shoe technique, right foot.

manage before. It was only then that I learned that delays in carers arriving in the morning were not merely a nuisance in that they prevented him planning his day, but in that they left him physically restrained within his home as he could not put his shoes on without aid.

It is vital, as such, to note that those practices that artificially impose or close thresholds for people living with dementia are burdened with moral undertones. Where restriction of activity leverages impairment effects to create barriers, there is disablement and the imposition of disability. In such contexts, it becomes difficult for individuals with dementia to control their interaction with their environment, and with their belongings. That these practices may echo those discussed briefly in Chapter Two, where items and doorways were disguised, or false 'holes' introduced to influence the movement of people with dementia (as in Kincaid & Peacock, 2003 and Vanderhorst & Koenig, 2015, for example) should not be overlooked. Indeed, these everyday methods of management should be subject to similar levels of scrutiny and trouble ethicists in much the same manner. This is not to say that these spaces were organised as an act of malice; keeping medication safe is a laudable and necessary activity, for example, but it is nevertheless a practice which should be acknowledged openly and considered critically rather than developed and employed without due consideration.

Navigating Shared Space and the Nachgebauer

To explore what it is to experience crossing the threshold out of their home place, it is necessary to clarify where it is a person goes when they are no longer 'at home'. As discussed in Chapter One, this project was predicated on the idea that assuming that what one sees outside one's window is one's neighbourhood- or that one enters it at the front door (c.f. Blackman, 2006)- risks expediting the research process at the cost of deeper understanding.

The concept that any individual who navigates the world without dementia can reliably intuit where a person who lives with dementia considers the home to end and Elsewhere to begin was challenged in more detail in Chapters Two and Three through considering a disability and dwelling perspective respectively. It is important to note, however, that the idea of a neat division between the home place and Elsewhere has already been challenged by the discussion of windows as both thresholds and *things* in their own right earlier in this chapter. As *things* windows and doors ‘gather’ together the home and the Elsewhere, bringing them “into each other’s neighbourhood” (Heidegger, 1954/1993, p.354). As such, the Elsewhere begins not “as we leave” the front door (Blackman, 2006 p.3), but on approaching threshold itself, where home and Elsewhere merge together and become one another. Where this crossing involves the participant staying within the home space, George’s example of Jehovah’s witnesses looking through the window earlier in this chapter is particularly apt. What this section does, therefore, is turn its focus explicitly on the experiences of physically crossing from the home place into the Elsewhere where the practices of dwelling with dementia come into contact with those near-dwellers who inhabit Elsewhere.

As discussed in Chapter Three, it is impossible to consider the practices and experience of dwelling as either building (*bauen*) or preservation (*wohnen*) without acknowledging the area in which dwelling occurs. For Heidegger (BDT) this necessarily includes thinking about, the “*Nachbar*”, “the *Nechgebur*, the *Nachgebauer*, the near-dweller” (p.349). It is therefore necessary to consider the ‘neighbourhood’ not only as a physical space in which objects are distributed, but as a place inhabited by the *Nachgebauer*, who are themselves involved in the business of dwelling. Those moments in which neighbours were drawn upon as resources to facilitate participants in navigating troublesome thresholds are discussed in more detail in Chapter Six. What is considered here is the presence or absence of the near-dweller as an outside force which influenced the ability of participants to cross the physical threshold from home place

to Elsewhere. Indeed, for participants, the presence of a neighbour could either support or impede passage into the neighbourhood- that is, into the area of their shared dwelling. For example, Mark's experience of moving into and out of his home place was regularly influenced by the presence of near-dwellers, something which became increasingly clear throughout the course of fieldwork. The following excerpt is taken from my first visit with Mark, having stepped into the communal hallway after a walk.

Mark: One of the problems living in a, in the block of flats, is people don't do things the way you- [...] You see this in here. What happens is, some people like to push that [a large rubber-bottomed mat] right up to the door and that, that-

I: And it gets folded up?

Mark: It gets folded and it spoils the, the, the thing. Could you jump off it for a second? [Pause as Mark moves the mat] That's how I like it.

I: No, that makes sense. So it doesn't curl back when the door opens.

(Mark, Interview Transcript)

There are two aspects of this extract that are important to note here. The first is the indication of the difficulty associated with negotiating with Mark's processes of dwelling-as-building with others in a shared space that is at once home and Elsewhere. The shared doorway into the building is an area in which both practices of building have equal legitimacy, and yet indirect conflict (in this case, carried out through the movement of an object in space) occurs on a regular basis. The second point to consider is that this failure of near-dwellers to arrange the shared space as Mark would prefer actively impedes how easily Mark can navigate this threshold. The following description is taken from the fieldnotes of the same visit.

Getting back into the close involved a series of actions that seemed so routine for Mark that they have become a dance. Keys, key hole, walking stick, stairs, handrail and doorway all come together to play their part: standing on the bottom step, Mark leans forward to put his key in the keyhole. As the door opens he shoves it (hard!) with the other hand, and quickly uses the walking stick and it's rubber stopper to stop it closing on him. He then uses the rail to mount the stairs, extracts stopper from doorway

and closes the door behind us. Apparently this dance is sometimes invaded by an unwelcome partner- the large (3ft by 5ft maybe?) doormat which will curl if put too close to the doorjamb, making pushing the door open more difficult..."

(CP Fieldnotes)

Clearly, as an item in isolation, the placement of the doormat might be seen as a minor long-running disagreement between neighbours. Here, by contrast, the mat perhaps too closely 'gathers' the door, impeding progress and introducing not only the potential for Mark to struggle to get into the hallway, but the potential for him to fall backwards down the stairs if the door pushes him backwards. Despite this, Mark discussed this contentious arrangement of the mat as simply one of the difficulties of living in a block of flats. A result of thoughtlessness, or at least, of not considering the reasoning behind other mat placements, rather than deliberate sabotage. As a man who cultivated a positive relationship with all of his neighbours, there was no suggestion that this shifting of the mat might be an act of malice- yet it nevertheless speaks to the disability and accessibility literatures. Through the mats placement, and the relationship between the neighbours as near-dwellers, and neighbours as dwellers in space, and thus builders in the sense dwelling-as-building (*bauen*), Mark's physical impairment meets socially arranged space to become disability in spite of both the mobility aid provided by his walking stick and the handrail outside the door. Nor are these clashes of dwelling limited to the threshold of the doorway or the block of flats. After one of our walks together, Mark paused before turning into the path that led to the door of the building and instead explained that he wanted to move the car from its place at the far end of the small parking lot to the empty space at the end of the path. At first this appeared to be a matter of preference, but Mark explained:

Mark: If it's raining tomorrow and there is rain due, isn't there?

I: I think so, yeah.

Mark: And if I've got to walk up there, you see, I walk very slowly. [...] And I'd get soaked by the time I get there.

I: Hadn't thought about that [...] I thought maybe you just liked this parking space and you saw it free.

Mark: Well, I did, I do, I do. He's got... his car's there and her car's there. They take, they're taking up both of them.

(Mark, Interview Transcript)

This extract demonstrates once again the impact of near-dwellers both as individuals who arrange themselves in space in line with their own desires (Mark highlights what he sees as the unfairness in this, as the couple are 'taking up' two of the three prime parking spaces between them) and as agents whose actions can easily complicate Mark's ability to traverse between home and Elsewhere, disabling him.

It is important to note that the restrictive and disabling impact of near-dwellers was not always an unwitting outcome of their behaviour. My discussions with Sybil, for example, often touched on the lengths her daughter went to, to ensure her safety and wellbeing. These efforts had a profound impact on Sybil's dwelling as both building (*bauen*) and maintaining (*wohnen*) as she not only influenced where Sybil lived, but the activities she could undertake there.

Sybil: "My husband...when he died, the house we were living in at the time, it...well I didn't want to move but my family said no. This house came on the market and they thought that was perfect because it was so near [my daughter's] house which is three doors along."

Sybil: "The only problem is I'm... 'cause I'm walking without [my walking sticks] in the house and I open the door and out the door and I get halfway across the...oh something missing. I have to go back and get them. I might...get my sticks before somebody sees me and tells [my daughter]. [...]It's...that's annoying because I like weeding and I can't get back up off my knees. [...] But I like weeding and making it nice. But got to restrain myself."

(Sybil, Interview Transcript)

While there are definite similarities in how Mark and Sybil are influenced by the presence of near-dwellers, and how this influences their practices of dwelling with dementia and physical impairment, there are profound differences between their experiences. The first point of to be noted is the somewhat unwelcome rearrangement of Sybil's home place to better integrate the support she needed with her daughters' dwelling. In this case, the redefinition of where and what home was represents a deliberate tactic in managing Sybil's widowed status and advancing age. Following this, the complex interaction between Sybil's physical impairment ("I can't get back up off my knees") is directly related to her daughter's management of her impairment, shown through Sybil's worry about being 'caught' walking without her sticks outside. This itself held extra levels of meaning, as Sybil was only diagnosed with dementia following being admitted to hospital with a broken ankle- an accident she blames on walking with her stick. Viewed in this context, the sticks became a troublesome and troubling item at Sybil's threshold, at once allowing her to feel secure when walking on concrete, and introducing risk on unpaved ground; enabling her to move independently while constantly reminding her of the watchfulness of others.

Throughout our conversations, Sybil often discussed her own impairments in relation to the restrictions placed on her by others, parsing her impairment as insignificant against the actions of others to manage them. Such an argument fits neatly into the paradigm of impairment and disablement, though it was not explained as such in the moment. There are questions to be asked, however, around whether appropriating the language of disability might provide an opportunity for people with dementia to frame their concerns, their irritations and experiences in a politically powerful way such that they engender action. To go further, drawing together the concept of dwelling as an aspect of being, how do such experiences of disablement impact one's ability to dwell? How can one be 'spared', or 'freed' or be set at peace? (Heidegger, 1954/1993). Certainly, in the most straightforward use of the

Social Relational Model of Disability, Sybil's sticks 'should' be considered freeing and enabling- and yet in their use, and in their mediating relationship between Sybil, her changing physicality, her navigation of physical space and her relationships with others, it takes on greater meaning. Indeed, Sybil is as such one of the clearest examples of a participant who must "ever learn to dwell", not only through a process of adaptation to processing the world through her dementia, but through those arrangements which occur in response to it. What it is to be 'free', to be 'at peace' must be constantly renegotiated as the changes introduced by time, aging, and relationality influence the permeability of the physical thresholds that interlace the spatial world.

Conflict at the Threshold

As with the thresholds that manifest at doorways and windows, however, it is necessary to examine the potential for threshold spaces to be challenged. It is also important to note that while Mark and Sybil's neighbours influenced their movement over physical thresholds through spatial means (by moving the rug, or watching to ensure Sybil had her sticks), such events could not always be so neatly separated from the social experiences of being-with. This was most clearly discussed by Hazel, who had formed a particular 'ideal' of how a good neighbour, or *Nachgebauer* (*near-dweller*) would behave. Through outlining the less than ideal traits of those who lived nearby, Hazel revealed that to be welcome they must be open to talking (being "too quiet" was a quality associated with being 'a funny sort'), but not *too* keen to hold a long conversation. This latter behaviour was strongly associated with her next-door neighbour, whom she actively sought to avoid. This conflict was key in understanding Hazel's use of her home place and her crossing into other spaces; it is this neighbour that she feared summoning by screaming in the earlier extract and was reassured when she realised he wasn't at home for her outburst. In speaking about how she managed her relationship with this neighbour, she reflected:

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

Hazel: "As long as he doesn't bother me, I'm okay. If he gets to the stage when he comes out and he starts talk, talk, talk, talk, talking you know he's had an awful lot and I'll say, oh sugar, I'll need to go in, there's the phone. Especially if John is not here, I go in as quick as I can. In fact most of the time if I know he's in... I'll not come out when I know he's there himself, you know, and John's not here. John's never, John's seen him a couple of times when he's been really bad but he's told him to, he's actually told him, will you stop it, [...]? Get in the house. And he'll go in. But once we go away he's back out again. So... And it's not so good. I mean if we have a nice day we'll come out with our chairs and things and we'll sit in the sunshine. And it's not that nice when he's sitting there boozing and talking away and all the rest of it"

(Hazel, Interview Transcript)

An important aspect of this extract is not only the concept of her neighbour as an unwelcome and talkative individual, who will talk to her if he sees her in her garden, but her portrayal of his drinking and drunkenness as a threat. Over the course of my visits with Hazel she often noted that while her glass bin was full of jars, his was 'all bottles'. Descriptions of his character flaws were used during conversation as a way to contextualise her unease, her dislike, and her avoidance. Interestingly, these factors receded when she knew his wife was at home. On several occasions Hazel reflected that she enjoyed "sitting out" with his wife, who also had dementia but was "further forward" and didn't speak as much. This companionship, therefore, and her friends' presence in the garden space mitigated the otherwise troublesome factor of her neighbour's behaviours- both in regards to talking, and to drinking. Without her presence, however, Hazel was left to draw on other techniques to secure the thresholds between them, and found it difficult to cross into shared dwelling spaces particularly the back step where she liked to sit, but could be spoken to across the knee-high fence, when she thought he might be present ("I'll not come out"). Importantly, however, such measures were only in place if her husband wasn't home- much as with George, the presence of a trusted person within the home was facilitative of taking greater

risks at the threshold. It is this interrelation between social aspects and threshold spaces that forms the crux of the next chapter.

Summary

This chapter has explored the physical thresholds that surround people with dementia. By focusing on several areas as discrete from one another it was possible to consider not how thresholds appear in physical spaces, but to acknowledge the complexity that occurs when thresholds overlap in the participant's lived experience. Throughout the analysis, the discussion of physical thresholds has centred primarily around their physicality, their manifestation in shared space, and the methods participants used to manage and navigate them, touching only briefly on their intrinsic multiplicity. Yet, rather than existing as objective, predetermined, or pre-social phenomena, physical thresholds were inherently relational, drawing together the home and Elsewhere spaces, the person and their neighbours as near-dwellers. They were constructed and influenced by not only the presence or absence of physical objects and architecture, but by the participants practices of dwelling, which could transform a permissive space into an impassable threshold and vice versa. This analysis demonstrates both the power available to people with dementia as dwellers in their own space, and the flexible nature of thresholds that they could be transformed not only in line with an individual's desire in response to their embodied experience of impairment.

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

6: RELATIONSHIPS, SOCIAL THRESHOLDS, AND BEING-WITH-OTHERS

Introduction

Having dedicated the last chapter to considering the ways in which thresholds can be arranged in physical space, it is now necessary to consider the importance of nonphysical thresholds. The following discussion begins by considering the ways in which individuals as social actors can influence the extent to which a person with dementia is disabled in a given context. As a result, this chapter draws upon Heideggerian concepts in the same manner as Chapter Five, by using key concepts to highlight the complexities of experience that occur when one lives with a dementia diagnosis. Where Chapter Five explored the concept of Dwelling, however, this chapter places particular emphasis upon the concept of being-with-others as a core aspect of Dasein's experience of being in-the-world. This chapter begins, therefore, by exploring the ways that social relationships could influence thresholds indirectly, through the introduction and maintenance of enabling objects. The analysis then explores the social threshold between a person's inner circle, and their wider social network. This serves as a clear example of how a social thresholds occurred as a relational space which is actively managed by people with dementia and subject to both invited and uninvited crossings. The chapter discusses how an individuals position in relation to this threshold determine whether they are allowed insight into the indignities and realities of living with dementia or presented with a carefully curated insight into the lives of participants. Finally, the focus then shifts to consider driving as a socially mediated activity, and the impact of engaging in 'constructive' social activities through activism, altruism and community engagement.

Although the concept of a social threshold lacks the tangible, observable, physical, properties that shaped participant's physical thresholds, they were often easily identified within the data corpus. Indeed, participants often expressed their experiences with others through physical metaphors, where unwelcome social actors were depicted as 'crossing a line', or 'going too far'- phrases that emulate the physical within the social context. As a result, it is worthwhile to consider social thresholds as fundamentally similar to the physical thresholds described in Chapter Five: as drawing together two phenomena (Dasein) to create an active (social) space that is distinct from, yet beholden to, the phenomena on either side. As with physical thresholds, social thresholds became subject to the same processes of creating (*bauen*) and protecting (*wohnen*) discussed in the previous chapter, but are further complicated by Heidegger's acknowledgement that Dasein is always with-others, even when physically separated from them. As such, social thresholds continue to manifest even where a participant expels an unwelcome person from their life, or loses a loved one in death.

Social Relationships and Physical Objects

Given the impact of objects on the physical threshold as discussed in the last chapter, it is pertinent to begin this chapter by acknowledging that these objects did not enter the environment of the person with dementia accidentally. Indeed, it is worth noting that participants were often surrounded by many more potentially enabling objects than they engaged with, marking the recursive processes involved in identifying, implementing,

maintaining, adapting and finally replacing these objects as the needs of the person with dementia changed.

Written Materials

Participants were surrounded by a wealth of written notes that had been introduced by others in an effort to mitigate the memory effects of dementia. These notes, whether handwritten, printed or laminated, differed from those discussed in Chapter Five in one key aspect: their intended audience. Critically, while many of the signs in the previous chapter had been introduced by someone other than the participant, and were intended to communicate with potential visitors, the notes discussed here were often primarily, if not exclusively, intended for the participant to read. Flash's home provided several clear examples of this, for each door in his small bedsit flat bore a black and white laminated label positioned at eye level that announced what was inside. His son,

Flash explained, had introduced these labels, when he first moved into the flat to help him easily find his way around. These had since been supplemented with further notes detailing his regularly taken medication and his family's contact numbers, which had been attached to the frame of a large family photograph above the telephone, and a simplified bus timetable attached to the window frame in his kitchen (Picture 9).



Picture 9: Simplified Bus Timetable & Notepad with Pencil

These creation and placement of these notes had two primary effects; firstly, they supported Flash's memory, allowing him to navigate his supported accommodation independently without relying on his own recall. The need for this system to be maintained and adapted by his family over time had resulted in the introduction of further notes, written on post-it notes in pencil, which had been attached to the outfit he was to wear the next morning. These, Flash's son explained, were in response to his father's propensity to rewear dirty clothes the following day if he could not readily identify the pre-assembled set that was hung on a hanger on his wardrobe door. This highlights not only the need for written materials to be constantly reassessed, but the labour involved in their production and maintenance. The process of creating such written directions over time and in a targeted way ensured that the notes themselves were at once useful physical objects in their own right and symbols of the ongoing relationship between Flash and his family. Such notes thereby became a physical representation of a social threshold that had a profound influence on Flash's day to day lived experience, even when the writer of the notes was not themselves present. It was this social threshold between Flash and his children, particularly his son, which ensured the constant evolution of the note system, captured clearly in the move away from the laminated labelling of dresser drawers that had previously aided Flash to select his own attire, and towards a more directive communication that better accommodated Flash's impairment. A similar process had prompted a shift in how the communications book was used, as it transformed from being primarily used to facilitate communication between family members and different members of care staff, to something that accomplished this while also providing Flash with the opportunity to review the activities of recent days, aiding his memory and his management of temporal thresholds, discussed further in Chapter Seven.

It is worth acknowledging here the complex relationship that existed between social thresholds as nonphysical, relational spaces and the physical, material aspects of notes and

signage. Indeed, the ability to identify the optimal position for written materials in physical space, often further evidenced the presence of a social threshold that was regularly and successfully negotiated. An example of this is captured in [Picture 9](#), as Flash's bus timetables had been carefully sized to fit in his wallet, and provided only information that was directly relevant to his journey, with outward and homeward journeys detailed on separate cards. As a result, these cards aid navigation over both physical and social thresholds in that they facilitate his movement to specific locations, and enable him to navigate the social thresholds necessary to do so, such as interacting with the bus driver and so on. Both of these passages are, therefore, contingent on the preliminary navigation of the social threshold between Flash, his children and his care staff, such that his desire to travel is respected and enabled without causing stress or distress for those who care for him. This facilitation allowed Flash to continue to construct himself as a man who was capable of managing such journeys unaccompanied, even though he increasingly preferred to venture out in the company of his family.

This intervention of key social contacts occurred in a range of situations, and varied in its manifestation for each participant. For example, while Flash's bus passes aided him in travelling independently if he wished, for Hazel many of the written materials were targeted towards enabling her to continue to attend to chores within the house, particularly those that influenced her ability to host others and maintain social connections. As a result, accompanying Hazel into the kitchen to carry tea and biscuits involved encountering a plethora of signs, all targeted towards her continued ability to attend to these gendered social expectations. The most striking example of this was Hazel's food waste bin, which had become a key component of the tea making ritual as the local authority continued to encourage waste reduction and recycling. [Picture 10](#) shows the directive sign that had been printed by Hazel's husband, John, and attached to the top of the bin to ensure she did not

mistake the food-waste bin for one intended general recycling. In stark contrast to the plain black-on-white signage used by Flash, Hazel's signs leveraged her interest in owls to draw her attention and prompt her compliance. While this strategy arguably created a design that was visually cluttered with limited contrast between image and text, it was effective in drawing Hazel's attention, to the point where she explicitly pointed it out during one of my early visits while supervising my efforts

to make tea. It was this combination of incorporating images that drew her attention, and ensuring that the bin itself was placed in a way that its spatiality indicated its role in the task of tea making, that John had successfully ensured that she could continue to provide herself and any guests with tea,



Picture 10: Hazel's Personalised Food Waste Bin

thus fulfilling the role of host.

The importance of this routine action should not be underestimated, as Hazel and I drank a substantial amount of tea during our visits together, a shared action that provided an opportunity for Hazel to not only redirect our conversations but to take the time to reflect upon them as either she or I passed briefly into the next room to make the tea, a process which was initiated by asking if the other was ready for a cup, and ended with the teabags being disposed of and the tea being brought through. Resultantly, the tea, and thus the food bin and its signage as part of the tea making process, enabled passages over a number of social thresholds, not least those that occurred between herself as a person with dementia and myself as a researcher, and herself as a host and myself as a familiar guest in her home.

Given the striking aesthetic differences between Flash's signage (Picture 9) and Hazel's (Picture 10), and the variation in which thresholds they were intended to facilitate, it is worth noting here that Hazel's home also held a number of written materials that had been used infrequently alongside those that were used regularly, demonstrating the processes of innovation adaptation required of her husband as the primary source of the material. However, where Flash's changing signage charted an increasing difficulty in remembering to assemble a clean outfit from various drawers when a pre-assembled, but already-worn outfit was readily available, Hazel's materials suggested a difficulty in remembering to use the tools at all. Picture 11 shows three separate calendars clustered together in Hazel's kitchen; a red bordered weekly planner showing each day of the working week, the weekend, and tasks to be completed; a monthly calendar with one line dedicated to each day arranged vertically; and a weekly planner with each day given its own space, arranged vertically with additional space for writing longer notes.



Picture 11: A Tale of Three Calendars

Of the three, only the centre calendar was used regularly, even though the two unused calendars are more in accordance with the principals of dementia design. Interestingly, just as Flash's bus timetables demonstrated the potential for a social relationship, and a facilitative social threshold, to ease passage over physical thresholds, Hazel's calendars demonstrate the

impact of social thresholds on the temporal thresholds that are the focus of Chapter Seven. Specifically, the maintenance of the calendar required not only identifying one that would draw Hazel's attention and prompt her usage of it, but the introduction of further practices to ensure that she could successfully identify where she was in the month, despite being presented with each day simultaneously. This had been achieved simply by John's introduction of the green pen which was used to highlight past dates and ensure Hazel could orientate herself in the present (the pen is visible in Picture 11, in its customary place on top of the control pad for the heating, which also performed a facilitator role in the process as it displayed both the date and time). Hazel often referred to the calendar in our conversations, using it as an aide memoir to prompt her recollection of what had occurred since our last visit, as well as a tool with which to organise our future visits together. Yet, even as the calendar, the product of her ability to navigate her social threshold with her husband, helped Hazel arrange herself and manage her temporal thresholds, it also acted as a social prompt, and she would often fetch it down as our meetings drew to a close to arrange my next visit, a process which, once complete, would prompt my withdrawal from her home space.

It is through capturing this interaction between different types of thresholds that the concept demonstrates its value, as it provides additional avenues for investigation should crossings become troublesome, prompting an investigation of physical, social and temporal components rather than presuming primacy in one particular area. This inter-relation was further exemplified during a discussion between Hazel, John, and myself about the use and maintenance of her calendar. Critically, while many of the entries on the calendar were in Hazel's handwriting as many or more were in John's, products of a routine transfer of information from his paper diary to the shared wall calendar- a process that Hazel could no longer undertake as she rarely remembered to write in her own diary. The on-going labour of maintaining such resources became a source of tension during our discussion, providing

an insight into Hazel's frustrations at her own progressive impairment as well as her reliance upon John as, increasingly, the keeper of the calendar. The following quote is taken from a point late in one visit, where Hazel, John and I were sat together in the living room, with she and he together on the sofa and I sat in the armchair perpendicular to them.

Hazel: What are you doing?

John: Looking at my diary.

Hazel: Oh, right. I'm just asking. [...]

John: [jokingly] Well, I'm a very busy man. I've got to keep it up to date.

I: You know what though, I laugh. And if things aren't in my diary, they don't happen at all.

Hazel: Here's my diary. [Hazel lifts it from under a book beside her and opens it towards me] It's empty [...] I'm supposed to write everything in it... I keep forgetting it's there. Don't I, John?

John: Yes. [...]

Hazel: I should have had your name down in there to say you were coming and I haven't.

I: It was my fault because [...] I arranged it with John, so...

Hazel: Well there's no point arranging anything with John, because he doesn't tell me nothing [...] I'm only joking, John, honest.

John: Yeah, I know.

(Hazel and John, Interview Transcript)

Hazel's reinforcement of her own failure to keep a diary, first through forgetting it was there, then by not having my name noted in it was tied to her wider frustrations about her impairments making things 'difficult'. Yet Hazel was not alone in this. Many participants used some variant of note-taking in order to supplement their impaired memory, whether

that was by using a calendar (Hazel, Isabel, Sybil), diary (Flash, Mark), notebook (Mark) or iPad (Nigel) successful use often required some input from others in their life. Indeed, taken more broadly, most objects that served to facilitate habits of dwelling or threshold crossings were in some way facilitated by others, either through their introduction or through some form of continued maintenance. That these materials, which were themselves important in facilitating threshold crossings, relied upon continued successful navigation of social thresholds indicates not only the complex web of thresholds that surrounded participants, but the particular importance of navigating social thresholds as facilitative of the others which would follow.

Beyond the Written Word

One example of the on-going labour involved in maintaining facilitative resources was provided by George and Anne. In our conversations together, George and Anne often discussed their engagement with numerous agencies and charities as a strategy in an attempt to assemble a range of techniques that could support and enable George in the context of his complex impairments as they resulted from severe macular degeneration, dementia, limb damage, problems with balance, and a chronic lung condition. The intersecting of this selection of impairments introduced a particular challenge, in that many things that were meant to enable people with one impairment were either inappropriate or inaccessible to George due to another impairment effect. This resulted in, among other things; George being unable to drive a motorised wheelchair, but unable to self-propel, and as such requiring Anne or another person to push him when he journeyed Elsewhere; special corrective glasses that could no longer successfully circumvent his macular degeneration, but that he continued to try to use as he forgot the reasoning behind no longer using them; and a particularly unsuccessful engagement with cognitive behavioural therapy where many of the suggested

interventions proved inaccessible for him. As each impairment proceeded at a different rate they were constantly engaged in trying novel solutions to existing and newly occurring difficulties.

It was in this context that I first became aware of myself not only as a researcher in the field, but as a resource for my participant- one which had already been drawn upon during several visits without it coming to my attention that this was what occurring. That this is, perhaps, an indication of the risk-focused orientation of the ethics process which itself tends to frame vulnerable people as at risk of being 'used' rather than entering into a bidirectional relationship where each party gains something of value is reflected upon in the discussion in chapter Eight. The initial conversation occurred after Anne took me to see the visual medication guide she had made to enable George to take his medication independently by providing a visual map of which medications were to be taken when (Picture 12).

Anne: But since you've been, we've made a little board for him.

I: How's that going for you?

George: Great.

Anne: We quite like that, actually.[...] I got him to choose the pictures he wanted, so that it wasn't kind of patronising.

I: Yes.

Anne: There was a picture of one of the dentists treating somebody, but it was too busy for him and he preferred ... that's not like our dentist [...] He picked them, you know. Because I thought, well, it has to be easy for him to see. I just put a text box on that to do the writing for us[...]

I: I love that so much. George?

George: What?

I: I've been seeing your visuals [...] This makes me giggle so much.

George: Aye, that's a haircut.

I: Is this what you look like before you go in, aye?

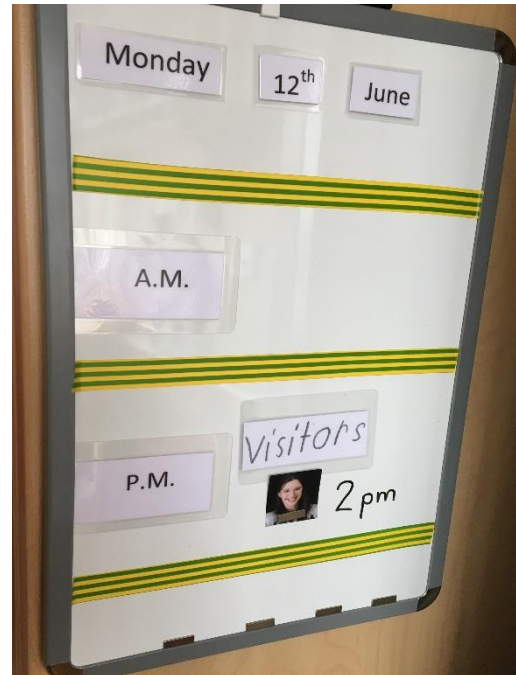
George: Aye, yes, just about. But this starts to stick up then.

(George and Anne, Interview Transcript)

In this example, Anne had actively enlisted George for his help in choosing the form and features of the visual daily planner. The result was a mixture of different image styles and shapes, from silhouette outlines to cartoons to photographs rather than a stylistically coherent 'set' that included a mixture of no text, printed text, and George's own handwriting. The haircut visual discussed in the extract is highlighted by the yellow square in Picture 13, and successfully became not only a visual guide for what George could expect in his day but a focus of conversation.



Picture 13: George's Visuals



Picture 14: George's Daily Planner

While this was, arguably, a secondary function of the visuals rather than an intended result, it was not inconsistent with other participants who identified material objects as facilitative of Being-with-others and thus of social thresholds. That these objects were both beholden to and facilitative of social thresholds, while also acting in other capacities (for example, as memory aids) captures the complexities introduced when social relationships influence the identification and implementation of materials that, in turn, facilitate further crossings of social thresholds. This is cleanly captured in the introduction of George's visuals. Such a process required first that George communicate his difficulty, then that Anne both recognise that difficulty and engage with it as a valid concern. Both George and Anne then accessed their social resources through talking to others, identified my research as something of interest, and to successfully leveraged our relationship in a way that resulted in an exchange of knowledge about the use of visuals for people with dementia. Anne then acted on this information in collaboration with George, (the collaborative process itself another social

threshold), and so on. Viewed in such a way, it becomes clear that the process of material introduction requires significant labour, which continues as the object is refined or impairment effects change and progress, thus making both the threshold crossing facilitated by the materials, and the materials themselves, reliant upon the ability to maintain an open social threshold between the person with dementia and their key person, in this case between Anne and George.

The Role of the Inner Circle

While the previous sections have detailed the role of social relationships, and thus the impact of social thresholds, on the production and maintenance of objects it is necessary to move beyond the discussion of which objects were being introduced and maintained and consider the relationships between those who undertook these duties and the individual with dementia. It is therefore helpful to consider a participant's social network, and an acknowledgement of the qualitative difference between those individuals in the participant's life who were permitted insight into the indignities and challenges of everyday life, and those from whom such knowledge was withheld. There were two aspects of this inner circle that were particularly influential in the lives of participants; the first was the particular status awarded to those within the inner circle and the second involved the measures that participants took to guard and manage that social threshold.

Inside the Inner Circle

One common example of the esteem in which participants held members of their inner circle was demonstrated in the way that they were featured as part of the participants' story of diagnosis. This is captured in the following extract, where Nigel reflects on the role played

by his adult son in highlighting his memory impairment, something both he and his wife had resisted acknowledging until it was unavoidably drawn to their attention.

Nigel: “[My Son] was the one who really...he didn’t diagnose it, but he said, I think you should see a doctor, ‘cause you’ve asked me the same silly question three times. So after the family, sort of, digested this and [my wife] digested it and then [...] [she said] I should go to see my GP. ‘Cause that’s the first stopping point. I mean, good GPs are very rare these days. I’m lucky that I’ve got two of the main GPs in [local] Medical Centre are both outstanding, [...] And they both know me by first name, which is good. So I think that they then said, well you...maybe you should go and see what the Memory Clinic says of you.”

(Nigel, Interview Transcript)

There are two points of particular interest here; the first is the value attributed by Nigel to his son’s opinion, such that his concerns are not dismissed out of hand or resisted, and the second is the importance of social thresholds in the process of securing a diagnosis. For Nigel, and for a number of other participants, it was difficulty at the social threshold that first prompted the journey towards diagnosis, which, in turn, necessitated navigating a multitude of additional social thresholds, between the person with dementia and the doctor, the doctor as a referrer and the consultant, the consultant and the person with dementia and so on. Importantly, members of the inner circle often continued to be active throughout the diagnostic journey. This was particularly true for Janet, whose husband had attended appointments with her and often advocated and fought for her concerns to be taken seriously by professionals who had initially attributed her symptoms to stress.

It is important to note, too, that the influence of those within the inner circle did not end with diagnosis, but continued forwards, transforming alongside the needs of the person with dementia. Indeed, it was often only the inner circle that were permitted an insight into the difficulties associated with an individual’s impairment effects, and as such they often became

facilitative resources in their own right, providing emotional as well as practical support. Examples of this often involved comments about how the person would need to ‘check in’ or ‘ask’ a particular person for clarification about something they felt unsure about. It was this ability to confirm their beliefs or seek new knowledge that often helped participants manage the uncertainty and anxiety that occurred when they felt like they had forgotten something important. This reliance, however, could result in problems as the individual members of the inner circle continued to navigate their own lives and responsibilities. The potential for the individuality of someone in the inner circle to conflict with their role as a facilitator is captured in Hazel’s quote, below, where she discusses her feelings of anxiety that she was experiencing in that moment, knowing that neither her daughter nor her husband were available to provide information or reassurance.

Hazel: I have to say hand on heart the memory is worse.

I: Is it worse?

Hazel: Yes. It’s definitely worse. Me talking just now like this is okay but trying to remember things is just hopeless. [...] I mean, just there just now, I mean, I’ve forgotten where John’s gone. [...] You know, I don’t know where he’s gone unless it’s written in the calendar and I don’t think it is written in the calendar today. [...] So, I don’t know where he is. I said to...I said to him before he went away I said, well, I said maybe [my daughter]Jill will come down today. He said, no, he said Jill’s not coming down. She’s away just now. And I thought... [...] oops, I’d forgotten she was away as well. She’s only away for two or three days right enough but...so I’d forgotten about that as well so...wherever he is, he’s there.

(Hazel, Interview Transcript)

In this section, the role of the calendar, John’s role in maintaining the calendar, and John’s position as an important social resource are all made evident. Hazel’s inability to remember where John has gone is then compounded when the calendar fails to provide the information she needs, which is framed as something John should have seen to as primary maintainer of

the calendar. This confusion builds then, compounded by the absence of Hazel's daughter (Jill) who she would normally call for information and reassurance in times where John was not available. In their (temporary) failure, the mechanisms of Hazel's systems of support are laid bare. In the moment that Hazel initially feels unsure about being left alone, she attempts to draw support over the social threshold she shares with her daughter, a process that is impaired by her unavailability. This experience is then exacerbated when John, who initially provides support, is then rendered incommunicado, a process which is further problematized by John's perceived failure to update the shared calendar, leaving Hazel in a state of uncertainty, where she is separated from her two main sources of social support by impermeable physical and temporal thresholds, with (she believes) no method of knowing when that support will reappear. Hazel communicates her sense of resignation and frustration in her acknowledgement "wherever he is, he's there". Unable to rely upon her usual mechanisms of support Hazel resigned herself to waiting either until she remembered where John had gone, or until he returned at an unspecified future time. John subsequently returned before the end of my visit, and the normal patterns of social relational support returned. This highlights not only the importance of the relationships and social thresholds between the person with dementia and those in their inner circle, but the particular strengths associated with a thresholds framework, as it can capture Hazel's sense of loss and isolation while simultaneously acknowledging the experiences of John, for whom there was never a concern about Hazel's wellbeing or his intention to return. This relationality, and particularly the thresholds existence as distinct from yet beholden to the phenomena on each side, allows for a nuanced insight into the experiences of people with dementia, allowing for an exploration of experience without necessarily conflicting with the realities of others.

It is important, too, to acknowledge those within the inner circle not only as individuals with valued and influential insights, or as valued social connections in their own right, but as

facilitative of other social thresholds more broadly. In particular, those within the inner circle were often called upon to act as repositories of both memory and knowledge, acting as filters and curators of information in a variety of settings. The following quote, in which George and Anne discuss a recent visit to the opticians, clearly demonstrates this.

George: What I still find annoying is because when I went to the optician earlier on they wouldn't give me any glasses. And they wouldn't give me any stronger reading glasses which I need, at least I thought I needed. But they refused to give me because I was going blind or something.

Anne: This is a problem we have a little bit too at these earlier stages, is that when George's talking to professionals like opticians and doctors he seems to understand at the time... [...] But then I come home...

George: I forgot what she said.

Anne: and it's not that he's forgotten, he hasn't understood. So the optician explained to him quite clearly that he's lost his central vision. So there's no way...they could not give him any stronger glasses. [...] George was saying 'oh yes, yes', and going along with all that. And she would say 'do you understand'? And he'd say 'yes, yeah'. And I thought he was understanding too. But when we came home and he said 'but why am I not getting...can they not just give me stronger glasses?' And he still can't understand that.

(George and Anne, Interview Transcript)

This is particularly telling when compared to the following quote, in which Hazel discusses her sisters continued efforts to influence her behaviour, a pattern that, Hazel stated, had become more pronounced since she had disclosed her dementia diagnosis.

Hazel: It's hard to say what [my sister] is like. She tries to say to me I should be doing this or I should be doing that. I says, '[sister],' I says, 'listen to me,' I says, 'I've got

a nice house, I says, I've got a husband. I says, and touch wood, I'm not short of anything.'

I: *Aye.*

Hazel: *I says, 'I don't need anything.' I says, 'I'm quite happy.' She says, 'but you must, there must be something you want.' I says, 'not really. I says, there's nothing I really need. There's nothing I want.' I says, 'I've got John, I says, I've got [granddaughter], I've got Jill and I've got Karen.' 'You never see Karen.' I says, 'but she's still there.' [...] I says, 'it doesn't matter whether I see her very often or not, she's still there and I can ask her anything and she'll do it for me.' [...] 'Oh but you never talk to her.' I says, 'I do talk to her.' I says, 'maybe once a month or something like that, but' I says, 'that's how Karen is.'*

(Hazel, Interview Transcript)

Contrasted with one another, the two quotes above provide a telling insight into the different statuses afforded to people inside and outside the inner circle. In the first, Anne is called upon to repeat and repackage the key information initially related by the optician in order to facilitate George's understanding. Of particular note is the lack of conflict between Anne, as a member of the inner circle, and George, and the echoes of conflict between George and the optician, who was not a member of the inner circle. This is almost diametrically opposed to Hazel's outright rejection of her sister's attempts to manage her behaviour. As someone outside the inner circle, Hazel responds to her sister's input by narrowing their shared threshold, going to significant lengths to not only demonstrate the quality of her life but the extent of her existing social networks. It is interesting to note, however, that Hazel's rejection of her sister's critique is not grounded in an attempt to convey her relationship with her daughter Karen as one of constant communication, but in defending the makeup of their social relationship: she and Karen may not communicate regularly, but "she's still there". This faith, that Hazel could rely on Karen in an emergency despite her placement outside the inner circle, was fundamental to the way in which Hazel experienced and explained her

security. By contrast, she often described her sister as an opposing force that is permitted only a carefully curated insight into her experience. Such practices raise profound questions around how individuals who are not included in a person with dementia's 'inner circle' might gain access, as the knowledge that is a prerequisite to entry may be disguised or withheld entirely by the person themselves. It is how the participant constructs themselves in different social situations, and how this influences the way in which they relate to others that forms the crux of the coming sections.

Restricting Access to the Inner Circle

Given the importance of the inner circle, and the benefits and responsibilities associated with being included within its ranks, it is perhaps unsurprising that the social threshold that separated members from non-members was one of the most carefully guarded social thresholds to emerge during fieldwork. The following quote was drawn from one of my visits with Hazel, and clearly demonstrates the way that people with dementia could call upon a range of techniques to secure their social thresholds and restrict the extent to which those outside the inner circle could gain clear insight into the challenging realities of navigating the world with dementia.

Hazel: "Did I say about my sister saying about driving? [...] She's still at it! I spoke to her I think it was about a week or two ago. 'How are you doing?' I said, 'aye, I'm fine. 'Oh right.' Next thing, 'are you still driving?' I said 'yes. 'Are you sure you should be?' I said '[sister] you've gone around that corner two or three times.' I said 'the corner's nearly done.' [...] She said 'well, if you're still... if you've got... what.. what...' and that's how she went on. She couldn't remember what to call it and I've got Alzheimer's and she said to me 'are you sure you're alright?' I said, 'well, am I talking alright to you on the phone?' 'Aye.' [...] 'I said, do I sound okay?' She said, 'yes', she said 'but I asked you a couple of times' she said 'and you couldn't remember'. I said, 'well, I'll ask you something'. So, I asked her something about

the family from way back. 'Oh, I don't know. I can't remember' I said 'there you go you couldn't remember either could you?' 'Oh, see you'

(Hazel, Interview Transcript)

There are a number of points in the quote above that are worthy of further consideration. The most important of these is, arguably, the tenacity with which not only Hazel resists her sisters attempts to influence her behaviour (in this case, driving) but the way in which she manages the conversation such that even an accurate insight into the effects of her impairments becomes impossible. This occurs first in her rebuke about having 'gone round that corner before', indicating that the imposition of her sisters opinion had been reluctantly tolerated before but would not be so again. She then proceeds to shift the conversational context, away from her ability to drive, towards an assessment of her sister's ability to recall information, capitalising on her sister's limited insight into the range of impairments that could accompany a dementia diagnosis. Were this quote to be viewed alone, however, it would provide only a limited insight into the deliberate efforts taken by Hazel to secure her social threshold. She continued:

Hazel: 'Oh, see you.'

I: That's what you get.

Hazel: Yes. I keep saying to John I said 'you'll need to take me through and see her because I said she's getting really...I'm beginning to worry about her'. 'So,' I said 'other than that' I said 'I'll drive through myself'. He said 'indeed you will not'. I said, 'oh, not you as well.' I said 'it's alright when you're going to [a club] and you want picked up though, isn't it?' 'Oh, that's only wee short journeys.' I said 'I know how to get to [my sister's]. It's only just up the road'. [...] in saying that even with... once before I got the, sort of, dementia thing the way it is now I was driving through and I had the satnav on because I always do when I go to [hers] because it's a roundabout road to get there. So, I put the satnav on and it said 'you have reached your destination' and I looked roundabout me. I was out in the wilds with fields all over me and I'm thinking [...] what the heck's that satnav doing. So, I phoned [her]

up. I said...she says, 'where are you?' [...] I said, 'well', I says 'to be quite honest with you I haven't got a clue'. I said 'I'm surrounded by field roundabout here and a couple of buildings and whatever'. 'How did you manage that you've got the satnav and you know how to get here?' I said, 'aye,' I says 'but the satnav brought me here [...]it's a bit like me, it's forgetful.'"

(Hazel, Interview Transcript)

The first point of note here is Hazel's sudden shift, from flatly rejecting the suggestion that she should not drive, to acknowledging her need to be driven to locations that were further away: "I keep saying to John [...] you'll need to take me through". John, as a member of Hazel's inner circle, is not only provided insight into Hazel's experience of memory impairment, but her increasing difficulty in regards to way finding. As a result, Hazel provides a clear example of how she responds to challenges to her behaviour from those outside her inner circle ("that corners nearly done") versus those within it ("It's alright when you're going to [a club] isn't it?"). Only those within the inner circle are permitted to see the indignities of a life lived with impairment (Shakespeare and Watson, 2001), and as such it is often only their attempts to respond to the changing impairments associated with a degenerative brain disease are considered as benevolent, where others are viewed through a lens of oppression, and are responded to as such.

Responding to Violations of the Social Threshold

While previous sections have discussed the ways in which participants may seek to actively permit or resist the attempts of others to cross the social threshold that separates the wider world from their trusted inner circle of confidantes, it is important to acknowledge that such relationships are not always so easily navigated. In each of the cases above, engaging with others in threshold spaces has predominantly required the participant to stand firm in their perceptions. It is in the face of people with dementia holding their ground that those in the

inner circle seek to identify and implement facilitative practices that allow such engagement to continue, and those outside that circle find themselves excluded. In my conversations with Mark, however, he discussed similar issues around regulating who was and was not considered part of his inner circle, with a key difference. For Mark, maintaining a trusted inner circle not only required a vigilant guard over the social threshold, but direct action to remove someone from a position of trust, forcibly moving them from inside the inner circle, to outside his confidence. The following quote is protracted, but provides necessary insight into both Mark's engagement with the state as an older man with dementia, his management of his social thresholds, his maintenance of his inner circle, and his practices of dwelling-as-protection as they manifested in redressing the situation.

Mark: [My daughter has lived abroad for] about 7 or 8 years. And when I got dementia, she decide- they decided I had to have a Power of Attorney and so she decided that she was going to be the Power of Attorney. So she went to my bank and did all that. And made herself the Power of Attorney and I didn't know much about it I just left it that she was going to be able and capable of looking after me. [...] But she lives [abroad].

I: Yeah, how does that work?

Mark: Well I realised – well she is in touch with the bank only [...] so she has a copy of my bank statement every month and, you know, would occasionally say 'what's that for?' She- she's the sort my daughter, she's.... she was a bully. She used to bully me. She used to get on my nerves sometimes when she was coming you know I'd think [sucks in breath] you know why come, you don't need to? [...] They were over here before Christmas and I told her then that if she was Power of Attorney and she wasn't going to be there to do things for me when I wanted them... [...] She says 'I'm always here for you to phone me'. I said 'but I can't ask you on the phone all sorts of things'. [...] And her husband he knows everything, you know, and he

said 'you could send it to me – send it to me in the post and I'd read it and come back to you on [...] any problems you have'. [...] You can't do things like that.

I: No

Mark: I can't live like that. [...] And I had spoken to a couple of people – not those two – a couple of people that they know about being Power of Attorney and they said I should have two people anyway, so I could appoint another one, and that's it. However I decided there were a couple of people I know I could have asked to do it so I told my daughter I was going to scrub her and get somebody else – 2 people. And she says 'No you're not. You're not going to do that. I won't sign anything for you'. And she was quite nasty with it.

I: Hold you hostage, is it not?

Mark: Oh well she's like that you see. 'Don't think you're going to do that'. [...] That was the end of it for me. [...] In fact I got an appointment for them this morning and... what was it came out this morning? Oh a letter came this morning saying that... this is from the man who stamped this Power of Attorney at [town], [...] letter came from him saying to me that he'd written to my daughter telling her that she was no longer a Power of Attorney, [...] She doesn't need to, she didn't need to sign anything anyway. And she's been now officially told by [him].

(Mark, Interview Transcript)

This extract is remarkable in a number of ways. In the first instance, it demonstrates the flexibility of the social threshold that separates the inner circle from the wider social network. That Mark's daughter was allowed to enter into a place of confidence with little conflict based on her kinship, gain formal recognition of her status by gaining Power of Attorney, thus being formally recognised as the de facto decision maker should Mark lose capacity, and then have her access to the social space and its benefits revoked using the same mechanisms with which she'd sought to secure her place demonstrates the relationality of thresholds. Rather than representing a fixed arrangement, Mark is able to not only redraw the social threshold such that his daughter is forcibly removed from his inner circle, but is able to leverage both

social resources (his lawyer, his neighbour, etc.) and material objects (his Power of Attorney, and latterly, his will) to render the threshold impassable to her subsequent attempts to regain entry. This, in turn, emphasises the power that people with dementia could leverage in threshold spaces, as they capitalised on the relational aspects of the threshold space to act, and react, to those who met them on the other side.

While examples like those provided by Mark, above, provide dramatic examples of renegotiated social thresholds, such events were not always characterised by direct conflict. In the quote below, Margaret was discussing her concern at being mistaken for weak by those she showed kindness to within her supported living facility. After relating how washing a cup for a fellow resident had (she felt) lead to him peeking through her keyhole as discussed in Chapter 5, Margret decided to hold other residents at a distance, saying:

Margaret: "You never get anybody kind of decent in here, it's all weirdos. But that big man's the latest one. And the way he came right up to me the first time, and I just kind of froze, and I went, 'no, I don't like the look of you.' [...] And he's awful nice, don't get me wrong, but he's just not, I don't know, there's just something about him that I just don't like. I don't like people that are too friendly. [...] I like, if he'd come up and just spoke naturally to me. Oh, he came right up, and I went, 'oh, alright'. I said, 'enough's enough, once bitten.'

I: Aye, twice shy, right enough.

Margaret: 'Oh', I said, 'it's nice to be nice, and kind-hearted, but I don't like to get made a mug of', and that's just what happened there. [...] That I was handing him, and I was going out and buying things, and then coming in and saying, oh that's a shame, maybe he could do with that. You clown, you, you know.

(Margaret, Interview Transcript)

Key to Margaret's distrust of other resident was her own experience of navigating the world not only as a person with dementia, but also as an older woman living alone with dementia.

In this case, not only does the ‘big man’ meet with resistance because of her experience of being spied upon but also as a result of her encounters with men more generally, which had been predominantly unpleasant. This construction of men as potentially dangerous has a profound influence on how she constructs and retells the story as she casts suspicion upon the genuineness of the resident’s apparent friendliness, and fears being taken advantage of. This experience, particularly as an older woman in a complex that had only started housing men after she moved in, significantly impacted the way in which Margaret organised her social space, and how she perceived those who attempted to cross her social and physical thresholds (n.b. that the man in the above quote does both, in that he ‘comes right up to’ her and was overly friendly). This raises questions about how those who are unknown might navigate their way successfully over social thresholds in their relationships with people with dementia- particularly where an expansive history is not known. Through the information I gleaned in our conversations, I was able to see Margaret’s distrust of men manifest throughout her timeline; in her relationship with her husband, with her brother, and with a number of men since including the one described above and the man peeking through her keyhole in Chapter Five. Without such insight- which I might not have been privy to in another role, or if I had started out with questions that were obviously directed towards such information- such connections would have been impossible to make. The impact of such lived, temporal aspects of threshold spaces is discussed more thoroughly in Chapter Seven, while the implications for practice are considered in the discussion in Chapter Eight.

Driving as a Social Threshold

Given the complexities that are inherently a part of the social threshold, as a relational space between two whole, nuanced Dasein, it is particularly valuable to explore the ways in which social thresholds can affect a range of behaviours, particularly those more readily associated

with physical or temporal thresholds. Driving provides just such an example. Although there were a number of my participants who had never obtained their driving licence (Margaret and Bob chief among them), driving remained a point of particular contention and focus in the lives of participants. More than any other activity, the ability to drive and the cessation of driving was discussed by participants in terms of profound biographical disruption, as they ceased to be drivers, and became, at best, pedestrians, but more often reliant on the timetables of others or the availability of taxi services. While there is a growing, valuable work detailing the experiences of people with dementia as they surrender their driving licence (including Chacko et al., 2015; McKillop, 2016 and Read, Toye and Wynaden, 2017), I direct the readers attention not to the loss of driving as an activity, or to the resulting restriction at the physical threshold, but to the profoundly impactful social factors that influence not only how people with dementia construct and communicate themselves as drivers but to how they seek to maintain that status, and the ways in which they manage its revocation. Thomas' understanding of disability as resulting from the interaction between impairment effects and socially constructed barriers is particularly informative in this case, as members of the inner circle were often considered as the ultimate guardians of the threshold between the participant as drivers, and as non-drivers, making the negotiation of that portion of their identity beholden upon their ability to navigate social thresholds between themselves and those within their inner circle.

As shown in Hazel's quotes in the previous section, driving was often constructed as a behaviour that was not only risky for the person for dementia, but as an activity that actively created risk for others. Taken from this perspective, John's assertion that Hazel can drive him to and from his social clubs can be viewed as actively enabling her role as a driver and as an equal partner in their relationship, while mitigating the risks that are associated with driving longer distances and to less familiar locations. By contrast, her sister's questions of

whether she “should” be driving rely not only on a generalised understanding of Alzheimer’s disease, but also on the propriety of her driving, rather than her ability to do so safely. This is, arguably, a powerful example of psychoemotional disablism as a force which seeks to restrict not only what people with impairments can do, but what they can be (Thomas, 2007). This is particularly impactful in the wider context. Of those who were drivers prior to diagnosis, only Nigel, Mark, and Hazel were still driving at the time of fieldwork, while others relied on family members, taxis and formal services, public transportation or some combination of the three. The loss of the ability to drive had been a distressing process, particularly for Sybil, Isobel and George, and was often intrinsically connected to the reconstruction of their identity post-diagnosis as they attempted to navigate the social expectations of what people with dementia could do, and what they could be. The profound impact of the disabling narrative, that people with dementia cannot or should not drive post diagnosis, and the expectation that this restriction would be applied to anyone with a diagnosis, is clear in the following extract from Sybil:

Sybil: “I had my own car. I’m missing it now, but at first I didn’t...it didn’t worry me, but it’s beginning to worry me more when I think of where I want to go, you used just...the car, you open the door out and jump in the car and there you go. It was a nice little car. [...] It was really a great...and I hadn’t been driving very much because [...] the traffic’s been building up and building up. And...well I just decided [...] not to drive again. When I think about it, the man that told me, he looked as if he was just going to say, don’t drive again in your state. [...]”

(Sybil, Interview Transcript)

Sybil: “And at that point in time, it didn’t really matter, but I wasn’t able to walk very far...much. But as the time’s going on, it’s beginning to niggle. I can’t do as I would do.”

(Sybil, Interview Transcript)

Analysing these quotes highlights a number of interesting and interrelated aspects which influenced the way in which Sybil understood her loss of driving ability. Firstly, there is the difficulty it introduces in relation to a physical crossing- the loss of a car means she cannot “do as [she] would do” or “jump in the car and there you go”. Instead, movement beyond her walking range that “wasn’t very far” and was carefully regulated by her daughter became reliant on others- predominantly the taxi drivers arranged by her daughter. The second point to consider is the presence of the social ‘other’ in the decision process; “the man” who needed only to “look as if” he would suggest that she should no longer drive with a diagnosis of dementia. This exemplifies the power both of the narratives of decay, the ableist dialogues surrounding dementia, and the stigma associated with receiving a diagnosis: it was never necessary for someone to request Sybil give up her driving licence, because she had already internalised the ableist narratives that cast her diagnosis, and her social status as a driver as incompatible.

Events like those above highlight the need to explicitly acknowledge the social and relational constructs of disablement and enablement that surround people with dementia. In the following segment, Nigel reflects upon his decision to keep driving, and critically, the two conditions under which he would surrender his driving licence voluntarily: his 70th birthday, or his wife’s request.

Nigel: You do things, yes intuitively, so I drive a car intuitively. Now I have to think carefully much more about where I’m driving and how I’m driving and [my wife]

bates me driving now 'cause it scares her to death. But I say, 'don't worry it's alright...'

I: So is it some of the things that you were taking for granted are getting muddled or are getting off...

Nigel: Yeab, I would take for granted that I would automatically know where I'd left my car. [...] So what I've been trying to do is create landmarks and do a quick reconnaissance and say, these are the main points. But the trouble is I forget what the main points were which is a bit of a problem. That's another thing about Alzheimer's, you get multiple problems occurring where things just don't happen where they would happen previously and they can range from just finding the word to being able to intuitively know how to put a car in gear or whatever it happens to be. So I've said to [her] 'I will stop driving when either two conditions, one that you tell me I should stop driving, because I'm not able to tell myself I'm driving badly, cause I'm driving alright, there is no danger'... 'abbb but it scares me to death'. 'And second when I turn 70'. I think that's probably a good time to stop because apart from anything else when you turn 70 you have got to re-do your licence test.

I: Yeab.

Nigel: And I would almost certainly fail. [...] Because it's only another year away.

(Nigel, Interview Transcript)

In reflecting on the quote there are arguably several factors that interact. Key to this section, however, is the interaction between his wife as someone who cares and worries ('it scares her to death'), Nigel as an intuitive driver, and his wife as an ultimate authority who can accurately judge the safety of his driving. Such a relationship, again, highlights the influence of social relationships, and particularly on the ability to navigate social thresholds, as a key component of maintaining a driver's status. Indeed, it is worth arguing that Nigel's assessment that he should stop driving at 70 may be more a reflection of his own internalised negative perceptions about what it means to age, rather than a manifestation

of psychoemotional disablism whereby what it means to age with dementia becomes incompatible with being a driver. Ultimately, however, it is Nigel's wife, and her trusted opinion, that successfully guards the threshold between Nigel-the-driver, and Nigel-the-non-driver at the time of fieldwork, emphasising a further importance of trusted people at the threshold.

Nigel was not the only participant who found it necessary to negotiate with an outside force in order to maintain his identity as a driver, however. Mark, too, sought to maintain his licence, and as such had to navigate a test every year as part of being considered fit to drive. Rather than being an objective, spatially informed test, however, Mark's continued driving was more reliant on his ability to portray himself as a careful, courteous, and safe driver in social conversation. In the quote below, Mark relates his experiences of this annual testing process in the context of a recent health-related driving restriction and his concerns about the future.

Mark: I had to do a three- point turn. Which I failed. I hit the kerb. I had to do another one, in another place. He told me, he said 'you're not supposed to hit the kerb you know'. I said 'Oh' He said 'because if you hit the kerb with the tyres, the rest of the car is on the...' [...] So he said 'that's dangerous isn't it?' I said 'oh yes'. So he said 'don't do that'. [...] What else? Oh, the 20 thing [sign]. I didn't know there were green and red lights on it, I thought there were just red lights on it [...] He said when I got to it, there were no lights on but there were cars behind me and I slowed up, and I shouldn't have slowed up.

Mark: I don't know whether I can pass it this year. [...] if I lose my licence... not being able to drive for the last couple of weeks after I had this thing [...] put me in the bad mood [...] I was terrible, really..."

(Mark, Interview Transcript)

Most noticeable in this abstract is that while Mark was “marked down” for a number of violations during the test, he was able to mitigate these effects verbally- by agreeing that hitting the curb was dangerous, by acknowledging the faster speed limit and so on. It is the presence of these social requirements which prompted him to reflect that he might not pass in the future, as the DVLA was “only interested in [his] dementia” rather than the cataracts he had recently had removed. As such, he felt that the focus was placed on his cognitive impairments- that he could neither influence nor predict- rather than on his visual acuity for which there were medical procedures and a potential for improvement. This experience of another person presiding in judgement over a participant’s ability to drive was common across a number of both driving and non-driving participants, from Sybil and Mark as they are discussed here, to Isobel whose daughters explained that they were worried she would make an incorrect turn on the local motorway and end up hundreds of miles from home. In each case, however, the potential cessation of driving was tied by participants not to the impairment effects of their dementia, but to a social threshold, where relationships, rather than impairment effects, were leveraged in such a way that they often felt they had little choice but to surrender their licence.

Guarding the Social Threshold: The Role of Community Engagement

Rather than drawing this chapter to a close by considering how participants actively sought to preserve their relationships, freedoms and social standing from the disabling and stigmatising aspects of dementia by managing social thresholds, it also important to consider the ways in which they maintained, and in some cases increased, their standing following their dementia diagnosis. One the most pertinent examples of this is in the participant’s decision to take part in this research in the first place, thus seeking to place themselves as both experts in their experience and contributing towards a wider societal good. Indeed, it is

only in the context of living with dementia that participants were able to surrender their time and undertake the emotional and psychological labour involved in taking part in a qualitative study. Rather than reflecting a desire to pass the time, or an expectation of reward, however, several participants saw participating in research as an opportunity to make a valuable contribution to society, which might produce real benefit for people diagnosed in the future.

As Nigel explains:

Nigel: Cause... you know, it...you know, I will have Alzheimer's 'til I die. And that will make me die quicker. But by taking part in a clinical trial, I might help someone who's perhaps younger than I am now or help someone to live longer. Perhaps being part of that clinical trial, there's a breakthrough...you know, who knows. [...] I think that there's no biochemistry coming through I suppose. Yeah, we – humans – will conquer dementia, but not yet. We will find out what causes dementia and how to [treat it] in exactly the same way as over the years we discovered what smallpox was and how to stop it. It's the same sort of thing. It's all about doing the science. And so if I can help in either of those capacities, then that's good. Gives me a sense of usefulness. But it doesn't help me on a day-to-day basis too much. [...] I've always been a person who gets involved in things and so on.

(Nigel, Interview Transcript)

Interestingly, this tendency to view their involvement with the research as a societal contribution was mainly discussed by male participants. Nigel, Bob, and Mark all regularly related my purpose to others in discussion, highlighting their role as experts and mine as an 'apprentice' who had come to learn from them. This often led to a broader exchange of knowledge in a variety of areas where the participant had expertise, including the uses of ammonia for household cleaning, the importance of a chamois cloth, government bonds and church history. This advice was often tightly linked to the participants' previous identities as working-men whose contribution was valued by a capitalistic system, and as such allowed participants to draw these aspects of their identities close across the temporal threshold (as

discussed in the next chapter) while still securing their societal place in the present moment. Female participants, by contrast, often discussed their participation in the context of my development, as an exchange between themselves as a person with dementia and myself as a young researcher, rather than between themselves and the wider society. From either perspective, however, the desire to participate, to 'give back', or in Nigel's case, 'give forward' to those who would come after him was indicative of an on-going desire not only to be treated as someone of worth, but to contribute in a way that they felt was meaningful and of value.

Summary

This chapter began by considering the ways in which social relationships could be leveraged as enabling forces for people with dementia, firstly through identifying, implementing and maintaining physical resources, and then through providing interpersonal support. Through exploring these relationships, the chapter was able to demonstrate not only the complex relationships that can manifest between physical and social thresholds, but the importance of exploring the ways in which participants organised, maintained, and protected the social thresholds that separated their inner circle from their wider social network. Critically, by adopting a thresholds perspective, it was possible to simultaneously acknowledge the important enabling influences of people within the participants life without repeating the narratives of decay that portray people with dementia as objects of diminishing power who are increasingly beholden to their social contacts. Indeed, the opposite was often true, as people with dementia actively cultivated and maintained their inner circle, guarded the threshold, and responded to violations of trust in a way that often transformed the way in which they shaped their social and physical thresholds moving forward.

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

7: I HOPE I'M IN THE CROWD THAT DOESN'T GET ON THE SILLY SIDE': MANAGING TEMPORAL THRESHOLDS

The chapter begins by discussing how people with dementia manage those temporal thresholds that separate their current everydayness from their past, though the use of objects, stories, and spoken word. This begins with an exploration of the ways in which people with dementia used stories and storytelling to express aspects of their character (such as resilience, honour, and determination) that were less visible in the context of their everyday lived experience as older people with dementia. The chapter then moves forward, considering how time is experienced in the present as both a factor that challenges access to the shared social world of others, and as the dimension within which changes in ability and impairment are charted. In the final sections of the chapter, the focus moves forwards again towards the future, investigating the way in which people with dementia made sense of their potentialities, their-being-towards-death, and being-towards-death-with-dementia. This chapter therefore draws strongly from Heidegger's construction of Dasein as fundamentally temporal, whose experiences are meaningful precisely because they are finite. As the focus moves steadily towards the future in the latter portions of the chapter, the findings become increasingly relevant to the construction of dementia as decay, the profound psychoemotional disablism that results from these messages and the effects this has on the way in which people with dementia understand their experience in the context of their temporality as Dasein who has-been, is, and is towards-death.

With Chapter Five providing an insight into the experiences of people with dementia as they manage the physical thresholds that they encounter in the process of dwelling, and Chapter

Six focusing on the complexities that result from when Dasein is viewed as simultaneously in-space and with-others, it becomes the work of this chapter to explore a different manner of threshold. Here, the temporal threshold is explored as distinct from the everyday temporalities that are managed at physical and social thresholds as they appear, for example, in Mark's management of his doorway to receive care, and the maintenance of Hazel's calendar. As such, the following sections build upon the foundation laid in Five and Six, while shifting the focus away from Dasein in its everydayness, to Dasein with dementia as a temporal being who gathers knowledge from their past, manages their present and faces ever towards their future. As such, temporal thresholds are presented here as the space where the present (as experienced by the person with dementia in the moment) meets either the past through memory and reminiscence or the future through imagination and prospective thinking.

Much as with the social thresholds in Chapter Six, the concept of temporal thresholds was determined by the way in which participants constructed and conveyed their experience in terms of physicality; the past was a 'location', understood through their having been 'there', while the future and its complexities was parsed as a foreign and unknown space. They were not 'there yet'. This chapter, therefore, uses the thresholds framework to examine ways in which participants could 'draw' past and future spaces such as they abutted with the present at the temporal threshold.

Objects as Guardians of the Temporal Threshold

Given the importance of objects at both the physical thresholds described in Chapter Five, and the social thresholds explored in Chapter Six, it is not surprising that objects played an important role at the temporal threshold. While some of my participants had moved into

supported living accommodations (Flash, Bob, Margaret) only Flash had moved recently. As a result, most participants had not been forced to reduce their material possessions in some time, and certainly not to the extent that would have been required had they moved into residential care (Lovatt 2018). The focus of this chapter is, therefore, on how people with dementia shaped and managed their temporal thresholds through material objects and discursive practices. One of the clearest examples of this was in my work with Mark, who had been widowed for several years. Throughout our conversations, Mark would refer to his late wife often as the person who had bought particular objects or who had enjoyed particular activities. Indeed, Mark's home space was shaped by his wife's previous illness, as he had arranged for them to be moved while she was in hospital following a severe stroke, as their previous home would not have been accessible for her upon discharge. As a result, many of the aspects of his home, and particularly his bathroom, that enabled Mark as an older man with impairments in the present had initially been installed as aids for his wife. Despite of the prevalence of his wife's influence on many aspects of his dwelling, it was not until we had spent several days together that Mark invited me to see those items that most strongly recalled his wife's presence. After proceeding into Mark's bedroom, he directed me to the

tall wardrobe on 'his side of the bed', and towards a brown envelope that was laid carefully beneath the final bottom shelf on the carpet beneath (Picture 15).

Mark: "I was going to show you the thing at the bottom, right at the bottom. [...] That was her membership thing, [my wife's]. Yeah.

I: Right. Oh 2012 this is... So was that what she wanted for her birthday was to give it to the charity?

Mark: That's right yeah, yeah. But we had the birthday at the golf club and that's the dementia thing [donation cheque] you see. [...] Strange that because I wasn't – hadn't dementia then.

I: Yeah. Did your [wife] have dementia? [...]

Mark: No. [...] Well it was coincidence. I don't know why. She didn't have dementia, in fact we knew nobody that had dementia. [...] But she had a stroke for twenty years. And [...] I keep that.

I: Why do you keep this one in particular close to [your bed]?

Mark: Well that's very little of what I've got of. [my wife]. [...] I don't have any clothes or anything like that [...] but I've got that and I've got her thing.



Picture 15: Mark's Bedside Possessions in Situ

(Mark, Interview Transcript)

At Mark's direction, I emptied the contents of the envelope onto the satin-finish of the bedspread, and found a number of photographs, a membership card and lanyard, and a number of personal objects, which are the focus of the discussion in the extract above. Through explaining the reasoning behind keeping this small and carefully curated selection of objects, Mark made present not only his wife, but also her illness and their experiences together in the context of his ongoing experiences living with dementia. The tone and reverence with which Mark interacted with these objects was in stark contrast to the easy manner with which he discussed other ornaments his wife had purchased, their shared history, or the legacy of her illness as it appeared through facilitative objects. Indeed, Mark often made light of his status, and related not only that he always dressed in a shirt and sweater vest in case he met a "rich widow" ("you never know"), but in regularly instructing newer members of his care staff not to turn down the other side of the bed at night because his wife "wasn't coming, again!". Yet, these particular objects were approached with care as they connected him to the wife he had lost, to his role of having-been husband and care giver, and to a woman with whom he had more experience in common now - as an elder man with dementia, cataracts, skin cancer and difficulty balancing - than he had when she passed away. By keeping these objects not only separate from the rest of his belongings (Picture 15), but in an opaque container (in this case, a brown envelope) Mark limited the possibility that he might inadvertently find himself at the temporal threshold that these objects stand at the forefront of. Notably, this differed from the practices of others, such as Isobel, who was surrounded by pictures of her family, including a number arranged within view of her chair specifically showing her deceased children. Yet, despite these different approaches, the effect is arguably the same: a managed temporal threshold, for while Mark's arrangement limited accidental crossings, having the envelope by his bedside made it easily accessible, and allowed him to access it easily when he chose. Isobel, by contrast, often drew

her deceased family members into conversation, making the threshold between the now without them and the then with them an oft travelled and much facilitated one.

It is possible, however, that Mark's arrangement might present a challenge in the future should he move into residential care environment. Would the sentimentality of these items be recognised, if Mark were not in a position to convey it himself? While there are clues in Mark's spatial arrangements - the items are kept alone on the bottom of the wardrobe (Picture 15), directly below the napkin-clasp and apron he preferred to use if he was eating food likely to spill, and to the right of that was the bag set aside should he need to go into hospital at short notice. Nevertheless, how significance is both recognised by others and communicated by people with dementia presents an important question that is discussed as part of the discussion in Chapter Eight.

While it has thus far been the focus of the thesis to outline with sufficient clarity some of the thresholds that people with dementia encounter in the course of their everyday lives; it is worth noting specifically that what was captured during fieldwork does not and cannot sufficiently encapsulate all of the complexities and contradictions of any Dasein's being-in-the-world. Rather, the practices of fieldwork allowed for an 'uncovering' of how participants, as Dasein-with-dementia experienced, navigated, and interpreted their engagement with the world. This idea of 'uncovering' resonated particularly strongly with the ways in which participants used stories and discursive practices to relate aspects of their being, as having-been being, and being-towards during the course of fieldwork. Flash provided a powerful example of storytelling as a method of 'uncovering' as we discussed his history of living in the area, which was interrupted by his military service. Below, Flash reminisces on his period in the army after being drafted in 1945 and being assigned to the Argyles (an infantry unit)

rather than his expected assignment in the Royal Electrical and Mechanical Engineers (REME).

Flash: The Argyles was a good service. [...] [I was] in Palestine, you were in looking for all these Jews that had come on boats and were put in a camp. And they [the superiors] were saying that 'if they're trying to escape, shoot them'. I says, 'they're just man and wives. Kids.' 'Aye, just shoot them.' [sarcastically] 'Aye, that'll be right.' They [Jews] were, sort of, coming up in the...you were all round about [patrolling] and [...] the boy would come and say, 'there's a load of them behind that shed. Wait until you go that way so they can get...' I says, 'aye...' I says, 'well we see when we go that way. Will we stay and do it that way?'

I: Aye. No one to see it.

Flash: Out of the blue he says, 'aye you just shoot them'. They're on the back...kids and everything, you know.

I: God. And you at 18...

Flash: It was a silly idea, you know. A silly situation. [...] And the place was full of prisoners of war, camps of them, you know. And they were all trying to get home to Germany. [...] Anyways a mixed up world at that time.

(Flash, Interview Transcript)

At its core, Flash's tale is a simple one: he was told to shoot refugees for attempting to escape a controlled area but refused. In reconstructing it as a narrative for a receptive audience interested in his experience, however, Flash conveys a number of key points about how he sees himself. Reading the quote in order, the first impression of Flash is a compassionate one, who as a young man from a poor industrial area in Scotland looked at refugees unlike himself and saw them in their humanity: as families trying to get home. This quickly shifts, and compassion is supported by principle: rather than responding aggressively to the news that there are people trying to leave the refugee camp, he first attempts to avoid confrontation by waiting ('will we stay?') and giving them time to escape, and then by refusing

to carry out what was being presented as the norm ('just shoot them' 'aye, that'll be right'). Rather than castigating his peer, however, in the closing section of the quote he instead places the responsibility on situational factors ('a mixed up world') rather than on individual preference. In doing so, something more subtle is communicated: an understanding of the complexities of life, of the effects of chaos and uncertainty on human beings. Taken as a whole, in this telling Flash becomes brave but humble, understating an action that might have caused significant issue in his own life had he in turn met resistance. Thus, by this process of remembering what has-been, that is 'gathering what endures' (Heidegger, 1971), Flash brings his younger self and past experiences towards his present, creating and managing the temporal threshold between them. That there might be no cause for Flash to behave in a way that demonstrates bravery, or integrity, or humility on an everyday basis as an older man in a supported living environment does not stop them reflecting on his being, or his having-been. Furnished with this information, it is possible to see the same resistance to authoritative voices he disagrees with in his steadfast feeding of the birds outside his window. That he does so indirectly in the present (by hiding behind the curtain and blaming the resident upstairs) is as harmonious with his instinct to look the other way in his retelling of the past.

As understandable as it might be to recall events that only cast us in the most favourable light, it is worth noting that many of my conversations with participants were permeated with complexities. The following quote is taken from a conversation with Margaret about her family, where she relayed the help and support she currently received from her niece and from her daughter as similar to the help she herself provided her family as a younger woman. The following section results from my asking if her sister, who lived in the same facility, was her only sibling.

Margaret: There's only two of us. No, we had a brother, but our brother committed suicide. [...] He stayed with my mother. And I used to go up and clean the house, to make sure everything was alright. [...] And then he said to me, 'see when you're finished, just put the keys through the door. Don't ever go into my bedroom', I said, 'I wouldn't dream of going into your bedroom, because I would die of shock looking under that bed of yours!' Bottles of, not gin or rum...brandy, bottles of brandy. [...]. And then my cousin phoned [...] said, that was [my brother]. '[He] committed suicide'. I said, 'how did he do that?' 'stabbed himself, and turned the knife in his stomach'. [...] I said, 'and that lassie had to go in and face that!' that was the home help, got him.

I: My god.

Margaret: A rotten, dirty thing to do to any young lassie, you know. Because they're all quite young, they home helps, you know. [...] And I thought, you dirty rathbag. I said, 'should have got hold of you and threw you out the window'. [...] [I was talking to the staff and] I said, 'to think what you went through [cleaning the house afterwards], I feel sorry for you.' He said, 'no don't do that, it's all part of what we've got to do'. I said, 'oh that was terrible'. [...] I said, 'well thank god I don't have to have that. It was bad enough with my mammy's funeral'. [My daughter] said, 'all I can remember is you greeting, "I want my mammy"' Can you imagine an old woman like me greeting for my mammy? But I broke my heart, when my mother died. Because I was up there every day, and she wouldn't go into hospital. She was in a couple of days and she came back home [...] I was up there every week, I went up, and if I couldn't clean and tidy her, and all the rest of it, oh. A shame. However, he'll get his day, and he did. He did the right thing. He did the right thing.

(Margaret, Interview Transcript)

In interrogating the way in which Margaret relays this period of her life it is possible to gain a greater insight into those aspects of her being that would otherwise remain hidden. We learn, for example, about her relationship with 'vices' and those who entertain them (via the focus on alcohol); about how she views communal responsibility (via the criticism of her brother's method of suicide and how it impacted others); about the depths of her feeling (as

an older Glaswegian woman weeping openly for her mother); and about her faith ('he'll get his day, and he did'). It is interesting to note in this case that the 'portrait' painted by the narrative is less flattering than the one presented by Flash, providing insight into a moral stance that could more easily be challenged than refusing to shoot refugees. Nevertheless, through her storytelling we learn of Margaret's complexities, her experiences, and- moreover - we learn that death is not sufficient to warrant forgiveness. Even when drawn to the threshold of her present, her brother is still not portrayed favourably, his actions still portrayed as selfish and her own role as permissive ('I should have got hold of you'). Thus, while Flash's tale brings towards the present those laudable traits of compassion and integrity, Margaret draws forth a turbulent experience and an image of herself as a caring woman of faith whose empathy is deep but not without its limits. Given the other experiences Margaret shared, including of people 'taking advantage', this story provides a valuable insight into not only how she chooses to see herself, but how she organises her social relationships and her willingness to stand by her principles. That this insight might be lost if her reminiscence is seen as off topic or out of place presents a problem for dementia practice where time may not favour seemingly tangential discussions. This tension between viewing stories as valid means of drawing together past and presents selves, a process which necessarily shapes not only the past and the present, but the temporal threshold at which they meet, and the practical considerations of time in a caring environment are discussed more broadly in Chapter Eight.

In each example discussed above, the manner in which objects or storytelling is used profoundly impacts the message. The act of retelling or sharing the history of objects draws together temporal realities, and past and present selves, providing context for the person listening, and justification for the person retelling the story. These thresholds stand between the having-been and the present, and as such can be viewed in much the same way as physical

and social aspects of dwelling. Telling stories build and maintain a place for participants as Dasein with rich lived experience of having-been. Rather than being reduced to shells, as in the narratives of decay, participants continually maintain, preserve and protect their understanding of being-in-the-world through their activities of dwelling (in this case, reminiscence and storytelling) gathering 'what endures' from the past to inform themselves in the present.

Making-Present with Dementia

While the notion of bringing the past forward to meet and inform the present is one which fits neatly within the threshold paradigm, it is worth noting that were analysis to cease at the previous section it would be incomplete. In the openings of Chapter Four I emphasised that thresholds are by their nature relational, in that they gather two phenomena together, as well as distinct, in that they are their own 'thing' while remaining reliant on the phenomena on either side. It is important to return to these core aspects, especially when considering temporal thresholds for people with dementia, because the threshold itself is dependable, in that it might "never yield either way" (Heidegger, 1971 p201). This requires further exploration when applying the framework to the experiences of people for whom the ability to situate oneself in 'the present' may be complicated in various ways by a variety of impairment effects resulting from their dementia. This becomes particularly impactful when the temporal organisation of everyday activities is considered as accessing physical spaces 'appropriately' or 'inappropriately'- indeed, suitable forms of dress, methods of greeting and other social phenomena are all contextualised through time. Wearing one's pyjamas to the local corner shop may (or may not) be overlooked early on a Sunday morning, but to do so in the middle of an afternoon on a weekday may be perceived differently, for example. Similarly, while calendars and pill bibles both provide prompts to aid in temporal orientation,

both require either some method of identifying which day is ‘today’. Hazel’s habit of scoring off the previous day on her calendar provides an example of this, as does her husband John needing to re-label her pill bible so that the first day in the ‘week’ matched the first day in which she started using that strip. While orientating oneself to the date may be seen as important, however, it would be a mistake to assume that temporal disorientation only occurred during long periods of time. The following section focuses on George’s experience using a ‘dementia-friendly’ clock in his bedroom. The clock shows the current time on a large display and provides textual guidance as to what day it is, and whether it is daytime or nighttime.

George: Because my wee clock’s nice. I liked that when we first got it because I could see the time but ...

Anne: But now you’re confused.

George: not so much I can’t see because I have to shine my torch on it because it doesn’t change ‘til...

Anne: Seven o’clock.[...]

George: In the morning it’s still Wednesday and that’s what knocks me off. [...] I thought this was Thursday and it’s only Wednesday, right enough. [...] If you’re up at half past twelve or something to go to the toilet or something it’s still the day before. [...] Then I thought, well, if the clock says it’s such and such a time, and then I thought, oh, no, it doesn’t change until, when is it? Is it seven o’clock in the morning?

Anne: Seven o’clock in the morning.

I: Oh, so you’ve got to keep track of not just what day it is but what day the clock says it is and when it...

Anne: Yes.

George: Aye. [...] [But] My watch is very accurate because it’s [presses the button on his watch] “today is Monday May 15 2017”. Oh, it’s Monday, aye. [...] It’s very clear.

(George and Anne, Interview Transcript)

George's frustrations here are a direct result of an insecure temporal threshold, and his inability to effectively place himself in time. While he could manage his anxiety during the day by using his visual planning board and his speaking watch, which he activates in the last part of the quote, neither of these tools provide the support George requires between midnight and 7am. He explains this through his example: where rising at 0:30 on Thursday leads the clock to read 0:30 on Wednesday due to the clock's display only showing a change of day at 07:00. According to the clock, therefore, 'Wednesday Day' runs between 07:00 and 18:59 on Wednesday, with 'Wednesday Night' occupying the hours between 19:00 and 06:59 on Thursday morning. During these hours the function of the clock contradicts George's habitual understanding of time- specifically where 'night' becomes 'morning', and where this early morning becomes a point at which it is reasonable to rise and begin the day, impeding his attempts to secure himself in time as a direct function of the same aspects intended to make it dementia 'friendly'. George's difficulty in placing himself successfully in time during the early morning hours resonates strongly with the expansive literature that focuses on the disturbed sleep patterns often exhibited by people living with dementia as the disease progresses, while providing a novel perspective on the phenomenon. The advantages of considering unsecured temporal thresholds in the context of sleeping patterns is therefore explored in the forthcoming discussion in Chapter Eight.

Lived Temporalities and the Speed of Elsewhere

It is interesting to note that the experience of time in the present was not limited to those moments when participants needed to pinpoint 'when' they were in relation to the time or the day. Rather, time was also experienced in an embodied way in relation to speed; their own, and that of others and their environment. As discussed in Chapter Four, the potential for people with dementia to need extra processing time during the research process was

factored into every stage of the research design. Despite this, and despite considering the disabling impact of a wider world that rewards quick movement and cognition, it is only through being alongside my participants that I became aware of the multitude of ways in which this temporal tension impacted their lived experience. The following two extracts, from Sybil and George respectively, highlight different aspects of their experience when accessing the shared social world as contrasted to their home space where they could complete tasks in their own time and at their own pace.

Sybil: "It's bad enough when I'm walking, not so fast, not so fast"

(Sybil, Interview Transcript)

I: Does that make it hard being out and about?

George: It does, very much so, yes. I can't stand the noise. It really...I don't know if that's...somebody said it was part of the condition or something.[...] I don't find the smell [bothers me] so much but I do find the colours and I do find...

Anne: It's busyness.

George: Aye, busyness. I can't stand a lot of people [...] I just don't like busyness and people because...

Anne: Claustrophobia, is it?

George: Is it claustrophobia? No, because I'm not frightened to go outside it was just...

Anne: We went into Edinburgh one evening.

George: Aye, that was at night. [...] I couldn't see. I was tripping over the pavements.

Anne: And it was because they had bright lights, the cars, the traffic, there was more people going about than during the day. We got the train in and then got a taxi up to [the venue]. At the top of [the train station] steps we were waiting for the taxi, there was such a rush of buses, cars, taxis, lights, people and there was a nearby...I think it's an Irish bar that's on [the main street] just for the summer, they were playing their music so it was an assault to the senses. [...]

George: I couldn't cope with that.

Anne: He got dizzy, physically, he physically just...

I: Just went straight off...?[...]

George: Felt like it as well.

Anne: We had to sit down somewhere quiet and we have to do that a lot.

(George and Anne, Interview Transcript)

In the extract above, both George and Sybil reflected on their difficulty adapting to the speed that they felt was expected in Elsewhere spaces. For Sybil, this was predominantly something she felt physically as she strove to maintain her balance with her walking sticks, making the experience of being ‘rushed’ not only irritating for her, but potentially threatening. This sense of threat is amplified for George, who lives with dementia, visual and hearing impairments, poor balance and restricted use of one arm. This interaction between impairment and environment results in disability, manifesting physically in restriction, and emotionally in distress and fear. This experience, of the unwelcoming, quick moving Elsewhere, reoccurred throughout the data and with most of the participants. Whether it was the need to take extra time to accomplish tasks like shopping, difficulty moving quickly through space, or the sensory overload associated with the bustle, light and noise of busy places, it was the speed of Elsewhere which most notably contributed to the participants’ disablement. In many cases, participants overcame this by using tools and practices; George, for example, no longer handled coinage but was given a number of £10 notes when leaving home so that he did not have to risk being slow while counting change in public. This practice was particularly interesting as it highlighted the potential risk associated in being rushed in financial situations, which is discussed further in Chapter Eight.

Another interesting factor to note is despite increasingly common use of technological and digital means to streamline public spaces, most participants did not express a feeling of the

world ‘speeding up’, but rather of them slowing down. This tendency crept through in many of the discussions where the participants and I went walking, where they would often apologise for being slow, justifying their need through reference to their physical impairments rather than expecting acceptance for the speed of their movements. In fact, it is important to note that Stan, Mark, Hazel and Isabel all initially ignored my reassurance that we would walk at their preferred speed and needed to be asked multiple times if they wanted to slow down before admitting their need. This is most aptly viewed through Thomas’ (2007) conceptualisation of psycho-emotional disablism, where this need for extra time is tacitly rejected and considered ‘lesser’ than the speed at which the Elsewhere functions - leading to participants resisting using a pace they were comfortable at until they felt the ill effects of mimicking the speed of Elsewhere. George, however, experienced the meeting of temporal paces differently:

I: Does you being late stress you out then?

George: Yes. [...] I like to be ready.

Anne: We’re everywhere early but I’m a bit like that too. I would rather be there half an hour early and sit...and just sit in the car or wait or read a book just so I know that I’m there.

George: Sometimes I don’t understand why we’re going so early but I’ve said that to you before.

Anne: You’ve not got much sense of a time now though, have you?

George: How do you mean?

Anne: You don’t seem to realise how slow you are at walking and getting somewhere.

George: Oh, right.

Anne: You know, for example, our doctors’ surgery is just down the road. It only just takes five minutes but that’s if you can get a parking space and leap out of the car and run in. [...] But George takes ages to get in and out of the car and to get going with walking but he doesn’t see that because that’s normal to him.

George: Aye.

I: Right, so are you still trying to run on the old...like the old...?

Anne: George is but I know I should make allowances for that so we leave half an hour early for the doctor now. It is just five minutes down the road but it's surprising by the time you get parked, well, get him in the car, down the road and then out of the car and sorted and then get into the surgery that takes a good 15, 20 minutes. So we end up only maybe five or ten minutes early which is fine but he can't understand it. [...] He says, it's just five minutes down the road but it's...he doesn't realise it takes him a good while to get him in the car.

George: The other thing that really...just when you're saying that if I've got a time for the doctors or whatever and they don't come at that particular time because I look up, what time is it? That really irritates me.

I: God, you must spend your whole life irritated. They're never on time.

Anne: He is.

George: Aye, I do.

(George and Anne, Interview Transcript)

Rather than a hyperawareness of his own slow movement, George's difficulty adapting to the temporalities of Elsewhere came from a lack of recognition of his own embodied experience in the context of the environment. As such, George framed himself as moving at the same speed as he had when he was younger (thus, did not understand the need to alter their schedule and leave earlier), while experiencing the world as faster but more inefficient as he encountered delays. This tension, between George's lived temporality, and the time shared by others, provides an apt example of a troublesome threshold, and the difficulties that could occur when thresholds were not necessarily tethered to concrete spaces. It is noteworthy, too, that George was not only frustrated by his attempts to navigate the temporalities of Elsewhere, but by the way in which the temporalities of others intersected his own in his home space, particularly if they were delayed or late in arriving for which he

had “no patience at all now”. Nor was this perspective representative of his overall orientation towards time, but his experience of movement across physical thresholds and through space as it occurred through time. His experience with attempting to think quickly or respond quickly to questions was quite different:

Anne: You were saying you find it harder to think quickly of what to do as well.

George: Oh aye, yes, aye, decisions. [...] Or for you explaining sort of, you know. [...] sometimes in the kitchen as well you'll say to me, that's something or... [...] If you're trying to tell me something or explain something to me I don't understand what it is. [...] It takes longer. [...] I can't remember but there have been occasions where I haven't a clue what you're talking about. [...] Sometimes I'll say to you I don't understand. [...]

I: Do you know you're not getting it? Are you aware that you've not quite got it yet or do you think you've got it and then it's not quite...?

George: No, I'm aware of...I don't know what that means or I don't understand why you're doing that certain thing or why that...I don't understand what it is or why it is or something like that, I think. [...] I have to have everything where it is or it'll get lost. [...] I sometimes do that or I get lost. [...] I find the slightest bit of things are more frustrating now or irritating now. I don't think I've ever had that before. I don't think so.

Anne: Just life's harder, isn't it?

George: Aye, it is harder.

(George and Anne, Interview Transcript)

This highlights the difficulties associated with presuming how an individual might experience thresholds, temporal or otherwise. In this case, while George's perception of his physical movement could be contrasted with those of others, like Sybil, there was commonality when the question was moved from physical movement to cognition. This complexity contributes to the tendency for trusted people in the 'inner circle' to become innovators and maintainers of facilitative tools. as discussed in Chapter Five, and raises questions for how it might be

achieved in settings where time is a more restricted resource, further discussed in Chapter Eight, as someone's impatience with others being slow or late in one situation may not necessarily extend a perception of themselves that acts quickly in all situations and at all times.

Managing Changes and the Import of Time

One of the other challenges that participants often faced when navigating thresholds was the unpredictability of their impairment effects. As such, temporal threshold often became particularly visible where it intertwined with physical thresholds, for example where being spatially removed from the home space during an episode of confusion made it more difficult to return to the home space. Nigel reflected:

Nigel: I knew [the thought] would come back, it's a bit...it was the thing about dogs. People with dogs. What can happen to people [who are afraid of] dogs is they don't go out because 'there might be a dog, oh, there might be a dog out there', it's a bit like that, 'oh, I might get lost', which is a bit debilitating actually. [...] but I've learnt strategies around it, I mean, I'm not stupid, I'm still not stupid.

[...]

Nigel: It is fairly debilitating actually, I don't know how you'd deal with that.

I: How do you deal with it?

Nigel: Well, I said I'm not stupid, no, I'm not stupid, my faculties are failing me slightly unfortunately, so I tend to do a fairly analytical approach and say, right, I know what the way points are and so on and I know if I do that, then I have to go right and then left, and so on, but that failed me yesterday.

(Nigel, Interview Transcript)

The importance of time here is clear. Firstly, Nigel charts his strategies and his abilities in time - shown particularly in his repetition of not being 'stupid'. This tendency to draw on his

past status, and his intellectual achievements offset any suggestion that dementia might have in any way compromised his abilities. Secondly, the acknowledgement that becoming lost is a risk, being afraid of being lost, and developing strategies to avoid it are all played out in time as well as place. Finally, the unpredictability of his impairment resulted in his strategies working sometimes, but not others. As such, Nigel's "analytical approach" had to account not only for those days where his impairments were more disruptive, but for the sudden intrusion of impairment into a day that was otherwise going well. In another conversation, Nigel and I discussed his experiences of wayfinding after he became disorientated on a familiar route.

Nigel: I find that increasingly I won't necessarily go for the shortest route because I will say, no, I'll go this way because I know this way. [...] I've got to look after myself and that's actually quite important so as I say to [my wife], I said, I always say to her, you've got to look after yourself because if you don't, no other bugger's going to look after you. [...]

I: Is it one of the things where, you know, if you feel that today's going to be a bad memory day you'll play it safe, kind of thing, whereas other days you'll maybe try for a different route or...?

Nigel: But memory is not necessarily the same [...] I can be disorientated but remember the name of something and I can remember the name of something without being disorientated. So it's quite a complex calculus, actually.

I: [...]do you get a feeling if today's going to be like a disorientating day?

Nigel: Yes. [...] fortunately I had an extremely good memory to start with. [...] I've got a long list of techniques for remembering things and so on so there are lots of...I might want to say something and I can't remember what it is but I can remember what a synonym is. [...] And I'm very lucky, without boasting at all, I was actually quite bright.

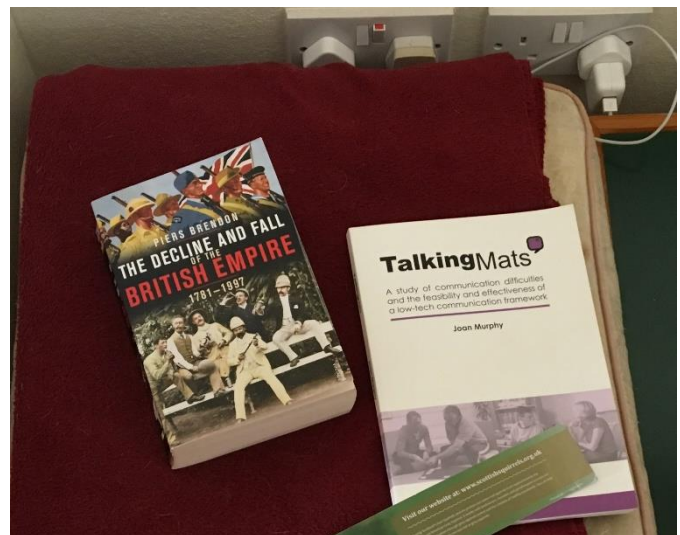
I: What? [...] You keep that light covered.

Nigel: Yes, I know it comes as a surprise. [...] But I'm very lucky because I've met so many people who have Alzheimer's who are not bright and that must be a terrible

load on them because they feel the...what's the word I'm looking for? [...] The weight of it.

(Nigel, Interview Transcript)

There are a number of interesting aspects that present themselves in the quote above, particularly when taken in the context of the previous quote, the clearest of which is the introduction of specific rather than generalised strategies to counterbalance his impairments. While Nigel overtly describes one example of this in finding synonyms for words, the very process of strategising and managing his impairment is arguably a strategy in and of itself. By using the ‘complex calculus’ necessary to ensure he is ‘looking after himself’, Nigel secures his own self concept and draws a strong boundary between himself and an unknown future where his impairments become more challenging. In this way Nigel is able to draw together the intelligence and capability he associates with his younger, pre-dementia self, with his present self and assert that while his diagnosis has challenged specific areas of his cognition, he is still ‘clever’. As a result, the experience of living with dementia no longer represents a threat to his innate intelligence, but rather relies upon it, as he navigates with, and around, his impairments. This dialogue two contrasting aspects of Nigel’s identity is captured visually in Picture 16, where the book Nigel was currently reading for pleasure sits alongside the published material for the ‘Talking Mats’



Picture 16: Nigel’s Reading Material

intervention, with the charging cable for his much-used iPad plugged in at the top of the image.

Yet, even in emphasising his ability to circumvent some of the impairment effects he experienced, Nigel's quote provides context to George's earlier assertion that everyday activities were "harder" than they were previously. The rejection of stupidity, therefore, speaks more strongly to the presence of internalised ablism and psychoemotional disablism than it does an incompatibility of experience. While Nigel's efforts might appear to be almost a conscious construction of a threshold between himself as someone who is 'not stupid' and who can strategize, and those who might feel a 'terrible weight', that was certainly not his intention. As discussed previously, a threshold space draws together which is on either side, becoming a discrete thing even as it shapes the phenomena on either side by drawing them together. What Nigel attempts in the quote above is the opposite: a strict deliniation between an experience he rejects (parsed as stupidity) and his own self-image. That his strategies were not always successful, however, speaks to what thresholds are, rather than what he might wish them to be. Put most simply, what Nigel desires is a wall - an impermiable boundary between his experience and that of those he wishes to set himself apart from. What he has, arguably, is a threshold that must be diligently guarded and patrolled lest he cross accidentally. The following quote from George provides some insight into what it feels like to be unable to secure that threshold, and to experience the shift of how one is in-the-world as demetnia progresses:

*George: These things are all...I'm beginning to realise that these things are happening. [...]
I think I feel things are sort of escalating and I sort of feel that some things are coming on too fast. I on't know where I'm going to end. You see some on the*

television they're really, really bad so I wonder how long I've got before I get to that stage.

I: Oh, aye, yes, the television ones.

George: Sometimes I feel like that. I know things are happening and I know things that I do feel are escalating a bit but I think, I can't help it. I don't know what to do about it.

Anne: We can't do anything either.

George: So these things become...

Anne: Remember [the dementia nurse] said to you though that... [...] you were looking at the end stage and we've not to do that, just to...

George: Not to do that. Oh, right, I forgot that.

Anne: ...move with whatever we're with. [...]

George: I know things within myself that they're not...things have sort of taken a momentum. I don't think I had them years ago.

Anne: Like what, George?

George: Well, getting anxious and forgetting. Well, I know I forget things anyway but if I'm not sure...I seem to be not sure about a lot of things that doesn't seem to... [...] I can't make a decision. [...] I find that not easy because you ask me what I want for tea and I just can't make up my mind what I really want. I don't know what I really want. That can be a bit frustrating as well. It must be frustrating for you. [...] There's a lot of things I'd like, like a ham and egg sandwich or something. [...] I can't help. [...] A lot of these little things I find they're more evident.

(George and Anne, Interview Transcript)

The lived experience of temporality once more takes a central role in how the experience of impairment, and progressive impairment, is both understood by the person and retold to others. For George, the movement is not of himself towards the threshold, but of the threshold rushing towards him at an increasing pace. That his explicit consideration of the future is derailed, in the first instance by the dementia nurse and in the conversation itself by

Anne, resulting in George piecing together his understanding of what might-be from televised depictions of dementia raises profound questions about how, and when, the conversation of death as the End towards which Dasein is always orientated should be facilitated rather than silenced. This, arguably, is one of the most detrimental effects of engaging with the narratives of decay (even where such engagement is to argue against their language) rather than reinforcing the foundations of dementia theory such that the entire premise is rejected outright. It is only through permitting the ongoing consideration that one might, as George said elsewhere become “almost like a vegetable”, that it becomes a possibility, whereas an outright rejection of the potential for a person to be magically transformed into plant life would necessitate a more candid discussion of what such constructions *mean*. Such conversations, in turn, can be facilitated such that the fear and spectre of dementia as a self-dissolving, slow death can be addressed directly for “If we are to kill the demon, first we must say its name.” (Pratchett, 2008). The mistake is to assume that the only demon worth slaying is the disease itself.

Avoiding the ‘Silly Side’: Looking Towards the Future with Dementia

Hazel: It feels...I don't really think it [dementia] feels anything, to be quite honest with you. It's just when I noticed I was starting to forget things, and I thought, 'oh my god, here we go,' that's the sort of thing I said to myself, and you're thinking about it, there's nothing I can do about it. Alright, you can get some sort of medication of some sort, but it really doesn't work, because there's for some other people it doesn't work, and I think to myself, 'I just have to continue the way I'm going, and hopefully stay compos mentis'. That's the biggest part about it, it's the staying compos mentis and not starting being silly, and I don't mean silly in the way it sounds, but I know that an awful lot of people when they get dementia, they have that silly thing, and they talk silly, some people do, not everybody, and I think to myself, 'I hope I'm in the crowd that doesn't get on the silly side', and I know what I mean by that, and I don't mean it to sound horrible to people. So I'm just keeping my fingers crossed

at the moment and hope that John gets through it more than me, not so much for myself, but for him. He thinks he knows, but he hasn't got a real clue of what actually goes on. You could end up one night just screaming for the sake of screaming, no reason, no rhyme or anything, you just scream, and I've heard it, and I thought, don't let me do that in front of John, because...

I: *Is that the kind of silliness that you're meaning, that kind of just doing things without a...?*

Hazel: *Without any reason, really, you get to the stage where you want to do...and you scream, I've seen people do that, and I keep trying to tell him that 'if that happens, please don't shout at me, there's nothing I can do'. 'Oh aye, right aye', that's his answers, but I think he knows, so I'm trying to tell him that if that does happen, please don't shout at me.*

(Hazel, Interview Transcript)

Throughout my visits with participants, whenever the conversation turned towards a consideration of their future as older people with a progressive degenerative disease, there was an expression of fear, resistance, or discomfort. Specifically, participants highlighted their concerns about what the future looked like for them once their dementia had progressed. Such a future was, almost always, constructed as 'away', somewhere that had yet to be reached and that should be avoided for as long as possible. Most importantly, however, it was also usually considered as a future inhabited by an unknown and unknowable version of themselves. Throughout Hazel's conversations with me, she often contrasted her own experiences of coping, of enjoying her life and managing her challenges, with the 'bad dementia'. This 'bad dementia' was characterised not by experiences she could share and understand through her experiences as a carer, or as a woman with dementia who attended dementia orientated groups, but by an innate otherness where she perceived the impairment effects to be so profound as to make the experience of living in such a way unfathomable. The bad dementia is an experience that exclusively belongs to others, known only from the

outside. In the extract above, Hazel explicitly considers the ways in which she avoids this: by continuing as she is, by ignoring urges to behave in a way that is ‘silly’, without rhyme or reason, while at the same time acknowledging that there is “nothing [she] can do about it”, and by seeking to explain the motivations of her unknown future self ahead of time as she attempts to warn her husband of her potential to scream, and relates how he would like him to respond.

For George, however, the fear he felt when viewing his unknown future self across the temporal threshold was based not in his potential victimhood, but his potential to make a victim of his wife. Future-George, he worried, would not become ‘a vegetable’, or even (as Hazel feared) someone who screamed without reason, but an unpredictable violent force.

George: I have accepted it [dementia] now. I had a great fear of...you see some people with dementia that, well, especially the chap next door as well, I've always had a fear of getting too volatile, is it?

I: Aye, the emotional.

George: Rough. Aye. Or hitting somebody...

Anne: You mean violent.

George: Violent, aye. But I think I've got passed that now. I don't worry about it so much. It's still maybe in the back of my mind but I don't dwell on it. [...]

Anne: He really was worried for a while. I had to just keep saying well, if that happens I'll get extra help, help from somebody.

George: You see people on television that their dementia is way further on than mine. We have a person at church, his wife is almost like a vegetable, isn't she?

Anne: But she's had a lot of problems for a lot of years that way.

George: Yeah. So that sort of... You look at them and think oh, are we going to come to that? But I'm not too bad just now, I think I've got over that. But there are things that I find strange. Bright sunlight. Bright lights bother me as well. I know that's getting away from the subject sort of thing. But memory wise, sometimes you'll say

oh, you've said that before. I've no recollection of anything. Or films or names or television, articles, they've all gone. And money wise I can't...if it's pound coins I can maybe count out one, two, three or whatever. But trying to count something up, I forget what the first number is. [...] I've forgotten it. So I don't know where I am. [...] Things like that I find hopeless now really.

(George and Anne, Interview Transcript)

Through George's description of his fears, it is possible to better understand the 'bad dementia' as a spectre (or, as Pratchett (2008) suggested, a demon), an entity unto itself, that might at once be less than human ("like a vegetable"), while also becoming an unknown and dangerous force that represented a threat to those the person with dementia holds dear. Two further factors are worth noting here. First, is the continuing presence of fear about the 'bad dementia' despite reassurance, and second is the influential role of the media in reinforcing this understanding of what it means to live with dementia. In the latter half of the quote, George reflects on the profound and enduring ways his experience of being-in-the-world has transformed through his dementia diagnosis, highlighting processes that affect both the way he interacts with the outer world (through perceiving colours and light), and how he experiences his internal life (memory, numeracy and cognitive impairment). Secondly, despite his lived experience of his impairment and the associated impairment effects and their progression over time, George did not see himself as anyone other than himself: knowable and known despite the progression of his disease. The fact George expresses his experiences of loss of ability as hopeless is also key to understanding the spectre of 'bad dementia'. It was not an experience that could be recovered from, even with medication (as Hazel notes above), or extra help (which Anne uses to reassure George of her future safety), but something that is deeply rooted in social and cultural contexts, manifested for George and Hazel in their fears of becoming either violent, or irrational respectively. As such, the 'bad dementia', the dementia that must be held at bay at all costs, arguably requires a fundamental

and permanent alteration of self – a transformation that necessitates the same mind-body duality and desecration of self that Dasein subverts. This is not to suggest that aggression, violence or screaming does not occur in the later stages of dementia. Instead, it is a question: how would these conversations, these constructions, change if the changes in behaviour were widely acknowledged as the result of impairment, rather than personal fault or the transformation of the self into a shell (and thus passive), or a zombie (and thus monstrous)? What insights could be gained if these actions could be viewed in the context of thresholds, as efforts to reinforce existing thresholds, repudiate ‘intruders’, or manage their own crossings? These questions are at the heart of Chapter Eight, as it explores the value of a threshold perspective more broadly in the context of disablement and the narratives of decay.

For others, like Nigel, the pressing concerns were not necessarily focused on the unknown future self, but rather a continued maintenance of themselves in the present. In the extract below, he reframes his health as primarily physical in the present, with dementia representing a chronic but future problem.

I: Do you find that people underestimate you if they find out you've got dementia?

Nigel: Ah, yes, it's an interesting question, I don't know the answer to that, but I think that's probably because I haven't really come across that to any extent, but I'll look out for it actually, because I think it could happen very easily. [...] And that's because I think people don't understand dementia. They don't understand that it's a degenerative disease and that if you say you're in your 60s and you've got dementia, there's still a long time for me to run before I die. [...] And apart from having a bad leg, which is just a mechanical thing, all my metabolism is great, my teeth are good, my blood pressure is outstanding, I generally eat well.

I: Yeah, so you're given a full check of health, you've passed the MOT.

Nigel: Yeah, oh yes, I passed the MOT and, in fact, I think [...] my GP, [...] I remember him saying at one stage, oh well, you'll never get a heart attack,

because...you know blood pressures? [...] Mine's about 110 on 30, something like that.

(Nigel, Interview Transcript)

Through suggesting that the tendency to focus on dementia, rather than other health conditions that may cause serious health complications in the short term, is a mistake, Nigel successfully reclaims his status as a healthy man in his sixties. As such, he regularly engaged in groups and walked regularly and extensively both alone and with others. For Nigel, this intersection of physical health and invisible disability introduced a different issue, as he rarely saw himself being represented by the images used to promote dementia-friendly activities or dementia specific support. For Nigel the experience of being-alongside others with dementia, therefore, was often one of separation as he found himself separated by his age, his physical ability, and what he understood as his intellectual resilience. This actively introduced hindrances at the thresholds to dementia-friendly spaces, as in addition to being geared towards feeling the 'terrible weight' of dementia (due to not having his intellectual capacity), he also saw them as populated by people decades his senior, making him feel ill at ease. This experience had led Nigel to seek out opportunities for activism, but simultaneously contributed to a narrative of himself as something set apart from others. This has profound implications for the provision of group support and intervention, and highlights some of the potential issues around the branding of 'dementia friendliness' as it becomes associated with particular images and age demographics. It is also notable that Nigel himself displayed such internalised ableism. This intersection of how society constructs dementia, how dementia friendly spaces are organised and marketed and how people with dementia see themselves raises significant questions moving forwards. It is clear from the quotes above that Nigel's experience of aging and his concerns about his health are different from those communicated by others, something that in part resulted from his early diagnosis. Any tendency to consider

people with dementia as a homogenised group, with a unified set of concerns or understandings would likely fail to account for Nigel's own beliefs as a man decades younger than many of the other participants who attended dementia friendly groups. What this means for the practical provision of support, and for the creation of dementia friendly spaces in the wider context of earlier diagnosis while people are living longer is discussed in Chapter Eight.

'I don't know where I'm going to end'

One of the most striking themes to emerge during analysis was the ways in which participants discussed their feelings towards, thoughts about, and experiences of death, particularly as people living with dementia. It is worth noting specifically here that at no point did I deliberately prompt such reflections. Instead, I found that through being a person present, alongside who was listening in a focused way, I was often made privy to stories that ran the length of the life course; from the birth of children and grandchildren, to the death of parents, loved ones, and siblings. While each of these stories was profoundly meaningful to the participants, there was on occasion a thread that bound together these reflections of mortality, between participants and across time. In these discussions, participants were often alongside death as older people, but also as people living with a degenerative disease that profoundly affected both their experiences of the deaths of others and their expectations of what the remainder of their life might look like. Mark relates some of the complexities in the quote below:

Mark: I've no other family now. My brother died a couple of months ago. He was 91. [...] I was unable to go to his funeral unfortunately. [...] I couldn't go [...] it's too much to go there and I didn't want to go to a funeral. [...] I haven't been to a funeral since my wife died. [...] I told [him] that I won't be going to his funeral because I hadn't been to one and he said 'ah that's alright, I'll not miss you' [...] I got the minister at – in his funeral, to read that God's garden [...] So he was

looked after very well. [...] We would phone each other at least once week. [...] just to say what have you got this week. [...] He'd say 'is there ont wrong with 'ee?'

(Mark, Interview Transcript)

In this extract it is possible to see how Mark's experience of aging is intimately tied to his experience of others aging and dying. Importantly, through the death of his brother, he becomes the 'last' of his generation in his family group, surviving both his brother and his wife. As the survivor, he navigates certain obligations - to attend the funeral, to make sure his brother is 'looked after' in death, and to continue - all of which are complicated by his experiences of living with dementia and comorbid conditions as well as by his experiences of having-been a survivor in the past. Seen from this perspective, Mark's reasoning for avoiding the funeral is twofold: the first is the difficulty presented by navigating the physical

God's Garden

God looked around his garden
And found an empty place
He looked down upon the earth
And saw his tired face.

He put his arms around him
And lifted him to rest
God's garden must be beautiful
He only takes the best.

He knew that he was suffering
He knew he was in pain
He knew that he would never
Be well on earth again

God saw the road was getting rough
And the hills were hard to climb
So He closed his weary eyelids
And whispered " Peace be thine ".

It broke our hearts to lose him
But he didn't go alone
For part of us went with him
The day God called him home.

Picture 17: Mark's Annotated God's Garden'

thresholds which separate him from his brother who lived hundreds of miles away, the second in his refusal to attend funerals after his wife's. Interestingly, however, he nevertheless negotiates ways in which he could meet these social obligations. In the first instance, despite not being physically present at the funeral, he found, copied, and edited the wording on the poem 'God's Garden'. (Picture 17) shows a copy of Mark's edited version, with the original text changed to read 'his' so as to refer specifically to his brother. The task of choosing readings allowed Mark to meaningfully contribute to making sure his brother was 'looked

after' while acknowledging his own grief in a way that was not impeded by his inability to attend the funeral himself. His decision not to physically attend the funeral is itself mediated through the way in which he relates his relationship with his brother; through both cultivating and maintaining a relationship where they could speak frankly about both their on-going experiences of aging and health ('is there owt wrong with 'ee?) and what would happen after his brother's death. These conversations, in turn, ensured Mark was able to secure his physical thresholds in the aftermath of his brothers' death: he could not attend the funeral, but even if the necessary affordances were put in place, he would not, a choice his brother supports in 'I'll not miss you'. This is in itself an enabling practice, supporting Mark's choice while protecting him from the social repercussions of his non-attendance allowing him to grieve in place.

Even where the death of someone close did not necessitate a shift in self-concept (in Mark's case from one of a pair of siblings to a sole survivor), it was still impactful. In the following quote George and Anne discuss the death of a cousin who, like George, had dementia:

George: I know my cousin died very quickly, he had dementia, but he was a very heavy drinker and a smoker, and a lot of them said that that was the cause of...

Anne: They said it was that type of dementia, alcohol related. [...]

George: But he died very suddenly, but I mean, I knew him...well, him and I were very close, like a father, but to see him like that was quite upsetting, to start with. [...] He didn't know who I was or...he didn't know who his wife was, actually, didn't know anybody, but he really was a sad soul to see, and I think, well, I had a bit of dementia then, but not like that, and I know myself it is graduating to the worse side, it's impossible to go back the way, but I don't want to go forward, but...and I know [he] died of...they say he died with dementia, but then explained sort of why he'd died, because he was such a heavy smoker and drinker, that didn't...he

was a heavy gambler, smoker... [...] There was a lot of side...like he was never ill to that extent.

Anne: And he still functioned at work, he had a good job.

George: Oh aye, he was head something in the bank. And then all of a sudden he deteriorated.

(George and Anne, Interview Transcript)

In reflecting on this quote, a number of factors become evident. First is George's use of language to separate his dementia from that of his cousin who was a 'drinker, and a smoker', later adding gambling to the list of behaviours that are being constructive as 'risky' and, importantly, unlike George himself. With this in mind, it is possible to outline part of George's unease, specifically the 'decline' he had witnessed that changed their relationship from one with paternal tones, to one between a 'sad soul' and a man diagnosed with dementia feeling anxiety as he faces towards the oncoming future. It is vital to note the role of internalised ableism here, as the 'decline' is parsed not in terms of his ability, but in what he *was*. It is this future that George expresses fear over sharing, acknowledging that while he cannot 'go back' he nevertheless does not want to 'go forward'. This reluctance is characteristic of the fundamental experience of being-towards-death, both as something inescapable and as something not to be outstripped (as discussed in Chapter Three). In this case, however, it is not the experience of dying that George fears specifically, but the 'decline' that manifested itself in his cousin's ability to recognise others. This is, arguably, the spectre that he had been dissuaded from discussing by the dementia worker - as related in the previous section- drawn into focus again, though this time through viewing the last months of his cousin's life. By separating out his cousin's negative traits, he can reinforce the same threshold in his own experience, accepting death as an inescapable fact, while holding back the idea of becoming a 'sad soul'.

Telling a Different Story

With such examples of grim fore-tellings and expectations of the future, it would be too easy to in these last throes replace the narrative of decay with one of grief and fear. This would, however, not be wholly accurate. Throughout my fieldwork, I was blessed by the openness and candour with which I was met by participants. Through our conversations, I gained a privileged insight to over five hundred years of lived experience; with Flash being my oldest participant at 90 and Nigel my youngest at 69. Their histories spanned continents, while in the present they all made time for our visits together and shared the messiness and the mundanity of their experiences of being-in-the-world, each unique, yet tied together in their journey in-the-world-with-dementia. This chapter ends, therefore, with a glimpse into how participants not only expressed their own understanding of being-towards-the-end as older people with a degenerative illness, but how they did so with humour, irreverence, and objects to mark the final threshold.

While objects marking forward-facing temporal thresholds were less commonly shared during fieldwork, they were present nevertheless. In many cases, these were objects of utility: powers of attorney, wills and testament and so on. For some participants, like Mark, it was an encompassing approach, where important paperwork was filed into separate, lockable hard plastic filing boxes to be easily found in the future. These not only aided him in navigating the on-going processes involved in maintaining his processes of dwelling and living independently, but in ensuring that his estate could be easily managed after his death. For other participants, however, the meaning of those objects at the future threshold towards-the-end were abstracted from their use. The following segment is drawn from my last visit with Nigel that was recorded as we made tea and coffee before sitting down in the

living room. Amidst discussing how it was ‘just not done’, to make tea without offering to do so for everyone in the house, the following exchange occurred:

I: Now, you have an array of cups. [Gesturing at several shelves of mugs]

Nigel: I do.

I: You can either have them with saucer or without saucer.

Nigel: I'm pretty good without saucer, I would like to pretend to be sophisticated enough to require a saucer, but I would suggest not. [...] Somewhere there should be a dishcloth. [...] It'll be in here somewhere. [...] This is indicative of me living in the elephant's graveyard, i.e. I'm going to die here, in other words I'm going to go on living here, until I die. Even though I hope to go back [abroad], but not to live. [...] I hope to go back [abroad], just to visit, like we did a couple of months ago.

(Nigel, Interview Transcript)

That the a regularly used dishcloth (tea-towel) could stand as a memento mori for the innate temporality of Dasein already presents a stark juxtaposition between the traditionally grim and morbid conversations of death and the everydayness of cleaning and drying dishes. That the object resided in the kitchen of a home that had had to adjust to a vision of the future that might be “very difficult [...] and so on and so on.” following Nigel’s dementia diagnosis might have aligned itself with a grim mood. Instead, as I turned from the counter where I had just poured tea, to face Nigel who had found the dishcloth after a short search, I was presented with something quite different.



Picture 18: Nigel Shows Off His Elephant's Graveyard Memento Mori

When compared with the grey filing boxes in Mark's flat, Nigel's tea towel creates humour in its irreverence. Indeed, its nonthreatening style lends itself to its purpose. Indeed, the design of the object was fundamental to its role. The paperwork boxes were business-like; they primarily occupied a space for business; where the practical matters of either maintaining or closing down the estate were at hand. The tea towel, by contrast, served a different purpose, and stood firmly on 'this' side of the threshold. It was a reminder not to take himself too seriously, and to find humour where he could. This is the nuance that many of the works that perpetuate the narratives of decay fail to encapsulate; a facing-forwards-with-dementia that is as multifaceted and difficult to categorise as life before dementia. Understanding people with dementia as innately future focused, despite their impairments is fundamental to

supporting them to live well, especially given the cultural understanding of dementia as a disease contracted towards the 'end of life'. Temporal thresholds by their nature have potential to draw together periods of great sadness with those of great joy. Similarly, for Isobel, this occurred often when she spoke about seeing her favourite granddaughter - and by extension called to mind her adult daughter who she had lost to cancer. For Mark, conversations about his relationships with his neighbours and friends often invited reflection on his relationship with his estranged daughter. Flash's recall of living in a small home as one of eleven children in a household of three adults, eating meals in shifts due to the size of the table brought into sharp relief his small bedsit where he lived alone. Yet, they were stories shared, freely, by those who were older, to one who was younger and eager to learn. Often, I learned about thresholds. Sometimes, I learned about the need to stand alongside Dasein-with-dementia and laugh. At the close of this final findings chapter, the following quote from Hazel captures these layered interactions between past, present, and future; sobriety and irreverence:

Hazel: [We had a] Wee Westie, but he loved it, and I keep saying to John, 'we'll get another [dog]', he says, 'no, we'll not be getting another [dog]'. Now, he was really distraught when she had to be put down, poor wee thing. [...] He didn't think that I was upset. He was really upset. He didn't want to show it though.

I: A man thing though, eh?

Hazel: Oh definitely, definitely. Quite funny actually...it wasn't quite funny, it was quite sad watching him, I've never seen him like that before, ever, and I haven't seen him like that since. It's unbelievable. He never spoke. The day that she went, he never spoke for a couple of days, it really was bad, but...and I keep saying, 'we'll get another dog'. No, no'. And I says, 'but you can't just go by one dog, you can have

another try'. 'No, I'm not going through that again'. What's he going to do when I die?

I: He'll not re-marry, apparently.

Hazel: Oh, I don't know. [... Hazel uses her inhaler] That's a laugh.

Summary

The work of this chapter has been to argue for an application of the threshold framework beyond the spatiality of physical thresholds and interpersonal aspects of social thresholds, and into the dimension of time. The chapter began by showing the ways in which participants used objects and stories to draw together aspects of their past with their present. Through viewing storytelling as more than a method of perpetuating conversation, a thresholds perspective allows insight into how recalling and retelling stories in certain ways can not only draw past events 'closer' over a temporal threshold, but can also uncover different facets of their personality and experience for others. Thus, by drawing on and sharing memories of bravery, people with dementia can again be seen as brave - even where their current environment does not demand it of them. The focus then moves forward to consider the ways in which people with dementia managed their impairments in the present over temporal thresholds; where instances of disorientation or confusion could not be reliably predicted. The presence of tension around these influential temporal thresholds demonstrates not only the value of a threshold perspective, but its ability to elucidate the relationship and interaction between personal and societal factors. Finally, the chapter considered how participants situate themselves relationally with others in the context of their current lived experience, and with others in the future - including after their death. That participants often experienced challenges around temporal thresholds both, in regard to navigating them and in resisting their own passage into an unwanted future with the 'bad dementia' highlights the contradictions and multiplicities that are part of being in the world. The experiential

complexity is often denied to people with dementia is seeded with tension, as dementia's status as a life limiting, disease (and is thus inherently future focused) alongside a resistance to future thinking. By closing down such conversations and denying people with dementia the opportunity to express themselves as innately being-towards-the-future, normative understandings of dementia perpetuates the belief that the only future for people with dementia is a frightening one, lived as an unknown and unknowing person in the grips of the 'bad dementia'. Such constructions demonstrate the discursive power of the narratives of decay, whilst additionally provide a keen insight into the harmful impact that such limited and ablest outlooks can have on the day-to-day lived experiences of people with dementia, as they influence not only how they perceive themselves in the present, but who and how they can hope to be in the future.

5: Managing Thresholds in Physical Space: The Art of Dwelling with Dementia.

8: SYNTHESIS AND DISCUSSION

Introduction

What is to be gained by adopting a threshold perspective? The data presented in the last three chapters has demonstrated that it is possible to identify, observe, and analyse activity within and around physical, social, and temporal thresholds. Yet, without consideration of how such a concept relates to the wider dementia and disability literatures, the task is not yet complete.

The following chapter is dedicated to providing a critical overview of the themes presented in Chapters Five, Six, and Seven and placing these findings in the context of the wider literature as it relates to dementia and disability. As such, the main body of the chapter is made of three main sections. The first section reflects upon the themes drawn out in Chapter Five. It highlights the significance of physical thresholds and the power wielded by people with dementia as dwellers at the threshold. This is carried forward into a discussion of how people with dementia manage physical thresholds, how they facilitate or impede access, and how they engage with thresholds which are in some manner 'troublesome' and the impact of such practices on care and support. The second section draws from Chapter Six and focuses on how a person with dementia manages their relationships in the context of being-with dementia and how social reactions may disable or enable them. Finally, the third section discusses the importance of viewing the person with dementia as undiminished Dasein, deeply situated in the context of their temporal experience. This section explores the concept of temporality as an influential factor in a person's experience of space, relationships, and self. As such, it challenges works which seek to present people with dementia as focused primarily on the past rather than their coming future and considers the implications of this

perspective as counter to the narratives of decay. The chapter then closes with a discussion of the study's limitations and potential directions of future research.

Dwelling at the Physical Threshold

Summary of Findings

The concept of physical thresholds provides valuable avenues for exploring the experiences of people with dementia both as disabled people with a progressive disease and as dwellers who are constantly engaged in the processes of dwelling-as-building (*bauen*) and dwelling-as-preserving (*wohnen*). This section draws on the lived experience of participants to evidence the significance of physical thresholds in their day to day life and the value that can be drawn from building the threshold concept atop a foundation of Heideggerian philosophy, particularly the notions of Dasein and dwelling. The result is a work that positions people with dementia as Dasein and thus as active and enduring dwellers (Heidegger, 1971) irrespective of their experiences of physical or cognitive impairment. This premise forestalls questions of *whether* people with dementia dwell and facilitates instead questions of *how* they dwell.

The Influence of Dwelling Practices on the Threshold

Although participants varied in their socioeconomic status, living arrangements, marital status, age at diagnosis, age at interview, overall health, and specific dementia diagnosis, they were all actively and consistently involved in dwelling as an act of creation or building (*bauen*) as spaces were defined and redefined by the participants. Critically, while the threshold concept allows for a multiplicity of practices, it can also provide additional insight to common practices, such as, for example the arrangement of meaningful objects in space. To this end, Hazel's growing flock of owl ornaments can be viewed as both in line with the

wider body of literature which explores the importance of meaningful objects as key components in feeling at home (as in Lovatt, 2018). Hazel's relationship with these objects also aligns itself with the work of authors like Miller (2010) and Smith and Ekerdt (2011), for example, as she the ornaments exist predominantly as passive items within the space and are only 'used' as they become the focus of Hazel's attention for a time, before fading into the background again *ad infinitum*. Where a threshold perspective challenges such interpretations, however, is in the assumption that i) the ornaments must be called to mind to be considered 'in use', and ii) that curation of meaningful objects in space is only impactful for the individual for whom they have meaning. The first point is captured neatly in Whitmore's (2001) work, which explores the role of cherished objects as tools for reinforcing identity. She declares:

"Embedded with the essence of life experiences, possessions lend elders at least two types of identity continuity. First, possessions serve as concrete and enduring representations of achievements and social relationships. Second, as external embodiments of personal goals and feelings, objects allow for a continuity of internal and external identity. Offering connections to intangible or lost social and personal connections, possessions link elders to aspects of identity that are no longer physically present. The sheer physicality of possessions creates a mass of evidence supporting a life of experiences."

(p59)

Critically, while the objects Whitmore discusses continue to exist when outside the consideration of the owner, they do as an impoverished version of themselves, stripped of the personal attachment and meaning they represent. Such possessions are, therefore, only 'in use' when being considered, as they become concrete representations and external signifiers of the owner's identity.

A threshold perspective, however, offers an additional layer of significance to such material objects. As such, while participants in this study were often surrounded by objects that helped them recall and reinforce aspects of their Being that were rooted in the past (as

discussed by Whitmore, 2001; Miller, 2010; Smith and Ekerdt, 2011 etc), use of those objects was not necessarily limited by their active consideration. Instead, objects which populated physical thresholds helped to shape and reinforce their practices of dwelling even when outside their consideration by, for example, influencing the behaviour of others, demarking the visual space, or enforcing particular threshold practices while discouraging others. Furthermore, objects could become meaningful not only by themselves embodying past identity (as per Whitmore, 2001) but through enabling participants to shape threshold spaces. Such engagement might manifest as creating the space through rearranging, clearing away, placing, or changing objects (thus exemplifying *bauen*) or by facilitating the maintenance of the dwelling space as in the chamois used to clean windows, the keys used to lock or unlock doors, the keychain used to block a keyhole, and so on (thus demonstrating *wohnen*). Such practices demonstrate a continued, though often changed and changing, engagement with physical spaces and thresholds, made possible through the use of material objects.

This research therefore aligns itself with Nord (2013) and calls for a wider interpretation of the processes that imbue objects with meaning. Like Nord, participants in this study often drew meaning not only from the object itself (as, for example, an item of reminiscence or identity reinforcement) but from practical objects that allowed them to accomplish a meaningful task. This is as true for Nord's visually impaired participant for whom a nightlight not only allowed her to continue to navigate her space in the event that staff turned off the main light in her flat. The presence and absence of illumination, and thus the light itself, transformed her perception of and engagement with her that space after nightfall. As a result, the nightlight object was both itself meaningful and "actually quite beautiful" (p140) and represented a meaningful visual threshold that separated the way the space was experienced during the day and during the hours of darkness. Such examples demonstrate the importance of adopting a perspective that is capable of capturing a multitude of practices and meanings

of ‘meaning’. A threshold perspective does this by encouraging an engagement with objects that looks beyond the perceived value of the object, be it sentimental, practical, or otherwise, and to include what such objects allow participants to accomplish. Threshold objects should, therefore, be considered meaningful in relation to (i) the history that they represent, and (ii) the ways in which they could enable participants to continue to dwell actively and manage their threshold spaces.

From such a perspective, the role of the night light in Nord’s (2013) study is not only to enable the resident to move around and cross the internal thresholds of her home during the night (by bridging the sensory threshold between light and dark) but to allow her to control when and how those thresholds are closed. This resonates strongly with the experiences of participants in this study as some participants relied on objects to navigate vertical thresholds (for example Mark’s technique for putting his shoes on with a litter picker) and others capitalised on the properties of objects to enable them to leave the horizontal thresholds separating their home and Elsewhere without fear of leaving their keys behind (for example Margaret’s large, fluffy key-chain). Such objects therefore become tools of enablement, and are meaningful both in what they enable participants to do, and in who they allow the person to continue to be as they assist in addressing and mitigating the challenges introduced by their embodied experience of the impairment resulting from their dementia. This introduces a further opportunity to expand our consideration of what renders objects ‘meaningful’. Enabling objects became not only facilitative in the moment but vital tools that facilitated participant’s efforts to manage physical thresholds in a way that allowed them to continue to dwell. They become, therefore, meaningful not only in relation to what they help people with dementia to do, but who they allow them to be (Thomas, 2007).

Managing Threshold Spaces

Objects arranged around threshold spaces could, in general, be considered as either facilitative or troubling. While a small number of examples demonstrated the potential for arrangements that could be experienced as facilitative by everyone, (for example with Liz's efforts to paint the edges of their garden steps to make them more clearly visible for George), most objects could were primarily facilitative of the person with dementia, and were often influential in aiding them to resist the influence of unwelcome parties approaching the threshold. Isobel's door alarm is a clear example of this. Installed initially as an object of reassurance, having a door alarm that was set up to alert the local police station once pushed allowed Isobel to refrain from interacting with it physically when she did not require it, while engaging with it on a conceptual level as a safeguard that could be used if necessary. Such an approach enabled her to continue to dwell in the manner she wished to, and supported her in acknowledging and responding to risks in a way that allowed her to feel both safe and respected (as in Rush, Murphy and Kozak, 2012). This in turn facilitated her ability to dwell and her bolstered confidence in doing so, without requiring the intervention of additional technologies designed to regulate or surveil her movements around the threshold (as in, for example, White & Montgomery, 2014; Fehling & Dassen, 2017).

Placing such emphasis on reinforcing the physical threshold that separates Elsewhere from the home resonates strongly with Buch's (2015) argument that doorways, as the primary entry points, can become sites of resistance as people age. This is discussed by Buch (2015) in relation to the introduction of home care packages for older people, where care workers were significant both as individuals and as embodied agents of an unwelcome system, a process that was certainly experienced by participants of this study. Where this work differs, however, is in its construction of home care as a stopgap measure and a harbinger of the

“social death” represented by the eventual move to residential care (Buch, 2015, p44). This represents the major differences between previous works that examine older people or people with dementia as existing at ‘the threshold’, and this research. Critically, I argue that those works that situate older people, and particularly older people with dementia as liminal often perpetuate rather than challenge the narratives of decay by exploring threshold practices only as they relate to the experience of a shrinking world and the potential “unmaking” of the person (*ibid*, p44). As noted throughout this thesis, these narratives rely upon the dual assumptions that people can become ‘unmade’ (which the Dasein perspective refutes), and that those who live in residential care have irrevocably already crossed this physical and social ‘threshold’ into being non-persons. Buch (2015) reflects:

“All but one of the elders I knew well acknowledged that the progression of their ailments would likely leave them requiring care that exceeded what they expected to receive through home care; however, several expressed the hope that they would die before this was necessary. Yet even as these elders came to see their homes as bulwarks against their social unmaking, their homes became increasingly crowded with assistive devices and technologies and frequented by a growing number of health care and social service providers, transforming them into increasingly liminal spaces”

(p.41)

“In this context, [of receiving home care] elders engaged in boundary practices that reflect and even attempt to sustain the ambiguity of their social positions—better to be only partly independent than to be useless, invisible, and utterly unmade as a social person.”

(p.43)

Yet, as much as Buch characterises this fear as one of becoming unmade, she also constructs the threshold practices of her participants as efforts to balance the need to remain secure with the threat of becoming “trapped and abandoned” (p.40) in their own home. This reoccurs elsewhere in the literatures around geographical gerontology, as older people are often pushed to the boundary of a literature that forefronts the experiences and manifestations of care (i.e. Milligan, 2000; Wang, 2019) and positions older people as

“prisoners of space” (Andrews et al., p1649). The consequences of such constructions are clear, as even works with emancipatory intentions are drawn into reinforcing the dominant, ablest, and oppressive message that older people with dementia become increasingly powerless as their cognitive capacity is compromised. That the increasing use of assistive technologies is presented as a symbol of this powerlessness in Buch (2015, p.41) as opposed to enabling or facilitative exemplifies the inherent nihilism of the narratives of decay, as each change becomes emblematic of a dissolution of personal power, freedom, and autonomy. Such arguments, however well intentioned, become pathways for civilized oppression (Harvey, 2015), and are ultimately opposed to both the ideals and the practicalities of a disability informed approach (Thomas, 1999; 2007; Thomas and Milligan, 2017) wherein technological aids can be viewed both practically and symbolically as objects of empowerment and support.

It is critical to note that, although such narratives are common within the dementia literatures, they are at their core an ablest account based in the medicalised assumptions that old age and impairment necessarily render the person as a less powerful individual. As such, they replicate rather than challenge ablest and ageist notions of older people and people with dementia as victims of a hostile society, whose manner of dwelling is limited to efforts to preserve and protect a past way of life. Such narratives run directly contrary to the findings of this research. Participants organised their thresholds such that they could facilitate both exclusion and inclusion; restricting or permitting access as required based on the identity of the person on the other side of the threshold. This process of managing and controlling the threshold was clear even where participants generally operated an ‘open-door’ policy. Critically, while each had developed strategic methods for securing their home against unwanted visitors should they need to do so they nevertheless continued to engage with home as a dwelling place and thus, a meaningful (Holland, 2015) homespace (Milligan,

2000) even when there was a need to facilitate and enable caring practices within it. The introduction of caring practices to the home certainly resulted in some adjustment in the participants habits of dwelling, yet each was able to do so in a way that allowed them to manage and negotiate the physical and social thresholds of care in a way that was aligned with their personal history and value system while still receiving support- an insight that is often absent from the existing work on caring and aging geographies (i.e. Buse & Twigg, 2014; Buse et al., 2017).

It is important to note that, despite the critique offered here, there are a number of aspects of Buch's work that resonate strongly with the perspectives and findings of this research. Nevertheless, it is in the construction of the threshold as a liminal space, entirely separate from the phenomena it connects, and of older people as reactive rather than proactive in their management that these works diverge. By working within an ablest narrative, where ageing and impairment are a source of 'tragedy' (see Swain & French, 2000; Swain, French & Cameron, 2003; Thomas, 2004; Kirkman, 2006; DiZazzo-Miller and Pociask, 2015) Buch's (2015) analysis provides limited opportunities to acknowledge the resilience of participants, or explore the wealth of their experience. This provides a strong contrast with this research, where I argue that the process of making and remaking physical thresholds can be proactive as well as reactive. As such, a threshold perspective acknowledges the efforts made by people with dementia as they manage thresholds in an increasingly complex context, wherein (for example) those who provide care must cross the physical threshold whether they are welcome or not. Most importantly, it is necessary to accept that the acceptance of care work and carers into the home space does not necessarily (or even appropriately) indicate an absence of power on the part of the person with dementia. To the contrary, participants in this research often leveraged their power as dwellers to influence how and where the institutions and practicalities of care entered into their lives. Examples of participants

exercising this power can be seen in both Bob's window-cleaning and Flash's determination to feed the birds outside his window. Both instances demonstrate the men's ability to resist pressure from care staff to shift their physical thresholds and reduce the area of their physical dwelling in ways that disrupt the narratives of decay, even as they relied on those self-same staff for care. Furthermore, such power was wielded even where resistance was not an option, as participants continued to remake and renegotiate their physical thresholds in the aftermath of change. Such renegotiation can be seen by contrasting Mark's consistently positive social relationships with his care workers to his tense relationship with his care provider, particularly where it related to consistency of care. Similarly, Sybil's willingness to allow her care workers into her home, but her strict oversight over their cleaning duties provides another example of the restructuring of thresholds such that passage into physical space does not mean the visitor has ultimate power there. In these cases, the physical threshold of the doorway might have been reshaped such that the care workers could access the home (as in Buch, 2015), but it nevertheless permitted entry into a space where the person with dementia dwelled as powerful and effective agent.

Influencing Troublesome Thresholds

While the recasting of people with dementia as powerful dwellers with significant influence over their home space strikes a distinctly emanatory tone, it would be disingenuous to present contests and conflicts around the physical threshold as exclusively untroubled, or untroubling. To the contrary, throughout fieldwork participants discussed the threat of their physical threshold being breached against their will. Both Margaret's disclosure of another resident watching her through her keyhole, and George's experience of being watched through his window by Jehovah's Witnesses demonstrate the potential for a threshold to be physically restrictive in situations where social norms are followed, but insufficiently protective where those on the other side act in an unexpected way. It is arguably this type of

risk that Mark's upstairs neighbour sought to mitigate when she insisted that he stop keeping his keys on the doorframe when the door was unlocked (a measure that was facilitative of his memory impairment) and that he move their location to deeper within his hallway where they could not be grabbed quickly by a potential intruder. Such examples speak to a number of dementia literatures (e.g. Rush, Murphy & Kozak, 2012; Egan et al., 2017), as well as ethical issues around disability, risk taking, and capacity. Had this effort been dictatorial in nature, or enforced without Mark's agreement, it would counteract his right as a self-determining adult to make decisions and take risks (Fetherstonhaugh, Tarzia, and Nay, 2013) as well as potentially contributing to his physical disablement. However because this intervention was introduced by a member of the inner circle and was implemented in a way that accounted for Mark's pre-existing patterns of dwelling to avoid introducing disabling factors, it was ultimately successful. Such an example highlights the importance of interpersonal relationships and supports Thomas' (1999; 2007) argument that both disablement and enablement are made manifest through relationships. Indeed, it is possible to argue that the approach taken by Mark's neighbour was successful not only in that it addressed a perceived risk without disabling Mark, but in that it did so without requiring Mark to internalise disabling beliefs about himself and what he should be able to do as an older man with dementia.

It at this point becomes necessary to emphasise that while separating physical thresholds from those that are social or temporal allows for greater clarity of analysis, this clarity comes at the cost of nuance. As much as the erasure of the body from the social model of disability lead to an impoverished understanding of the ways in which social factors impacted a body in space, so too does excluding social factors from the consideration of physical thresholds. Explored exclusively in relation to physicality, the insistence of Mark's neighbour that he change where he stores his keys might result in disablement, and contribute to his oppression

(per Thomas, 2004 and Harvey, 2015) through tacitly perpetuating the belief that people with dementia should remain close to home. This is evident in much of the literature on wandering (see Algase et al., 2004 for a discussion). From this perspective, the neighbour's belief that her way of arranging Mark's home space has more validity than his standard practice could be parsed as springing forth from ablest beliefs about competence and what it means to live with dementia. In the context of their social relationship, however, and specifically her place within Mark's inner circle, her influence on his physical threshold is re-contextualised into one of enablement, in line with Swain, French, Barns and Thomas (2013). Key to this shift was the neighbour's knowledge of Mark, and their ability to compromise. The result was an arrangement where the keys were removed from the door (as per the neighbours request) but kept beneath the entry phone and where Mark kept his notebook, without which he never left the house. This arrangement allowed Mark to adjust his patterns of dwelling such that he could still find his keys, leave his house and lock his doors at night without difficulty, while still accommodating his neighbours concern. Such an example, while mundane, resonates deeply with the difficulties that surround risk taking, enablement, and living with dementia (i.e. Rush, Murphy and Kozak, 2012). Particularly, through viewing the doorway as a site of resistance, wherein Mark's management of the physical threshold was influenced more by the intervention of someone he trusted and cared for than by a risk he did not himself perceive. Similar patterns emerged with Sybil, though with more strains of resistance, as she reflected that she used her sticks when navigating the garden primarily in order to avoid her daughter's irritation and concern, rather than as a response to her own mobility needs.

Throughout fieldwork, participants discussed their experiences of managing physical thresholds. Each of these reflections was deeply personal and tied to their lived history, their gender, their social class, and their physical health. As a result, it is impossible to identify a

single threshold that all people with dementia will find either facilitative or disabling, just as it is impossible to dictate that their 'dwelling' must be confined by the walls of their home, beginning and ending at the front door. Such diversity in experience highlights the need to recognise the experience of dementia as diverse in both physiological progression and experiential meaning (as in Nygard and Borell, 1998). It was only through listening and analysing from a perspective that was open to multiple interpretations of what and where a physical threshold might be that it became possible to understand the extent of management that occurred there. Mark, for example, maintained an open threshold at his front door, through which visitors like myself, his neighbours, or friends could walk after only a cursory knock once they had been instructed how to bypass the buzzer. The site of Mark's dwelling-as-protection (*wohnen*) in fact manifested in the shared space at the door to his close. Here visitors met with a technological barrier in the form of the buzzer, and here Mark's congenial relationship with his neighbours exhibited tension over the placement of the large mat inside the door. How this threshold was arranged affected, in turn, how Mark engaged with his front door, as only those known to himself or his neighbours could bypass the buzzer system without first announcing themselves. Secure in this knowledge, his front door could remain unlocked. This strategy runs contrary to Margaret's method of management, which treated other residents as a potential threat who should be barred from entry by default rather than congenial near-dwellers. Such differences highlight not only the impact of the individual and their personal experience on the manifestation and management of the threshold space, but makes it necessary to consider their negotiation as a social (as well as physical) phenomena.

Relational Arrangements and Social Thresholds

Summary of Findings

Chapter Six explored the ways in which participants experienced, managed, and navigated social thresholds and relationships as part of their day-to-day experience of living with dementia. The following section explores the ways in which viewing social thresholds concurrently through the lenses provided by Thomas' social-relational approach to disability, and Heidegger's understanding of Dasein provides valuable insights into the complexities involved in navigating social relationships with dementia. To allow for clear analysis, and to build coherent connections to existing literature, this section consists of four parts. The first acknowledges the importance of separating the difficulties associated with dementia, through either impairment effects or the imposition of disability, from a person's impairment. This is particularly important given both the potential for an individual to experience different levels of impairment over time and the difficulty associated with accurately predicting the progression of the dementias. The second builds upon this understanding to highlight the ways in which people with dementia engage with key people as facilitators, innovators, and curators as their dementia progresses. The third segment explores the ways in which individuals who contribute to the oppression, disablement, or disrespect of the person with dementia are met at the social threshold. Finally the fourth explores the impact of relational ableism and civilised oppression on the way in which participants conceptualised and constructed themselves as people with dementia.

Always With-Dementia

While much of the strength of the social model comes from its dramatic inversion of the biomedical understanding of disability, and its easily communicated sound bite of "disability = social barriers" (Thomas, 2004, p.24) it is worth noting that one of the most influential

aspects of 'Thomas' social-relational approach comes from its nuance. By separating (additional) disability from (biological) impairment and (experiential) impairment effects, the social relational approach facilitates a discussion about how people experience their impairments without presuming that this is either predictable or consistent. Such recognition of the personal experience of impairment creates a space wherein the social aspects that affect how one processes bodily sensations, such as pain (e.g. Corker and French, 1998; Wall, 1999) or, in this study, forgetfulness, confusion, irritability, and anxiety, can be discussed alongside discussions of the biological factors at the root of that impairment. Such accommodations are necessary, particularly when discussing the experience of living as an older person with dementia, as each participant parsed their experience in different ways, as they sought to differentiate between impairment effects resulting from their dementia, and the 'normal' ageing process.

One factor that was of particular note, however, was the ubiquitousness of each person's dementia. While research literatures must by design limit the scope of their investigation to a few aspects of the phenomena they intend to elucidate, broadening the scope over time and successive publications, the lived experience allows for no neat division. There are a number of points throughout Chapters Five, Six and Seven, (and indeed in the whole data corpus) where participants expressed awareness that while they might at any moment feel secure, capable, and confident, this did not indicate a 'freedom' from their condition. Rather, the unpredictability of the dementia disease lead to participants cultivating a state of regular awareness, wherein they were perpetually with-dementia, despite not necessarily experiencing significant impairment effects in the moment. This is perhaps the one area in which this research expands upon Thomas' construction of disability as a phenomenon that occurs where impairment effect meets social reaction (2004, p579) and does so by placing a specific focus on the temporality of Dasein. Indeed, it is the consideration of participants as Dasein,

and thus innately temporal Beings with a past, present, and oncoming future, allowed for a particular insight into the ways in which potential, or expected, impairment effects can contribute to disability for people with dementia.

This prospective disablement is clear, for example, where participants discussed the need to change their current ways of dwelling and being to accommodate a potential future incidence of impairment. Importantly, while some of these efforts were targeted towards avoiding a potentially negative social reaction should their impairments become obvious to others (and thus, arguably fall within 'Thomas' 2007 construction), others were concerned with the pragmatic aspects of managing unpredictable impairment effects. Nigel's efforts to plan out strategies ahead of time that he could use should he become disorientated while in the community provides a key example of this. Such instances arguably challenge the social relational approach, as Nigel was not concerned with the social responses associated with being 'outed' as someone with dementia, but with the practical challenges presented by being suddenly and unpredictably unable to find his way home. It is this unpredictability of the disease and its associated impairment effects that necessitated a constant and active management of situations such that *if* the person became confused or distressed, there were strategies in place that would allow them to manage the situation independently or seek the necessary support. Indeed, for several participants including Margaret and Nigel continuing to access public spaces was contingent on feeling confident in their ability to manage a 'relapse' while accessing that space. That such strategies were required implies that there was a need for enabling measures to counterbalance disabling factors; yet the factors that would contribute to such future disablement were not yet clear.

Such insight is vital when considered in the context of the current push towards the creation of 'dementia friendly' communities and initiatives (Lin, 2017). Approaching these initiatives

with a threshold perspective allow for additional insights how the four ‘cornerstones’ (Crampton, Dean & Eley, 2012) of place, people, resources, and networks are made manifest in each community as interested parties are encouraged to question anew the location and character of physical thresholds in space, social thresholds between people with dementia, others in the community and the place itself, and the temporal thresholds that have the potential to radically influence the accessibility and ‘friendliness’ of the space depending on the time of day or season. Resultantly, this work demonstrates the importance of considering dementia friendliness as a phenomena that extends beyond the end ‘phase’ of the project and instead involves including people with dementia throughout planning, implementation, and assessment (Alzheimer’s Disease International, 2016). It is only by listening to and seeking to understand at a deeper level the experiences of people with dementia as powerful disabled agents in their own right (as in Thomas, 2007 and Boyle, 2014), that these initiatives might avoid inadvertently recreating in new spaces the same troubled and oppressive thresholds that existed before the introduction of supposedly ‘friendly’ interventions (Harvey, 2015).

It is in acknowledging this temporality as a key aspect of the embodied experience of the person with dementia that it is possible to explore more fully the experience of living with the impairments and impairment effects resulting from the dementia disease. Nevertheless, in doing so this work raises key questions around how people with dementia could, or should, be enabled to continue to live their lives as they choose when the temporal aspects of their condition represents a profound unknown.

Dementia, Relationships and the Social Threshold

How participants tailored and refined their methods of managing their physical threshold was often profoundly influenced by how they managed their social thresholds. This can be seen in the earlier example of Mark’s neighbour requesting that he change his habits of

storing his keys at the doorway to lessen the risk they could be stolen, as well as throughout the body of Chapter Six. While such exemplars provide support for the adoption and implementation of person-centred approaches which are rooted in a knowledge of the individual as an individual, it would be incorrect to suggest that mere knowledge of Mark's practices and the opportunity to suggest the change would necessarily result in the same outcome. Put more succinctly; the change required not only the opportunity to identify a potential risk and introduce a new strategy, but a position of familiarity and esteem from which to suggest it. The effect of trying to approach such matters from outside the person's circle of confidence, by contrast, can be seen in Hazel's resistance to her sister's efforts to curtail her driving on the basis of her dementia diagnosis. Indeed, it is worth noting that those outside the inner circle may never be offered the opportunity to contribute such insight as it was with Margaret's decision to block her keyhole without disclosing to staff her experiences of being spied upon. Crossing this threshold is therefore, arguably, an even greater challenge than successfully navigating a person with dementia's physical thresholds, particularly where wider relationships of care render those thresholds more permeable than they might be otherwise.

So how might one navigate this threshold? What separates those who are permitted to 'see' the daily indignities of life, the "aches and pains and urinary tract infections" (Shakespeare and Watson, 2001 p.12) that, however unwelcome, have a profound impact on a person's experience of being-in-the-world? Clearly, such passage does not rely on kinship bonds, or on the provision of care, for Mark revoked his daughter's access to his inner circle both legally (through revoking her power of attorney and removing her from his will) and informally through ceasing his communication with her. Hazel, too, rejected, deflected, and redirected her sister's attempts to manage her 'risky' activity of driving, resisting her sibling's influence based on her perceived lack of understanding. While much might be learned from

examining those patterns of interaction that typified the relationships between participants with dementia and those in their inner circle, it is equally valuable to explore examples of failed threshold crossings.

Throughout fieldwork, tales of failed crossings were typified by a belief that the person attempting to cross could not be ‘trusted’ in some manner with the insight afforded to the inner circle. By contrast, those in the inner circle could be relied upon to interact with the person with dementia as a whole, undiminished individual who was living with, but not defined by, a chronic and degenerative health condition. While this distinction was often couched in the language of knowledge- particularly that those who were held outside the inner circle would not or did not ‘understand’- that friends, professionals and clinicians could be rejected with the same justification suggests that a lack of empirical knowledge was not the primary concern. Rather, where participants discussed those who tried to ‘pry’, or intrude into the inner circle, they often reflected that while the individual might understand dementia, they did not understand *their* dementia, or the reverse, that the individual knew them well, but did not know what it was like for them to live with dementia. Such resistance to intrusion across the social threshold ensured not only the ability to restrict the experience of vulnerability to those relationships that were enabling, but to reject and mask the ‘indignities’ from those who might introduce the very patterns of civilized oppression (Harvey, 2015), disablism and psychoemotional disablism (Thomas, 1999; 2007) that feed the narratives of decay. Yet, the relationality of the threshold space (whether physical or social in nature) often required compromise on both sides, such as in Sybil’s acceptance of care- on her terms- and Margaret’s protection of her bathroom space as entirely private despite the presence of support in other areas of her home. This arguably reflects a tension inherent in the construction of care, as argued by Morris (1997). From her perspective as an accomplished disability theorist and disabled woman, Morris argued that the social construction of care

and caring created insurmountable power imbalances and devalued the person who received it. While such a radical position is beyond the remit of this work, it is worth noting that many of those who failed to cross into the inner circle were seen as potential providers of this oppressive care, where they would assume power over the person with dementia, introducing dependence and inequity, while those within the inner circle provided “assistance”. This assistance (in line with Morris, 1997, p.59) was communicated as a more equitable arrangement where trusted people provided assistance, much as the person with dementia themselves either had in the past, or might in the future (such as with Isobel and her change in position from the person who provided lifts for her family, to someone who received them after she surrendered her car).

It is the acknowledgement of the person with dementia as someone of equal value to those without dementia, someone who requires ‘assistance’ but perhaps, not ‘care’ (Morris, 1997) that arguably lies at the heart of Kitwood’s wider works (1990, 1997). Such relationships reflect the continuing obligation of one individual to another as they are bound together in relationships of support and concern. Critically however this connection is deeper than a spoken, written, or formalized recognition of the individual as a person with a lived history, (Kitwood, 1997). All participants of this study who regularly received care would have experienced person centered care in practice (given the values of the Scottish Social Services Council, 2013) yet the challenges negotiating thresholds in the context of human care staff and inhuman systems of care had a significant impact on how Sybil, Mark, Margret, Bob, and Flash managed their thresholds and organized their lives. A relational perspective allows for greater nuance and acknowledges the person as not only an individual with preferences based in the past but as someone who inhabits the present and looks forwards into the future. Furthermore, while person centered care focuses on the person being “at the heart” (SSSC, 2013) of their care, it presents this relationship as primarily mono-directional. By contrast,

participants in this study constantly negotiated bidirectional relationships between themselves and their carers, and themselves and the institutions of care. Taking a Dasein perspective requires an active acknowledgement of the enduring web of connections within which each person is situated. Such an approach, therefore, highlights the power the individual can wield in the telling and retelling of their experiences, as well as in their organization of threshold spaces.

It is worth noting that throughout fieldwork and throughout the analysis of the data, particularly as it is presented in Chapter Six, one factor that was often present but rarely directly addressed was the language that the participants used to communicate their story and the ways in which they anchored their experiences to the wider dementia narrative. This theme is expressed most clearly in Hazel's efforts to separate herself as a person with dementia from others who have what she considers 'the bad dementia'. Diametrically opposed to the paradigmatic "healthy disabled" person, who is "permanently and predictably impaired" presented by Wendell, (2001, p.21) the person with 'bad' dementia is someone who has lost their reason, and their ability to be reasoned with. As a spectral threat, the 'bad dementia' touched each of the participants in a different way, rearing its head in George's fear of becoming like those he saw on TV, in the way Hazel contrasted herself to her neighbour whose dementia was more advanced, in Nigel's repeated assertion that he was *still* 'quite clever' and so on. Just as the social model created an allegorical disabled person that at once represented all disabled people and none, so too does the 'bad dementia' reflect the realities of dementia without accurately capturing the totality and depth of the experience. As a cohort, participants discussed a variety of impairment effects related to their dementia, including aggression, frustration, memory loss, anxiety, depression, confusion, hallucinations, sensory distortion, executive dysfunction, and slowed cognition, in effect discussing common symptoms of dementia (Zhao et al., 2016) as they were experienced the

context of, and understood through, their lived experience. Yet, despite sharing numerous traits and experiences with the allegorical ‘other’ with bad dementia, participants always constructed themselves as separated from that dementia, incapable of aligning their rich, lived experiences as undiminished Dasein with the caricature constructed by the narratives of decay. The result was the construction of a spectral entity that must always be resisted. The ‘bad dementia’ walked alongside, showing itself in the lives of others with dementia who were ‘further along’ (Hazel) casting a long shadow that introduced fear and doubt to their own thoughts of the future. It is this continued construction of the ‘bad’ dementia, and those who live with it, as less knowable, less whole, and less human that the dementia literatures must seek to actively reject. It is crucial to recognize, however, that such a radical deviation from the narratives of decay cannot be implicit in the philosophy of the work. It is not sufficient to argue, for example, for the agency and voice of those with dementia who can overcome the disabling aspects of the sociopolitical environment to engage with activism, for example (as in Bartlett, 2014) for while such works are valuable they do not directly challenge the societal link between cognition and selfhood or value. Instead, active, strategic and continued steps must be taken to acknowledge and facilitate the agency of people with dementia throughout their life course, especially where traditional vocal modes of communication and advocacy are complicated by cognitive impairment (as in Boyle, 2014).

Being-Towards and Temporal Thresholds with Dementia

The exploration and analysis of temporal thresholds arguably represent the most contentious argument put forth by this thesis. It is only through acknowledging the influence of time as the medium through which Dasein moves and experiences that the importance of the temporal threshold can be explored. Indeed, each of the literatures discussed in this thesis can only manifest temporally. From this perspective both disabling and enabling

relationships can only be played out through time; whether this is the time required to identify, implement, and maintain physical objects such as calendars and taxi bookings, or the willingness to allow the person with dementia extra time to think during a conversation. Similarly, disabling factors played out over and through time, in the difficulty of accessing clinical support for diagnosis, in short appointment times or meeting slow physical or cognitive processes with exasperation rather than empathy. To this end, the first two themes considered in this last section relate to the interaction between dementia, time, and social spaces; and dementia, time, and physical spaces respectively. The chapter concludes by highlighting the value of exploring the thresholds experiences of people with dementia as undiminished embodied disabled Dasein and identifying future directions.

Relationships, Time and Dementia.

Time, and a sense of temporality, had a profound influence on how participants understood and discussed their relationships with others, particularly those within their inner circle. Such an observation is not, in and of itself, novel. How people with dementia and their trusted people engage with time has been the subject of a range of investigations, from those which pinpoint key narrative events as “existential coordinates” around which an individual’s understanding of lived experience is organised (Orona, 1990, p.1253), to those that investigate the use of specialised clocks and technologies to aid with temporal positioning (Topo et al., 2007 and George’s clock in Chapter Six). Participants were also often acutely aware of the time family members dedicated to their care, and, as Kitwood (1997b) noted, on guard against becoming “burdensome” (p.15), something that for participants in this study was often judged on the basis of the amount of time their care required. Whether it was in Mark’s discussion of his carers as struggling under excessive caseloads with insufficient time and support, Sybil’s frustrations at being visited at a time that was convenient to the staff but that often varied in line with their other commitments, or,

contrastingly, her concerns at how much time her daughter spent organising her care, time often played a key role in how participants organised their lives, and managed thresholds. It is important to note, too, that while participants might struggle to keep track of time (Topo et al., 2007), that did not stop it being an object of frequent attention, and frustration. Time, and thus temporal thresholds, became contentious not only when participants needed to leave the house or attend events at an appointed time, thus contending with a difficulty in keeping time (Phinney, 1998), but when others crossed into their home space, carrying their temporality with them. Such temporalities contributed to the frustration discussed by Sybil, Mark, and George in relation to waiting for people to attend their home, in either a caring (Sybil or Mark) or contracting (George) capacity. In each case, participants related a sense of frustration at being unable to rely upon the punctuality of others, something each saw as disrespectful even when they understood the structural problems that might contribute to a loss of consistency. It is particularly critical to note at this juncture that the problem was not lateness per se, particularly for Mark and Sybil who were visited by care workers multiple times a day, but a lack of predictability in general. While waiting for care workers to help them dress in the morning might influence their plans for the day, it was equally frustrating to have care arrive early to prepare them for bed at night, limiting their evening activities.

The friction between the temporalities of Elsewhere, particularly as it affected the provision of care services, and the controlled time of the home represents the most unruly threshold. Drawing its character from either 'side' of itself, the threshold represents a space of active negotiation and compromise, where the phenomena on each side meet and intermingle in a space that is at once discrete and beholden to the phenomena that meet there. Where this causes friction, however, is in the creation of a space that potentially pleases neither party. The care worker with a large caseload finds the pace of the home too slow, or the preferred timing incompatible with their responsibilities and the person with dementia finds the pace

of Elsewhere too fast, or restricting. Such friction results in difficult negotiations; is it better that Mark receive his care too early, or too late? Does arranging care workers to aid with changing into sleep attire tacitly restrict the freedom of people with dementia such that they cannot access Elsewhere spaces after a certain hour in the same manner as other adults without impairment? Taken from this perspective, does changing the clothes of a grown adult into sleepwear early and arriving late in the morning to aid with daytime dressing represent a method of control, curfew and restriction? It would certainly be inappropriate to suggest that these methods are usually or routinely targeted to restrict and oppress people with dementia. Such maliciousness is not required, however, where people with dementia are restricted through the processes of civilized oppression as the subtlety of Harvey's framework renders it possible to at once recognize the good faith and intentions of care workers, and the contributions of their actions towards oppression (Harvey, 2015). To raise such questions however highlights a complex tangle wherein people with dementia as disabled people can as easily be enabled and disabled by the provision of providers of care as in other relationships (Morris, 2004; Thomas & Milligan, 2017) yet the temporal reality of care requires individuals to be supported sequentially. As such, there must be someone who is visited first, and who is by extension 'restricted' by the processes of dressing and night-time personal care earlier in the day than those who are visited later.? This is a problem that is difficult to solve, and stretches far beyond the remit of these thesis into questions that require the balancing of care prioritisation, provision, and financing against personal rights, freedoms and desires. Nevertheless it manifests at, and is a prime example of, a temporal threshold drawn between two competing temporalities.

It is also important to note that the narratives of decay, the tales of diminishment and reduction that this thesis is diametrically opposed to, operate on similar contested temporal thresholds. Indeed, time is an instrumental component of the narratives of decay, in which

dementia is constructed as a process which “violates the spirit” through a process of decay that is tantamount to a living death that leaves only the body as a physical reminder of the person that has been ‘lost’ (Post, 2000 p245; Davis, 2004; Milne and Peet, 2008; Beard, Knauss and Moyer, 2009 and Herskovits, 1995 respectively). It is the portrayal of dementia as a diagnosis of inevitable decline and loss that can lead those who provide care to adopt pessimistic and defeatist attitudes (Kissel and Carpenter, 2007; McCleery, 2008) as dementia care fails to provide the cure that the medial model extols as the ultimate and only goal of care (Shakespeare and Watson, 2002). It is this sense of nihilism and the construction of a dementia diagnosis as the loss of both future potential and potential futures that the narratives of decay perpetuate. It is this narrative that the use of Dasein and disability theory is intended to disrupt. Indeed, this study aligns itself with the perspectives of Beard, Knaus, and Moyer (2009) in viewing dementia not as a cause of “immediate debilitation” but “a circumstance requiring new and innovative types of interaction” (p.234). Indeed, I argue that a Dasein perspective facilitates this further by untethering cognition from Being; undercutting arguments that contend that increasing cognitive impairment is comparable to a diminishment of the person themselves. Such a positioning allows for an engagement with the concept of thresholds that constructs relationships as occurring between two (or more) equally valuable Dasein who are drawn together across a social threshold. Proceeding from this premise allows relationships to be viewed through the lens provided by Thomas’ (1999; 2007) Social Relational Approach to disability which highlights the disabling and enabling practices as they are made manifest in the moment at the social threshold.

Taken together, these two frameworks demand that individuals without dementia accept the enduring humanity, validity, and value of those with a dementia diagnosis. It demands that they engage with them in a way that respects their rights and agency even as they provide support for their impairments. Such a stance requires committing to an understanding of

dementia that includes not only the person's past (as clearly required by personhood, Kitwood 1997) but by being present with them in the now, and understanding their continued existence as a being who is always towards the future. Refusing to engage with that future-facing temporal threshold contributes to the fear of the unknown. It reinforces the negative images that present people with dementia as those who have been 'deprived' of their mind "little by little" (Van Gorp and Vercuysse, 2012, p.1276); victims of a "terrifying" "time bomb" that will affect everyone "if [they] live long enough" (Peel, 2014, p.892) while simultaneously attempting to justify an erosion of rights and dignities (see Bailey, Ridley and Greenhill, 2010). It is necessary, therefore, to acknowledge not only the ways in which people with dementia control, manage, or cross temporal spaces, but the ways in which those without dementia contribute to and perpetuate the very systems of civilized oppression that disable them. People with dementia must have the opportunity to consider their future, both as they continue to live, and as they reach the end of their life (see Hellstrom and Torres, 2015). This change, too, shall take time and likely meet with resistance (Harvey, 2015).

Time and Physicality

In many ways, the challenges of adapting the temporalities of physical spaces for people with dementia presents less difficulty than addressing those relational and cultural barriers discussed in the previous section. As mentioned at the outset of this thesis, an appetite already exists for the creation of dementia friendly spaces and communities. This is fuelled in no small part by the Department of Health's aim to ensure that 'over half' of all people living with dementia will be living within a dementia friendly community by 2020 (Department of Health, 2015). The question raised by this research however is whether the creation of dementia friendly spaces represents a 'siloining' of people with dementia, a process that maintains the disabling aspects of public spaces in exchange for 'special' provisions to allow people with dementia to access the space. This danger has been explored elsewhere,

highlighting areas where the creation of accessible space has created “grey ghettos” (Ayalon and Green, 2012), where the very adaptation of this space has resulted in a lack of broader action, resulting in a marginalisation of residents and a loss of opportunity. Taken from a disability perspective, and leveraging the powers provided by the Equalities Act (2010), it is possible to make a strong argument that much as wheelchair users have a right to access public facilities, so too do people with dementia. The provision of special spaces is, in this regard, certainly not preferable to the recognition of people with dementia’s rights as citizens (Rochford-Brennan, 2018), just as creating ghettos (Ayalon and Green, 2012; Harhaj, 2014) or warehouses (Wild et al., 2018) is not comparable to the creation of an accessible society.

Where deference is owed to people with dementia, however, is in the primacy of their experiences of disablement (Thomas, 2006). The assumption that a person who does not live with a cognitive impairment, particularly a degenerative cognitive impairment, might intuit the systematic barriers that oppress disabled people with dementia is the very hubris that much of the disability literatures seek to address. Critically, researchers must engage in reflection to explore the ways in which their language (DEEP, 2015), actions, practice, or underlying beliefs might contribute to the civilised oppression of those they mean to research with. This, too requires time- both to facilitate people with dementia to take part in research and to allow researchers time to reflect on their own ways of being-in-the-world as people without dementia. This research drew significant benefit from creating a fieldwork space where the participant could dictate how long each visit lasted and when they might be undertaken. This process required me to leave my own temporalities ‘outside’ when I entered the research space. It is through recognising temporal thresholds, and the embodied temporalities we enact as Beings-in-the-world that we might be more facilitative as researchers, and thus facilitate rather than disable people with dementia to participate (Dewing, 2007).

By approaching the temporal threshold with a Dasein perspective, it is possible to highlight the importance of viewing the person not only as someone with a lived history, but someone with a future that is perpetually coming-towards. Where people with dementia are denied agency, where they are restricted based on their diagnosis rather than their embodied impairment effects, they are robbed of their ability to effectively manage their future threshold. Whether it is in attempting to convey to others the potential outcome of the disease, in wondering if spouses would remarry, or in collecting elephant tea towels, it is as important to facilitate future threshold crossings, as it is to reminisce and cross the threshold to the past. It is necessary, therefore, to not only attend to and facilitate the growth of the dementia literatures and dementia activism into citizenship and beyond, but to ensure it is rooted deeply in an acceptance of a perpetually undiminished self. It is only by doing so, only by rejecting outright the narratives of decay and dissolution that we may move forward, as researchers, activists, practitioners, and people to assert: we do not treat people living with dementia as people to honour their past, but to enrich their present and enable their future. They are not lost, lesser, shadows, or shells. They are valid, valuable, whole, and undiminished. Always.

Limitations

While the research generally, and this thesis specifically, drew great strength from its ethnographic method, it by its nature inherits the weaknesses of a written ethnography. As such, the design of the study, the recruitment of participants, the gathering of data, and the analysis and composition of the written text are all tightly bound to who I am as a researcher and my experiences of being with participants in the field. My findings and reflections are therefore a reflection of my observations in the field. These are filtered through the narrative process and reconstructed in a written format that must then be taken in and processed by

an audience. I have however done my best to capture a world that is both shared and “worlds apart” (Ashforth, 2005 pxi), portraying the undiminished brilliance of their being as best as I am able in the process.

It should be noted that this study has its procedural limitations. Recruiting primarily through groups that advertised themselves as dementia inclusive or dementia friendly tacitly, though unintentionally, excludes those who do not attend such groups or do not see themselves as represented by them. It is possible, even likely, that their lived experiences would offer further nuance and different insights into managing and navigating threshold spaces. Similarly the inclusion of people of colour, of people whose dementia was more advanced, or people who were more geographically diverse might all have provided new illuminations. As such this work is, as all ethnographies are, limited in its generalisability and scope; and yet it is only through undertaking this work on a small scale and with sufficient depth that the findings have come to be.

9: CONCLUSION

This thesis offers a number of meaningful contributions to the body of academic knowledge. Principle amongst these is the introduction and exploration of the threshold concept, for it is through examining the experiences of people with dementia at the various physical, social, and temporal thresholds that we might better understand the ways in which disablism, civilised oppression, and the narratives of decay are made manifest in peoples lives. This work therefore owes much to the work of previous scholars, for meaningful progress can only be forged incrementally and collaboratively, by drawing together the expertise and perspectives of people with a wide range of thought and experience. The following sections, therefore, detail the ways in which this thesis has make particular contributions to the academe, before returning to consider each of the research questions in turn, in light of the findings presented in Chapters Five, Six and Seven, and ending with a discussion of potential avenues for future research.

Thresholds

The primary contribution made by this thesis is in the development and application of the concept of thresholds as transcending architectural features and physical space. By moving beyond such limited notions about what and where a threshold might be, this thesis constructs an analytical concept that is both internally consistent and sufficiently flexible to be applied in a range of fields. There are two aspects of the threshold concept that are particularly valuable in this respect– the construction of the threshold as an active space, and its construction as a relational phenomenon. Firstly, through viewing a threshold as a ‘space’ that is both distinct and beholden to the phenomena that it draws together, a threshold approach acknowledges both activity (through the ‘drawing together’) and the capacity for

change and evolution as the phenomena on either side shift. An optimistic example of this might be seen in returning to this thesis a decade from now, and re-reading it in a sociocultural climate where people with dementia do not experience the same degree of stigmatisation, marginalisation and dehumanisation that they do at present. I would hope that such a reader would find the contents of Chapter Five, and the subsequent discussions of social thresholds as painstakingly negotiated to avoid disablement and derision, dated and difficult to apply to their lived reality. That such a reader could, however, explore anew the ways in which people with dementia encountered and managed social thresholds in this future context demonstrates the value of the threshold perspective as a flexible approach that enables the capture of multiple ways of being-in-the-world. Furthermore, by viewing thresholds as a space where two phenomena meet, it is possible to move beyond the physical, social and temporal thresholds explored in this thesis. Indeed, there is a strong argument for applying a threshold perspective to other social-relational barriers highlighted in Thomas' (1999; 2007) work, whether they occur between individual and care staff, frontline staff and management, practice and policy, or along other culturally relevant lines such as gender, religion, ethnicity and so on. Such investigations would further benefit from a framework which explicitly positions both 'sides' of the threshold as powerful and active in their respective areas, avoiding any reconstruction of narratives where either side is constructed as powerless, passive, or objects of pity, something that is crucial when exploring the experiences of marginalised people.

The Dasein Perspective

A further contribution of this thesis is grounded in its use of Heideggerian theory, and particularly its construction of the person with dementia as Dasein-with-dementia. This shift away from implicit Cartesian constructions of the person that forefront cognitive function a

prerequisite to self allows for a unilateral rejection of the narratives of decay. The implications of this are profound. Because Dasein is not contingent on cognition, it cannot be eroded through cognitive impairment. Because Dasein is always present in-the-world and experiencing it, people with dementia can never be constructed as removed or absent from the world, nor can they be discussed as empty, hollow, or lost. Instead, it becomes necessary to explore the experiences of people with dementia from a position that both explicitly and implicitly affirms the enduring undiminished character of Dasein-with-dementia, whose experiences of being in the world may be transformed, but are valid nevertheless. As a result, adopting a Dasein perspective becomes about more than a flight of philosophical fancy. By understanding people with dementia as Dasein, it becomes possible to erase not only the harmful effects of the narratives of decay, but to silence the narrative entirely, for Dasein is immune to the very processes these constructions rely on. To be able to reject these narratives out of hand rather than battling with them as adversaries worthy of engagement has the potential to profoundly impact the way in which we as researchers communicate, how we convey our results to practice, how practitioners engage, and ultimately how people with dementia come to understand what it means to be-with-dementia. That a Dasein perspective allows an explicit consideration of the spatial and relational aspects of being-in-the-world as dwelling and as being-with-others allows for greater nuance of conceptualisation and, ultimately, a richer understanding of what it means to live with dementia.

Dwelling

In 2011, Buffel et al., sought to capture the complex relationships that develop places and the people who dwell there. “Individuals”, they argued “are not only shaped by exchanges with places; people also shape and create the environment in everyday (inter)action” (p.20). While such a statement opens the way for a nuanced discussion of relational thresholds, it

does so only in relation to geographical gerontology and place making practices. This is, in part, the thinking that I have sought to extend by drawing on Heidegger's concept of dwelling, and of Dasein as dwellers (1957/1993, p15). Because those who dwell are constantly engaged in practices of building and creating (*bauen*) and preservation (*wohnen*) there will always be a meaningful and on-going relationship between the dweller and the place in which they dwell. From such a perspective, the understanding of people with dementia as undiminished dwellers allows this work to situate itself both within the context of the Neighbourhoods and Dementia Project, and the wider dementia literatures.

It is worth noting, too, that this field is still in its relative infancy. Keady et al., (2012) highlighted a distinct trend in the way in which people with dementia were treated in the literature as distinct and separate from the wider social and material world. This construction of people with dementia as fundamentally passive and separate from resulted in there being "no research [...] that explore[d] everyday neighbourhood practices for those affected by [dementia]" (p.160) at the time of the review. This has changed substantially over the last six years, in no small part due to the work of researchers aligned with the wider Neighbourhoods and Dementia project. It is through drawing together eight distinct work packages that the Neighbourhoods project has been able to

"centralise the vision and values of people living with dementia and their carers in research practice; embrace creativity, innovation and shared stories; and empower the experience of people living with dementia, their carers and neighbourhood networks."

(Swarbrick et al., 2016, p3)

Being attached to this project has, in turn, played a significant role in furthering the empirical contributions of this thesis. For example, where Ward et al., (2017) used walking interviews as a major component of their data collection, I was able to incorporate walking interviews

as an optional activity, creating a more egalitarian distribution of power between myself and my participants who chose not only when, where, and for how long we walked, but if we walked at all. Similarly, my work drew valuable insight from that of Ferguson-Coleman and Young, (2017) in relation to the challenges that arise when people live with both hearing impairments and dementia, while broadening the scope to include a broader range of sensory impairment. This thesis also contributes to the Neighbourhoods project by offering novel insights; through interpreting inaccessible spaces as potentially oppressive and disabling, through exploring the experiences of people with dementia as they negotiate the physical thresholds between home and the neighbourhood spaces of Elsewhere, and by providing a philosophical grounding that makes the person with dementia as Dasein and, thus, dweller as inextricable from their lived environment. As a result, this thesis contributes both to the neighbourhood project and to the wider dementia literature by exploring not only how people with dementia experience spaces, relationships and temporalities, but also how they draw, redraw and manage the threshold spaces that separate them from Elsewhere.

What thresholds do people with dementia encounter in the course of their everyday lives?

People with dementia encounter a range of thresholds in the course of their day-to-day experience, including physical, social, and temporal thresholds. Through the use of hermeneutic phenomenology, this thesis was able to conclude that thresholds occurred where participants encountered phenomena beyond their control, creating a threshold that was at once managed by the participant, and beholden on outside forces. As a result, physical thresholds often manifested horizontally at doorways and windows. Social thresholds occurred between the participant and others, and were particularly evident when differentiating between trusted people within a participants 'inner circle' and those who were not, for example in contrasting Hazel's relationship with her husband, and her relationship

with her sister. Finally, temporal thresholds occurred where the present as it was lived, intersected with past as it was gathered together in memory and the future as it was looked towards. It is important to note, however, that while all of the participants in this study all routinely encountered physical, social and temporal thresholds in the course of their day-to-day lives, they differed significantly in how they drew upon their sense of dwelling, their lived history and their use of resources to manage and navigate these threshold spaces.

How do people with dementia manage threshold spaces?

While participants differed significantly in regards to the specific resources they called upon to manage threshold spaces, there were nevertheless commonalities between participants in what kinds of resources were used for what purpose. An example of this is the use of the 'inner circle' of trusted people who could be relied upon to act as confidantes, innovators and aides without fear of stigmatisation or disablement. While the makeup of this inner circle varied dramatically depending on the individuals social network and lived experience, these relationships were key to maintaining independence and managing situations that might otherwise result in disablement, whether that was through providing direct aid, or indirect help through managing physical resources like pill diaries, colanders, or technologies. I contend that it is this enabling aspect that differentiates individuals within the inner circle from those outside of it. The inner circle were always discussed in a way that aligns itself from a Dasein perspective; as individuals who interacted with the person with dementia as a whole, undiminished person with impairments, rather than a remnant of a former self, now lost to disease and decay. As a result, those within the inner circle were often the only people who could be trusted with insight into the difficulties that the person with dementia experienced in everyday life. The introduction of this vulnerability into the relationship ensured that neither kinship nor formal arrangement could guarantee access to this relational

space, and outside efforts to forcefully situate an individual into the inner circle often met with targeted acts of resistance and threshold renegotiation.

How does investigating thresholds facilitate greater insight and support better outcomes for people living with dementia?

As one of the main contributions of this thesis, it is necessary at this point to highlight the three key advantages that are associated with adopting the threshold perspective. The first of these is a core facet of the threshold concept; its nonprescriptive approach. It is only by recognising that thresholds will manifest differently for different people over the course of their lives that it is possible to gain a meaningful insight into how they are made manifest in the present moment. Participants in this study, for example, all engaged in threshold practices around the main doorways into and out of their homes, however such a finding may hold true in other cultural contexts, in intergenerational homes, or where the person was admitted to a hospital ward, and so on. This is not to say that physical thresholds would not prove meaningful in such situations. Rather, adopting a thresholds perspective that allows for a multifaceted and relational experience of space that does not presuppose the location of the threshold based the assumptions of the person without dementia.

The second advantage to the threshold perspective further builds on this foundation, by explicitly requiring those adopting a threshold perspective to engage with both 'sides' as wielding agency and power. This positioning is particularly impactful in the context of dementia research and practice, where the narratives of loss and decay too often cast people living with dementia as passive victims of a shrinking world (c.f. Duggan et al., 2008; Buch, 2015). Such an assumption is antithetical to a threshold approach, which recognises not only the external forces that shape the threshold between home and Elsewhere, self and other and so on, but the efforts and strategies employed by the individual, and their impact on the

threshold. This relationality allows for an acknowledgement of the micro and macro social forces that may serve to enable or disable the person with dementia without resorting to a nihilistic view wherein the person themselves is powerless to resist such contestations. Such an approach, therefore, would allow for those providing care services to recognise the influence wielded by both the care provider and the service user, as well as prompting meaningful reflections upon how these relations are played out in threshold spaces.

Finally, taking a threshold perspective invites a recursive engagement with both the space itself, and the forces that shape either side of the threshold. This builds both upon the first advantage mentioned above, in that it recognises the subjective nature of threshold spaces, and upon the second, as it acknowledges that changes on either side of the threshold may impact the threshold itself. This allows both for improvement in cases where, for example, the neighbourhood surrounding the person's home is altered such that it enables easier transition between home and Elsewhere, and challenges where, for example, adverse weather, changes in infrastructure or a deterioration in health shift or remake the threshold entirely. Engaging with the threshold perspective in this way, therefore, not only facilitates a meaningful discussion around the enabling and disabling factors that shape the thresholds itself, but encourage all involved to explicitly engage with people with dementia as whole and undiminished individuals with a lived present and an oncoming future.

What is the benefit of exploring the experiences of people with dementia as disabled people?

There are significant benefits to be gained from approaching dementia from a disability perspective, both for people with dementia and for the wider dementia community. The most significant of these is entirely straightforward at a superficial level, but becomes more complex and contested when examined further: people with dementia are disabled people.

The implications of adopting this position are twofold. Firstly, considering people with dementia as disabled people rather than people with disabilities necessitates a social model perspective, challenging established notions of how people with dementia become disabled. Specifically, this requires a distinction between impairment –in slowed cognition, impairments in memory, executive function, way-finding and so on– and disability, which is introduced and reinforced through societal expectations, social stigma, building design etc. Adopting a disability perspective transforms the narrative from one that constructs people as victims of dementia to one that situates them as people living with impairment who are victims of civilised oppression (Harvey, 2015). It is this oppression, and not the presence of impairment, that results in systematic marginalisation, stigmatisation, and fear. Indeed, to follow Thomas’ social-relational approach allows for a more nuanced insight of how this oppression can be enacted in the life of the individual than is achievable through the frameworks provided by the traditional social model, or other post-structuralist interpretations. Moving beyond the physical oppression of the original social model to one in which bureaucratic, architectural and political barriers are acknowledged alongside the interpersonal and internal mechanisms of disablement allows for a greater insight into the lived experiences of people with dementia for whom many of the barriers are not physical but attitudinal. Similarly, by accepting the body as a pre-social object, there is a greater opportunity to acknowledge narratives and experiences of embodied discomfort in a way that enables communication between professionals rooted in the broader disciplines of biology, psychology and sociology, facilitating a holistic approach to care. Critically, because this approach communicates in a way that is accessible to those from different disciplines, it can recognise the reality of dementia as a degenerative cognitive disease with ‘real’, pre-social biological effects while still offering a critique of those mechanisms of oppression which serve to limit what people with dementia can do, and who they can be. This final point creates

opportunities to open avenues between the growing fields of dementia research and activism with the well-established, politically powerful, disability movement. This serves to amplify the voices of people with dementia as people disabled by society, providing greater avenues for challenging the ableist assumptions that serve to undermine and oppress people with dementia, to their significant detriment.

Future Directions

This thesis makes original contributions through its introduction of the thresholds approach and its exploration of the experiences of people with dementia at physical, social and temporal thresholds; there are areas of the research that warrant further attention and opens up two primary avenues for future research.

Firstly, there is the opportunity to expand the geographic scope of the study. While this thesis explored which thresholds were meaningful for people with dementia in Central Scotland, these participants were predominantly living in urban or suburban environments where access to services including public transportation could be managed with relative ease. This is easily contrasted with the difficulties associated with accessing services such as pharmacies in the Highlands (Rushworth, Cunningham, Pflieger, Hall and Stewart, 2017). Participants in this study arranged their relationships and physical practices in a manner in keeping with living in or near large population centres, and participants often knew their neighbours by sight, but not by name. It is likely, given the particular culture associated with rural Scotland, and particularly the Scottish Highlands and Islands (for example, as described in Foster, Munoz and Leslie's 2018 investigation into Men's Sheds in the Highlands) that these thresholds would be experienced and negotiated differently by those living in these areas. As such, further research into experiences of people with dementia living in these rural settings

is warranted. Secondly, there is the potential to develop a participatory and activist study that moves beyond dementia. Although this thesis has argued for the inclusion of people with dementia into the wider disability community, and for their concerns to be addressed by disability activism, there remains a distinct divide between recommendation and action. There is, as a result, a need for future research to draw on the experiences of those disability researchers who have faced similar challenges in incorporating groups with mental illnesses or chronic illness into the wider disability community in order to identify and address potential barriers to inclusion.

Final Thoughts

This ethnographic exploration of thresholds reframes what it means to live with dementia. Viewed through a social relational lens, living with dementia is living life as a whole and undiminished person who remains powerful agents in their own right. The result is a call to challenge not only the oppressive systems of power that disable people with dementia, but to examine closely the belief systems upon which our practices are built. To what extent do we, as researchers, practitioners, professionals and members of society ascribe to the belief that an individual's worth can be measured by their cognitive capacity. How do we betray our best intentions, how do we contribute, through action or inaction, to the systems of civilised oppression which target people with dementia on the basis of their impairment? Moreover, having reflected upon our role, what do we do next?

9: Conclusion

The phrase “Someone ought to do something” was not, by itself, a helpful one. People who used it never added the rider “and that someone is me”.

(Pratchett, 1996, p111)

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APPENDIX A: MENTAL CAPACITY PROTOCOL.

CROSSING THE THRESHOLD

IS THE POTENTIAL PARTICIPANT ORIENTATED IN TIME, PLACE AND PERSON?

'Hello my name is Catherine, I'm here today to talk to you about the Threshold project...' Casually introduce questions that relate to date and time without them being too obvious, e.g. 'Before we start can I just get a few details please?'

IS THE PARTICIPANT ABLE TO TELL THEIR NAME, WHERE THEY LIVE AND THE MONTH?

(The researcher should use their discretion here. Even in the early stages of dementia it is possible that people may get dates and years wrong, this shouldn't be a 'test'. The point is to ensure that the participant is orientated to the here and now, can tell us who they are and more or less the time of year.)

PROTOCOL

SECTION 1

GIVE PERSON INFORMATION ABOUT STUDY, WHAT IT IS ABOUT AND WHAT IT WILL INVOLVE.

References

This study is looking at peoples experiences of moving between spaces: what it is like to go from being at home to being out in the neighbourhood, before coming home again. I'm interest in what these places mean to you, how they make you feel, and if anything makes it easier or harder for you to go between them. I'm particularly interest in whether this has changed as you've gotten older, or since you received your dementia diagnosis.

To do this, I would like to visit you at home several times, for as short or as long as you like. This might mean I visit you about three times for a longer period, or about six times for a short while. During my visits I would like to do a number of things with you.

I would like to talk with you about what your home, community and neighbourhood mean to you- how you think about them and how being there makes you feel. I would also like to talk about what it is like to go from your home, out into your neighbourhood and back; I would like to get an idea of the things that make this easier and harder for you.

If it is possible, I would like to have these conversations with you as we go out and about. This can be going somewhere close by you were planning on visiting anyway, or somewhere in your neighbourhood that we can visit together. If it is alright with you, I would like you to wear a small microphone during these walks so I can accurately capture what you are saying.

I would also like you to take photographs of places or items that are important to you as you move around between being at home and being out in your neighbourhood. You can use your own device for this, like a phone or an ipad, or I can lend you a camera to use if you like. We will talk about these pictures together the next time I visit you, before we go out and about.

During this research you might notice that I spend a lot of time taking notes. This is to help me remember what has happened during my visit, what I was thinking, and anything else that might be

useful in my next visit. You can ask to see my notes at any time.

If you wanted to stop a visit early, or to stop being part of the study entirely, you only have to let me know. It is your right as a participant to withdraw from the study at any time. You do not have to tell me why you want to stop if you don't want to.

"Do you have any questions you'd like to ask me anything from the information sheet?"



SECTION 2

The participant will be encouraged to talk to a friend/relative/carer about the project, and also have them present at the consent process. Different options in terms of the formats of information and how consent is recorded are detailed below.

The researcher will go through the information sheet with the potential participant.

1. Has the person understood the information?

"Given what I've just said, or what was in the information sheet; could you tell me in your own words what you think this study is about?"

2. Is the person able to retain the information?

"Could you tell me what you would do as part of the study?"

References

3. Has person understood the information relevant to their decision whether to take part in the study?
4. Has the person used the information given in deciding whether to take part?

“Are you happy to take part in the study? Can you tell me why?”

5. Has the person communicated their decision to you on whether or not to take part?



SECTION 3

EVIDENCE OF THE ABOVE FIVE POINTS

1. **Understanding** means being able to grasp the facts and being able to weigh the options of against one another.

In answering the questions in section 2, the participant will demonstrate their comprehension of what is being asked of them as well as their ability to retain information.

The researcher will maintain a record of the capacity check process and the conversation held with the participant.

2. Can the person use their understanding to weigh up their choices and make a decision? Researchers can gauge this through asking about specific parts of the study and how the participant would be involved.

'What do you think this means for you if you decide to take part?

Can you tell me a little bit about how many times I will visit you?

Can you tell me if you would prefer longer visits, shorter visits or a mix?

3. The participant is able to communicate that they want to take part in the research and wh

IS THE PERSON ABLE TO PROVIDE EVIDENCE AS ABOVE?

YES



Advise the participant that they may like to identify a personal consultee or advise who their welfare attorney or guardian is at this point in case they should lose the capacity to make decisions regarding the research project during their participation (refer to the information booklet).

NO



Find out if the person is feeling unwell or if there is any reason why they might not be able to show capacity to consent today. If they have been poorly talk to their family carer and consider whether it may be better to return another day to carry out consent. If the person does not have capacity for the first stage of the fieldwork then they will not be recruited to the study.

Ask the person if they agree to take part in the study and if so ask them to sign a consent form.

Offer:

1. A standard consent whereby the person

agrees to and initials each aspect of the study that they agree to. This includes understanding about voluntary withdrawal and issues of confidentiality along with how the interview will be recorded. The person is then able to sign, print and provide the date. The participant will receive a copy of their consent.

2. The altered consent form allows the participant to tick the boxes to show that they have read and understood each aspect of the study that they are agreeing to. They will be offered this alternative if they are having some difficulty with writing and are struggling to carry out the process of initializing each box. They will be asked to sign the form but again may be supported with printing their name and dating the consent. We will ask for their family carer or a nominated person to be present to ensure that they can support the participant with the process of consent. The participant will receive a copy of their consent.

3. If the person is able to give informed consent but can no longer write with ease then they will have their consent process filmed/audio-recorded. This will be stored in a consent file on university systems in the same way as for written consents. An

accompanying form will be completed with a witness to the recording process. This will be kept on file and the participant will be given a copy.

Process Consent

At each subsequent research visit the researcher will undertake a verbal assessment of the participants' desire to remain within the research study.

She will remind them that their participation is voluntary and that they are free to stop the interview at any stage, or to withdraw completely from the study at any time, without prejudice.

The researcher will remind participants that the data will be confidential and of how it will be stored.

She will check that the participant still wishes to continue with the research project and the next data collection exercise.

This Protocol was Adapted from the Neighbourhoods; Our People, Our Places study.

This Protocol has been drawn up with reference to the:

The Adults with Incapacity (Scotland) Act 2000

The Mental Capacity Act, (2005) for England and Wales

Communication and Assessing Capacity: A guide for social work and health care staff.

(2008) The Scottish Government: Edinburgh.

Dewing, J 2008, 'Process consent and research with older persons living with dementia', *Association of Research Ethics Journal*, vol. 4, no. 2, pp. 59-64.

APPENDIX B: INFORMATION SHEET.



Crossing Thresholds Study Participant Information Sheet.

Hello! My name is Catherine

I am a PhD student at the University of Stirling



About My Study

I am interested in how people with dementia move
between spaces

Like from their home to their neighbourhood or
community.



I would like you to help me with my project.

I would like to visit you at home

These can be short visits or long visits, it depends what works for you.



I can come to your home up to six times, so if you would like short visits, or are tired or unwell, I can come back another day.

We will talk about what 'home' means to you

And what your community and neighbourhood mean to you.



Then we will talk about what it is like to move between these places.

What makes it easier?

What makes it harder?

What do you do to help you get out and about?



Some of these chats might take place in your home, I would like to audio or video record these. You can choose which you would like.

I would like to come with you on a trip into your neighbourhood.

It doesn't have to be anything special; if you are going for your groceries, that's just fine.

I would like to audio record our chats while we are getting ready to go out, taking a walk and coming back into the house. For this you would wear a small microphone clipped to your coat or jacket, and carry the recorder in your pocket.

You can always ask to see, or hear, any of the audio or video I have taken during my visits.

References

Things I Need you to Know

You do not have to agree to talk to me, or take part in my study.



Even if you say yes now, you can change your mind at any time.

You will still get the help you need if you decide not to speak to me.

You can ask your friends or relatives what they think before you give your answer.

I will keep your information confidential; I will not tell anyone your name or where you live.



I will only share something you tell me if it indicates that someone else is at risk of harm.

I would talk to you about this before I speak to anyone else.



The films, Photographs, Writing and Audio records of our meetings will be stored safely.

If I would like to use any film or photographs that might identify you (at meetings, or in articles) I will always ask.



What Now?

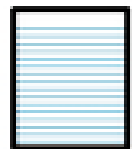
If you would **not** like to take part in the study, please let me know when I speak with you again.

If you would like to take part I need to keep a record that you have agreed to do so.

You can do this in two ways;

You can sign a consent form

Or we can film your decision.



In case you become unhappy, stressed or unwell during one of my visits I would like to take the name and telephone number of someone I can call to check in on you after I leave.

I will not tell this person what we have spoken about without your permission.



Because you have the right to change your mind between visits, I will check again each time I visit with you to make sure you are still happy to take part.

If you are not happy, or feel uncomfortable, you can choose to:

Stop a visit- I will make sure you are in your own home, and go away. I will call and check on you 3 days later to see if you want to schedule another visit.



Stop taking part in the study- I will make sure you are in your own home, and go away. I will not visit



you again, but I will use the information that came out of our previous visits.

Stop and withdraw your data from the study- I will make sure you are in your own home, and go away. I will not visit you again, and I will not use any information from our previous visits in my study.



You do not have to tell me why you want to stop if you do not want to: It is your choice to take part or not.

Who do I speak to?

If you would like to speak to me, you can reach me by:

Phoning 01786 467623 and asking for Catherine Pemble.



References

Emailing catherine.pemble@stir.ac.uk



Mailing Room 3T5
School of Applied Social Science
Colin Bell Building
University of Stirling, Stirling
FK9 4LA



If you have a problem or a complaint, you can talk to Dr. Richard Ward by:



Phoning 01786 466324



Emailing richard.ward1@stir.ac.uk



Mailing Room 4S43
School of Applied Social Science
Colin Bell Building
University of Stirling, Stirling
FK9 4LA



APPENDIX C: CONSENT FORM.



Crossing Thresholds Study

Participant Consent Form

Please initial:

<p>I have read and understood the information sheet for Crossing Thresholds study.</p>	
<p>I have been given the chance to think about the information, ask questions and receive satisfactory answers about the Crossing Thresholds study.</p>	
<p>I know that my participation is voluntary and that I can choose to stop or withdraw at any time.</p>	
<p>I know that if I choose to stop, or withdraw, I do not have to give a reason.</p>	

I understand that all information will be kept confidential.	
I agree to being visited by the researcher (Catherine Pemble).	
I agree to allow the researcher (Catherine Pemble) to take notes during her visits.	
I agree to interviews being audio recorded.	
I agree to interviews being video recorded.	
I agree that the researcher can use the pictures I take for this study for analysis.	
I know that the researcher will not use any image or information that can be used to identify me in published work.	

References

I understand that the research team may use pictures or images for published work where I or my home cannot be identified.	
I agree to the use of anonymised quotes in publications.	
I agree to take part in the above study.	

Participant Name _____

Signature _____

Date _____

Researcher Name _____

Signature _____

Date _____

If I become unhappy, stressed or unwell during one of Catherine Pemble's visits, I would like her to contact:

Name _____

Telephone _____

Relationship _____