LIVING WHILST DYING:

Exploring ‘a life worth living’ for people with heart failure living at home towards the end of life



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ABSTRACT

BACKGROUND: End of life literature is dominated by narratives of deterioration and death. Research is predominantly conducted in hospitals or hospices, involving terminal illnesses such as cancer during the final weeks or days of life. For those with heart failure, health can fluctuate over months and years through turbulent trajectories from diagnosis to (sometimes unexpected) death. Through anthropological exploration of everyday bodily experiences of living, I sought to illuminate what kind of life people deem 'worth living' whilst dying.

METHODS: Positively reframing dying around living well at home, and taking a phenomenological approach, I undertook ethnography in people's homes. I conducted life history interviews and ongoing participant observation with fourteen participants (67-98 years old) over eighteen months. This was supplemented by multiple conversations with family members, observations of two specialist heart failure support groups, observations of eight heart failure clinics, and forty home visits with heart failure specialist nurses.

FINDINGS: Throughout the process of living whilst dying with heart failure, bodies, lifeworlds, and priorities fluctuate as participants continuously experiment with how they move through daily life. I explore how this negotiation of a life that participants deem meaningful and worth living is enacted in three ways: attending to and interpreting one's body; sensuous engagement with the lifeworld and material relations; and wrapping up one's narrative whilst settling into stillness. I build on work by Scarry (1985), Mattingly (1994), Mol (2010), and Ingold (2010) to develop a theoretical framework of iterative unmaking/remaking as people position themselves towards the end of life.

CONCLUSIONS: Living whilst dying with heart failure is characterised by gradual slowing and settling into stillness, as participants turn away from making altogether, and towards 'being done' with living. Attending to processes of making – through the movement and stillness of bodies, things, and stories – allows us to reconsider dominant biomedical discourses of care, technologies, and decision-making towards the end of life. Making a life worth living is not complete until stories no longer look to the future in some way, and movement is stilled. Settling into stillness, and being done, might thus be respected.

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TABLE of CONTENTS

LIST of FIGURES i

LIST of ABBREVIATIONS ii

1. CHAPTER ONE - Introduction 1

1.1. INTRODUCTION: Making, Moving, Living 2

1.2. JOURNEYS THROUGH LIVING and DYING: A Question of Vitality 5

1.3. THE CLINICAL CONDITION: Heart Failure 7

1.4. BIOMEDICAL CONTEXT: Managing Heart Failure towards End of Life in the UK 9

1.5. LITERATURE CONTEXT: A Brief Introduction to Death and Dying 12

1.6. RATIONALE: Arriving at a Research Question 15

1.7. PHENOMENOLOGICAL APPROACH 16

1.8. THEORETICAL FRAMEWORK: Unmaking and Remaking 18

1.9. THESIS STRUCTURE 22

2. CHAPTER TWO - Literature Review 25

2.1. INTRODUCTION 25

2.2. MEDICALISATION and BIOMEDICALISATION at END OF LIFE 26

2.3. TECHNOLOGIES and MATERIALITIES at HOME 30

2.4. MAKING DECISIONS towards the END OF LIFE 34

2.5. QUALITY, QUANTITY, and LIVING WELL 40

2.6. MAKING SENSE and MAKING MEANING 43

2.7. SUMMARY: Making a Life Worth Living 46

3. CHAPTER THREE - Methodology and Methods 48

3.1. INTRODUCTION: Researching Death and Dying 48

3.2. METHODOLOGY: Anthropological Orientations 50

3.3. METHODOLOGY TO METHODS: Implications for Empirical Study 53

3.4. ETHICS: Approval and Governance 55

3.5. RESEARCH PROCEDURES: Overview 56

3.6. RECRUITMENT: Access and Participants 57

3.7. RESEARCH STRATEGY: Exploratory Phase 61

3.8. LAYERING METHODS: Ethnographic Phase 63

3.9. ANALYSIS: Handling and Presenting Data 66

4. CHAPTER FOUR - Portraits: living whilst dying, dying whilst living 69

4.1. INTRODUCTION 69

4.2. Rosemary 70

4.3. Emily 73

4.4. Nicholas (Nick) 75

4.5. Carol 78

4.6. Theodore (Theo) 80

4.7. Nancy 83

4.8. Noémie 86

4.9. Baylee 90

4.10. Philip 93

4.11. Norma 97

4.12. Kent 100

4.13. Jeanne 104

4.14. Kenneth 106

4.15. Edwin (Ed) 109

5. CHAPTER FIVE - Unmaking and remaking everyday lifeworlds: the fraying of life around the edges 111

5.1. INTRODUCTION 111

5.2. THEORETICAL PERSPECTIVE 113

5.3. FINDINGS 120

5.3.1. “You just have to sit down until you can go again.” 120

5.3.2. “You have to listen to your body.” 126

5.3.3. “There are good days and bad days.” 131

5.4. DISCCUSSION: Bodily Attitudes and Dispositions 134

6. CHAPTER SIX - Material extensions of the self: moving through everyday lifeworlds 142

6.1. INTRODUCTION 143

6.2. LITERATURE SUMMARY 144

6.3. FINDINGS 146

6.3.1. Navigating structural change 146

6.3.2. Moving with and relating to things 151

6.3.3. Keeping things close, letting things go 156

6.4. DISCUSSION: Negotiating With and Through the Body 160

7. CHAPTER SEVEN - Looking back and settling into stillness 170

7.1. INTRODUCTION 170

7.2. LITERATURE SUMMARY 172

7.3. FINDINGS 174
7.3.1. “I think I’m done.” 174
7.3.2. “Life became more worth living again.” 180
7.3.3. “We all knew it wasn’t good enough.” 185
7.4. DISCUSSION: Away from Making 188
8. CHAPTER EIGHT - Reflections and Conclusions 195
8.1. SUMMARY: Expressing the Inexpressible 195
8.2. DISCUSSION: Questioning Dominant Narratives 198
8.3. IMPLICATIONS and FUTURE DIRECTIONS 206
9. EPILOGUE - Saying Goodbye 211
10. BIBLIOGRAPHY 214
11. APPENDICES 230
11.1. APPENDIX I: Fieldwork Logs 230
11.2. APPENDIX II: Participant Information Sheet (V2) 240
11.3. APPENDIX III: Participant Consent Forms 245
11.4. APPENDIX IV: Interview Guides 247
11.5. APPENDIX V: Ethical Approval 250

LIST of FIGURES

Figure 1: Heart Failure Trajectory……8

LIST of ABBREVIATIONS

ACP	Advanced Care Planning
ALT	Assisted Living Technology
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
DNAR	Do Not Attempt Resuscitation
HFSN	Heart Failure Specialist Nurse
ICD	Implantable Cardioverter-Defibrillator
OT	Occupational Therapist

CHAPTER ONE

Introduction

I heard once that roadkill blackbirds make old women cry
And day-shine filtered through touchless blinds drench sunlight
Into empty houses in all the wrong places,
Where half-unfinished projects puncture half-unfinished lives
Watched and wondered at, loved and lingered on.
Where do they flee before they have fled?
Is there a hiding place in the memory of doing?
Where no one fathoms what dying is supposed to feel like;
What hurts and why, what heals and what doesn't.
'We don't cry for ourselves, or what we let go,'
Sighing to settle into the experience of enough –
'We cry for the blackbirds, and lean back from living,'
And still the motion of making.
So I watch their worlds for frail hands' lost purpose:
Delicate and shadow-white, nails long in disuse and
Veins proud through paper skin.
These fingers wove stories, changed patterns,
Shaped lives – now rest.
The princess-idle hands she holds in her lap
Palm-up in front of me, as if showing me, telling
'Empty-handed'
That she had nothing left.

- Poetic excerpt from field diary entitled 'Her Romanov Hands', dated 21/08/2018, based on no individual participant, illustrating part of how I made sense of my experiences, thoughts, and findings during this project.

1.1. INTRODUCTION: Making, Moving, Living

What does dying feel like?

For those with chronic, degenerative, terminal illness, dying may be incremental; the trajectory uncertain and fluctuating. In this thesis, I explore how dying may be experienced in the ebb and flow of feeling well and unwell. Processes of dying may be evident in everyday experiences: being able to do things and being unable, keeping things close and letting things go, looking to the future, and looking to the past, moving and being still. For those with heart failure, dying is gradual and chronic, and necessarily involves living. In particular, it involves negotiating how to continue living in ways that people themselves deem 'worth it'. This negotiation occurs in the context of the home, where people live their daily lives and manage their health over their life-courses.

Bodies, circumstances, lifeworlds, and priorities are constantly shifting, not only as a result of ill health. To accommodate these shifts, people negotiate the ebb and flow of terminal heart failure (and potentially co-morbidities) by making adjustments in many aspects of their lives. Whilst also striving to continue going about daily living in recognisable ways, such accommodations must be negotiated and renegotiated as time goes on. I frame these (re)negotiations here as persistent, attentive unmaking and remaking. This framework is grounded in and inspired by anthropological considerations of making (e.g. Ingold, 2010) in relation to ill health (e.g. Mattingly, 1994; Mol et al., 2010; Scarry, 1985).

This thesis is, at its heart, an ethnography. Here, I embrace complexity and lean into uncertainty, much as those with whom I spent time have done. I could have started with sensitively recounting all the times I cried in my car after a visit with a participant, to introduce my experiences researching death and dying. Or I could have related the few but memorable occasions when I opened fieldwork logs on my computer and incongruously typed the word 'deceased' next to a participant's pseudonym and initials; taking pause over this oddly administrative yet personal ritual. But that is not my aim here.

One of the central aims of this thesis, as the title suggests, is to highlight the importance of living whilst dying, and living well. I do not mean to diminish or ignore the imminence of and potential sadness involved in death and dying. Rather, I wish to emphasise that the decisions, actions, and stories people may undertake to make – or not – towards the end of life are as geared towards a life worth living, as much as how to die. I thus offer a framework to understand how these negotiations might unfold. Research on terminal conditions, often cancer, predominately focus on institutional and informal care at the end of life. However, there is relatively little known about the mundane, fleshy processes of gradual, chronic dying at home with other kinds of ill health. A key objective of this thesis is therefore to contribute insights into how people with heart failure compromise in and navigate daily living at home, with and through their bodies.

I conducted detailed ethnography with fourteen people in their homes in Oxfordshire, UK. They were aged 67 to 98 years old, a spectrum of people who represent some of the possibilities of living whilst dying with heart failure at home. Some had severe heart failure and multiple co-morbidities, whilst others had mild heart failure; some were married, others widowed; some wealthy, some not; some with large families, some more solitary. Without asking too much from participants, I spent time going about some of their daily activities with them; building relationships with them and their families; and continuing to remember and think about them after they died, or I had drawn my research to a close. I feel humbly privileged to have been invited into their lives, and most of all to hear their stories. Amongst the pain of gradual, chronic dying and vicissitudes of life itself, they told me about many of the most meaningful things in their lives. Often, they showed me how thankful they were to have lived such a good life. With this understanding of history and narrative, people's homes struck me as a site of lifelong daily activity and normalcy – but with a seeping sense of alterity. The people I spent time with experimented, in larger or smaller ways, with how it is possible to continue going about these meaningful daily activities, things, and plans; feeling their way through what they wanted to preserve in moving forwards, and what they could let go.

Throughout this project, I interweave what is life-affecting with what is life-affirming. This mirrors the ebb and flow of what shapes and is shaped by fluctuations in someone's lifeworld and body. In moving through fragments of daily living with participants, I became sensitised to the importance of movement through the lifeworld. Movement encompasses the everyday active engagement in doing and being in place that furnishes people's lives with stories, networks, and specificities. It involves moving with others and material things, as well as moving one's own life story forwards. In paying attention to movement, therefore, I became particularly aware of the slowing and eventual stilling of that vital movement. In stillness, people are not doing in the same way; they become less engaged in creating stories, or driving their life forwards.

Settling into stillness, people turn away from making entirely. Less and less, they engage in experimenting with changes and adjustments in response to their shifting bodies, lifeworlds, and priorities. Having let go of many of the meaningful things in their lives, they may come to find that the effort of sustained unmaking and remaking is no longer worth it; that they are done with living. Many of the decisions that must be made towards the end of life – to do with clinical treatments and death itself – may thus be at odds with settling into stillness. In stillness, participants were no longer investing in imagining different goals and endings, or tinkering with how to better go about living. It is therefore a further aim of this thesis to interweave notions of, and an important sensitivity to, movement and stillness within the study of dying. Acknowledging how people feel their way through living, and how illness may disrupt this movement, understandings of chronic dying may be equally informed by the nature of movement and sensuous engagement in the lifeworld.

The importance of movement, stillness, and making in this thesis is underpinned by established and innovative anthropological and phenomenological methods and epistemology, where moving with people is paramount. As above, these perspectives foreground how the phenomenological condition of being-in-the-world involves movement through it, the nature

of which is both creative and destructive of local lifeworlds and experiences. Building on such insights, I suggest how this entails iterative unmaking/remaking, which goes on throughout life. My focus is therefore on making, moving, and meaning as vital aspects of living. It is through these common threads that I approached the people with whom I spent time, the handling of data, and construction of this thesis. A core sinew of these notions is in an understanding of vitality itself – what is vital to a life worth living?

1.2. JOURNEYS THROUGH LIVING and DYING: A Question of Vitality

I started my exploration into death and dying with pursuing an understanding of vitality. I wanted to acknowledge that dying is a part of living, and therefore informed by the lifelong experiences that people collect along the way. I wanted to explore how we reach the point at which we say: 'Enough is enough, I'm done with living.' Informed by my own training in anthropology at undergraduate and graduate level, as well as family experiences with terminal degenerative illness, to me this never seemed like a straightforward question of quality and/or quantity of life. I sought answers initially in philosophy.

The term vitality has been defined in many ways, grounded in the notion of *élan vital,* the 'vital force' or 'impetus' of life itself (Bergson, 1911; F. C. Ross, 2014:4). Georges Canguilhem (2008) posited vitalism as a way of explaining the vital energy and movement with which all living things are imbued, i.e. the animating principle of life. These notions were starkly replaced during the Enlightenment era with 'mechanism'. Canguilhem, however, suggests vitalism as a philosophical stance that there is something more than purely chemical and physical forces that create and sustain life itself as a form, and experience (Rabinow & Caduff, 2006). Vitality, in this sense, is not accessible through biomedicine or science, but rather emergent to living.

Discussing the opposition of mind and body that arises in biological determinism and mechanistic understandings of life, Canguilhem explores the knowledge that we have of life (e.g. in the life sciences), but also the knowledge that arises from and is reincorporated into the experience of living. For Canguilhem, in other words, there is knowledge that we have of

life when we take life as an object, but there is also knowledge that life itself produces. Although Canguilhem's vitalism was further-reaching than this, what struck me was how far vitality is therefore grounded in the lived, experiencing body; an inexpressible quality that escapes being apprehended by the life sciences (Elden, 2019:36-43; Greco, 2005:17-19). Further breaking down boundaries between mind and body, what is considered animate and inanimate, political theorist Jane Bennett (2010) suggests that all kinds of materials have vitality, as they interact, move, and recombine. She suggests that attending to the vitality of matter allows a "greater appreciation of the complex entanglements of humans and nonhumans." (Bennett, 2010:112) Sensuous engagement with materiality is explored further in Chapter 6 of the thesis.

Canguilhem's conceptualisation of vitality fits well with phenomenology, and is indeed mobilised in phenomenological studies of health. For example, Smith and Lloyd (2006:249) posit a phenomenology of vitality to explore the meaning of health; they suggest that vitality is the "essential movement of the body." Smith and Lloyd (2006:263) assert that health means "to be able to," particularly to be able to continue the various projects of living in which people are engaged. As Merleau-Ponty (1962) states, people exist in movement. However, Smith and Lloyd (2006) contrast the rhythmic movements of health – breathing, walking, living – with the disordered, irregular, unsettled movements of ill health.

Building on this, Dahlberg et al. (2009) utilise concepts of vitality, movement, and peace to construct an 'existential view of wellbeing'. An existential view of wellbeing means one that is oriented towards existential possibility, rather than already being categorised (e.g. physical, psychosocial, etc.). They describe being-in-process, where people make meaning in the lifeworld, and thereby suggest 'lifeworld-led care' in lieu of patient-led care. Vitality as wellbeing is therefore a patient's "capacity for movement in a sense of being able to move into possibilities of engagement that connect us with others, other space, other times, and other moods." (Dahlberg et al., 2009:267) Giving examples of how those with Alzheimer's go about gardening and cooking, Dahlberg et al. (2009:268) illustrate the possibilities and importance

of "find[ing] a sense of vitality and movement that [is] possible even within severe illness." It is in the vein of moving and making that the undercurrent of vitality runs through the thesis, discussed in the final chapter.

1.3. THE CLINICAL CONDITION: Heart Failure

Exley (2004:119), in her review of sociological literature on end of life, writes of "the disadvantaged dying," i.e. those who are less likely to be told that they are dying, and less likely to be able to access palliative care resources. She cites heart failure as one of these cases. I first considered heart failure as an illustrative ethnographic example when I saw the following graph (see Figure 1). Heart failure is a clinically complex condition affecting and representing a significant proportion of those managing chronic illnesses at home: 900,000 individuals in the UK, 67% of whom are over the age of 75 (BSH, 2013; NICE Guideline, 2010). Linked to coronary heart disease, often coinciding with multiple co-morbidities and frailty related to old age, heart failure as a diagnosis is often ill understood by patients (Glogowska et al., 2016).

The lived experience of heart failure for patients is characterised in qualitative research as highly uncertain and turbulent, with deceptive periods of relatively good health embedded in a general narrative of deterioration and loss of control (Greenhalgh et al., 2017; Kaufman et al., 2011). The typical trajectory of heart failure is simplified and given below (Figure 1); the graph also contains contextual information about the grading and severity of heart failure, from the hermeneutic review on heart failure by Greenhalgh et al. (2017). The graph illustrates the fluctuating journey from diagnosis to death characterised by up-titration of medications, increasingly frequent hospitalisations relative to periods of good health, and correspondingly reduced quality of life over time.

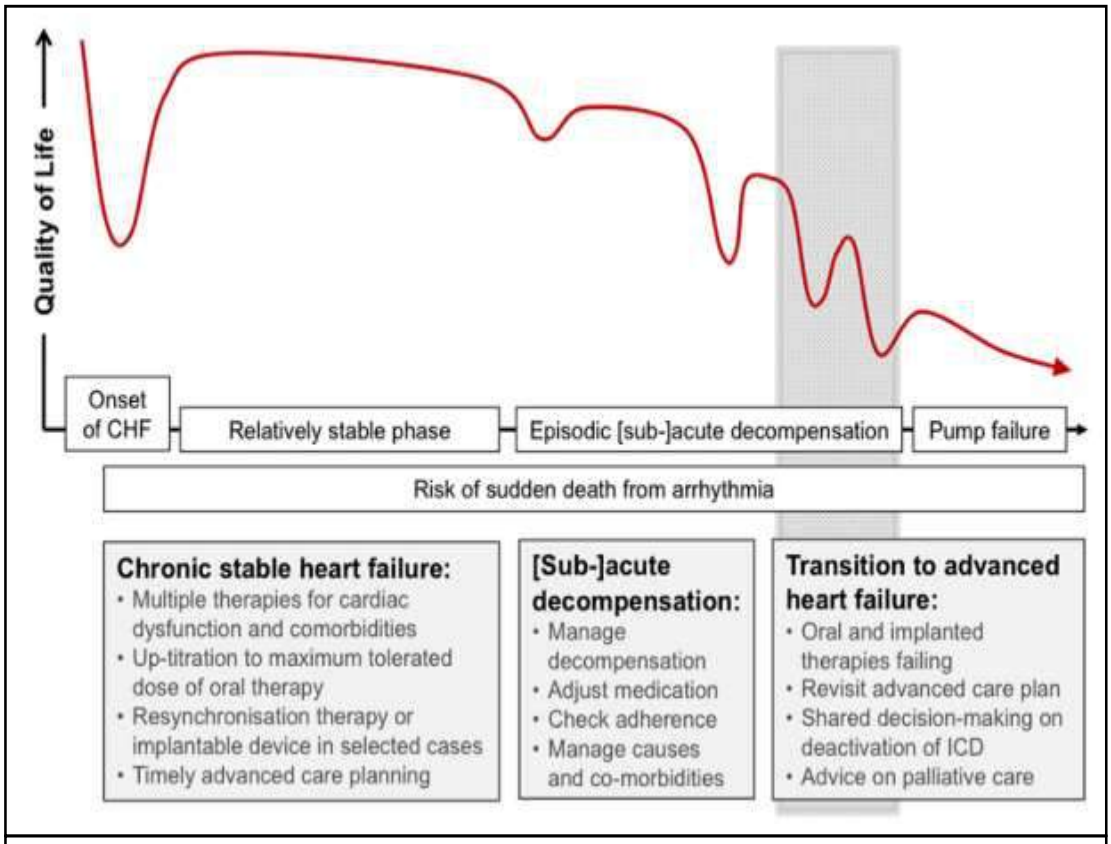


Figure 1: The clinical trajectory of heart failure over time in terms of quality of life, reproduced with permission from Greenhalgh et al. (2017:161)

What this graph so devastatingly illustrates is the vast amount of uncertainty that characterises heart failure. As shown, death in heart failure can occur as part of a natural progression or unexpectedly. Although mortality rates in heart failure may be higher than some cancers, heart failure patients are treated very differently: whilst cancer is treated as terminal, heart failure is treated more habitually as a chronic condition (Kaufman et al., 2011; Klindtworth et al., 2015; Steinhauser et al., 2011). Healthcare practitioners find it very difficult to discuss end of life with heart failure patients, citing a number of barriers including: the clinically ambiguous/variable nature of heart failure, uncertainty of prognosis, difficulty isolating end of life in heart failure, clinician training and personal feelings, lack of palliative care resources for heart failure patients, worry of perpetuating fear of death rather than hope of recovery, and patients changing their minds about treatment preferences (Clark et al., 2012;

Hjelmfors et al., 2014; Hopp et al., 2010). Further compounding the issue, there is a lack of consensus definition of palliative and end of life care (Pastrana et al., 2008). Poor communication between healthcare practitioners and patients has contributed to lack of patient understanding of diagnosis and prognosis, potentially unnecessary treatment, lack of planning for end of life care and events, and patient values being overlooked (Glogowska et al., 2016; Jones et al., 2017; McNamara, 2001; Östman et al., 2015).

1.4. BIOMEDICAL CONTEXT: Managing Heart Failure towards End of Life in the UK

Equipped with an overview of heart failure itself, and phenomenological premises about the importance of the body, movement, and sensuous engagement with the lived environment, I now turn to the biomedical landscape of primary care management of heart failure in the NHS and the resources available to patients. This context maps the (primarily biomedical) support and points of contact that punctuate participants' lives, resources which I organically encountered during fieldwork; I further highlight the specifics of Oxfordshire in Chapter 3. This landscape also underlines the need to understand diverse aspects of daily living beyond the biomedical that may equally inform how people feel about their lives, how care is undertaken, and how end of life decisions are made.

Heart failure in the UK has been described as an ongoing 'epidemic' (Cowie, 2017; Redfield, 2002). In the UK, 10% of those aged over 70 have some form of heart failure; between 20%-40% of patients die within one year of diagnosis (British Heart Foundation, 2017). As described above, there is a concomitant paucity of resources to deliver consistent, quality care (Cowie, 2017; Morton et al., 2018; Riley & Masters, 2016:G43). Compounded by the unpredictable and fluctuating trajectory of heart failure, reports from health organisations (e.g. NHS, Health Foundation, Heart Failure Policy Network) principally highlight the need to address patient experiences of repeated hospitalisations, poor quality of life, and sudden death; being discharged home from hospital after an acute decompensation is found to be a

particularly vulnerable time (Connolly et al., 2014; Sutherland, 2010; The Heart Failure Policy Network, 2018).

Visions of high-quality care in heart failure call for holistic individualised care that flexibly responds to patients' changing needs across the disease course. There are, however, systemic challenges to implementing this in practice (Chalton, 2018; Cowie, 2017; Morton et al., 2018). Key challenges are seen to revolve around: (1) smooth transitions between acute secondary and long-term community (primary) care; and (2) communication between secondary and primary healthcare providers (Masters et al., 2019; NICE Guideline, 2018; Riley & Masters, 2016; The Heart Failure Policy Network, 2018). There is therefore an emphasis on "integrated care" and management, delivered through "multidisciplinary teams" responding to the "multisystem dysfunction" characteristic of heart failure (Cowie, 2017; Morton et al., 2018:1376; Otto et al., 2018; Riley & Masters, 2016).

Practical approaches to delivering seamless, coordinated acute hospital and long-term community care include: "Heart failure management programmes, structured discharge planning, medicines reconciliation, nurse-led 'in-reach' and 'out-reach' approaches, and long-term follow-up and monitoring." (Riley & Masters, 2016:G43) Although these kinds of recommendations are widely cited in guidelines, levels of adherence are found to be disappointingly low (Masters et al., 2019; Riley & Masters, 2016). This has partly led to a plethora of reports suggesting pathways and guidelines for implementation (Otto et al., 2018). There is also an emphasis on empowering and engaging patients and their families for self-care and self-management (Schjoedt et al., 2016; Sutherland, 2010). As this thesis is concerned with how people live with heart failure at home towards the end of life, and the healthcare providers I encountered in these contexts, I focus on primary and community care resources available.

Multidisciplinary heart failure teams in community include an array of practitioners; their overarching aim is to deliver the "right care from the right person at the right time" on an

ongoing basis (Morton et al., 2018:1376). These include, but are not limited to: GPs, heart failure specialist nurses (HFSNs), occupational therapists, pharmacists, community matrons, palliative care specialists, and day- or live-in carers (Chalton, 2018; The Heart Failure Policy Network, 2018). Practitioners are involved in provisioning a number of resources to monitor and manage symptoms, medications, and side-effects. For example: standard GP appointments, specialist cardiac clinics, home visits, exercise-based cardiac rehabilitation programmes, support groups and workshops, and day-centres (Chalton, 2018; The Heart Failure Policy Network, 2018). However, access to such resources for heart failure patients and further provision specifically for palliative care, is often considered a 'postcode lottery' (e.g. Masters et al., 2019; Vogel, 2011). During my experiences in Oxfordshire, I was struck by how much of HFSN time seems to be taken up by liaising between different practitioners and teams; but similarly how far practitioners of many kinds try to visit patients at home when possible.

The overarching narrative of heart failure is that symptoms gradually get worse, and palliative care becomes relevant; however, as discussed above, end of life in heart failure is difficult to isolate and manage, and many resources are not aimed at heart failure patients often with multiple co-morbidities (Boyd et al., 2009; S. A. Murray et al., 2005; Vogel, 2011). This partly leads to the relatively late referral of heart failure patients to palliative resources (Masters et al., 2019; The Heart Failure Policy Network, 2018:23). A 2014 comparative study using a primary care database found that whilst almost half of all cancer patients in the UK are on the palliative care register, only around 7% of those living with heart failure are registered (Gadoud et al., 2014). In particular, hospice services predominantly cater to and care for those with cancer, resulting in a large unmet need for specialist palliative care which is less readily accessible to those with heart failure (Johnson & Brice, 2017).

Although palliative care generally adopts a biopsychosocial-spiritual approach (e.g. Steinhauser et al., 2011), in cases of heart failure there is concomitant emphasis on the necessity of advanced care planning (ACP) (American Heart Association, 2012; Cowie, 2017;

NICE Guideline, 2018; Singh et al., 2019). ACP in heart failure primarily involves ascertaining patient treatment preferences, for example in terms of signing 'do no attempt CPR' orders or deactivating internal cardiac defibrillators (Connolly et al., 2014; Singh et al., 2019; Whellan et al., 2014). With the unpredictable trajectory and risk of sudden death in heart failure, ACP is recommended as early as possible so that end of life decisions do not exclusively get made in acute situations under pressure (Connolly et al., 2014). However, ACP is rarely undertaken by clinicians, citing disease-specific and general barriers, as above (Johnson & Brice, 2017; Singh et al., 2019). These circulate around unpredictability, and the difficulty of starting discussions about death and end of life when patients may not necessarily understand that they are dying.

1.5. LITERATURE CONTEXT: A Brief Introduction to Death and Dying

Anthropologist Margaret Lock (2002:192) writes of death and dying as an event and a process, considering how these relate to the ebbing of a "vital essence" at once or over time, are tied to a single bodily organ, and are reckoned socially. Once focussing on ritual and social aspects, the anthropology of death and dying has further developed critical lenses for encountering biomedical practices and innovations (Kaufman & Morgan, 2005; Panter-Brick & Eggerman, 2018; M. Singer et al., 1990). Indeed, "experiences of dying benefit from being situated and analysed in sociocultural context." (Kellehear, 2009a:338) Whilst death and dying are taken as human universals, anthropology seeks particularly to highlight the diversity of aspects and practices that mutually constitute and shape these 'universals' in specific contexts (Becker & Kaufman, 2004; Green, 2008; Hockey et al., 2010). An anthropology of dying therefore often foregrounds "the lived experience, subjectivity, and particularity" that is less emphasised in biomedical accounts (Kaufman, 2010; Krawczyk & Richards, 2019; Rosaldo, 1989:173).

It has long been noted that death presents a challenge to biomedicine as that which cannot be cured (Kaufman, 2010; Navarro, 2001; Tulle, 2015), signifying the failure of science and medicine, and the triumph of nature over culture. As Sankar (1984:274) poignantly states, it seems that "western medicine wages war not against disease, but against death." In a literature

review of social science writing on dying, Kellehear (2009b:19) highlights the focus on negative aspects of dying, as most studies "contribute little in the way of description and understanding about positive aspects of dying." Kellehear thus calls for more personal narratives from those dying themselves, as well as focussing on different populations, including ageing and other kinds of terminal illness. This call is echoed by others in similar fields (Borgstrom & Ellis, 2017; Broom, 2015; Exley, 2004; Hockey et al., 2010; McNamara, 2001).

The nature and organisation of death and dying has transformed over the last century, in combination with demographic and sociocultural changes. According to the model of epidemiological transition (Olshansky & Ault, 1986; Pickard & Rogers, 2012), reflected in global morbidity and mortality statistics (C. J. Murray & Lopez, 1997; WHO, 2014), the burden of disease is shifting in many developed countries from communicable to non-communicable disease, into an "age of delayed degenerative disease" (Olshansky & Ault, 1986); life expectancies are extended, and sudden death is far rarer. Historian Philippe Ariès (1975), reviewing historical European treatments of death and dying, argues that where once death and dying was visible and talked about in community, as people habitually died suddenly in their own homes, death is now 'hidden' in medical institutions such as hospitals, care or nursing homes (Ariès, 1975; Glaser & Strauss, 1965; Gorer, 1965; Mellor & Shilling, 1993; Sudnow, 1967). Although this stance has been critiqued for its romantic lens and general bias toward cherry-picking past practices (Elias, 1985:12-13; Lawton, 2000:11), Ariès nevertheless serves to highlight the medicalisation and professionalisation of death and dying that has emerged in the last century (Kastenbaum & Moreman, 2018:1-5, 35-43; 60-64).

In the case of incurable illness, clinicians had little choice other than to discontinue treatment when they could not cure patients, who then died swiftly. Dying now has rather come under the purview of "progressive illness", particularly in cases of heart disease and cancer (Kennedy et al., 2014; S. A. Murray et al., 2005:1007; Ohnsorge et al., 2019; Strauss & Glaser, 1977). Heart

disease in particular, as discussed above, is among the leading causes of death worldwide, representing a particular way of dying. Indeed, in a review of illness trajectories towards the end of life described in literature, Murray et al. (2005) suggest that trajectories can be grouped into three distinctive types for those with progressive illness:

> A trajectory with steady progression and usually a clear terminal phase, mostly cancer; a trajectory (for example, respiratory and heart failure) with gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected death; and a trajectory with prolonged gradual decline (typical of frail elderly people or people with dementia). (S. A. Murray et al., 2005:1007)

As shown by the graph of heart failure (Figure 1) shown previously, this thesis focusses on exploring the second trajectory: "long-term limitations with intermittent serious episodes," (S. A. Murray et al., 2005:1008-9) carrying the risk of unexpected death at any point in this trajectory, specifically in the case of heart failure. Murray et al. (2005:1007) particularly highlight how differing trajectories may also bring differing "physical, social, psychological, and spiritual needs" and experiences, for patients and carers.

Together with a predominantly biological/physiological understanding of the patient in biomedicine, end of life in western biomedical contexts has been defined predominantly by terminal cancer (American Heart Association, 2012; Barclay et al., 2011; Exley, 2004). Indeed, cancer was central in shaping and giving rise to the hospice movement, palliative care provision, the ideal of the good death, and death acceptance (Barclay et al., 2011; Exley, 2004; Kayser-Jones, 2002). However, modelled after cancer as a particular kind of experience and trajectory of dying, understandings of end of life seem overwhelmingly oriented towards inevitable deterioration and death, where steep decline in the final stages of life signals a palliative regime, and often admittance into hospital or hospice (Barclay et al., 2011; Kaufman et al., 2011; Kayser-Jones, 2002). Although a diverse category of illnesses and experiences, this fundamentally represents a particular way of dying that may not be generalisable to other areas, especially chronic degenerative conditions such as heart failure (Kaufman et al., 2011; Klindtworth et al., 2015; Steinhauser et al., 2011).

There is similarly a focus, even in qualitative studies, on clinical settings including hospitals, hospices, care and nursing homes (e.g. Davies, 2017; Hockey, 1990; Lawton, 2000; Mattingly, 2010; McNamara, 2001; Sankar, 1984). With a further lack of emphasis on life as lived outside of clinical context, the patient-centred model still privileges the physiological and the functional over the experiential (Macartney et al., 2016; McNamara, 2004; Östman et al., 2015), further maintaining a negative death-centric focus of bodily decline in biomedical approaches to end of life. Finally, studies which focus on rehabilitation and healing during catastrophic illness, often stemming from Occupational Therapy, tend not to address chronic dying (e.g. Bontje et al., 2019; Mattingly, 1994; Maynard, 2010). This brief context thus illustrates some of the gaps in literature around end of life care, and how the case of living whilst dying with heart failure addresses these gaps.

1.6. RATIONALE: Arriving at a Research Question

In summary, biomedical and social science end of life literature is heavily oriented towards deterioration and death, dominated by research on terminal illnesses, such as cancer, in hospital or hospice environments during the last months or weeks of life. Although these constitute important aspects of end of life research, there is also a need to study life as lived day-to-day beyond clinical contexts, and the reintegration that this entails in cases of chronic dying. In alienating accounts of end of life from the everyday bodily experience of living, a skewed account of dying is produced. However, it is through these experiences that understandings can emerge concerning what kind of life people deem worth living whilst dying.

I therefore propose to re-embed end of life in everyday lived bodily experience. I adopt appropriate phenomenological and ethnographic approaches to render contextualised fleshy accounts of people diagnosed with heart failure who are living at home towards end of life. In this study, I met one participant in a care home, but nevertheless also focus on his daily life prior to his moving there. With this positive reframing of end of life towards meaning and living

well, this study explores the research question: *How do people living with heart failure at home towards the end of life make 'a life worth living', given the circumstances of their illness?*

The particular wording of this question is intended to maintain the open-endedness of anthropological enquiries, and stems from the terms that participants used in the exploratory stage of research, discussed in Chapter 3. Further, I chose 'towards the end of life' to accommodate not only for chronic dying that may take years, but also the ambiguity of this category in the first place. My research differs from other investigations into death and dying in primary care predominantly in three ways: (1) approach, (2), context, and (3) orientation. Firstly, I am utilising a person-, meaning-, and experience-centred lens typical of anthropological approaches (i.e. phenomenology). Secondly, I am focusing on the home rather than hospitals, hospices, or care homes in which (qualitative) end of life research is predominantly conducted. Finally, I am explicitly reframing my discussion of death and dying to positively highlight living, rather than relying on the predominantly negative narratives of deterioration and functional decline that are prevalent in biomedical end of life literature. As an anthropologist, I am therefore well-placed to investigate these emerging tensions, entanglements, and relations. Indeed, anthropologists have often adopted "the margins of life as a site for examining the making and unmaking of persons and relationships, social and corporeal bodies, and life itself." (Kaufman & Morgan, 2005:318)

1.7. PHENOMENOLOGICAL APPROACH

Phenomenology is a philosophical tradition that emerged from the existentialist writings of Husserl, Heidegger, Sartre, Merleau-Ponty, and Schutz (Desjarlais & Throop, 2011; Morris, 2005). There are many different, subtle traditions of phenomenology, the details of which are beyond the scope of this thesis. In anthropology (e.g. Csordas, 2008; Desjarlais, 2003; M. Jackson, 2002), phenomenology may be used as an "analytic approach" or "method of inquiry" by which to explore and attend to the human condition (Desjarlais, 2003:6); phenomenology thus seeks "to understand and describe in words phenomena as they appear to the

consciousness of certain peoples." (Desjarlais, 2003:6) This philosophical stance has implications for how research is approached, conducted, and interpreted (Dahlberg et al., 2009; M. Jackson, 2002; Pink et al., 2016; van Manen, 2007).

Most generally, phenomenology concerns lived bodily experience, rendering an account of phenomena, space, and time as lived. Dealing only in the "world-to-consciousness," phenomenological lenses take there to be "no objective world in itself, nor an inner, subjective world in itself." (Todres et al., 2007:55) Through the introduction of concepts such as 'being-in-the-world' and 'the lifeworld', phenomenological lenses anchor the body as the central means through which the world is experienced and perceived, i.e. embodiment (Csordas, 1990; Merleau-Ponty, 1962). This approach to knowing and being allows for multiple perspectives and experiences to be seen as accurate, valid, and 'real' (Desjarlais & Throop, 2011).

As the lived context of being-in-the-world, the lifeworld is understood as a "humanly relational world, full of meanings," (Todres et al., 2007:55) acknowledging the wider sociocultural contexts of the subject, others, and objects. This implies that the lifeworld is: (1) peopled, emphasising the consideration of a person as interacting with others in their lifeworld, rather than in isolation (Csordas, 2008); and (2) historical, allowing an understanding of a person as incorporating current and past experiences into a lifelong narrative, rather than treating each event as discrete (Morris, 2015). Phenomenological approaches therefore acknowledge the centrality of stories and meaning-making; embracing the ambiguities, contradictions, and uncertainty of human existence in a productive way that may be accessed through ethnographic methods (Mattingly, 2010).

In medical anthropology, Merleau-Ponty's (1962) phenomenology of perception is often drawn upon due to the philosopher's particular engagement with "the science of his day" (Morris, 2005:340) and his reconceptualisation of the body that further rejects mind-body dualism (Howells, 2011:24, 40-44; Leder, 1990). "My body," Merleau-Ponty writes (1962:234), "is not a collection of adjacent organs but a synergic system, all the functions of which are

exercised and linked together in the general action of being in the world." Merleau-Ponty's being-in-the-world suggests that consciousness 'confronts' the world, and is therefore intersubjective, dialectical, and intentional (Howells, 2011:41-2). Rather than passively existing as discrete objects in a structured world, body-subjects are engaged in intentional acts of perception and are therefore actively involved in living (Howells, 2011:41-2). As a generative principle, the body is thus something that humans both have and are, and to a certain extent that humans 'do' (Mol & Law, 2004), always-already embedded in lifeworlds.

The notion of the engaged body-subject or lived body contrasts the medicalised Cartesian body-object. However, bodies can be conceptualised as entangled in systems of meaning and influential structures without reducing bodies to passive objects to be simply (or only) inscribed with cultural scripts and/or power relations. A phenomenological approach neither robs individuals of agency nor attributes them an Enlightenment vision of 'rationality' (Crossley, 1996; Leder, 1992; van Manen, 2007:20). Preconceived subject/object binaries such as performance and utterance, cognition and behaviour, person and environment, therefore do not fit here; rather than conceiving of these aspects as separable, and prioritising one aspect as a primary source of data, Merleau-Ponty's phenomenology (amongst others') is as an "anti-dualist ontology" that rather acknowledges co-constitution (Howells, 2011:25). As an example of a pre-objective approach in healthcare, the 'reflective lifeworld research' strategy developed by Dahlberg et al. (2007, 2009), discussed above, led to an existential view of wellbeing, i.e. refocussing on the lived bodily experience of wellbeing "before it is subdivided into different domains." (Dahlberg et al., 2009:267)

1.8. THEORETICAL FRAMEWORK: Unmaking and Remaking

This thesis concerns the everyday realities of larger or smaller adjustments that people make in order to continue going about their daily lives in meaningful ways whilst dying gradually. I theorise these ongoing endeavours as intertwined processes of unmaking and remaking. The theorisation of unmaking/remaking is based upon the premise that to be engaged in the

project of living is to be engaged in processes of making and moving. For those with whom I spent time, living at home with chronic degenerative heart failure, this is a struggle of constantly shifting to finds ways to be comfortable in one's life and body, and to feel like the way one is living is worth the effort.

Processes of unmaking/remaking are about iterative toing and froing from place to place that is intentional, meaningful, and practical. This movement, towards and away from people and things, shifts as lifeworlds fray around the edges through the uncertain course of ill health. When it is no longer possible to engage with all the meaningful things in life, some things are kept close whilst others are left behind as people move towards end of life. Eventually, this movement may come to settle in stillness. This stillness is about turning away from making, moving, and living. In better understanding how people go about making (indeed unmaking/remaking) their lives worth living, caring for the dying might better support and accommodate for these processes.

Key scholarly works that form the basis of this argument include those of Scarry (1985), Mattingly (1994; 1998), and Mol (2010). Scarry's analysis of torture finds that extreme pain unmakes the world of the subject, a notion that is similarly relevant in cases of chronic illness (Leder, 1990). Complementarily, Mattingly's (1994; 1998) narrative phenomenology posits that the co-construction of forward-looking narratives remakes the world for those with life-altering illnesses. Mol's (2010) notion of 'tinkering' further highlights the ongoing adjustment work that is necessary in processes of caring for oneself and others in ill health. These notions, their benefits and shortcomings, are more thoroughly interrogated in Chapter 5.

Taken together, and in combination with ethnographic examples from my fieldwork, these concepts form a theoretical framework with which I unpack how participants continue (or become unable to) make their daily lives worth living with respect to their changing bodies, lifeworlds, and priorities. I argue that unmaking and remaking are mutually constitutive, and show that they comprise constantly-shifting, ongoing processes of negotiation. In later

chapters, I illustrate how these processes of unmaking/remaking unfold in the lifeworld with respect to lifelong experiences (Chapter 4), learning how to listen to and interpret one's changing body (Chapter 5), material relations with things in the lifeworld (Chapter 6), and making decisions whilst settling into stillness (Chapter 7). These findings chapters deal with phenomena ranging from seemingly mundane, to more broadly disruptive, exploring how unmaking/remaking shapes and is shaped by how people (re)position themselves towards the end of life. I argue that it is through recursive unmaking/remaking that people encounter and make their lives worth living, or not. This is a thoroughly bodily and embodied negotiation that involves other people, objects and things in, as well as routes through, the lifeworld.

This thesis therefore rests on the critical juncture between making and movement. Whilst I saw this connection illustrated and evidenced during fieldwork, my analysis was informed by the notion of making developed by anthropologist Tim Ingold (Hallam & Ingold, 2014; Ingold, 2000, 2010). At its core, Ingold's making states that in living, we move; and in moving we make. In particular, Ingold treats lived environments as constituted in bodily movement, rather than conceptualising environments, and the things in them, as entirely discrete from people. He emphasises instead how people "feel their way *through* a world that is itself in motion, continually coming into being through the combined action of human and non-human agencies." (Ingold, 2011:115, original emphasis)

Ingold is particularly concerned with the material conditions of the lifeworld, and emphasises sensuous engagement with objects therein as part of moving and making (indeed, he spends some time describing the feeling of a rock beneath his fingertips (Ingold, 2013:17-9)). Ingold zooms into the entanglement of people and things that does not simply happen in the world, but continuously produces the world. Ingold thus treats objects or technologies in the lifeworld as tools that are made, but are also fundamentally about 'making' itself. In going through daily life with these tools – i.e. making, using, and engaging with them – Ingold argues that

knowledge and skills are also made, or 'grown' (Hallam & Ingold, 2014:9). Indeed, this allows "knowledge to grow from the inside of being in the unfolding of life." (Ingold, 2013:8)

In this way, Ingold writes of 'thinking through making' (rather than making through thinking) to describe and analyse people's practical engagement with the varied materials that make up their dynamic lifeworlds (Ingold, 2013:xi). Inspired by Martin Heidegger's (1971:145-161) phenomenological essay 'Building, Dwelling, Thinking', Ingold turns his attention to the continual dynamic growth and change that characterises ongoing processes of living that "works things out as it goes along."

> [Making] does not begin here, with the pre-formed plan, and end there, with a finished artefact. The 'final form' is but a fleeting moment in the life of any feature, when it is matched to a human purpose, likewise cut out from the flow of intentional activity. (Ingold, 2000:188).

Objects, lifeworlds, and narratives are therefore always in flux and coming-into-being; "so-called 'ends' or 'goals' are but landmarks on a journey." (Ingold, 2000:172) By contrasting what he calls the building with dwelling perspective, Ingold collapses the idea that humans construct material environments and then live in them; instead emphasising the ongoing nature of lived environments as dynamic lifeworlds which humans co-constitute and co-construct as they move through them (Ingold, 2000:154). In concretely linking materials with moving body-subjects, Ingold further foregrounds important embodied dimensions of material relations:

> Making has to be understood in the sense implied when we say of people that they 'make their way' in the world. It is not a construction, governed by cognitive mechanisms of one sort or another, but an improvisatory movement – of 'going along' or wayfaring – that is open-ended and knows no final destination. (Ingold, 2010:S122)

Embedding materials in the ongoing project of daily living, Ingold thus highlights how bodies moving with materials are together integral parts of the lived environment. This environment, or lifeworld, is therefore equally bound up in and produced by the ongoing movement of daily living. Just as life is "always *going on,"* lifeworlds are "never complete but are continually under construction." (Ingold, 2000:172, original emphasis) This framing thus forms the basis for how I developed my conceptualisation of unmaking/remaking as iterative and recursive, involving

situated doing- and being-in-the-world, with many kinds of things. Diverging from Ingold, I consider how these processes are intertwined in meaning- and sense-making in chronic dying. I further consider how this unfolds through lifelong narratives and imagining motivating futures, and what happens when moving and making become still.

1.9. THESIS STRUCTURE

This thesis explores experiences of living whilst dying: what it might feel like, how this unfolds, what is at stake, and how people cope with these uncertain and intensely human experiences. This introduction laid out the groundwork of framing literature and concepts for the exploration that follows, and how I came to do this research personally, encountering my own positionality. With a background in anthropology and phenomenology, I have taken great care to conduct and write ethnographic work that is reflexive, casting myself into my own field of view, as well as sensitive, striving to honour the experiences and relationships with all those involved. The structure of the thesis is as follows.

Chapter 2 builds on the broader context reviewed here in Chapter 1, reviewing specific literature that is mobilised in the findings chapters and links to the foundations of the overall framework of unmaking/remaking. I introduce the medicalisation and biomedicalisation of death and dying, technology use towards end of life and materialities of care, changing notions and practices of care, end of life and chronic dying as sites of intervention and choice, different ways of conceptualising and parsing priorities at the end of life, and how people make sense of and meaning in end of life experiences through narrative.

Chapter 3 discusses anthropological methodology and methods, building on the ontological and epistemological framing of phenomenology given here in Chapter 1. I similarly discuss the sensory ethnographic underpinnings that inspired me, and the impact this had on my research strategy, analysis, and presentation of data. This chapter also deals with the particular difficulties associated with researching death and dying, situated in an emerging literature that calls for such reflexivity in this field.

Chapter 4 is the first of the findings chapters, taking inspiration from innovative ethnographic techniques to present short but in-depth case summaries of individual participants. Beginning with an ethnographic 'portrait' of each person, I crafted their stories and my experiences with them to signal cross-cutting themes; focussing on significant life events, their current living situation and future outlook, as well as their health and family status, and what is particularly important or concerning to them. This chapter thus deals in whole people, living whole lives, echoing the remit of this thesis to re-embed dying in the continuous experience of living.

Chapter 5 primarily elaborates the analytical framework of unmaking and remaking. I first demonstrate how I derived this from literature, and later work it through ethnographic examples. These include how participants have to sit down in the middle of things to take a rest before they can go again; learn how to interpret and listen to their changing bodies' signals anew; and take advantage of the good days whilst accommodating for the bad, in the unpredictable ebb and flow of feeling well enough to do things, or not.

Chapter 6 explores materiality, and the engagement with material extensions of the self which are unmade and remade as people negotiate living and moving through their changing bodies. Linking this to earlier considerations of technology use towards the end of life and Ingold's dwelling, I consider how participants tinker with things and repeatedly layer solutions. Illustratively, I discuss how participants structurally alter their homes; move with things through their lifeworlds; and how the nature of that movement inevitably lets things drop away as people begin to lean back from living.

Chapter 7 primarily considers stillness and 'being done' with living, drawing on Mattingly's narrative phenomenology of practice in the context of end of life decision-making. Acknowledging that people change their minds about end of life plans and decisions, I explore how movement and narrative may mirror and track these changes. As participants begin to experience life as no longer worth living, stillness suggests turning away from making entirely as people engage in wrapping up their lifelong narratives.

Chapter 8 presents a discussion of findings and potential future directions. I do this through engaging with wider discussions of death and dying, interweaving the academic literature cited throughout. I illustrate how an understanding of unmaking/remaking, movement, and stillness challenges dominant biomedical discourses of dying, care, technology, and interventions towards end of life. I also return to some of the difficulties I encountered, considering my ongoing commitment to the participants who made this study possible.

CHAPTER TWO

Literature Review

"Terminally ill people live until they die,

but their living is irretrievably changed as they begin to live their dying."

- Beverley McNamara (2001:66)

2.1. INTRODUCTION

Chapter 1 introduced considerations of death and dying mainly in biomedical perspective. With the nature and organisation of death and dying changing, highlighting emerging chronic degenerative illness and concomitant new forms of care, research still predominantly focusses on terminal conditions such as cancer in clinical contexts. The physiological understandings and priorities dominant in these settings thus contribute to shaping particular narratives of death and dying. These accounts do not fully consider the daily lives, concerns, and experiences of whole people outside clinical contexts.

Whilst some social science studies work to fill such gaps, highlighting specificities and critically encountering biomedical practices, there is an absence of subtle, longitudinal understandings of dying that infiltrates people's daily lives in impactful ways. This context provides the foundation and rationale for the thesis, focussing on chronic dying in people's own homes. I also expounded the philosophical and methodological underpinnings that support my exploration of this area. In delineating my ethnographic and phenomenological approach, I signalled cross-cutting themes that inform and feature throughout the thesis. I particularly highlight the centrality and importance of making, bodily and sensory aspects, as well as interpersonal, material, and contextual ones.

Through this chapter's literature review, I further explore the dying body, decisions and distinctions between life and death, and the vital aspects of wellness and meaning that intertwine in living whilst dying. As introduced in the previous chapter, the experiences of and

practices surrounding death and dying have occupied historians and philosophers (e.g. Ariès, 1975; Canguilhem, 2008), physicians (e.g. Berger, 1967; Cassell, 1998; Gawande, 2014; Kleinman, 1995), psychiatrists (e.g. Good, 1977; Kübler-Ross, 1969), sociologists (e.g. Bauman, 1992; Broom, 2015; Glaser & Strauss, 1965; Kellehear, 2009a; Mellor & Shilling, 1993), anthropologists (e.g. Das & Han, 2016; Kaufman & Morgan, 2005; Lock, 2004; Scheper-Hughes, 1993), and those in Science and Technology Studies (STS) (e.g. Mol et al., 2010; Oudshoorn, 2011; Pols, 2012), to name but a few seminal authors. Drawing on a range of literature, this review focusses on forming the basis for interpreting the findings of this study. The literature review therefore extends beyond this chapter and is woven through the rest of the thesis, reflecting my experience of researching and writing as an iterative process. At the beginning of findings Chapters 5, 6, and 7, I therefore include a brief literature summary that elaborates what is introduced here, and to further develop the thematic analysis in each chapter.

This chapter is structured as follows. Building on Chapter 1, specifically that death presents a problem to biomedicine and dying has become more chronic in character, I start with discussing the concomitant medicalisation and latter biomedicalisation of death and dying. I then review some of the implications of technology in healthcare and the home, as well as responses to the over-medicalisation of end of life, such as the hospice movement. Given the importance placed on death awareness and acceptance, I then focus on how decisions towards end of life are made. This explores how end of life and chronic dying are increasingly constructed as sites of intervention and choice. Considering quality versus quantity of life as this relates to decision-making (i.e. what people are deciding on), I more deeply discuss understandings of wellness and wellbeing as different ways of parsing priorities at the end of life. Finally, I introduce meaning-making as a vital part of living well with chronic dying, particularly drawing on Mattingly's narrative phenomenology of practice.

2.2. MEDICALISATION and BIOMEDICALISATION at END OF LIFE

In Chapter 1, I highlighted recent changes in the nature and organisation of dying, particularly medicalisation and professionalisation (Glaser & Strauss, 1965; Kastenbaum & Moreman,

2018). This section elaborates how these processes are implicated in recent material, definitional, and social changes in relation to death and dying. Clarke et al. (2003:161) define medicalisation as "the processes through which aspects of life previously outside the jurisdiction of medicine come to be construed as medical problems." Death and dying moved out of the home and purview of the family and the spiritual, becoming more individualised, institutionalised, and hidden. Whilst death is not curable as such in biomedicine, processes of medicalisation may serve to demystify the dying body, open it up to intervention, and render it more 'fixable' (Bauman, 1992; Kaufman, 2010; Navarro, 2001; Tulle, 2015),

Eric Cassell (1998), a physician actively engaged with the medical humanities, asserts that medicine's inability to accept or deal with death derives largely from the Cartesian dualism of mind and body. Mirroring the biological understanding of health and disease (Kleinman, 1995), biomedical approaches to death and dying prioritise a predominantly biological understanding of these phenomena. Taking a phenomenological perspective, physician-philosopher Drew Leder (1992) prominently discusses the body-as-machine metaphor. This conceptualisation informs the linear relationship between symptom, pathology, and treatment which renders broken bodies fixable through biomedical intervention – much as a mechanic fixes a car, for example. This biomedical gaze thus transforms the lived body-subject into a body-object, which has important impacts on care.

Cassell (1998:130) highlights how clinicians make a distinction "between physical and nonphysical sources of suffering," in ways that patients and their families do not in everyday lived experience. Indeed, many models of dying centre around the inevitable decline and decay of the failing body, potentially at the expense of wider social, political, and existential experiences (Kellehear, 2009b; Lawton, 2000; McNamara, 2004). In rendering the dying body primarily a physical, biomedical body-object, the phenomenological experience of being-in-the-world whilst dying as a body-subject is mostly lost.

Medicalisation of end of life may partly serve to demystify the dying process, rendering this more knowable and manageable for clinicians, patients, and their families. There are many different models of dying that underpin and inform how to deal with and what to expect in dying (Exley, 2004; Green, 2008; Kellehear, 2009b; McNamara, 2001). For example, staged theories such as psychiatrist Kübler-Ross' (1969) provide a kind of map. This is highlighted by Alan Kellehear (2009b:5), writing of the sociology of dying: understanding dying as a journey (linear, oscillating, or otherwise) from point A (alive) to point B (dead) renders dying a "process and series of 'critical junctures' that others could employ to help them determine what to do next."

Technological responses to death and dying denote further biomedicalisation, which not only demystifies but opens the body-object up to intervention at ever finer levels (Clarke et al., 2003; Novas & Rose, 2000; Rabinow, 2005; Vaz & Bruno, 2003). Clarke et al. (2003:162) define biomedicalisation as "the increasingly complex, multisited, multidirectional processes of medicalisation that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine." These technological responses may be used for diagnosis, treatment, and different kinds of therapeutic practices. In the context of death and dying, sociologist Beverly McNamara (2001:121) suggests that such 'post-modern' dying "pushes the phenomenon of dying away through technology and pretence." Where medicalisation may serve to demystify, biomedicalisation may serve to intervene.

Social scientists (in the vein of anthropology, STS, sociology, and philosophy) writing about biomedicalisation highlight the pervasiveness of technology in biomedicine which infiltrates and contributes to shaping the mundane to the full spectrum of human health and lifespans, from birth to death (Franklin & Lock, 2003; Kaufman & Morgan, 2005; Lupton, 2014). Technologies are depicted as being capable of isolating ever finer levels of health and risk, from the genetic to the molecular, and thus represent new cultural contexts of dying. Disease risk

factors identified at the level of the gene, for example, potentially confer novel rights and responsibilities onto these individuals (e.g. biological citizenship, see Gibbon & Novas, 2008; Rabinow, 2005; Rose & Novas, 2014).

The social and political nature of technologies must not be overlooked; far from operating in a vacuum, such technologies involve and impact multiple contexts, networks, and actors (Clarke et al., 2003; Mol et al., 2010; Pols, 2012; Rose, 2007; Timmermans & Berg, 2003; Webster, 2002). Writing from sociological and STS perspectives respectively, Rose and Mol both elaborate how technologies are essentially bound up in intensely human processes of care and caring, enmeshed together and requiring new kinds of relations to be made, e.g. between people, professionals, patients, etc. Rose (2007:17) poignantly highlights that technologies, therefore, cannot intervene simply in discrete aspects: "These are not merely technologies or technologies of health, these are technologies of life."

The definition of technology may be quite expansive (e.g. Clarke et al., 2003; Park & Fitzgerald, 2011; Rabinow & Rose, 2006), and include the understanding of technologies as material tools, moving beyond the strictly health-related such as Assisted Living Technologies (Lewin et al., 2010, p. e.g.; Mol et al., 2010; Pols, 2012; Wherton et al., 2015); to more mundane everyday objects (e.g. Brownlie & Spandler, 2018; Buse et al., 2018; Fox, 2016; Pink, 2012). In this way, technologies not only influence the care and living with illness that is undertaken, but also opens up new possibilities for action (Lock, 2004; Mol, 2006; Mol et al., 2010; Pols, 2012). Rose goes on to suggest what this might imply:

> Biomedicine, throughout the twentieth century and into our own, has thus not simply changed our relation to health and illness but has modified the things we think we might hope for and the objectives we aspire to. (Rose, 2007:25)

Not only are there more possible solutions available to experiment with towards the end of life; but these may fundamentally change our relationship with our bodies, quality of life, and our future. This is further explored below and in Chapters 6 and 7. For example, anthropologist Sharon Kaufman (2010) writes of how clinical consultations with those dying of chronic

conditions involve discussing biomedical, and often technological, interventions. She argues that this opens up the potential for more "time left." (Kaufman, 2010:225) Such interventions therefore entail patients having to weigh the value of time left against the value of life itself, considering what life is worth as part of deciding whether to pursue further, potentially life-extending, treatment (Marsland & Prince, 2012).

Similarly, anthropologist Margaret Lock (2002, 2004) cross-culturally contrasts the ways in which the very parameters of death itself are renegotiated as a result of technological innovations. Resulting from the artificial ventilator/respirator, the category of brain death signifies individuals as no longer alive, even though their bodies still function. This enables these individuals to be eligible organ donors in North America and Europe. Based on original research and analyses of public discourses, Lock contrasts these norms with those in Japan, where brain-dead individuals were considered to be "not-yet-dead" until a change in law in 1997 (Lock, 2004:136). Drawing on insights from anthropology, such as social death, Lock (2002) highlights intertwined sociocultural and politico-legal dimensions, problematising the notion that medical technologies can act on biology alone. In this way, technologies and relations with them are increasingly recognised as profoundly impactful not only to the way care itself is provisioned and implemented, but also wider experiences of that care. Part of processes of medicalisation and biomedicalisation, isolating and defining death, dying, and end of life is difficult, contested, and changeable (Borgstrom, 2018; Hui et al., 2014; Pastrana et al., 2008; P. Singer, 1994).

2.3. TECHNOLOGIES and MATERIALITIES at HOME

With expansion of technological innovations and incorporation of normal life processes into the purview of biomedicine, there is a concomitant move towards ongoing self-care and self-management of chronic illnesses in patients' homes (Hunt & Arar, 2004; Mattingly et al., 2011; Oudshoorn, 2011; Pickard & Rogers, 2012). Health technologies are thus increasingly moving out of clinical spaces and into others, notably the home. This is particularly relevant to heart failure, as many people self-care at home over years, often with multiple co-morbidities

(Greenhalgh et al., 2017; Klindtworth et al., 2015; Schjoedt et al., 2016). Caring in this way might include technology-enabled care, such as Assisted Living Technologies (henceforth ALTs), telehealth (i.e. remote medical treatment or monitoring) and telecare (i.e. remote social care services or monitoring) (Greenhalgh et al., 2012:1; Oudshoorn, 2011; Webster, 2002).

Inspired by STS, Oudshoorn (2011:7-10) writes of this return of healthcare to the home. She highlights how this differs from earlier practices, as patients themselves are expected to use medical equipment. The work of care is also therefore shifted around multiple different kinds of healthcare practitioners and patients. This shifting of work away from healthcare institutions has been an aim of technology-fuelled visions of the future (Brown & Webster, 2004:86; Criado et al., 2016; Marsland & Prince, 2012; Pickard & Rogers, 2012). This further underlines an established sense of technophilia in digital health discourses; i.e. technological innovation as a revolutionary solution that will increase the efficacy and efficiency of future healthcare (Greenhalgh et al., 2012; Mol et al., 2010; Oudshoorn, 2011; Pols, 2012). Whilst many technophiles thus expound the positive potential for health technologies, there are also worries that technologies might take care over in sanitised, mechanical, "cold" ways (Pols, 2012:12-22).

Exploring the "organising vision" of telehealth and telecare, a study by Greenhalgh et al. (2012) surfaces four conflicting discourses underpinning the design and implementation, as well as many studies, of technologically-enabled care. Modernism features prominently in medical literature. Modernism sees technological innovation and implementation at scale as an inherently good, rational solution that will improve the quality and efficiency of healthcare. Determinist in nature, this kind of discourse leads to instrumental utopian visions of plug-and-play technological solutions (Timmermans & Berg, 2003), i.e. technologies as universal "problem solvers." (Oudshoorn, 2011:17) Applied outside of medical contexts, however, these technologies are adopted and used (or not) in combined and often unexpected ways (Oudshoorn & Pinch, 2005; Sugarhood et al., 2014).

Context therefore matters in the case of technology, as technologies do not work universally in the same way everywhere. In particular, Oudshoorn (2012:122-3) draws on the theoretical distinction between 'place' and 'space' in human geography to show how "the same technological device can do and mean different things in different places." Indeed, therefore, the home cannot be conceptualised as a blank slate where healthcare technologies can be un-problematically introduced. She therefore argues for a "technogeography" of care in STS, highlighting the local interaction of technologies, people, and places (Oudshoorn, 2012:124). In her study of those using telecare, people's experiences of certain domestic spaces are thus transformed. Acknowledging the situated and social nature of technology-enabled care echoes findings from earlier anthropological studies of chronic illness. Kleinman and Hall-Clifford (2010:247) in particular note how chronic illness reorganises social and material relations, for example contributing to shifting family roles and repurposing certain rooms in the home.

The important distinction between space and place is partly in the grounded nature of place, where people make meaning and memories, versus the abstract and emptier sense of space (Casey, 1996; Ingold, 2011:169). Whilst space is undifferentiated and homogeneous; place is specific, with proclivities, histories, and diverse textures (Casey, 1996; Irving, 2007:205-7). It is not simply that space is inscribed with meaning through culture to achieve place. Places are rather made and remade through sensuous engagement as bodies make their way purposely through, to, and from them whilst engaging in the project of living (Lee & Ingold, 2006).

People therefore engage in meaningful place-making and "being-in-place" as part of being-in-the-world: "This active redefinition of place puts the body back into experience." (Irving, 2007:206) Following Edward Casey's (1996) philosophy, Andrew Irving in anthropology clarifies that place is thus a "product of the body, its limitations, imperfections, and potentiality." As Irving (2007:206) points out, illness is disruptive in ways that may render 'being' in one's body and lifeworld unfamiliar, a place that is "strange and alienated, requiring it to be re-inhabited and made familiar after disruptions of illness, disease, and death." In this

sense, place-making is an ongoing endeavour involving the body as much as the lived environment, and material relations therein. This links closely to vitality and movement, as well as Ingold's notions of making and dwelling in environments, discussed in Chapter 1 and further explored in Chapters 6 and 8.

Considering the contingent and dynamic nature of people, places, and things thus problematises revolutionary visions of plug-and-play, comparatively static technologies. Health technologies, therefore, are far from neat stable fixes for neat stable problems. Qualitative findings further emphasise the complex and contingent nature of challenges faced by real people leading real lives. Situated in lived social and material contexts, dynamic challenges require dynamic solutions. Yet, day-to-day experiences and priorities of using technologies are out-of-step with the logic underpinning these technological fixes, which by contrast ultimately aim to make healthcare more cost-effective and efficient (Mol et al., 2010; Oudshoorn, 2011).

Whilst it is the intertwining of technology-in-practice and –in-place that make technologies 'work', local specificities are broadly removed from the clinical trials that test these technologies out of context (Greenhalgh et al., 2013:86-7; Timmermans & Berg, 2003:109). ALTs are thus often not designed with such specificities in mind, nor co-designed with users (Wherton et al., 2015). Indeed, Woolgar (1990) emphasises how technologies "configure the user," i.e. contain inscribed assumptions about who will use them, for what, and in what ways, which may be inappropriate. In a phenomenological study of what matters to those using ALTs in daily life, Greenhalgh et al. (2013:86) find that people engage in '*bricolage*', i.e. "pragmatic customisation," where they layer multiple different technological solutions in order to fulfil their needs. Informed by STS, Mol et al. (2010:13-14) similarly highlight the vast amount of "tinkering" required for technologies to work in shifting everyday contexts (elaborated below, and in Chapter 5). In this way, they insist on the mutual constitution and interdependence of caring practices and technology (Mol et al., 2010:14). Technologies are therefore neither

separable nor at odds with other kinds of caring practices; caring can be neither simply facilitated nor destroyed by technologies (Pols, 2012:24).

Diverse and interacting materialities, beyond healthcare technologies specifically, are thus important and co-constitutive aspects of health and care. These perspectives echo recent trends towards considering health "assemblages." (Fox, 2016; Locock et al., 2016) Here, subjects are embedded in diverse webs involving inter-relational, affective, and material or physical aspects (Buse et al., 2018:244). Writing more specifically about health sociology, Fox (2016:62) describes "new materialist perspectives" in healthcare research which "turn away from a textual or linguistic focus" and instead highlight "the range of materialities that affect health." Critiquing the predominant focus on (purpose-built) technological innovations, these studies emphasise instead the taken-for-granted materialities which already populate people's lives (Buse et al., 2018:244); they examine how "everyday or mundane materialities actively mediate health and care practices." (Brownlie & Spandler, 2018:256) A 2018 special issue of *Sociology of Health and Illness* was dedicated to this end, spanning analyses of architecture, ordinary household objects, clothing, and cleaning materials. These items may equally be used for self-care purposes, even if they are not strictly related to ill-health. They also form part of the familiarity of the home lifeworld that Ingold highlights as part of the sensuous engagement of moving and living, and Irving emphasises as part of place-making in illness. This is particularly brought to bear on material relations and home adaptations in Chapter 6.

2.4. MAKING DECISIONS towards the END OF LIFE

Part of responding to the medicalisation and sequestered (potentially 'taboo' (Kastenbaum & Moreman, 2018:112)) nature of death comes in the form of the differing values of the hospice movement, and the introduction of palliative and end of life care (Corr, 1992; Exley, 2004; Macartney et al., 2016; McNamara, 2001; Strauss & Glaser, 1977). Responses to medicalisation in the UK "focussed on the medical "neglect" of dying people; whereas in the United States a reaction to futile treatments in the face of suffering and inevitable death began to take root." (D. Clark, 2002:905) Although this thesis focusses on home rather than hospice or other

clinical environments, here I consider the approach to care that hospice advocates to begin exploring more holistic understandings of wellbeing and care towards end of life. Initially arising and developing in the late 1960s, '70s, and '80s, hospice ideology and practices developed in combination with the need for effective pain management for those suffering with cancer and/or HIV/AIDS; hospice ideology critiqued the impersonal and inadequate care of the dying in hospital contexts (Chatterji, 2016; Strauss & Glaser, 1977).

This alternative hospice philosophy asserts that dying and mourning are normal parts of life. Hospice advocates caring for, comforting, and supporting people in a holistic way that explicitly does not deal in cures, nor exclusively in physical symptom relief, but rather supplements biomedical practices towards end of life (Kaufman, 1988; Kellehear, 2009a; Lawton, 2000; McNamara et al., 1994:1501). Lofland's 1978 (republished 2019) exploration of social movements around death and dying anticipated some of the changes that would later occur partly as a result of the HIV/AIDS epidemic, and how this transformed the experience of death and dying. She identifies three social movements which sought to cast these experiences as positive: Death Acceptance, Death with Dignity, and Natural Death.

A growing realisation of the spiritual and psychosocial aspects of end of life, and the legacy of founding thinker Cecily Saunders' "total pain" as existential suffering, partly informed these shifts in emphasis towards the whole person (Broom, 2015:92; Kellehear, 2009a:390-1; McNamara, 2001:96-7; Parker-Oliver, 2000:499). The aim of hospice care is "not to prolong life, but to enhance its quality and help individuals renegotiate meaning and purpose by redefining their lives, not in terms of being "sick," but in terms of living until they die." (Parker-Oliver, 2000:500) The hospice movement thus pioneered concern for a "timely, dignified, and peaceful death." (S. A. Murray et al., 2005:1008) The distinct notion of a 'good death' in palliative or end of life care therefore addresses patients' and their families' varying needs and experiences, including physical, social, emotional, and spiritual (Corr, 1992; Exley, 2004; Kennedy et al., 2014; S. A. Murray et al., 2005).

Although there are diverse and contested definitions of palliative care, a discourse analysis of over sixty definitions corroborates that this kind of care is unified in its aim to alleviate pain and suffering, and improve quality of life for patients and their families (Pastrana et al., 2008). A statement from the WHO further suggests that palliative care now has a far broader remit, the principles of which should be "applied as early as possible in the case of any chronic, ultimately fatal disease." (Sepúlveda et al., 2002:92) This early implementation acknowledges the ongoing holistic needs of patients and families who are dealing with terminal or life-threatening progressive illnesses such as heart failure, who must manage them over years, beyond those who are officially classified as end of life (Dragojlovic & Broom, 2018; Hopp et al., 2010; S. A. Murray et al., 2005; Singh et al., 2019). Palliative care can therefore be combined with curative efforts as dying becomes more chronic in character, and linked with the progressive difficulties of living in old age (Klindtworth et al., 2015; S. A. Murray et al., 2005; Otto et al., 2018).

There is growing recognition that "doing everything that can be done for a possible cure" may not always be the appropriate course of action (S. A. Murray et al., 2005:1008). In a chapter in their edited volume, *Care: Putting Practice into Theory,* Mol, Moser, and Pols (2010) emphasises the logic of care that is not considered to have failed in the absence of a cure. In the commodification of care in today's Western healthcare systems, the specificities, "generosity," and "devotion" of caring in practice become lost (Mol et al., 2010:6-9). Rather, the ethic of caring that Mol et al. (2010:13) suggest is attentive, and repeatedly addresses issues in different ways, "tinkering" until some of the discomfort or suffering is alleviated. "Care seeks to lighten what is heavy, and even if it fails it keeps on trying." (Mol et al., 2010:14) They thus suggest that 'good' care is 'done' in practice; this practice includes negotiating between the multiple actors (patients, families, healthcare practitioners) who inevitably may all have different and shifting priorities about what is best. This logic of caring therefore builds on the deficits of other kinds of biomedical interventions. Specifically, Mol et al. (2010:14) build it on

the explicit and pragmatic premise that "the hope that one might live happily ever after is not endlessly fuelled," as "at some point, sooner or later, you are bound to die."

Hospice, palliative, and end of life care similarly acknowledge and centre this endpoint of death; in many cases the ideal endpoint is conceptualised as a 'good death'. The notion of a good death as a historical concept has undergone transformation over centuries, linked with changing pressures in the West, including secularisation and a move towards individualism, away from community (Green, 2008; Kellehear, 2009b; Macartney et al., 2016; McNamara, 2004; Walter, 2003). Tracing the history of the good death, Beverly McNamara (1994:1501) builds on Ariés' Good Death, as an "acceptable" way of dying and a social phenomenon; she suggests that a good death is not "a fixed moment in time" but rather a "complex set of relations and preparations," and therefore "a series of social events." Kellehear (1990), through exploring the social life of the dying person, suggests five key features of the good death and attending social interactions: (1) awareness of dying, (2) private life of the dying person, (3) public preparations, (4) arrangements relating to work, and (5) farewells. A good death therefore includes not only the experience of the person who dies, but also a communal experience involving those surrounding them (Kellehear, 2009b; McNamara, 2004; Mellor & Shilling, 1993). Broom et al. (2016:987) suggest that the "cultural imaginary" of the good death by extension indicates a good life, the hallmarks of which are given by the closeness of friends and family, "reciprocity, intimacy, and closure."

However, McNamara (1994:1501) responds to recent concerns that the "founding ideals" of the hospice may be compromised by and/or incompatible with the "encroachment of mainstream medicine and medical technological imperative to treat." She thus writes about the "institutionalisation of the good death." (McNamara et al., 1994:1501) The biomedical rhetoric of patient autonomy and choice seeps into end of life in ways that cannot be realised in daily palliative care practice on the ground, yielding greater uncertainty for practitioners (McNamara, 2004:932). Towards the very end of life, patients may not have the capacity to

make decisions for themselves any more, for example. In this ensuing uncertainty, practitioners may be drawn to an approach that prioritises the management of physical symptoms and needs over the holistic values (e.g. psychological, social, spiritual, emotional) upon which the hospice movement was founded. McNamara (2004:930-5) finds that Australian palliative care practitioners consider this a "good enough death," when founding values are unmet but they are able to somewhat relieve their patients' physical pain and discomfort.

Kellehear (2009b:3-4) asserts that agency is central in hospice versions of a good death. He finds, in his review of social science literature on death and dying, that the most common view of dying is being under "personal control." He cites "active negotiations with physicians and other healthcare workers, the use of advanced directives or the pursuit of advanced technological interventions" as "well-described signs of agency and control while dying." Increasing patients' personal involvement with their own medical paths, McNamara (2001:18) discusses the move towards shared decision-making towards the end of life. She suggests this also results partly from the public's dissatisfaction with the medicalised, technologised, and institutionalised treatment of dying discussed above. Ivan Illich's (1976) original critique of the medicalisation of dying highlights the potential for social control, the inability to accept dying as a meaningful part of life, and the erosion of caring practices in the family. Whilst processes of (bio)medicalisation further bring broader aspects of life under the jurisdiction of biomedicine, the holistic approach concomitantly "advocates patient responsibility for learning about his or her condition, for making treatment decisions, and for actively participating as a member of the health care team." (Kaufman, 1988:339)

Indeed, questions of agency particularly arise where holistic approaches meet biomedical approaches to health and healing; these concern decisions about the limits of biomedicine, without assuming a dichotomy between "medical control and patient autonomy." (Kaufman, 1988:338) In practice, however, agency is not evenly distributed. Beyond the questions of

capacity that McNamara (2004) brings up, not only are there power-dynamics at play in clinical encounters (e.g. Kleinman, 1995), agency over mortality is itself linked to a position of wider affluence and advantage (e.g. Kellehear, 2009b). Further, Exley's (2004:119) "disadvantaged dying" highlights how agency and possibilities may be equally constrained by the particular disease one happens to have, the research and funding that has gone into it, and the available resources relating to this disease.

Decision-making is an important part of what renders someone's death 'good', or a social success. Rarely is dying written about as a voluntary relinquishing of agency, as I suggest in Chapter 7 happens incrementally in daily life. As previously described in Chapter 1, heart failure is most commonly treated as a chronic rather than terminal condition. This contributes to reduced patient understanding of diagnosis and prognosis, potentially unnecessary treatment, lack of planning for end of life care and events, and patient values potentially being overlooked (Glogowska et al., 2016; Jones et al., 2017; McNamara, 2001; Östman et al., 2015). In heart failure and other uncertain cases of chronic dying, a truly 'informed' decision about treatment options may be difficult to make, given the disease's fluctuating trajectory, lack of palliative resources, and difficulty in isolating end of life periods (Becker & Kaufman, 2004). Clinicians report further worrying about perpetuating fear of death rather than hope of recovery, and patients changing their minds about treatment preferences (Stevenson et al., 2008). As Becker and Kaufman write:

> Uncertainty is a central feature of a chronic illness trajectory, resulting from questions about the effects of illness on daily life, what symptoms mean, and what the future holds. When chronic illness occurs later in life, uncertainty is magnified, and serious questions arise about whether the individual will be able to weather the disruption and go on with daily life. (Becker & Kaufman, 2004:166)

Clinically-oriented decision-making in these contexts revolves around whether to continue with treatment, sign a Do Not Attempt CPR order, to install or deactivate an Internal Cardiac Defibrillator (henceforth ICD), choosing between different kinds of death. These decisions therefore encompass wide-ranging considerations of daily lived experience in order to

establish when 'enough is enough'. Such considerations also concern what kind of life one wants, not only what kind of death.

Exploring ICDs in the elderly, Kaufman et al. (2011:5) report one patient participant saying that "the longer it [the ICD] prolongs my life, the more things happen to me that it can't correct." With moralising pressure to choose normalised interventions, these may not always lead to the improvement of quality of life and extension of meaningful life (Glogowska et al., 2016; Kaufman et al., 2006; Lock & Nguyen, 2010:234-8; Russ et al., 2005). Kaufman et al. (2011) thus point out the irony of life-extending and potentially life-saving biomedical interventions that at the same time work to prolong dying, as well. This emphasises that whilst interventions and decisions may be a means to an end, these "'ends' are not static and already known," but uncertain and subject to change (Kaufman et al., 2011:6).

2.5. QUALITY, QUANTITY, and LIVING WELL

Wider considerations of how one wants to live and die are therefore important to decision-making and living towards the end of life. This is often conceptualised as a complex trade-off between quantity and quality of life. Rather than delving into these potentially polarising debates, I wish to consider quality and quantity of life here as an entry-point into discussing living well towards the end of life, how this has been parsed and conceptualised, and how these multiple lived factors are negotiated in the practice of daily life.

There is much debate around quality versus quantity (Bowling, 1995; Farquhar, 1995; Rapley, 2003; Wilk, 1999; Williams, 2000) that is outside the scope of this thesis. Quality of life is another marker of "medical responsibility to the 'whole' patient'," and recognition that "a long life is not necessarily a good life increased." (Farquhar, 1995:1440) Entering mainstream healthcare around the mid-1970s and originating in the pharmaceutical industry, multiple measures of quality of life (henceforth QoL) have since been developed and are well-shown to be indicative of health outcomes (Felce & Perry, 1995; Rapley, 2003; A. Smith, 2000; Wilk, 1999). Many QoL measures are delineated on a Likert scale of numbers or words, and split into

domains that may also relate to contemporary changing social ideals of the good life (Bowling & Dieppe, 2005; Cummins, 2005; Rapley, 2003:20-23).

These domains vary, but are usually defined as 'objective' and 'subjective' indicators, such as George and Bearon's (1980) commonly-cited four underlying categories: functional status and socioeconomic status (objective); life satisfaction and self-esteem (subjective). These can be measured separately through census or other demographic data, and/or questionnaire; or together, such as in disease-specific QoL measures (Costanza et al., 2007; Cummins, 2005; Lercher, 2003; Rapley, 2003). Quality of life is therefore described as a "multi-scale" and "multi-dimensional" concept containing "interacting subjective and objective elements." (Costanza et al., 2007:267) However, Calman (1984) argues that QoL can only be described and measured on individual terms, as it so intensely personal that it may be more appropriate for participants to create their own definitions. He hypothesises and specifies that what quality of life actually measures is "the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences." (Calman, 1984:124)

Quality of life, according to Bowling and Dieppe (2005:5), is meant to "theoretically encompass the individual's physical health, psychosocial wellbeing and functioning, and independence," emphasising "control over life, material circumstances, and the external environment." In this way, quality of life is meant to take account of macro- and micro-level influences embedded in society, acknowledging both objective and subjective dimensions that crucially interact with each other (Cella, 1994; Cummins, 2005; Rapley, 2003). Bowling (2014) however, later highlights the tendency in research to misuse concepts of quality of life by reducing this more wide-ranging concept specifically to health-related quality of life (HRQoL). As Farquhar (1995:1439) emphasises, HRQoL reflects only one domain of QoL, i.e. physical functioning, yet there is "more to QoL than health." In her study of elderly people's definitions of QoL, she found physical health to be one of many interwoven aspects of individual lives.

Towards end of life, patient's views on quality and length of life may be elicited through the use of time trade-off utilities, i.e. the "hypothetical trade-off between living shorter and living healthier." (Arnesen & Trommald, 2005:39) These explore how far people with terminal and/or degenerative illness are willing to "trade nothing or virtually everything for better health," (Lewis et al., 2001:1016) and how stable these preferences are over time (e.g. Stevenson et al., 2008). There is therefore a tendency for clinical QoL to focus on and prioritise the treatment of pure functioning rather than capability, i.e. capture extremes of achievement or non-achievement of physical, functional outcomes, insensitive to subtle changes and offering only a snapshot (Costanza et al., 2007; Lercher, 2003; Rapley, 2003:67). Indeed, Wilk (1999:93) argues that any purely 'objective' measure of life is going to "miss an essential quality of what needs to be measured," i.e. what those measures mean to those being measured.

Turning to less somatic notions of wellness and wellbeing, investigations are proliferating over the last two to three decades particularly in economics, public health, and psychology (Mathews & Izquierdo, 2009:1-4). In combination with some qualitative studies, statistical measurement and comparison is the primary method of investigation into wellbeing in these disciplines (Mathews, 2012:300). Notably, there is research on living well and Aristotelian notions of Eudaimonia (e.g. Ryan et al., 2008), Sen's (1993) capabilities approach, and Diener's (2011; 1999) concept of subjective wellbeing in positive psychology. There are also multiple different ways of delimiting psychological, psychosocial, cognitive wellbeing, life satisfaction, surviving and thriving, etc. (Kahneman & Krueger, 2006; Rapley, 2003; Sen & Nussbaum, 1993). I partially enumerate them here to illustrate, as Mathews and Izquierdo (2009:1) do when writing of wellbeing in anthropological perspective, that there can be no such thing as a "single pursuit of happiness – rather, there are multiple "pursuits of happiness"."

In considering these multiple manners of conceptualising and parsing the components of living well, phenomenological approaches stand out in contrast. Here, I return to Dahlberg et al.

(2009:266-7), who use phenomenology as a blueprint to argue for an "existential view of being human" and of wellbeing in lifeworld-led healthcare. Unlike those enumerated above, wellbeing here is reformulated around a central focus on the lived bodily experience of being well "before it is subdivided into different domains." (Dahlberg et al., 2009:267) This existential view of wellbeing is therefore non-prescriptive, referring to and encompassing myriad possibilities of living well. "Rather," they write, "it focuses on what makes well-being an experiential possibility, so that its various forms can be recognised." (Dahlberg et al., 2009:267).

The reflective lifeworld approach (see Dahlberg et al., 2007) they employ has been similarly undertaken by others researching wellbeing (e.g. Bremer et al., 2009; Johansson & Ekebergh, 2006; van Wijngaarden et al., 2015) in order to "not make definite what is indefinite." (Johansson & Ekebergh, 2006:101) As Atul Gawande (2014:259) poignantly emphasises: "well-being is about the reasons one wishes to be alive." These reasons are more easily overlooked in conceptualisations of wellbeing that parse it into different a priori categories, which in lived experience fundamentally overlap and are mutually constitutive. It is therefore in this non-prescriptive vein of living well that I proceed with my study; this orientation and sensitivity is mirrored in the methodology and methods I undertook, described in the next chapter.

2.6. MAKING SENSE and MAKING MEANING

In this final section of the literature review, I turn to considering how people make sense of decisions in the case of chronic illness and dying, set future goals and priorities, and make meaning as they continue to go about their daily lives under these circumstances. Anthropologist Carolyn Smith-Morris (2010:34) suggests that research focusses on "the 'disrupted' portions of life" because these are most visible, resulting in these periods being over-emphasised. She (2010:34) rather calls for researchers to refocus on the "connecting sinews between diagnosed and undiagnosed periods of life […] to produce a more holistic

discourse about lifelong health." Such narratives are multi-vocal, practical accomplishments (Alsaker et al., 2009; Hunt & Mattingly, 1998; Mattingly & Lawlor, 2004; Ochs & Capps, 2002).

Indeed, health is embedded in familiar and diverse stories that populate one's experience across a lifetime (Desjarlais, 2003; Garro, 1992; Mattingly & Garro, 2000); part of making continuity and sense of these experiences is retaining this sense of familiarity in daily life, especially when health and situations change (Bontje et al., 2019; Carabante et al., 2018). Seeing "health as a punctuated but inherently integrated, lifelong experience," (Smith-Morris, 2010:34) holistic reconceptualisations have included a refocus on suffering (e.g. Kleinman, 1992). Most relevant to this thesis, however, is Mattingly's reworking of narrative in ill health through her narrative phenomenology of practice, revisited and elaborated in Chapters 5 and 7.

Much of Mattingly's (e.g. 1994, 1998) work is based on individuals who have suffered catastrophic illness, such as spinal cord injury. Much contemporary narrative theory asserts that narrative structures lived experience into coherence (perhaps somewhat artificially); rather than focussing simply on coherence in telling narratives, however, Mattingly argues that narrative is equally performed and essentially corresponds to lived experience in terms of drama, intersubjectivity, and practice. As Arthur Frank (1998:187) writes, illness disrupts old stories and new; "people [feel] submerged in stories they cannot change, and people [try] to tell new stories that are part of a project of living." Mattingly, therefore, focusses on how occupational therapists (OTs) in particular co-construct new narratives with their patients out of that disruption. Indeed, returning to Kaufman (2012:4), this requires someone to engage in "imagining certain kinds of futures in which one's corporeality is central, choosing among medical options in order to move toward one kind of future instead of others."

These narratives should be motivating for individuals and allow them to continue to live their lives in meaningful ways despite illness. These reconstructions are crucially sedimented in daily bodily practice through movement, i.e. repetitive motion of the newly-changed body. In

her 1994 paper on therapeutic emplotment, Mattingly focusses on practice and "practical reasoning," i.e. learning through doing to build capacity to achieve specific desired ends (Hunt & Mattingly, 1998:270). Mattingly describes in painstaking detail a hospital tour undertaken by Steven, a 20-year-old recently woken from a coma resulting from a car accident, and Donna, his OT. Together learning how to move again, Donna and Steven go through small movements that become connected to mundane everyday activities and a wider narrative of daily living through "narrative emplotment", from brushing one's hair to walking.

In this way, Mattingly writes of emplotment as a sense- and meaning-making, practical activity. Patients themselves perform emplotment in the sense that their practical actions are built into and made sense of within the narrative structure of their personal and therapeutic history, current state, and future goals. The succession of otherwise disjointed therapeutic events, and small measures of progress, can thus be made coherent and meaningful in relation to the more holistic 'plot' of the given patient's life. Rather than stories simply having plots that lend structure to lived experience, then, Mattingly's treatment of narrative acknowledges and incorporates the incoherent, i.e. the "unfinished, idiosyncratic, unpredictable, suspenseful qualities of life." (Mattingly, 1998:44) Emplotment is therefore conceptualised as imaginative engagement, and is seen as "a crucial […] response of those who face the sudden threat of an illness." (DelVecchio-Good & Good, 1994:856)

Mattingly writes particularly of emplotment in narrative. She defines narrative time as "marked by change", i.e. what pushes plots forward is the movement of one state of affairs into a transformed state, from a beginning to an ending (Mattingly, 1994:819). For example, Steven's OT Donna often tells him how much better or easier an activity was than yesterday's attempt. Narratives and daily living (whilst healing/rehabilitating in the case of Mattingly's work) are 'dramatic' in the sense that they may "involve multiple characters, risks, suspense, and above all, a heightened sense that something is at stake." (Mattingly & Lawlor, 2004:30) In many cases, what is at stake is a recognisable daily life that the patient themselves deems a

motivating goal, or in other words deems worth living. The emplotment of clinical time brings these kinds of future goals under present action. Narratives, therefore, are intertwined with lived bodily practice and experience; they are about actively doing something, and what happens as a result. Approaching end of life, however, narratives may no longer be future-facing, but may rather look to the past, which is discussed in Chapter 7.

2.7. SUMMARY: Making a Life Worth Living

This literature review focussed on experiences of the dying and chronically ill body, and the boundaries between life and death that are blurred in technological innovation, quality and quantity, decision- and sense-making. Starting from the well-established premise of medicalisation, I discussed recent changes in and the contested nature of dying, emphasising competing understandings and priorities. I also used the concept of biomedicalisation to highlight the role of health technologies in shaping life processes such as dying.

With a better sense of what is at stake for people, making decisions about a life worth living towards the end of life is thus cast as far wider than treatment, technology, and quality versus quantity. These aspects are also to do with the existential possibilities of living well. People's relations with their bodies, things, and lifelong stories are equally important as and intertwined with biomedical considerations of the body, technological interventions, and clinical prognoses and decisions.

This underlines the inadequacy of biomedical approaches to death and dying that produce disembodied, technologically determinist accounts of inevitable deterioration or life at any cost. I thus emphasised the utility and open-endedness of considering a non-prescriptive, processual phenomenological understanding of living well. This highlights the importance of embedding experiences of poor health within diverse lifelong experiences, and how these are vital aspects of making sense of and meaning through healing. In dying, however, people are not necessarily healing – how, then, do we know what it should feel like, and what needs to happen?

Self-management of terminal illness at home over years is not well-studied. With the possibility of intervention, in combination with technophilic discourses in digital health, the home emerges as a key context in which to explore emerging pressures, decisions, and understandings. The home is the place of daily living, made meaningful over a lifetime of habits with people, things, and stories. This is not merely disrupted in dying, but is the context in which people continue striving to make their lives meaningful and worth living. The processes by which this occurs, and people reach the ultimate end point of death, may concern quality and quantity, but are nevertheless experienced by people as lived bodily practice, through sensuous engagement with the worlds around them.

From here, I go on to ethnographically explore making, moving, and meaning as vital aspects of living. I frame this investigation as exploring how people make a life worth living, whilst dying with heart failure at home. Taking cues from the literature discussed above, I utilise, extend, and challenge understandings of how people deal daily with chronic dying, and death. The following chapter describes the methodology and methods I undertook in this exploration. Chapter 3 is similarly informed by and complementary to the focus on situated movement, making, and living attentionally with people and things.

CHAPTER THREE

Methodology and Methods

"In clinically-focussed accounts of dying, we have lost a sense of living."

- John Van Maanen, 1988

3.1. INTRODUCTION: Researching Death and Dying

This study explores how people with heart failure negotiate daily living in their own homes towards the end of life. Informed by the literature review in the previous chapter, this research responds to the lack of home-based studies (i.e. not in clinics, hospitals, hospices, or care homes); relatively little attention paid to chronic degenerative disease (i.e. not cancer) towards end of life; and lack of emphasis on non-prescriptive, processual understandings and pursuits of living well whilst dying. Accommodating the observation that dying has become more 'chronic', and end of life difficult to isolate, I therefore seek to explore the mundanities and practicalities of continuing to go about everyday living in one's own home whilst dying with a chronic degenerative condition potentially over years.

Whilst this focus is linked to quality of life, I do not wish to invoke the potentially narrowing lens of 'quality versus quantity' debates, as in the previous chapter. In considering a more holistic and general sense of living well, I am led to positively reframe this investigation as 'living whilst dying'. This serves to reconnect the management of one's health and approaching end of life with wider considerations of how to live well and continue to engage meaningfully in living under these circumstances. Given the centrality of the body in accounts of living with chronic illness and pain (e.g. DelVecchio-Good et al., 1992; Kleinman, 1992; Leder, 1992), I thereby seek to highlight the body in chronic dying outside strictly clinical contexts. The ethnographic and phenomenological approach I adopt supports an orientation towards lived bodily experience that allows end of life to be explicitly embedded within a person's lifelong narratives, and the peopled and material lifeworlds in which they are entangled. The

methodology and methods chosen thus appropriately support the exploration of the research question: *How do people with heart failure encounter and make 'a life worth living' towards the end of life, given the circumstances of their illness?*

In this chapter, I critically reflect on the positionality and tools I undertook during the course of this research project. It is worth noting that the chapter is contextualised in an emerging body of literature concerning the practice of in-depth research in the field of death and dying (sometimes including bereavement). My writing here reflects a wider call for rigorous, reflexive, and transparent considerations of methodology and methods in this field (e.g. Borgstrom & Ellis, 2017; Hockey, 2010; Woodthorpe, 2011). Death and dying are argued to be uniquely 'sensitive' topics, having "universal reach" that renders a "sense of complete detachment" during research "unrealistic." (Woodthorpe, 2011:99-100) Experienced ethnographic researchers in the field of death and dying rather suggest that high-quality research is produced through acknowledging and exploring the emotional engagement that such research calls for, throughout data collection and analysis (Hockey, 2014; Rolls & Relf, 2006; Woodthorpe, 2011).

The chapter is structured as follows. I first define and develop the anthropological orientation that informs my approach to the project, introduced in Chapter 1. I particularly take inspiration from innovative ethnographic approaches, such as sensory and walking ethnography, which build on more classical anthropological tools, methods, and orientations to extend ethnographic practice. Regarding access to field sites and participants, I discuss ethics and governance. I then describe methods and research procedures, including identification and recruitment of participants; the exploratory and ethnographic phases; and drawing fieldwork to a close. Finally, I explore the iterative analytical work undertaken with the materials produced, and how this is presented in relation to the structure and content of the findings Chapters 4 to 7. Throughout, I engage in critically reflecting on the difficulties (often particular

to end of life research) that I experienced at various stages of the project, both ethical and personal in nature.

3.2. METHODOLOGY: Anthropological Orientations

Anthropology is particularly well-suited to exploring how people with heart failure (and other co-morbidities) encounter and make a life worth living towards the end of life. Anthropological research in the interpretivist vein seeks to understand what people do, say, and think from the inside out, i.e. exploring emic rather than etic perspectives (Geertz, 1973; Russell Bernard, 2006:31). Research therefore aims to be immersive, reflexive, and participant-led as far as possible. Although there is debate around the conflation and separation of anthropology and ethnography (e.g. see Clifford & Marcus, 1986; Ingold, 2014), ethnographic approaches are a key part of anthropological practice. Such practices crucially involve cultivating a sensitivity towards the world as researchers go about moving and "living *attentionally* with others." (Ingold, 2014:389, original emphasis)

There are many different manners of undertaking ethnography, involving diverse methods and orientations. In this thesis, I draw on insights from sensory (Pink, 2011, 2015a) and walking ethnography (Ingold & Vergunst, 2014; Irving, 2017) to partly inform the collection and analysis of data, discussed below. Phenomenological lenses are also highly complementary to such anthropological approaches, explicitly paying particular attention to life as lived (Desjarlais & Throop, 2011), explored in Chapter 1. Despite divergent practices, ethnographic approaches nevertheless broadly share important hallmarks. These were flexible enough to allow emergent understandings and themes to iteratively inform and shape my research activities as data collection was ongoing.

Ethnography is historically taken to involve a researcher being present for an extended period of time, immersed in a society or culture (e.g. Evans-Pritchard, 1940; Malinowski, 1922), challenging their own assumptions through 'making the familiar strange and the strange familiar' (Miner, 1956). These societies may be remote, but more recently researchers have

undertaken ethnography in different and/or emerging field sites. This may include ethnography 'at home', i.e. in the researcher's own society or culture (e.g. A. Jackson, 1987; Messerschmidt, 1981); digital ethnography, i.e. online (e.g. Murthy, 2008; Pink et al., 2016); visual ethnography, i.e. including multimodality, multimedia, art, design, etc. (e.g. Dicks et al., 2006; Irving, 2017; Pink, 2013); and multi-sited ethnography responding to the increasingly globalised character and transnational flow of objects, ideas, practices, and people (e.g. Marcus, 2012; Ong & Collier, 2008).

Ethnography, given its immersive nature, may therefore involve the layering of multiple flexible methods. Employed together, these methods complement each other through capturing different aspects of a given phenomenon, and thus painting a more nuanced picture of life as lived. What people say, do, and think may be very different things, and may not be accessible through a singular method, such as a structured interview. Whilst formal interviews may be used to explicitly draw out how people make sense of their worlds, attending to the "sensoriality of the interview" (discussed below) further nuances observations and what is said (Pink, 2015a:73). This involves attending to body language and interactions with the wider context as the researcher engages in "doing with" people (Pink, 2015a:73-93).

These activities may be supplemented with informal conversations which build rapport, and may reveal aspects that the researcher may not initially have been aware of or intended to explore (Emerson et al., 2001:355-7). These examples particularly demonstrate how multiple, flexible, open-ended methods allow for the direction and understanding of research to be co-produced by participants and researchers together. This is particularly important in the home; rather than in institutional settings (e.g. clinics) where one can melt into the background more easily; in someone's home the researcher may be treated as a guest whilst being most interested in life as normal.

Acknowledging that there is no neutral position from which to conduct research, reflexivity is an essential part of ethnographic practice and sense-making. The researcher continually casts

themselves into view and critically encounters their positionality, i.e. their own evolving assumptions, experiences, and understandings (Pool & Geissler, 2005:17). There are a number of ways to do this, including (but not limited to) keeping fieldnotes that may be later incorporated into data analysis. Notes such as these, or in many other forms, constitute "the raw, or partly cooked, descriptive database for later […] theoretical elaboration." (Clifford, 1990:52) These reflections draw on the researcher's own experiences, sensations, and perceptions as part of an ongoing process of making sense of participants' lives and experiences.

Through these key features and practices, the process of doing ethnography captures and produces a wide range of rich (experiential) data that moves beyond simple description (Clifford, 1990). These diverse data can be analysed, synthesised, and written in nuanced ways that constitute the "thick description" forwarded by Geertz (1973); this goes beyond purely observing and reporting, involving interpretation that unravels complexity. This interpretive methodology does not take 'facts' to speak for themselves, nor does it approach the transformation of lived experience to text as a straightforward exercise in translation (Emerson et al., 2001); cultures and social life comprise intertwined, often conflicting discourses, and cannot simply be 'read' or reproduced in a smoothed-over account (Asad, 1986).

Further ethical concerns in writing ethnography centre around who has the authority to speak for people, or give voice to their stories (e.g. the Writing Culture debate) (Clifford & Marcus, 1986). This is partly addressed here in the understanding that research is mutually participatory and co-constructed, i.e. researching *with* people rather than researching people (Ingold & Vergunst, 2014; Lock & Nguyen, 2010:10). Rather than claiming to directly speak for people, I acknowledge my own role in this production, and that knowledge is always "a temporal, historical, and a political act." (Fabian, 1983:1) Here, rather than making a priori assumptions about people's priorities towards the end of life – of which biomedicine has been

accused (e.g. Dahlberg et al., 2009; Gawande, 2014; Kaufman, 1988) – I adopt an ethnographic methodology oriented towards doing and being (Ingold, 2014). This kind of phenomenological approach allows the emergence of sensitive understandings and fleshy accounts of the diverse yet equally valid ways in which people negotiate daily life in chronic dying.

3.3. METHODOLOGY TO METHODS: Implications for Empirical Study

In practice, phenomenological lenses in anthropology have inspired nuanced ethnographic tools and approaches. Those relevant here include Desjarlais' (2003) and Pink's (2015a) sensory ethnography; Mattingly's (1998, 2010) narrative phenomenology of practice; Ingold's (2000) dwelling in the environment; Csordas' (1990, 1993, 2008) as well as Mol and Law's (2004) later elaboration of embodiment. In this thesis, I draw upon these developing and innovative ethnographic areas and techniques as an informative lens through which to view the various (kinds of) data gathered. Bodily experience and attention, sensoriality, and movement are recurrent themes. These are explored further in later findings chapters, demonstrating the critical flow and coherence between methodology, methods, and interpretation in my iterative analytical process.

In particular, Thomas Csordas' (1990, 1993, 2008) cultural phenomenology extends embodiment as a "paradigm for anthropology." Embodiment in this way explicitly takes the body as the methodological starting point rather than considering it an object of study (Csordas, 1990:5-6). Specifically, Csordas (1993) introduces the notion of "somatic modes of attention." Redefining traditionally psychologised understandings of attention to instead relate to a bodily 'turning towards' of multisensory attention, he defines these as situated ways of attending to and with the body. This is explored further in relation to findings in Chapter 5.

In his monograph on the "sensory biographies" of two Yolmo Buddhist elders in Nepal, Desjarlais (2003) demonstrates the different ways the ethnographer might understand an interview. Emphasising how the sensoriality of daily life is preserved in memory, he finds that in life history interviews, sensory experience and value systems may be accessed (partly)

through language in the portrayal of life-long narratives. He suggests the researcher attends to an interview as a shared activity; this attention and inter-relationality should extend to other activities that one might do with research participants. In my research, life history interviews formed the basis for descriptive portraits of each participant, presented in Chapter 4, which served as a springboard for other activities that I pursued with them. Pink (2015a) similarly discusses sensoriality in interviews, a seminal author in sensory ethnography.

Pink (2012) asserts that phenomenologically-informed ethnographic practice is an "emplaced" practice oriented towards "people's embodied and multisensory participation in their environments." (Pink, 2015a:105) Practically, this involves interacting and corresponding with people and "their social, material, discursive and sensory environments." (Pink, 2015a:28) These approaches therefore build on the ethnographic imperative to "live and move as others do," i.e. be present and do things with people in their everyday contexts; but further emphasise how "the researcher learns and knows through her or his whole experiencing body." (Pink, 2015a:27).

Some ethnographic techniques thus suggest literally moving with participants, such as by walking with them through their shifting lifeworlds (e.g. Ingold & Vergunst, 2014; Lee & Ingold, 2006). Ingold (2000, 2011), as described in Chapter 1, similarly seeks to nuance understandings of the environment in phenomenological thought, and reconcile this with embodiment. For Ingold, embodiment is a process that unavoidably implicates the environment; people are involved through their bodies in multisensory engagement with their lived environments as they move through them. This is explored in relation to findings in Chapter 6.

Annemarie Mol, writing with John Law (2004), emphasises performativity, or action. Although embodiment in this way has been critiqued for over-emphasising performativity (Pink, 2011), Mol and Law further complicate embodiment by suggesting that the body has "leaky boundaries": "Bits and pieces of the outside get incorporated within the active body; while the

centre of some bodily activities is beyond the skin." (Mol & Law, 2004:1) The body is not whole in this sense, as managing one's health and one's body in practice requires myriad actions that embodied persons undertake. We therefore 'do' our bodies in meaningful ways, as well as having and being bodies. Through the example of how people manage hypoglycaemia, Mol and Law (2004:17) describe "living-in-tension":

> There are tensions between the body's organs; between the control under which we put our bodies and the erratic character of their behaviour; and between the various needs and desires single bodies somehow try to combine. (Mol & Law, 2004:1)

Mol's (2004:16) work thus highlights the multi-vocal, non-linear accounts of living that involve the complex interplay of many factors, foregrounding "the practices for dealing with reality." She explains that bodies are not pre-given wholes, but are rather complex configurations that require work: "Keeping ourselves together is one of the tasks of life." (Mol & Law, 2004:15) Mol et al. (2010) suggest that this is the work of tinkering, a kind of attentive experimentation that layers multiple solutions to multiple issues as it goes along. This is explored further in Chapters 5 and 6.

Equipped with a sensitivity to these kinds of notions and practices – concerning how to conceptualise the body and its relationship to experience, the lifeworld, and materiality – these are the orientations through which I encountered fieldwork, data analysis, and presentation.

3.4. ETHICS: Approval and Governance

I gained ethical approval from the Health Research Authority for this study (15/SC/0553) through submitting a Substantial Amendment to the original SCALS (Studies in Co-Creating Assisted Living Solutions) protocol. My DPhil research falls under the umbrella of the broader SCALS heart failure theme, Case Study 3: Oxford Telehealth Qualitative Study. Although funding for a DPhil study was written into the original budget, the focus and methods of this study were left for the student to specify. In order to conduct research in and recruit from NHS organisations, I made an application to the appropriate organisation for NHS R&D approvals. Relevant documentation can be found in the Appendix V. All data are anonymised with the use

of pseudonyms, and confidential data or identifying information (audio recordings, transcripts, participant contact details) were kept in password-protected files on a secure University server.

Undertaking discussions with colleagues and reading accounts of conducting similar research, I entered my project aware of some of the challenges associated with researching end of life. Concerns particularly centre around the safety of the researcher, as well as the perceived sensitivity of the topic, and vulnerability of participants (Borgstrom, 2018; Kendall et al., 2007; Lawton, 2001; Witham et al., 2015; Woodthorpe, 2011). In accordance with the Association of Social Anthropologists' (2011) guidelines for ethical practice, I therefore sought to be particularly mindful of and continually reflexive about the potentially intrusive nature of anthropological methods; honouring trusting relationships with participants; and protecting as far as possible the wellbeing of all those involved in the research, including myself.

Echoing how different challenges arose and were dealt with at various stages of the research process, these considerations will be further woven through the rest of this chapter, in context. In particular, I discuss the difficulty of building, maintaining, and then drawing back from relationships with participants; reporting findings regarding death and dying to participants who may not consider themselves to be dying; and making sure I did not place too much burden on participants, balancing their health and priorities with my own.

3.5. RESEARCH PROCEDURES: Overview

Research was undertaken in Oxfordshire, UK over twenty-four months from February 2017 to February 2019. Overall, 21 participants were involved, all diagnosed with heart failure and living in their own homes, aged between 57 and 99 years. The study is split into two phases: a six-month exploratory phase and eighteen-month ethnographic phase. I present these phases as separate here, yet in reality they organically fed into each other. As some participants and methods were involved in both phases, there was not a hard cut-off ending one phase and beginning the next.

The exploratory phase aimed to map the broader context of heart failure, build rapport with clinical practitioners that would later help to recruit, and encounter diverse patient experiences. Anthropologists may explore, hang out in, and scope fields before they begin their research proper (e.g. Borgstrom, 2018; Mattingly, 2010), familiarising themselves with the context the better to encounter their own assumptions, and identify key actors and potential participants. This might be considered in a similar vein to PPI (patient and public involvement) (e.g. Brett et al., 2014). During the exploratory phase, I conducted life history interviews with six patient participants, and observations of eight HFSN-led heart failure clinics, two heart failure support groups (cardiac rehabilitation, and end of life), and forty home visits with four HFSNs.

Findings from the exploratory phase informed the structure and focus of the ethnographic phase, allowing me to refine my research question in line with emerging themes, specifically 'a life worth living'. The ethnographic phase aimed to explore the everyday mundane and nitty gritty detail of being-in-the-world described in interview accounts, anchoring themes in people's immediate lived bodily experience (Ingold, 2000:19,173). During the ethnographic phase, I regularly visited fourteen participants between the ages of 67 to 98 years old, getting to know them and doing different activities of daily life together (e.g. shopping, gardening, knitting, walking, etc.). I also met and spent time with ten family members and/or primary caregivers. Findings were iteratively analysed to better understand what is at stake for people with heart failure in 'a life worth living', and how this is negotiated in the process of daily living towards the end of life.

3.6. RECRUITMENT: Access and Participants

Recruitment and maintaining access was an ongoing negotiation of people's changing needs, desires, and limitations, requiring a correspondingly dynamic and flexible approach. Participant recruitment was ongoing for over half of the study (sixteen months, from February 2017 to June 2018). This strategy responded to challenges in end of life research regarding

attrition and maintaining longer-term participation; people's health was not stable over time, leading them to sometimes decline continuing with participation as they were simply too unwell, or passed away (Greenhalgh et al., 2013; Gysels et al., 2013; Kendall et al., 2007:521). Four participants died during the course of this study. Initially, appropriate participants were identified by a GP with a cardiac interest (lead on SCALS Case Study 3); later, further participants were identified through my contact with the HFSNs, to whom the lead GP initially introduced me. In spending time with people in their own homes, I also sometimes crossed paths with family members and/or primary caregivers who were willing to talk with me. In a couple of cases, after the death of a participant, the lead GP sought verbal consent from a family member or practitioner to be contacted by me as well. Utilising local networks to gain access and recruit is seen as an appropriate strategy in this kind of research (Pope, 2005).

Patients were deemed eligible to participate in the study if they (a) had been diagnosed with heart failure (clinical assessment via echocardiogram of heart-pump capacity <40%) and (b) were psychologically and physically suitable by the GP or HFSN's own judgement (Kendall et al., 2007). Although I do not claim to have a representative sample of those living with heart failure across Oxfordshire or the UK, participants were recruited with a view to exploring a spectrum of disease severity, co-morbidities, care, and socioeconomic status. When appropriate potential participants were identified, the GP or HFSN initially approached them with written information about the study and researcher (see Participant Information Sheet in Appendix II). Potential participants then gave verbal consent for their contact details to be shared with me, which were securely transferred. I contacted them by phone or postal letter to give more information, the opportunity to ask questions, and arrange a time for a preliminarily meeting in their home if they were interested.

There is debate around the vulnerability of participants in end of life research, where the benefit of exploring this life-stage must be balanced with the perceived danger of placing undue stress on participants through research activities, or pressure to see this through to

completion (Gysels et al., 2013; Hockey, 2010; Kellehear, 2009b; Kendall et al., 2007; Woodthorpe, 2011). Together, the difficulty of accurately isolating end of life, fluctuating wellness, and flexibility I maintained to accommodate these aspects, led to some participants being visited only once before passing away; whist others were involved in more than ten visits over the entire twenty-four months. This variation is not uncommon in end of life research (Gysels et al., 2012; Kendall et al., 2007), and was taken into consideration in the interpretation of findings.

Ethnography may nevertheless offer a viable way to conduct in-depth research without placing "significant demands on [participants'] time and emotional reserves." (Lawton, 2001:693) A focus group study around end of life research by Kendall et al. (2007), with patient participants and researchers, suggested that whilst some people may feel pressure to participate if asked, others may feel they want to 'give back' and often are positive about feeling listened to. For these reasons, especially during initial conversations with participants, I assured them that their commitment would be as long as they felt able to participate, that they would not have to give any reason to discontinue, and that this would have no adverse effect on their healthcare.

In the home, I obtained fully informed written consent before commencing the first interview. Lawton (2001), drawing on her own ethnographic research experiences, discusses the validity of consent throughout end of life research; participants may experience severe declines in physical health and emotional wellbeing during the research process in ways that call their initial consent into question. Throughout the research process, therefore, I liaised with healthcare practitioners and family members, and reiterated to people that their continuing participation was less important than their own (changing) needs. In practice, this meant that many visits had to be rescheduled multiple times; whilst being flexible and keeping participation open-ended, I tried to fit visits into and around people's lives, keeping them regular but not too frequent or infrequent (about once every four to six weeks). I therefore

kept in regular contact with participants over the phone (at least once a week with most people), continuing to build rapport and keep up-to-date with their activities and health.

Beyond the documented limitations of end of life research, during my study I found that attrition occurred at two different time-points: initial recruitment, and after the first or second visit. Many people felt intimidated by the ethnographic components as described in the Participant Information Sheet (Version 1), reflecting that it sounded like a big commitment; it described the study as involving multiple interviews, activities, and excursions. Continually trying to recruit, I reflected on and reworked the information sheet (Version 2) after six months as part of consolidating what I had learned from the exploratory phase. These minor amendments made it clearer that each phase of the ethnographic study was entirely optional and flexible, and activities were based on whatever participants would usually do. This indeed seemed to impact recruitment, as people were far more easily and successfully recruited with Version 2.

The second related barrier was about retention of participants past the first visit or two. Participants were more comfortable having a researcher come into their homes for an interview, rather than having a researcher ambiguously 'visit' and 'help out' in their home. Whilst interviews seem to be comprehensible, finite, familiar activities, ethnography is more unfamiliar and nebulous; some participants therefore declined to continue their participation into the ethnographic phase (regardless of the version of information sheet). In combination with the physical fatigue that is a hallmark of heart failure, participants also seemed to reach a level of research and/or interview fatigue. Participants were recruited through a GP who is often involved in research activities, referring patients to participate in studies; when asked if they would be willing to be interviewed again in a few weeks or months, some of the more health-stable participants said that they did not know what else they could tell me.

3.7. RESEARCH STRATEGY: Exploratory Phase

The exploratory phase was key in developing an overall research strategy. Through these experiences, I started mapping the fieldwork landscape I outlined above through exposing myself to some of resources and practitioners that wove in and out of participants' lives. In the vein of PPI, many of the lessons learned and adjustments made around recruitment and access were gleaned through the efforts and mistakes made during the exploratory phase. The exploratory phase had three strands: (1) life history interviews with patient participants; (2) observations with four HFSNs (as there were concurrently only four HFSNs in Oxfordshire) during home visits and heart failure clinics; and (3) observations of two heart failure support groups. As the main contribution was to refine and frame the ethnographic phase, these activities and data are less visible in the thesis and I therefore spend less time discussing them here.

Life history interviews allowed me to organically build understandings of participants and their lives from the person outwards; these interview data highlight what participants find important, yielding salient stories from and insights into lifelong narratives. HFSN observations exposed me to a spectrum of challenges, successes, and care practices associated with long-term community management of heart failure, and the more or less formal support provisioned at end of life; I picked up on key language and actors, exploring how care is conceptualised and facilitated through diverse networks. Complementarily, I came into contact with multiple support groups during these activities, and was able to observe two different support groups: one focussed on living well towards the end of life with heart failure for patients and their spouses, and another on cardiac rehabilitation. This drove home to me the stark contrasts between day-to-day feelings of wellness, not only for different people with the same diagnosis but also for the same individual and their families.

Life history interviews with individual patient participants allowed me to discuss with people how heart failure fits into the rest of their lives; exploring what is important to them in thinking

through past, present, and future experiences. I conducted and audio-recorded interviews with six people, lasting between 1-2 hours. Interviews were deliberately open-ended, following the principles of life history interview (Desjarlais, 2003; Pink, 2015b) where the researcher asks broad/minimal guiding questions whilst primarily allowing the interview to be participant-led. Guiding questions included prompts such as "tell me about your daily life", "tell me about how you first realised you were unwell", and "tell me about how your life has changed" (interview guides are included in Appendix V). Maintaining the ethnographic character of my research strategy and underpinning epistemology, I kept extensive fieldnotes reflecting on the phenomenological and embodied aspects (Desjarlais, 2003; Pink, 2015a) of these interviews. This attention allowed a richer picture to emerge from interviews beyond merely what was uttered by participants.

Although participants had all been diagnosed with heart failure at least 1 year prior to interviews, few participants considered themselves to be dying; as previous discussed, heart failure is not habitually treated as a terminal illness and in fact lengths are taken to reassure patients that they are not suddenly about to die. End of life researchers often cite that participants may not consider themselves to be dying; researchers must delicately and ethically navigate this, exploring end of life themes without labelling that participant as dying (Hockey, 2010; Kendall et al., 2007; Woodthorpe, 2007). I encountered the same difficulty, balancing my desire to explore end of life whilst also not wishing to cause anyone distress. Life history interviews, with their reflexive narrative character, allowed me to explore with people their pasts, presents, and possible futures. This allowed the subject of death and dying to arise more naturally in conversation, and more easily be pursued or dropped depending on how participants engaged.

This phase also allowed me to explore how I felt doing this kind of research, and reflect on the methods I wanted to use in the ethnographic phase. In particular, I found that my own wariness around bringing up death made me hesitate in following this line of questioning, more than

unwillingness expressed by participants, a recognised difficulty in end of life research (Borgstrom & Ellis, 2017; Hockey, 1990; Woodthorpe, 2009). In this way, conversations around life history narratives offered a sound introduction, a good way to begin to build rapport and a rounded initial impression of people. I therefore wished to preserve this practice in future visits. Emergent findings from the exploratory phase suggested that living whilst dying over months and years produces ambiguous, negotiated, and multi-vocal accounts. What captured my attention, however, was that most interviews converged around discussing that which 'makes life worth living'.

3.8. LAYERING METHODS: Ethnographic Phase

The ethnographic phase involved fourteen participants, whom I visited on multiple occasions and with whom I kept in regular contact. The ethnographic phase was oriented towards doing and being, and aimed to explore the research question: *How do people living with heart failure at home towards the end of life encounter and make their lives worth living, given the circumstances of their illness?* Throughout the exploratory phase, I critically challenged my own assumptions and thus use participants' terminology, i.e. 'make life worth living.' I therefore deliberately posed the research question in an open-ended, exploratory way. As the central focus is on home-based daily living, all data were collected in, around, or nearby the home. The visits I participated in generally lasted about 2 hours (between 1-3 hours). Visits were diverse, as I tried to get a flavour of the many different things with which participants engage; what we were able to do was partly dependent on participant's daily activities, but also the weather and their health (and sometimes also mine).

After or during initial life history interviews, I opened space for thinking about what sorts of things to do together. I did this by offering help and/or companionship around the home (e.g. gardening, cooking) or outside of the home (e.g. walking for pleasure, grocery shopping). I explicitly cited what participants had previously mentioned in their interviews: "You mentioned that you love to garden, maybe I could help with that sometime?" or "You

mentioned you like to go grocery shopping most days, maybe I could come with you on one day?"

Overall, activities and excursions included: informal catch-ups over tea; cooking; gardening; lace-making; knitting; spinning wool; looking through old photographs, diaries, and letters; going through stored belongings; home tours; meeting family members; going to the local grocery shops; going for local walks; playing Scrabble; going to the pharmacist; going to the podiatrist. For a full catalogue of research activities and emergent themes, see Appendix I. Actually doing everyday activities (or at least things they would also usually have done without me) with participants usually happened after the first few visits, when the foundations of a relationship of mutual trust and confidence had settled; 'doing with' participants similarly contributed to building rapport, and often triggered deeper discussions.

I thus focussed on doing many things once, rather than the same thing many times. The overarching design of the ethnographic phase was therefore one of layering methods in order to access different aspects of someone's daily life, whilst allowing for the limited time I was able to spend with them. This is also a common limiting factor in end of life research (Gysels et al., 2012; Kendall et al., 2007; Lawton, 2001). Layering different activities in this way allows a complementary embodied understanding of life as lived to emerge alongside that which is articulated in conversation (or informal interviews), also addressing the important differences between what people say and what people do and think (Tilley, 2006). 'Doing with' similarly fulfilled the aim of exploring lived practice (Ingold, 2000), i.e. the lived experience of going about daily life and doing meaningful things, how these things become meaningful, and how doing these things is made easier or more difficult, more or less appealing, in the reckoning of making life worth living.

Taking inspiration from the aforementioned sensory ethnographic techniques of Pink and Ingold, I therefore tried to pay particular attention to how people feel their way through their worlds, highlighting co-production and doing in movement. Although I do not claim to

explicitly have undertaken a sensory ethnography, as Pink (2005:277) suggests, in this research "my task was to understand my informants' experiences by sharing the smells, textures and visual appearances [i.e. sensory aspects] they demonstrated, and imagining those that they narrated."

Although it is inevitable that the researcher's presence impacts daily practices and experiences, I sought to understand rather than shape these; the latter would have been the case had I taken on a formal live-in carer role, for example (something I considered earlier in the research process). Rather, many smaller activities came up as part of chatty conversations, where participants would be describing something, and then invite me to come see (e.g. garden, contents of the fridge, gadgets); often retrieve something to show me; or ask me to come help them find something. Expressing curiosity about and interest in these objects or hobbies, I noticed how participants enthusiastically explained and demonstrated, teaching me how to do things like plant potatoes, or make lace. Whilst longer, more involved activities sometimes required planning, I reassured people that these were not essential; we should only continue if they wanted and felt able to.

There was a further difficulty, a particular challenge in end of life research, in sharing findings with research participants who may not necessarily consider themselves to be dying (Gysels et al., 2013; Hockey, 2014; Kendall et al., 2007). To avoid this, and reflect the generally positive framing of my research around living (allowing dying to arise more organically as a topic), I explained my research to participants as focussing on everyday activities in living well with heart failure; looking backwards, and considerations moving forwards. Similarly, as the participant pool was quite diverse in health status and life stage, it was difficult to put together a short summary that represented this diversity whilst also allowing me to receive meaningful feedback. I settled on including a couple of emergent themes that related to many, if not always all, participants' experiences; and decided to neither shy away from nor emphasise dying as a topic. This showed a sound strategy, honouring the frank discussions I had had with people

about end of life; their feedback suggested general agreement with my thoughts at this stage. I further explore the difficulties of negotiating end of research in an Epilogue to the thesis.

3.9. ANALYSIS: Handling and Presenting Data

Most conversations were audio recorded (conversations during activities outside the home tended not to be) and transcribed verbatim. All visits were captured in systematic reflective fieldnotes; I would also often draw or paint representations of participants; and write poetry, ethnographic vignettes, and case summaries about participants. I handled and used all these materials as data, yet felt uncomfortable describing them thus; these felt more to me like playful, engaging sense-making exercises. Ethnographic practice may not be primarily data (or ends) oriented, especially given the "highly personal, temporally bound, and intersubjective" nature of ethnographic experiences (Engelke, 2008:S2). Writing of the "social life of interview material" in end of life research, Hockey (2014:93-111) describes the complex negotiation of these fragments that bear pieces of people who have died, such as audio-recordings. I therefore similarly sought to treat all materials respectfully, mindful that they represented feelings, experiences, and stories of real people (including myself).

Overall, I employed a data analysis strategy that was iterative and interpretive in order to pull out salient cross-cutting or contrasting themes. An open-ended approach was important, keeping a general phenomenological orientation in mind without artificially fitting the data to theoretically-informed expectations; rather allowing materials to speak for themselves, as it were (Desjarlais & Throop, 2011; Pool & Geissler, 2005). During data analysis, I broadly strove for familiarisation and sense-making through attending to and following the threads of many stories. This process involved holistic read-throughs (Van Manen, 1997) of interview transcripts that I transcribed verbatim myself (another familiarisation technique), allowing salient themes to emerge from the materials themselves; an understanding of the whole was important before breaking these data down.

I therefore spent time connecting disparate materials and organising data in predominantly in two ways: in NVivo, and writing ethnographic vignettes. Collecting stories and quotations around similar subject-matter in NVivo concretely organised my understandings of what is meaningful to a specific person, what kinds of experiences give form to this meaning, and commonalities between participants. This rendered write-up easier as relevant quotations were usually collected in one place.

To re-embed these stories in people's lives as I understood them, I used fieldnotes and other materials to write ethnographic vignettes that introduce each participant in what I hope is a thoroughly human, relatable way. These portraits are presented in Chapter 4 to familiarise the reader with each participant and their particular stories. Ethnographic portraiture is part of a multi-modal tradition of approaching ethnography in a more artistic, often sensory manner; it is an established method of engaging with and communicating diverse kinds of data (e.g. Dyson & Jeffrey, 2008). I grounded the portraits particularly using the fieldnotes I had taken before, during, and after each visit. Fieldnotes served as a free, expressive space to reflexively focus on my surroundings, perceived changes, features of the participant's speech and bodily movements, my own feelings, my role as a researcher, and any arising ethical aspects. As a complementary kind of data, fieldnotes were thus predominantly experiential, capturing aspects other than direct speech and thereby further nuancing the stories told.

More formal case summaries allowed me to refocus on specific themes through synthesising data in a systematic way, asking set questions in order to better fit together accounts of past events and current impressions. Producing these various outputs fulfilled the aim of isolating and reflecting on emergent themes and unexplained tensions as they related to the original research question. Exploring the emerging narratives as they relate to the question of a life worth living transformed my understanding from a concrete level grounded in data to a more abstract level, and back again. Through reading, writing, and discussing my thesis, I built a

theoretical framework through which to approach and understand my data, explicated in Chapter 5.

Given the multi-modal, sensory tendencies of my working throughout this thesis, I sought to present ethnographic materials in a number of different ways here. This reflects the diverse methods, experiences, and analytical processes that comprise this research. Ethnographic vignettes and portraits, as well as direct quotes from participants and from my own fieldnotes, are the foundations of the findings chapters. Staying close to the original sense-making materials in this way should give an immersive sense to the reader, and maintain transparency about how I interpreted these materials. Findings chapters 5, 6, and 7 are more explicitly analytical than Chapter 4, which I have mentioned is entirely dedicated to introducing individual participants.

As there are so many participants in the study, whom I continue to treat as whole people (with corresponding whole lives) throughout the thesis, this introduction therefore also serves as an anchoring reference point and map for the forthcoming threads. This is done in the vein of Jeanette Davies' (2017) ethnographic work with care-home residents towards the end of life. Similarly, in the volume exploring "telling lives" edited by Jeffrey and Dyson (2008), multiple authors innovatively write portraits of young people to highlight and illustrate wider issues. In focussing on one person at a time, exploring single lives may "reveal insights not just into the experiences and attitudes of the individuals directly concerned, but also of the wider society or social segment of which they are also part." (Arnold & Blackburn, 2004:43)

Chapter 4 introduces the landscape of my findings in an organised yet intense way; signalling specific and overarching themes, yet demonstrating the rich, fleshy, raw accounts of each individual. I felt this was best accomplished through ethnographic portraiture, honouring the sensory details and lifelong narratives that I became involved in as I got to know people. My descriptions are deliberately spare, meant as thought-provoking whilst echoing the uncertain and unfinished narratives of living whilst dying with heart failure.

CHAPTER FOUR

Portraits: living whilst dying, dying whilst living

"He who has a 'why' to live for can bear with almost any 'how'."

– Viktor Frankl quoting Nietzsche, in *Man's Search for Meaning* (1959:97)

4.1. INTRODUCTION

This chapter is a culmination of close analysis dedicated to each person who participated in the main body of this study. The way the data are presented here has ethnographic importance. Through these portraits, I mean to give a sense of what is at stake for the people with whom I spent time; the daily negotiation of how they try to continue to meaningfully engage with what is important to them; and important life events surrounding these experiences. I signal cross-cutting themes through giving snapshots of daily lives and life histories of each participant in turn, before fragmenting their accounts in later chapters. These later fragments would not make sense without spending the time to first embed and contextualise them here in the lives of participants as whole people. I similarly use this space to demonstrate my relationship with each participant. For a condensed tabularised summary of the formal meetings with participants during fieldwork, including synopses of what was discussed on each occasion, please refer to Appendix I.

There is therefore analysis embedded in this chapter, which introduces each participant in turn first through an ethnographic vignette, and then traces family and living situation as well as particularly salient recent and past life events. In this way, the individual specificity of each participant is preserved whilst also being connected to the wider themes which are explored in Chapters 5, 6, and 7. I wish to both immerse and sensitise the reader to the importance of knowing and trusting one's changing body and movement; lifelong stories; material (including technological) adaptations; making and changing decisions; and finding the effort of living to be no longer worth it, as some participants did.

4.2. Rosemary

> *I followed her through a house that was notably minimalist except for walls that are lined with photos and a large number of clocks. Otherwise, inevitable household conveniences are pushed back to the perimeter of each room to create deceptively large floor-spaces. Upon seeing her zip through the house, I began to realise that these open spaces were strategic, allowing for easy manoeuvrability with a walker. Further signs of mobility difficulties – a stair-lift, walking frames stationed purposefully around the house, ramps into the garden – gave way to a narrative of a life where the importance of and struggle for movement predominates. Living in such a pragmatic house, Rosemary herself was a pragmatic woman: her skin was ruddy from years in the sun, her cheeks shiny and free of lines, her face bare of makeup, her short hair untampered with, her clothes simple (a fleece and some black slacks), and her shoes sensible, with the occasional appearance of pink fluffy socks. She fashioned herself functionally and conducted herself practically. Rosemary was built for* doing. (Excerpt from field diary 20/02/2017)

Rosemary is 83 years old and widowed, an ex-farmer's-wife with 4 children and a great number of grandchildren. She never re-married after her husband died 25 years ago, and now lives alone in a 2-storey detached house in a small town in rural Oxfordshire. The house has a good-sized back-garden, which Rosemary delights in cultivating, and she tells me her neighbours are lovely people who check on her regularly. Medically, Rosemary is highly complex. Diagnosed with heart failure 10 years ago, Rosemary is now beginning to feel breathless even whilst sitting, with fluid periodically building up in her legs and on her lungs. Rosemary has also since developed a number of other conditions, including gout, recurrent kidney and urine infections, spinal spondyloses, and peripheral neuropathy. It is this last issue that she finds most problematic, which is systemically numbing her limbs: as her ability to walk slowly weakens, the possibility of a wheelchair threatens the way she is currently living.

I have spent a lot of time with Rosemary over the past two years, building a relationship supplemented by regular phone calls to each other with news, and/or to reschedule an appointment due to ill health on her part. I have visited Rosemary in her home on ten occasions, where we most often sat in her living room, looking out onto the garden and chatting over a cool drink (she does not drink tea as she gets awfully hot and red in the face if she does). On other occasions, she has driven me to her medical appointments in her specially-adapted car; I have accompanied her on her daily trip to the shops, walking next to her whilst she rides

her mobility scooter and chats to passers-by; and we have gardened together, planting and growing vegetables (some of which she later insisted on giving me when matured) in elevated 'veg trug' planters, at which Rosemary can sit on her walker, tucking her knees underneath. As the veg trug demonstrates, many things in Rosemary's life have had to be adapted in some way in order to maintain independent living, whilst coping with her changing mobility and fine motor needs. From everyday mundane tasks such as buttoning up her shirts and locking her front door, to undertaking larger projects like remodelling her kitchen to be wheelchair-accessible so she can continue to cook (and grow) most of her own food, Rosemary has mobilised many options available to her. She has entreated family members, healthcare workers, and servicemen to help her maintain her way of living.

Through our conversations, both in more formal interviews and informal chats whilst we are doing other things, I have got to know Rosemary, how she chooses to live, and how she is unwilling to live. Rosemary's life is negotiated around profound mobility challenges, from getting dressed in the morning without being able to feel or move her fingers very well, to going to the bathroom at night on numb wobbly legs whilst on diuretic water tablets; yet she continues to demonstrate to me her stoic desire to live independently. Adopting a pragmatic attitude of perseverance (getting up and just doing things, sitting down if you need to until you can go again) and planning, with help and support, Rosemary enables herself to better accommodate her needs and continues to engage in many of the essential aspects of her life. Rosemary organises her life around a set routine oriented towards staying as safe as possible (she is trying her best to slow any deterioration in her health that she might notice), whilst still doing the things she enjoys that are 'worth it'. Her experiences highlight the shifting line between difficult trade-offs, shared by many participants.

During the last few visits, Rosemary has told me she is beginning to notice that things are getting more difficult. For example, she is having to get up much earlier in the mornings now in order to get herself ready to begin her day at the same time; she has to take her day much

more slowly and carefully, as she is more wobbly due to further numbed legs and breathlessness, and a few falls; she has come to have a lie down in the middle of the day, each day, in order to not feel entirely drained the next day. At the referral of her GP and occupational therapist, she is now being visited by a Community Matron, who is talking to her specifically about end of life and funeral arrangements; Rosemary says she appreciates the space and the support to think through these things, and with her characteristic can-do attitude, has started incorporating these aspects into her organising. Years of raising children on her own, as well as years in farming and latterly primary school teaching, have equipped Rosemary to be organised, to look forward and plan with dexterity. Those she encounters seem amazed that she keeps finding creative solutions as she is faced with new challenges, managing to stave off the wheelchair that she swears will render impossible most of the ways in which she makes meaning in her life: “If I go into a wheelchair,” she says, “I shall be dead.”

4.3. Emily

> *Entering through a number of gates, I am greeted by an impressively cluttered conservatory, what seemed to me like a graveyard for generations of toys. Picking my way carefully through the precious paraphernalia of many lifetimes, I knock uncertainly on the interior door. A woman soon opens it, Emily. She stands tall, her back pulls over forwards, her shoulders rolling stiffly towards her neck, but she does not use a cane and walks with slow deliberation. She is well-presented, as per her routine, her hair soft white and done each week at the hairdresser's, her glasses thick and gold-rimmed; the years have printed themselves discretely on her skin like dark spots on pale crinkled paper. Her feet are sturdily clad in bright red leather clasped tightly around slightly swollen ankles, the red rather clashing with her baby-blue cashmere sweater and dark wool skirt. Behind her face, her eyes make a strange kind of sense to me: they are laughing, crinkled at the sides, bright and interested. When she smiles, not broadly but quietly, she reveals strong, even teeth. My impression of Emily is immediately one of comfortable happy abandon, a security of self, that is appropriately staid, invitingly personal, and even, somehow, youthful.* (Excerpt from field diary, 10/02/2017)

Emily is 89 years old, and has had heart failure for the last 40 years, now complemented by COPD. She is fairly well, a bit breathless, walking slowly indoors and using a mobility scooter outdoors. She lives alone in the same cluttered, homely, two bedroom bungalow in which she raised her family for the last 50 years, wondering aloud how they all managed to fit in such a tiny house. It is a good size for Emily to manage now alone, and she is still doing much of her own cooking and shopping. Her husband, who had had chronic health issues, died 10 years ago; their two daughters, Beverly and Carol, are very involved in Emily's life, despite Carol not living nearby. Emily herself is actively interested in her extended family (most of whom are female), spanning four generations in a close-knit, caring network in which Emily is lovingly supported. She makes most sense to me in the context and company of the rest of her family, particularly her youngest great granddaughter, 3-year old Hope, around whom Emily appears to light up.

I have visited Emily on six occasions, becoming used to various family members dropping in and out, staying far longer than I intend when Hope comes over and demands to be played with. I have met and interviewed both of her daughters, the presence of her family members visibly animating Emily and motivating her to do more. When visited alone, Emily is quietly

capable, slowly pottering around the tiny house to make us tea or find a biscuit, and is more than happy to sit for hours with me, gently chatting to and fro. However, when a family member pops by – sometimes surprising Emily, who seems delighted by their presence, expected or otherwise – Emily springs into more agile action. She gets down on the floor to play with Hope; will get on the trike offered by her teenage grand-daughters; take up a bit of spinning, knitting, or sewing when Beverly brings her loom with her; will happily be taken along for the trip up to the farm where Carol lives in Yorkshire, and will not particularly bother about when or whether she is coming back.

With an attitude cultivated across almost half a lifetime of living with heart failure, and caring for her chronically ill husband, Emily and her family take one day at a time, and Emily is thankful for each breath. Family is a central source of joy for Emily, and much of the meaning she makes in her life is around these indispensable people. Learning through the unpredictability of both her husband's and her own illnesses, Emily's flexibility enables her to enjoy and partake in her family's comings and goings, but she is also quite content to slow herself down and reminisce about how wonderful her life has been.

Emily has had a number of health scares over the years; however, each family member I have come across has spoken at length about the most recent cardiac arrest three years ago, only a few months after Emily signed a do-not-resuscitate (DNR) order. "It is very difficult to know the circumstances of what is going to happen," family members say, explaining to me that after Emily had recovered from the worst of the cardiac arrest, she had requested that the DNR be made redundant. Emily tells me it was just before Hope was born, and she told the doctor: "I want to live long enough to see that baby born."

4.4. Nicholas (Nick)

> *In the nursing home that I am told he was only recently checked into, I am finally allowed to see Nick. When I enter the room, it is narrow and dim, the curtains are half-drawn against the sunlight. "Hello!" I greeted Nick enthusiastically as a nurse manoeuvred a chair nearer to his bed, a narrow piece of furniture that was somehow reminiscent of home in shape and sentiment, but peculiarly clinical in material and posture, high-sided with grey-white panels and tilted so he could sit up slightly whilst being supported. "Hello," he greeted me back with a hoarse, breathy voice, a voice that sounded somehow like a texture more than a noise. "You must be the Anthropologist." The first thing I noticed was that he was so pale, half-sitting/half-lying in this half-light room, wearing a cardigan that was blood-red against the monochrome walls and his wash-out skin. So many contradictions, so disjointed. In gaining informed consent, and Nick takes the pen I give him. I hover uncertainly by his side, half leaning over the bed, half trying to give him space as I agonise over watching him grasp the tip with trembling hands. The silence we shared is dappled by his laboured breathing as he prints his initials painstakingly onto my consent form. I had been warned about Nick's wicked, deadpan sense of humour, and he may have smiled while he traced his name, but his face had been partially paralysed from a stroke months ago. "My name doesn't belong to me any more," he said as he wrote his signature, not looking at me whilst still concentrating devotedly on the final curving movements of pen on paper. "It belongs to Parkinson's now." By the end of the visit, I was fairly convinced that Nick's face, his limbs, and his life didn't belong to him any more, either. Only his memories.* (Excerpt from field diary 28/02/2017)

Nick passed away at 86 years old, just a few weeks after my single visit with him, about which the excerpt above was written. I sat with Nick for over 2 hours in the nursing home, where a significant proportion of the recording was the silence we shared. An engineer by background and blood, Nick had lived a dynamic life travelling to set up oil plants in over a dozen countries around the world. After his retirement, life was never quite the same, a combination of progressively worsening health (primarily Parkinson's and heart failure), boredom, and divorce. It was very difficult to know what precisely was important to Nick now; he hardly spoke at all of a current event or recent happening. He resided, instead, in the stories and memories of his youth and work. He trawled through the depths of a laptop to show me technical photographs, keeping them for that 'just in case' moment he hoped would be in the future. But he knew, he said, that he probably would not be getting out of the nursing home; he knew that this was where he was going to end his days, saying with a poignant and somehow desperate humour: "You know? It's bloody boring waiting to die!"

After Nick's passing, I interviewed his daughter and primary carer, Linda, as well as his GP. I began to build a picture both of his life before moving into the nursing home, and afterwards, the circumstances leading up to his death. After Nick retired, he was becoming progressively more unwell, and it was deemed financially and practically prudent for him to buy a house together with his youngest daughter, Linda, where he could live in a self-contained annexe. How far this move was initially motivated by health issues is unclear, but it did allow Linda to care for Nick when his health deteriorated past the point where he was able to cope on his own. Post-retirement, Linda described Nick's life as being characterised by a progressively reduced social life, and the constant struggle to be independent despite his health. Discussing how difficult it was to do things for him, and how she eventually decided to always give him the choice of her help rather than forcing the issue, Linda said that it seemed like her father's central value was trying to impact her life as little as possible. She openly labels his feelings as "depressed", and said she could understand why. These priorities and feelings mingling, Linda told me of the numerous occasions that Nick would refuse to ask for help, and she would find him having fallen and unable to get up; sometimes, she related that he was even sitting in his own excrement, insisting that she just leave it.

Having worked professionally as a carer, Linda told me that she had known what would be required to care for her father; yet she repeated to me how she had not anticipated how different and impactful caring would be when it was your own family, a realisation that went both ways for Nick and Linda. Linda told me that she felt that there was a mutual acknowledgement that neither of them wanted to be doing this, or wanted to live like this. They both knew that the circumstances of Nick's life were intolerable: "It wasn't good enough, I knew it wasn't good enough," Linda told me frankly. In response to the circumstances and against Nick's insistence, Linda tried to leave her job in order care for him full-time, but was unable to due to financial reasons and a pending divorce.

One day, Nick asked directly for a plastic bag: he did not want to continue living like this. Linda began to realise that Nick was stuck in a cycle of health issues, the same things kept going wrong; but even after this realisation and being admitted to the nursing home for palliative care, Linda found how very difficult it was to let Nick die. During this period towards Nick's end of life, the family experienced repeated encounters with the medical system in which Nick's life was 'saved' through an emergency intervention. Eventually, different professionals agreed, along with Nick and his family, that they would not initiate heroic life-saving measures next time the recurring health issue came around. Even so, in the last hours of Nick's life, Linda said she had found it difficult to continually refuse the offers of nursing home staff to call an ambulance, which would have taken him to hospital and continued the cycle they had all been in for so long.

4.5. Carol

> *She is a stylishly neat woman in her mid-70s, although I would have guessed her age to be closer to 55. She had a tanned complexion, and her blonde hair seemed professionally dyed and highlighted, and freshly styled. She had a slim figure, and was wearing a very nice outfit that was hip and cool in the easiness she exuded whilst wearing it. She welcomed me inside an immaculate and well-decorated house, all creams and duck-egg blues and sage greens, calling casually out to her husband to make us some tea. She was a curious combination of this elegant appearance with an accent hailing somewhere from inner-city London and an attitude of someone who would invite you to indulge yourself in that extra biscuit with a 'oh, go on, then!' I knew, from the colleague who had interviewed her previously, that she had run a bridal shop, an endeavour to which I was sure she was expertly suited. I also knew that, after her retirement at 65 over 10 years ago, she was excruciatingly bored.* (Excerpt from field diary, 21/09/2017)

Carol and her husband have both been retired for over a decade, and live comfortably in an elegant, modest detached house with a private driveway on the outskirts of city suburbs in the South Midlands. They live sociable lives together, enjoying regular sun-seeking holidays, and occasionally venturing to the south of England, and rarely Australia to visit their children and grandchildren. Mainly, however, they find it difficult to fill their time to their satisfaction.

Carol describes herself and her husband as both having always been fairly fit in a general sense, despite her husband developing gastro-intestinal issues several years ago. Five years ago, Carol had an unexpected heart attack, having never before been ill a day in her life. It was a shock to her system that resulted in the baffling diagnosis of 'heart failure'. She is not the first participant to say to me that the term itself is horrendous, and that as a result of how she was feeling at the time, the unexpected nature of her ill health, and the lack of forthcoming explanation, that she simply presumed that she was going to die. After careful questioning, and a rehabilitation programme at the gym to which she easily took, she now feels mostly very well. The most frustrating things, Carol tells me however, are the small niggling reminders that she is not *quite* well. They are reminders, she reiterated to me, that she does not want: walking up a hill too fast, not being able to drink quite as much as she would have liked whilst out with friends; having to weigh herself, and having other technologies in her home, which together niggle at her sense of wellbeing. These feelings do not pervade her everyday life, yet her daily

life is indeed punctuated by these consistent reminders that she is not 100% capable, that she is 'ill' with a heart that does not pump properly, and that there are and will be consequences.

Carol and her husband are very open with each other about death and dying, having discussed at length how it is tolerable to live and how it is not. However, what struck me about the way that Carol was talking with me about these issues, was that she continually emphasised that she is perfectly entitled to changing her mind about it all. "It is all very well for me to be sitting here whilst I'm feeling perfectly well, and tell you that I don't want this or this – but how do you know until you're in that situation?" Carol explained to me the two particularly pivotal occasions which highlighted how she both did and did not change her mind. The first came through the death and funeral of a friend; and the second was after her heart attack, where she made sure that she reiterated to her husband and her medical team that she did not, under any circumstances, want to wake up a vegetable. The latter story she regaled with a wonderful sense of humour, something she shares with her husband, and insisting that you must have a sense of humour to discuss death with your partner. Whilst in the back of an ambulance, she regales, she called out to her husband sitting next to her that he better make sure to kill her if she did not "wake up properly" – and to check on the internet if he was not entirely sure.

Although Carol declined to continue to participate after the initial interviews, I learnt a great deal about what it is to be in the world feeling well, yet whilst simultaneously being 'ill'. I fully respected Carol's decision to no longer take part in the study. It seemed to me that perhaps it reminded Carol of her heart failure in uncomfortable ways; indeed, she may have avoided doing some of things that reminded her being less-than-well (resonating with some of the literature on the lived experience of heart failure discussed in Chapter 1).

4.6. Theodore (Theo)

> *A brief email from Theo's GP was all I knew going in: "Mildly dementing wife Kathleen, ex-ballroom dancers, super tidy house. Near EoL but still hoping for the best. Just agreed DNAR." I was met at the door of the bungalow, curiously decorated with an assortment of ornamental animals, by a small woman who reminded me somehow of a hummingbird in how fine-boned and quietly energetic she seemed. She hugged me, and greeted me like an old friend. She knew my name and why I was there, but welcomed me with such unwarranted warmth that it brought tears to my eyes, in bewildered and touched confusion. Theo was sitting inside the living room, and I managed to squeeze in a greeting before I was spirited away for a house tour by his wife. As I was shown each bedroom and introduced to the cat, Theo's humorous sarcastic comments drifted into the rest of the small house every now and then from the sofa upon which he lived out his life: "See you at dinner-time!" […] When I left, I wrote in my field-notebook: "They are* <u>*unbearably lovely*</u> [underlined twice], *especially his wife, Kathleen. They are dancers in heart and by soul, and without that, they have lost a little bit of light from their lives." (*Excerpt from field diary 13/11/2017)

My conclusion from my brief visit with Theodore, before he passed away at 86 years old a few weeks later in December 2017, was this: 'he is done'. Having met his wife very young and been a ballroom dancer with her all his life, they were a team. Moreover, Theo and Kathleen knew how to be an effective team, and I imagined that they knew how to practice the complex dance of life itself. Theo and Kathleen lived together in a modest one-storey house in the suburbs of a town in Oxfordshire, a house which was not modern but that they were beginning to slowly adapt to Theo's health needs. I noticed permanent braces and supports in the bathroom, and the helpfully open-plan arrangement of the house lent itself to easy manoeuvrability with a walker or wheelchair.

I was particularly struck by how the pair were aptly complementary in the way that they cared for each other: whilst Theo had been diagnosed with Parkinson's and heart failure, his body a primary challenge, Kathleen had been diagnosed with dementia but was still nimble and able-bodied. As a team, they held their lives together very successfully in many practical senses: Kathleen would wash, bathe, dress, and do intimate care for Theo; Theo would instruct, remind, and generally orient Kathleen when she was trying to cook, clean, or run errands.

However, Theo was aware of a growing sense within himself that this was not really enough for him.

The pair had only stopped dancing a couple of years ago, Theo told me: "the Parkinson's put a stop to that." With the end of dancing, came the end of life as they knew it: they emphasised that dancing was exercise, competition, social, travel, challenging, rewarding. It was everything. When I went to see the pair, it was after Theo had undergone a particularly long hospitalisation as a result of particularly poor heart health, and Theo had not left the house in 6 months. Before the winter, he had still been driving, was still in the mode of taking care of Kathleen, the house and the garden. Now, he could not bear to be inside for much longer. He was bored, he named himself depressed, he got frustrated with Kathleen, and he wished he could still cook. For the most part, although he enjoyed reading and spending time with his wife, Theo was not doing anything that he felt was of much value. I was not entirely surprised when I was told by his GP that he had passed away. Yet, I found myself dwelling on the practical and tender intentionality with which Theo and Kathleen had approached the world, getting through things one day at a time, together. Kathleen's life would be fundamentally altered now, without Theo there to be the anchor which enabled her to encounter the world safely, with a warm heart and open arms, despite the haze of what she described as 'not-quite-knowing'. I had got the impression from the conversation I had had with them that an underlying fear was that neither of them would be able to cope independently without the other; indeed, after Theo passed away, Kathleen was checked into a nursing home.

Theo died at home, attended coincidentally by the district nurse, Lorraine, who had scheduled a home visit to change a wound dressing. I interviewed Lorraine subsequent to Theo's passing, which she repeatedly described as "a good death for him", emphasising that it was an "expected unexpected" death; he was at home, it was not prolonged, he did not appear to suffer unduly. Lorraine recalled the feeling of not-right-ness that had descended upon her as soon as she entered the living room and saw him lying there; she remembered particularly noting the

freshly-signed DNAR in her clinical notes that she had checked in the car before coming inside the house. The district nurse told that she was glad that she was attending, getting Theo into a restful position and sitting with him whilst the relevant healthcare professionals were on their way to confirm the death and offer support to the family. Yet, the worst thing, Lorraine told me, was that Kathleen had to realise again and again that Theo had died, before becoming distracted and absorbed by something else, her world flickering from normalcy to unknown, and back again, back again.

4.7. Nancy

> *She was a gentle lady, a lady who called me 'honey' at every opportunity, with the kind of accent that pronounces every letter the way you'd learn the sounds when you are little. Her name is Nancy, but she referred to herself as 'Nance'. At 84 years old with COPD and heart failure, Nancy is described by her GP as "feisty and slightly mischievous." The word 'wire-y' echoed around my head when Nancy first opened the door of her home to me, and I saw how painfully thin she was. I would have thought her far frailer had she not smiled quite so often, or quite so broadly. Her form was mostly hidden underneath comfortable layers of baggy clothing: today it was thick black sweatpants and a lilac top that gaped so I could see a once-white vest and the lace-y strap of a bra, her collapsed chest making me want to put a hand on my heart. Her bright blue eyes were set amongst soft wrinkled skin, gazing gently at the world from behind round gold-rimmed glasses. I noticed that her hair was entirely white and perfectly blow-dried into an elegant curled bob, pinned behind the ears with a couple of pink sparkly clips. Welcoming me with a warm hug, when I felt her bones press into mine, she invited me inside where I immediately smelled cigarette smoke. It called to mind what else the GP had related: "still enjoys a fag!", and what I thought in response: 'well, good for her!' The house was single-storey and had a sprawling garden through panoramic windows; it was relatively clean and mostly uncluttered. She took me into the kitchen and offered me a cup of tea, proceeding to boil the kettle and flit about the cupboards. I soon realised that Nancy could not sit still for long; it was not as much a sense of restlessness so much as little sparks of interest that captured her attention and made her dance between conversations, activities, and topics. But her breathing brought on a visceral reaction in me: I could hear her stifling every breath so that it would not come as a gasp, even when she wasn't hacking a wet cough. Every word brought images of raw strands of vocal cords rubbing against each other like sandpaper on silver, destructive. She navigated the discomfort by not speaking too loudly – too loudly would bring on the coughing – and pitched her voice low, using her chest as a resonating chamber where it seemed her voice box had fallen, and was rattling.* (Excerpt from field diary, 21/02/2018)

I visited Nancy and her husband, David, on two occasions before she passed away in late June 2018. Once Nancy fell seriously ill, I called her husband every couple of weeks to see how she was doing; where Nancy had called me 'honey', David called me 'darling'. On one of the last phone calls before she died, I asked David if she was going to be well again, and he just said: "I don't think so, darling. But I'm still going to sit with her."

One of the first things that struck me about this couple was their absolute devotion to one another. When Nancy was having a 'bad day' with her health, she had no qualms about getting straight back into bed – and David, in solidarity, would go back to bed with her for a while. Although they had a number of health issues between them, they continued with their daily

lives as they had always done, albeit slowing their pace. What interested me most about my visits with them was the distinct contrast between the first and second; I was therefore not particularly surprised when I called the next time to discover that Nancy was very unwell. After the final visit, I described in my fieldnotes that I felt as if Nancy had "leaned back from living."

In the first visit Nancy told me stories of a life she said had been wonderful, moving around whilst David was in the Air Force: the Sheikhs they conversed with, the beaches they had let their kids grow up on, the animals and people they met. Nancy punctuated these reminiscences with more current stories of pottering around the house doing 'silly things', going to car boot sales, how she loved finding a good deal in the shops. Come and see her beautiful garden; come and see the chairs she just bought (although David does not like them, she giggled). The thing I noticed most strongly about this woman was her characteristic attitude: you do what you can until you cannot, and then you lie down for a while; things in life happen, and there is no use complaining about them, you just get on with it; I have had an amazing life, and I have my memory and that is what is important.

During the second visit, I remember the moment I registered the change. It was after she had spent some time reading me her diaries and poetry from when she had not been feeling well over the last few years. As the conversation meandered, I asked her what her plans for the garden were this summer, and she responded very simply and peacefully: "Oh honey, I'm not investing in that any more. I'm just going to enjoy it." To me, it seemed as if this stance could be extended to the rest of her life: she was content to be in the garden, as it were, but she was not going to be doing the gardening any more.

Although they live alone and are self-sufficient for the most part, David still driving (Nancy never drove), they have a daughter who lives nearby and picks up anything that needs to be done; she brings meals over occasionally, does some light cleaning and gardening, runs extra errands. In order to keep the family a bit closer, Nancy and David do a weekly meal to 'lure' their son over as well. When Nancy fell ill for the final time, David told me that his daughter

was a “God-send” who was always there, for anything that was needed. Nancy and David showed me that this kind of caring was a family value: the house had already been set up for the needs of someone older with health challenges. I noticed, for example, when I used the washroom that there were grab-rails fastened to the wall next to the toilet. I was told that this had all been for Nancy’s mother, who died so quickly that they hardly got any use out of the equipment. During the last visit, neither of them sounded worried when discussing and looking into the future: they were secure in the knowledge that they would be well-looked after at home, by beloved family. In our last phone conversation, David assured me that this was how Nancy ‘went’, and although the family was adjusting, they were all at peace with that.

4.8. Noémie

> *"Come, I'll show you!" She gestured enthusiastically and sprung from her seat on the sofa over to a cabinet in the corner of the living room, telling me that it was one her husband had made and running her fingers briefly over the exquisite inlay. Whilst I waited during her rummaging, I got distracted and started to read the titles of all the books that were piled around the room. I realised that they were all beautiful instructional manuals on lace-making, cross-stitch, knitting, and other crafty artistries. Looking around the room with renewed understanding, I re-encountered the hazy elegant paintings that adorned every available wall-space, ones that I had initially discarded from my attention – African elephants, sky-lines and cityscapes, red hills and desserts. They weren't paintings at all, I realised. "Did you do these?" I asked, pointing to the framed pieces of art. "Oh, yes," she said breezily. "Ages ago, all inspired from my trips, most of them are cross-stitch." I had to look closer, at the thousands of perfect tiny threads that formed this paint-like effect, what must be painstakingly focussed work. My attention was again demanded elsewhere when Noémie started pulling out all the little drawers from the cabinet and proffering me the contents. Hundreds, literally hundreds, of miniature bobbins, exquisitely carved ivory and bone and wood. "For the lace, look, look." she explained, overwhelming me by passing handfuls of cheaper wooden bobbins with tiny paintings and engravings on them, or two by two, pairs and pairs of carved ivory inlayed with gold.* (Excerpt from field diary, 27/03/2018)

Noémie is 69 years old, an artistic lady, married to and living with an accomplished British carpenter, Harry. She had been born and raised in France, coming to England initially to au pair when she was 16, meeting her husband on later visits when they happened to be working for the same family. They had three children, bright and high-achieving, one now living in the United States and two still in England; she is closest with her youngest daughter. Her primary diagnoses are hypertrophic cardiomyopathy and valve disease, a compounding combination on a bad day, but she was fairly well throughout the year that I visited her. Noémie tells me that she has had had heart trouble since she was born, so the heart failure, she insists, is nothing really new for her to deal with. She knows how to deal with it, she demonstrates, as she has always had to compromise; for example, whilst planning one of the many trips abroad that she tells me she lives for. Whilst talking about upcoming or future trips, she always adds

the caveat with a short laugh or a wave of a hand: "If my heart lets me." During the last few visits, however, Noémie reflected more seriously to me that she was finally starting to notice the beginnings of a downward turn in her health: "I could never keep up with others when they walked fast, I got too breathless…but, now, I cannot even keep up with my own pace."

I visited Noémie on six occasions, spending time chatting over tea, which is always real English tea leaves, poured in a silver tea service that she prepared just before I arrived each time. We went through old arty-crafty books, or looked at photos from her various trips; or I helped her organise her crafts room/spare bedroom where she kept all her unframed or unfinished pieces. My mind swam with colours and patterns and threads after every visit, and I found myself amazed by her artistry every time we found half-forgotten treasures in the spare room. One of my favourite pieces of hers is a forlorn, half-finished lace tablecloth. There is something so heartbreakingly elegant about lace that is undergoing construction, almost mobile in its freeze-frame liminal state of uncertainty, unravelling or ravelling. Some other favourites we share are a series of unframed cross-stitch pieces inspired by her trip to Egypt a few years ago, done in rich royal blues, violent vibrant yellows, and decadently shining gold thread,

Noémie lives for her travels, and the stories she most often told and took most pleasure in telling were those from the places she had seen and the people she met whilst there. From Jordan to Palestine to India to Chile, Noémie does not shy away from harsh conditions or the nitty gritty experiences of staying with local families and following local guides. She realises that these trips stress her body, telling me how dehydrated and exhausted she gets, how unwell she feels sometimes, but she is not willing to face the possibility of not going. She has outlasted all of her travel companions, who have become too unwell to travel so far and so basically. Although she worries about travelling alone, Noémie powers forward. Her most recent trip was the first she took completely solo, to Rajasthan, during the course of my research. After getting all the health insurance and go-aheads from doctors, her heart was fine but Noémie returned with dysentery. The illness knocked her so far sideways that she called me and told

me to bring a hammer with me next time I visited – to knock her off, she said, if her suffering like this did not improve. After she recovered sufficiently, she started planning her next trip, somewhere obscure in South America.

Punctuated as her life is by her trips, weeks and weeks long, I understand the rest of her life as a kind of paraphernalia that surrounds these most meaningful experiences. In her day-to-day life, Noémie chooses to relive her trips, and further make meaning around them. "I have two trips!" she exclaimed to me on one occasion. "Once there, and once when I do the photo albums after I am back." She keeps multi-lingual travel diaries, which she reads to and translates for me; she puts together elaborate photo albums of printed and digital photos, all diligently labelled with people, times, places, and completed with an anecdote she handwrites underneath or onto the backs of each printed photo. Such a time-intensive endeavour seems to me to be a labour of love, and perhaps necessity. She further creates art around her trips, cross-stitch and quilts and lace-patterns. She is inspired by great artisanship (and great bargains!), filling her house brim-full with all the treasures she has found on and brought back from her trips. Each time her attention is captured by an object, a story is immediately sparked, and she will hand the object to me as she launches into the memory.

The great sadnesses of Noémie's life are two-fold: the lack of grandchildren, and her husband's Multiple Sclerosis (MS). It seems perhaps that Noémie's day to day life is a bit at a loss, without the next generation of little ones she expected to be caring for or hearing about. And she is, for all intents and purposes, on her own: "My husband is not the man I married." She says this frankly to me one day, pushing the door to our living room domain closed. I could hear the TV in the kitchen on loudly and knew that Harry would be sitting in his nightclothes, eating breakfast at one o'clock in the afternoon, balancing the cereal bowl and tea paraphernalia on the too-small surface of his walker. His bedroom is downstairs, whilst Noémie sleeps upstairs, next to the artistic spare bedroom, and there is no chair-lift on the stairs. Noémie talks quietly about how he has become difficult for her to handle, in a number of ways from physically

managing to manoeuvre him when necessary (e.g. in and out of the car), as well as managing his daily life in a way that he finds satisfactory. Noémie explains how his illness has made him forgetful and disinterested in ways that he does not recognise: "The hardest thing is that he thinks he fine – and he's *not*." Noémie speaks of his expectations and desires for the future that he continues to insist on, such as going to live in France with or her without her; she confides in me how most of the things he demands are completely impractical given his health, their finances, and his lack of French language skills.

As a result, Noémie has seen that Harry has become discontent; but she waves this away and simply ignores the meanness he has come to adopt. It is, we both agree, a sad situation. Noémie looks into the future, and instead of seeing her own health and wellbeing, she sees his deterioration and shakes her head. She admits, "I don't want to care for him. I just don't." But she is unable to leave him. "Guilt," she says simply. "Duty. I have lost friends because I won't leave him, but how I can do that? How can I leave him?" Noémie worries about the day that it will get too much for them both, unsure of when or whether it will come. She spoke somewhat speculatively once about a supply of poisonous plants, but did not at the time of the visit have actual plans to harm either herself or husband. Although feeling immensely guilty about leaving him when she goes away on one of her trips, small and large, when she has to ask her youngest daughter to come and 'dad-sit', Noémie refuses to live a life without her adventures; adventures that she initially started taking with her husband.

4.9. Baylee

> *We had come to the end of our conversation, and it was time for me to go. I began to notice, however, that Baylee was fiddling with his iPad, balancing it on his rounded stomach and squinting at it, not wearing his glasses. I resettled myself, minding not to disturb the Springer Spaniel, Louis, who had fallen asleep at my feet, and asked Baylee what he tended to use the iPad for. Emails, he said without looking up, keeping up with some people. He stopped squinting and looked at me: recently, he'd tried to figure out audio-books. "What kind of books do you want to listen to?" I asked. He named those that he had read during his childhood, great fantasy adventure stories that I had heard of or read myself, often filled with some kind of magic. I asked whether he could just get them out the library and read hardcopies instead, and he just shook his head and shrugged. "I don't know, just felt like hearing them, you know." It wasn't until I had left and was casually chatting about the encounter with a fellow anthropologist that I wondered: perhaps he just wants someone to read to him?* (Excerpt from field diary, 09/04/2018)

Baylee is 67 years old, and lives alone in a small yet immaculate semi-detached house that looks as if it is out of a home-décor magazine. Throughout the five visits I had with Baylee, I watched as the house transformed in subtle ways to periodically accumulate more mass-produced decorations, which would slowly replace others in an ebb and flow of cluttering and de-cluttering. This, I came to discover, was the response of his cleaning lady, Mylie, to Baylee's decorating skills and impulsive purchases. "Mylie is responsible for all this," Baylee said on more than one occasion, gesturing to encompass the house in its entirety. When I interviewed them together, I saw the extent of their confounding relationship: it was not simply cleaner and employer, or friendship, or carer. It was something more complex and hybrid that I never quite grasped. Neither of them wanted to dwell on the past, so never illuminated to me exactly what had happened over the many years they had known each other; they simply wanted me to know that they were there for each other.

Aside from Mylie and Louis the Springer Spaniel, who is essential to Baylee's life, Baylee is alone. His wife died 8 years, and he still talks about how life would be different if she were alive. Unable to have kids, there is a conspicuous absence of photos anywhere in the house, especially where usually I would expect to see a few family portraits. Save for the large number of potted plants around the admittedly half-hearted attempts at gardening, there is little if any evidence of hobbies, no personal touch to anything that I could see. Baylee himself is a military

man, serving in the Royal Artillery in the British Army for about two decades, stationed in multiple active war-zones and often manning air-defence outposts with a small number of men. With my own family connections to the British military, I recognise Baylee's sense of humour and attitude towards his health particularly as deriving from the relationships and communication styles that are formed between those who train, live, and serve together. There is a sense of making light of even the darkest situations, an underpinning value of stoicism, and Baylee says to me on more than one occasion: "I've stared death in the face *n* hundred times, I'm not scared of dying."

It seems to me that Baylee has learned to adopt an attitude of doing exactly what he is told, and does not openly think through, with me, any kinds of issues he might have. Baylee appears to take the same approach to his health: he is overweight, so he goes for walks with his dog and eats what he has been advised is a healthy diet, diligently showing me the contents of his fridge; he needs to be sociable, so he goes to a few clubs and societies; he needs a hobby to tell people about, so he gardens; he needs to take medications for his health, so he takes the medications without fail. He tells me that he would take a thousand pills a day if a doctor told him he should. The message Baylee repeats to me is that he feels like there is nothing much wrong with him: "Everything I've got is *mild,"* he says. Our conversations feel to me as if he is trying very hard to convince himself that there is nothing wrong with his health, and therefore by extension there should be nothing wrong with his life. Each time I saw him, I would say something like: "You sound like you feel well, and like you are enjoying some of the things in your life?" as part of a reflective exercise, and on one occasion during the penultimate visit, he responded to me: "Well, that is the image I try very hard to portray."

Baylee was diagnosed with heart failure after a heart attack 10 years ago, when his wife was still alive. The heart failure does not seem to affect his daily life very much, although his breathlessness prevents him from doing more rigorous exercise or manual labour in the garden. Five years ago, he was diagnosed with depression and was prescribed anti-

depressants. He has frequent bouts of high alcohol intake, admitting to me that this is out of "sheer bloody boredom." He describes the repetitiveness of his daily life, the long evenings when there is nothing to do, when he drinks out of an acute need just to feel something different. He declares frequently to me that he is going dry, but then admits to having another story of what he calls "self-inflicted illness" the next time I come to see him. During one of my later visits, he told me that he needed his antidepressants changed, as they were not working any more: "You know they're working when you feel nothing." He said this more than once, before and after he had got the dose raised. "You know it's all right when you don't feel a thing."

4.10. Philip

> *He was sitting in his chair as expected, and did not get up when I entered, but extended a hand with a smile. "Hello darling," he said in a pleasant, put-together, throaty voice. His voice struck me as sounding weathered and with-it. At 88, his hair was pure white but thick, with only a hint of a widow's peak, emphasised by being combed straight back. He had large gold-rimmed glasses, and wore a small, closed-lipped smile most of the time when he spoke to me […] He locked me in an intense stare: "Best years of my life, with that woman." He said of his late wife. As Philip's eyes filled up with tears and his voice broke, I felt my heart give way. I was surprised by how quickly a tear trailed its way down my cheek before I could catch either myself or the tear. "You should be so lucky." He said, finally looking down and covering his eyes with a hand. "God, I miss her."* (Excerpt from field diary, 19/06/2018)

Philip has severe heart failure which had been recently diagnosed after a heart attack, when he also had an ICD (Implantable Cardioverter Defibrillator) fitted. Philip lives in a tiny two-storey semi-detached house that has not been updated since the 70s, in a quiet housing estate on the outskirts of an Oxfordshire town. He has a full-time live-in carer, called Lucy, who was always pottering around doing household chores whilst I was around; I also joined them for their daily game of Scrabble. I had a total of four visits with Philip, and was struck by the changes I saw each time. On the first visit, he told me how he had got up and walked to the post office for the first time in months. On the second, he told me about the successes and stability of his children, who he is sure will be fine after he is gone, lamenting the lack of grandchildren; he was not getting out much any more, but accepted my challenge to a game of Scrabble next time. The third visit was when he told me he might be too tired to continue with the research, asking frequently "is this what you want to hear?"; although he also mischievously showed me how the pendant alarm operating service works by pressing the alarm for fun. On the fourth, he told me he was feeling generally okay, but he seemed to me to be – as I described in my fieldnotes – 'leaning back from living'.

Philip lives his life predominantly from the single armchair in his miniature living room, having arranged the phone, TV, reading and puzzle books, and Scrabble all to be within easy reach. This is a fairly common set-up that I have found across the heart failure patients I saw whilst shadowing the specialist nurses on home visits, and is also described in literature (reviewed

in Chapter 1); it seems to be a setup that is particularly practicable for those with mobility difficulties, where the space that one occupies in the flow of daily life shrinks. Initially, Philip maintained that he would be perfectly capable of moving around the house and taking care of himself, saying to me that he 'lets' Lucy do the cooking and other housework simply because it is a bit easier. As my visits progressed, Philip told me that Lucy also washes and dresses him; by the final visit, Philip told me: "Thank God for Lucy, I don't actually think I would be able to cope otherwise." Altogether, Philip seems reluctant to trouble me or his family with what he has called, on more than one occasion, his "complaints". Mostly, Philip gives the impression that he is fairly content with the way he lives, when not dwelling on the loss of his wife; when questioned about what he misses and what he would like to be doing, he waves the question away with the air of 'things change', and says he is fine with that.

However, I detect a sense of resignation in him when he speaks of the reasons he is living like this, particularly after the first visits where he tells me that really he would prefer to live entirely independently. His three daughters check up on him frequently (I have been present for a number of phone calls), and one daughter has him over for Sunday lunch every weekend, fetching Philip to and fro. Philip says he is grateful for all that they do, commending them all on their generosity and lack of complaint, which he might have expected. He tells me that they do more for him than he could ever have asked, and he is careful to say that he respects their decisions, although he hopes that the time they put into him is not detracting from leading their own lives: "They have their own lives, they shouldn't be worrying about me." Philip's experiences surface the tension between not wanting to be a burden, and the value his daughters place on the sentiment that "family should take care of family". Explaining this during my second visit, Philip shrugs and looks at me: "What can you do?" He describes how his daughters are obviously very worried about him, and that none of them live quite close enough for their comfort.

During the winter of 2017/18, in response to the concerns of his family and in combination with a particularly bad bout of ill health, Philip checked himself into a nursing home. "I couldn't last more than four months in there," he admits to me, relieved that he managed to get himself checked out. The alternative condition that his family insisted upon, however, was that Philip take on a full-time carer if he would not live in the nursing home. Now, Philip calibrates how he is feeling against this central bout of poor health, during that winter of 2017/18. Just prior to this, Philip had had a heart attack that had incapacitated him, chest infections had settled in with the cold weather, and his arthritic pain was constant and excruciating: "I was screaming," he says simply. He is emphatic that he never wants to go back to feeling like that, an intolerable way of living. Although it has taken many months, he now takes a combination of medications, including experimental drugs, to manage the arthritic pain. He is pleased with the results, appreciative that he feels a lot better now, although he once had to cancel a visit with me due to a flare-up.

Given Philip's concerns about being a burden to others, I wondered whether he was giving me an accurate picture of how he was feeling about his own life, and gently probed these kinds of questions as I got to know him better. During my third visit, he tells me he does not get depressed about things, and is rarely bored; but he chooses his words carefully before admitting to getting what he describes as "fed up" sometimes. I cannot entreat him to elaborate, but I detect that the 'fed up' feeling is more pervasive than he is willing to dwell upon with me in that moment, and potentially related to his resignation about the rest of his life. I was particularly curious to discover that he had given power of attorney to his three daughters, many months ago. "Chuck me in a grave, I don't care what happens!" he says, leaving me feeling like he wanted to discontinue the discussion when I ask if he had discussed with his daughters anything about his death. Philip says he does not want to worry about the finances or the future, so they can figure it out. This, I think, is testimony to a more pervasive kind of 'fed up' that he has been trying to ignore, or at least from which he has been trying to shield his

daughters. It is not until my final visit, whilst he was beating me at Scrabble over half a year after initially meeting him, that Philip tells me quite plainly: “I’m done.”

4.11. Norma

> *"I've got a new lease on life!" she exclaims enthusiastically, in her low scratchy voice. "It's just brilliant!" Despite being such a small woman, four foot something, she motors around the kitchen as I watch her make tea. She wipes a surface absently and moves things around perhaps unnecessarily, the bustle punctuated by an infrequent but chesty-sounding cough. When she is done, we move back to the living room – and the way Norma moves seems to me to just be distinctly* busy. *She does not walk particularly quickly as such, but just busily. We sit on opposite sides of the living room, a little too far for an interview or conversation I felt, but this was the way the sofas were set up, peering across the width of the room at each other. Norma's feet hardly touched the ground as she sat back in her armchair, resting her head of cropped white hair against the back cushion, twirling her toes and feet around for the duration of our chat. She repeatedly removed and donned her house slippers, periodically hiding painful-looking arthritic feet, and what I suspected were bunions on each hallux, moving her ankles to keep them loose and abstract the constant pain.* (Excerpt from field dairy, 21/08/2018)

Norma is 75 years old, and lives alone in a small two-storey house with a modest gravel garden, filled with pots. She tells me she often takes pleasure in pottering around it, with or without her grandchildren. Her husband died 12 years ago, suddenly, of lung cancer; and she has two daughters who live close by, although she worries that one of them will move abroad again. I have visited Norma on three occasions, and have observed a most gratifying upward trajectory of health and wellbeing. The first time I met Norma was a few weeks after she had had an operation to put a stent in her heart, my periodic visits allowing me to witness the positive changes she was feeling in her body and making in her life.

After having a stroke in 2016, Norma never quite recovered, becoming so run-down that she kept getting severely ill with chest infections over the following two winters. She described to me "feeling just horrible" for months on end. Everything she attempted had become an insurmountable labour that made her feel like she could not breathe, exhausting her further and frustrating her. She tells me how her life shrank to the point where she did not even want to do anything any more. Then, after being hospitalised for a particularly nasty chest infection that allowed doctors to discover that she had heart failure, a stent was put in. Now, Norma feels better every day.

During the first visit, Norma was in a state of general gratitude but dubious disbelief; she was astounded by the profound difference she had felt almost immediately. She explained her routines to me, sounding wary whilst telling me that she was still taking it easy and taking stock of how she was feeling at every turn. Yet, she wondered aloud whether she might be able to volunteer at the local hospice shop again, getting tentatively excited about the idea. However, the caveat in each musing is that she simply does not know how long she will be feeling like this.

During the second visit two months later, as she speaks, it becomes clearer that she has begun planning again, wanting to do things again: she is living for herself again. "If my daughter rings me up and tells me that she and the grandson might not make it this week, that's okay!" Norma tells me emphatically. "Everyone has their own lives, and I feel like I've got mine again now!" Part of the difference in Norma's attitude she locates as stemming from having gone through pulmonary rehabilitation, 2 hour gym sessions each week for 6 weeks. Although she openly hated the enforced exercise, she admits that she learnt a valuable lesson: that she can do more than she thought. From the previous state of suspicion and mistrusting her body, she is now planning trips with her daughters and grandchildren, and is triumphantly getting out the house every single day and walking further.

By my final visit, Norma has got herself on top of things and has learned again how to listen to and interpret her body. She tells me that she knows how to handle the symptoms of heart failure, particularly not feeling like she can breathe, without panicking; she has a policy of telling her daughters clearly how she feels day-to-day, to assuage their worrying, and has adopted a general attitude of "being kind" to herself. In between my last two visits, Norma had had another chest infection, catching it early by going as soon as possible to the doctor because she "just knew something wasn't right." Norma is determined to not feel as poorly as she did over the past two winters, and I ask if she is worried about catching a cold and falling ill this winter. She responds that she cannot let things like that stop her from doing what she wants

to do, and it seems to me that Norma is negotiating a familiar balancing act between the risk of compromising her health and compromising the activities that are most meaningful in her life.

As part of this balancing act, Norma tells me with a knowing smile that she now also accepts that if she feels like sitting for most of the day and reading or watching TV, then that is okay. If she cannot quite get all the housework done in one go, that is okay, too. She gets up each day, and decides what she is going to do based on how she is feeling in herself, and what she feels like doing. Engaging herself in a good book or puzzle, going out and seeing people, keeping up with old friends via telephone, doing the housework; Norma feels that she can keep her life organised again, a very tidy and prepared person by nature. However, she has also given herself the space to be not quite as organised as she used to be, making allowances for her fluctuating health by not being quite as busy as she would perhaps ideally like. Mostly, she just loves playing with her grandchildren, and is so thankful that she is able to continue to do this: "They are my world, absolutely, family is my world, it's just wonderful." She follows this with a satisfied caveat: "But I don't live *for* them, you see. I have my own life, too."

4.12. Kent

> *"The trouble is," Kent says to me in a hoarse voice, smiling softly at the joke to come in a good-humoured way that feels to me like it is tinged with sadness. "I look perfectly healthy sitting here in this chair. And to a certain extent, I feel perfectly healthy. It's just when I try to actually* do *anything, then…" I nod, and let the sentence trail off into an open-ended silence that I hope he will interpret as my holding space for him to just be, if that's what he feels like doing in that moment. I think about what he said, the tragic ironic humour of it. The cosmic joke is that he is bound to be occasionally fooled into believing that he is fine, whilst sitting in his chair, doing what he admits is very little. As he sits, he fiddles with the electric fittings on the chair which raise the foot-board or lower the back support. The chair makes little mechanical zz-ing noises as he constantly adjusts and re-adjusts his posture, his being in the world, striving for a slightly more comfortable position, or perhaps one that can trick him entirely into wellness.* (Excerpt from field diary, 21/06/2018)

Kent is 88 years old, and strikes me a gentle soul, usually smiling a little through soft-spoken words, sitting quietly and gazing, often seeming deep in thought. He has severe heart failure and bad gout in his feet, combined with progressing Parkinson's; together rendering him now mostly chair-bound. He lives with his wife, Carolyn, who is 83, in a large yet oddly-shaped double barn conversion that they both admit is far too long from one end to the other. They have a large, beautiful garden filled with roses and mature trees that Carolyn and a gardener tend, giving way to a view of farmland beyond. The garden also contains an outdoor heated pool in which Carolyn regularly swims, and I am told Kent occasionally paddles.

Due to a number of mobility and sleep issues, Kent now lives in a downstairs annexe that had been converted for Carolyn's mother, though she only spent one night in the room before she passed away. They agree that it is very convenient for Kent, now, with a spectacular view of the garden. He tells me he enjoys watching for the comings and goings of various people and animals, particularly the birds, and naming them for me if he catches sight of one during one of my visits. Kent has outfitted his small living room with a large flat-screen TV and surround-sound, both controllable through one of his iPads, as well as an Amazon Echo, which he demonstrates to me by asking 'Alexa' to play a famous piece of classical music. Kent likes technology, playing with it, not only making his life functionally easier but also allowing him to explore and keep his mind interestedly busy whilst he is sitting in his chair, indefinitely.

I have met Kent on four occasions, all of which Carolyn enthusiastically joined, and even after my second visit, I observed that Kent was in better spirits. His health improved and general demeanour seemed to get more positive every time I visited. I noticed these changes predominantly through his increasing willingness to chat with me about all sorts of things and the tight, white bandages on his gouty feet thinning until I could finally make out the actual contours of his toes by the final visit. Carolyn has noticed the uptick in his spirits, too. The first visit I arranged with them had had to be cancelled: I turned up at their house only to find no one there, calling the heart failure nurse who had referred me to Kent in order to register my concern. He had been in a car accident, she told me. When I finally met Kent the following week, he was badly bruised and had decided that he was no longer going to drive, which he said was a good decision even if he was saddened to feel that he was becoming even less independent.

After each visit, Carolyn would walk me out and continue to talk with me about relevant titbits she felt I needed to know, things that she could say more bluntly when Kent was not in the room. Over the last winter, she explained after my second visit, Kent had become very ill and the doctors had encouraged him to sign a DNR, moving him into the palliative end of life phase. "And we just gave up, we just accepted it, we let it all go. And now, you know, I think that was entirely the wrong thing to do." Carolyn related to me how she had immediately sprang into caretaker mode, as they both prepared for his death; she now saw that this just meant that both of them let Kent sink into a deep unhappiness, where he eventually requested that his ICD be turned off. He did not want to live any more. But then, Carolyn explained, the winter passed and they both got a bit tired of waiting; Kent began to feel better as the weather turned milder, and their first great-grandchild was born. Indeed, by my final visit, after wondering aloud to me about the ICD, he had gone to the hospital and had his ICD turned back on. He told me, with a decisive nod, that the nurse who had conducted the procedure had been quite touched by his whole case: she had turned many ICDs off, but had never turned one back on before.

After spending a bit of time with Kent and Carolyn together, it was during the third visit that I got the opportunity to talk to Kent alone. Whilst Carolyn was outside by the pool, with her visiting daughter-in-law and grand-daughter, Kent took the opportunity to tell me how worried he was about his wife and her own health. She had an autoimmune disease, progressive and degenerative although he never told me the name, which made it more and more difficult for her to keep moving and keep up with her friends, who were mostly 20 years younger than she. He could see she was getting frustrated that she could not do the gardening as vigorously and easily as she used to, and he worried what would happen when she could no longer keep herself so busy. Then there would be just the two of them, staring at the same four walls of this house, in companionable misery. It was not until the final visit that Carolyn brought up her ailing health herself, expressing the same worries and frustrations.

Although they both enjoyed being social, Kent and Carolyn could no longer manage to entertain as much as they used to, and Carolyn was visibly the chattier of the pair. However, Kent did particularly enjoy getting to see his daughter-in-law and granddaughter, Bridget and nine-year-old May, from their late son's second marriage. These two lived the closest to Carolyn and Kent, out of their extended family, and I got the chance to meet Bridget and May during my second visit. Kent would wade through the discomfort of sitting at the table in the formal dining room when Bridget came over to cook a fantastic meal for them all to enjoy together.

Aside from coming together at meal-times, it seems that otherwise Carolyn and Kent live interwoven yet predominantly separate lives; Kent's in the house, and Carolyn's outside. Amongst the things Kent misses, he dearly misses cooking; Carolyn cooks without too much complaint (although she makes faces at me when she discusses it), but Kent tells me privately that her tastes are much more conservative than his, so he misses many of the more exciting flavours he used to use. The kitchen was redone in 2016 to be wheelchair accessible, countertops low down with spaces underneath. But by the time it was ready, Kent's health and

spirits had declined so far that this new layout was hardly ever used for purpose (although at 4ft 4inches, Carolyn herself found it most helpful).

Still, Kent enjoys sending his young family members cooking books from Amazon.co.uk, as a distant way of showing affection, hoping to inspire. For the most part, Kent accepts his ill health and the limitations that comes with it, having been very ill and hospital-bound as a child for long periods of time. However, believing himself to not be so talkative, he wishes that he could instead get to know his grandkids through teaching them to cook, or showing them how to do silver-work, a hobby he had taken up after his retirement from being a chemist in a research lab. Kent had bashfully shown me, at Carolyn's encouragement, some of the most exquisite things he had made. Yet, his family does not seem very interested in learning, and when I question him about continuing these hobbies, he raises his hands to show how badly they shake. He squeezes his fingers into a fist a few times, becoming absorbed in watching the movement in his gentle way: "Not any more," is all he says in a quiet voice, his expression impenetrable. "Not any more."

4.13. Jeanne

> *She took me into the tiny garden, playfully catching a wooden pole which supported the pergola, swaying gently as she pointed out the flower petals in the bird-bath that her great-granddaughter had decided to carefully pick and place there. Nodding and appreciating the garden, I glanced back at Jeanne and suddenly caught a flash of the young woman she would have been. The kind of woman who went barefoot and had a miscellany of kids dodging around her legs at all times. There were hardly any lines on her face, at 96, her limbs robust and her skin aglow. I marvelled at how she moved with agility about the house and garden without the aid even of a walking stick, although she had said she did use one when she was out and about, and was not bothered by it.* (Excerpt from field diary, 05/07/2018)

Jeanne, as stated above, was 96 years old and was indeed quite well until she passed away in her sleep in October 2018. She lived alone in a very small two-storey semi-detached home, once social housing. She had two daughters living nearby, having had five children of her own in total, who are now all in their 60s and 70s. She was once divorced and once widowed, her second husband dying only a few years after they married over 40 years ago. I visited Jeanne on three occasions, arranging the visits through her daughters because Jeanne's hearing aid did not agree with her phone, and Jeanne openly welcomed my company. She was very content with her life, but told me plainly that she was a bit lonely. After years of driving and caring for her family as a single working mother, by the time I met Jeanne, she was only able to go out if someone was able to take her. The two daughters who live close by came to see her at least once a week to keep the house clean and tidy, and usually take Jeanne out for an afternoon.

Jeanne was very capable, ignoring her daughters for the most part when they told her to sit back and let everything be done for her: after being a full-time mother for a period, Jeanne had later entered the catering industry, and used to grow all her own food to cook. Now, she still does most of her own cooking (cannot abide by ready-meals!), gardens as far as possible, and does laundry when her daughters are not looking. Since retiring, Jeanne had to give up the car, as she could no longer afford it, and although she thought she probably would not be still be driving at 96, she would have appreciated some more independence.

Jeanne was diagnosed with heart failure about 6 years ago, and was offered various treatments including an ICD, which she declined due to the fact that she believed she "probably wouldn't be here in a few years." After 94, Jeanne said that she had to get used to the idea that perhaps she would be around for a little bit longer. She had a loose routine that kept her busy enough, pottering about the house and refusing to sit for too long; she had a lot of photographs and a lot of family members to remember, but she confided in me: "I'm a bit tired of children now – you'd never guess I had five of my own!" Although Jeanne assured me she was perfectly content with how she was living, not worrying about the future too much, she was generally aware that she was getting a bit tired of being alive.

"I think about the coming winter," she said with a wry smile, "and think to myself that I really don't want to do another one." She described the inevitable illness, darkness, and loneliness that comes in winter; Jeanne did not feel the need to live through this next one. Jeanne's life seems particularly coloured and shaped by these kinds of cycles, especially the births and deaths of friends and family. This became specifically apparent during my second visit with Jeanne, where she showed me a number of very old photographs (more than 80 years old). She was the last one left of her siblings, and one of her children has passed away as well. "It's a relief to talk about death," she said to me. "It's always coming, and everyone tends to ignore it, but it feels good to talk about it!"

4.14. Kenneth

> *The doorbell rings, and Kenneth's wife, Fran, finishes her train of thought as she gets up, talking about how the lady who lives across the street is caring for her husband as well, also finding it really hard and needs support, how everyone needs support and it is only human to get frustrated occasionally... Leaving the room, Fran interrupts herself: "I wonder who that could be? Will be back!" I hear the door open and give myself a moment to think: I have been worried about how Fran may be dominating the conversation during my visits, but I am very willing to let her speak, as she seems so relieved to have someone to talk to. I have to speak more loudly to Kenneth, who is partially deaf, but he also gave me the impression that he does not particularly like talking: during my very first visit, he told me that he prefers silence and quiet reading to conversation, and could not bear to have carers or neighbours come in to chat to him. He refused to go into a nursing home because of it, and Fran honours that. And yet, much to my surprise, as soon as Fran leaves the room and I am just about to turn my attention more fully towards him, Kenneth breaks his silence swiftly, with a tone that suggests he cannot contain himself any longer: "What I miss more than anything is fishing."* (Excerpt from field diary, 17/08/2018)

Kenneth is 90 years old, and lives with his wife and carer, Fran, who is 12 years his junior. They live in a good-sized two-storey house, in a suburban setting, with a modest garden that attracts birds and the neighbours' cats. The couple chose not to have children, and have adorned their walls instead with portraits of the various stray cats they have adopted and cared for over the years, none of which survive today. I have visited Kenneth and Fran on three occasions, and the central topic of conversation is caring: caring for each other, caring for those who cannot care for themselves, caring for animals. Although Fran does tend to lead our conversations, she is acutely aware of Kenneth's needs and reacts readily to him, giving him space to speak when he does pipe up. Despite not always fully hearing my questions, Kenneth responds openly when I offer him the floor and hold space for him. Otherwise, Kenneth seems to be a quiet man who enjoys reading and would pretty much rather be left alone, which Fran respects.

Kenneth's health is not good, by all accounts. Although Fran and he agree that there has been an improvement since his ill health over winter, everything is slowly getting more difficult. Kenneth was diagnosed with heart failure and COPD, together with arthritis and particularly bad gout, but manages to move around the house with the aid of two walking sticks. When he leaves the house, to go to medical appointments or occasionally accompany Fran food

shopping, he uses a wheelchair. Medical appointments have become increasingly disruptive to their lives, and there is now a problem with his kidneys that requires regular blood tests and administration of medication through IV at the local hospital three times a week. Fran particularly demonstrates the negotiation of everyday life at the juncture of where living meets healing, and she says she finds herself up at night thinking over every detail of their routines. She worries, trying to find ways to make things more efficient, easier, less painful, more comfortable; generally trying to help their lives to run more smoothly.

Together, Fran and Kenneth have incrementally adapted their house and routines so that Kenneth has the most comfortable days possible. Nevertheless, they both agree that there are frequent sleepless nights and 'bad days' when Kenneth is not feeling so well, and/or Fran is particularly short-tempered. They have just got Kenneth a second new bed (because the last one was too hard); this one is much softer but far too high, so Fran has recently fashioned a small stepladder. When she washes him in the mornings, she checks him for fluid retention, weighs him, and administers medications, before they retire downstairs for the day into the well-lit living room. Neither of them are interested in food or cooking, so Fran regularly heats up microwave meals, which they both insist must always be eaten at the dining room table, properly. I imagine this to give them a sense of continuity in lives that are otherwise constantly in a state of minute flux.

In terms of forward-planning, Kenneth keeps his mind busy by continuing to deal with their finances, and entertains himself with books and documentaries, usually on steam trains or spies. Kenneth and Fran have recently been confronted with the possibility of signing a DNR, and when I asked about how they were going to make the decision, Fran said with dry humour: "We made the decision a long time ago, we're both going out of here in boxes!" There did not seem to be an acknowledgement at this point that Fran was significantly younger and fitter than Kenneth (although she has lost all her toes to amputation due to arthritis, and needs to go back for surgery but has not found the time between caring for her husband and her sister,

who has now passed away from cancer). There also seems very little acknowledgement that things probably are not going to get any better, or easier. Fran never mentions prognoses, and with a stoic attitude of continuing regardless to plant one foot front of the other, the pair encounter each day as much the same as the one before. Zooming into the minutiae of their daily lives, Fran continues to make small adjustments throughout their routines in order to cope with the day-to-day fluctuations of both of their health, wellbeing, and changing moods. Kenneth, on the other hand, appears to prefer to absolve himself through the escapism of books, predominantly ignoring Fran's busyness around him, sitting in a silence that I cannot divine is confused or simply accepting.

4.15. Edwin (Ed)

> *I arrive at the assisted living facility where Edwin resides, and as soon as I walk from my car to his mews, I have to get out my phone and type the following: 'This place makes me want to cry, it is so peaceful and beautiful, people slowly going about their lives in brief. They have erected bird feeders and decorated their walls, they have made this impermanent place their home. I see people in wheelchairs and walking with zimmers, hear a phone ring…the sights and sounds of an everyday life, slightly altered. This peaceful place, which is not so much waiting as the care homes have seen, but more 'suspended'. People are not so much waiting as 'pretending to live'? Pretending." I have distracted myself so long by hesitating at each person I see, that I am now a few minutes late. When I arrive at Edwin's apartment, all I can hear is classical music blaring ever so loudly from his small home into the vacant corridor, where everyone else's doors stood closed, and the tile floor made everything echo. I immediately recognised the music as the 1994 live recording of Pavarotti singing 'Nessun Dorma'. I try the doorbell, mainly because I am worried that I am late, and knock a couple of times before I realise that he is never going to hear me above the music. So I lean against the cool wall, close my eyes and listen to the music, imagining that Edwin is doing the same, enveloped in sound and in another world on the other side of the door. When the music comes to an end and quieter applause echoes, I ring the doorbell again, and the door is almost immediately unlocked and opened. "You're here!" Edwin smiles beneath his moustache, already breathless, a stout man 'built like a barrel' he calls himself, short but standing straight and without aid. "Come in, I have something to show you…"* (Excerpt from field diary, 15/08/2018)

Edwin is 98 years old and lives alone in an assisted living facility set in beautiful gardens, into which he only recently moved. His home is a miniature apartment set a bit away from the main nursing home and other assisted living facilities; he lives independently and has his own cleaner (a lifelong friend), but has access to the security system and support workers of the nursing home, should he ever require assistance. Ed has mild heart failure and struggles with characteristic breathlessness and fatigue. He walks around the small flat without the aid of a cane, although he uses one or two when walking outside, and is always beautifully dressed whenever I see him, a habit I expect that he is unwilling to break (although he says that he has found a gadget that makes putting his socks on far easier, now). One of the aspects he finds most limiting about his heart failure is the inconvenience of having to empty his bladder so frequently, and therefore be nearby a bathroom for the most part. Despite this, he still drives, and often takes a friend who lives upstairs out to a pub lunch; occasionally, he will take his cleaner/friend (sharing the driving) to another part of the country to visit family or others. He

also involves himself in some of the activities that are put on at the nursing home, his favourites being the reading of the news and the occasional general knowledge quiz, which he tells me he is quite good at.

I have visited him on three occasions, taking a long walk around the gardens during the second visit. Although he is very switched on and motivated, he walks slowly and with frequent stops; even talking whilst sitting inside with me, he gets breathless during a long sentence, so I am impressed by the relatively lengthy walk. He confesses to me that he daydreams quite a lot, and has been known to fall asleep in the afternoons now in his chair. He does not seem to be bothered by this, rather telling me with satisfaction about the life he had lived as an aerospace engineer and play-time drag-racer, how he met his late wife, how they adopted a little girl who is now an estranged daughter. Upon the last visit, however, Ed confided in me that there are times when he wonders whether it is "really worthwhile hanging on".

Ed talks a lot about his wife, particularly caught up with how they met over 75 years ago (on a blind date that ended two weeks later with their wedding ceremony), showing me many photos and the letters he wrote to her when he was working away from home. In particular, he tells me about how her passing was, in his eyes, particularly brutal. She died two years ago, a time during which Ed was unable to care for her due to his own health issues (which get burdensomely worse during the winter). She went into a nursing home, where she had slowly lost sight of him and the world. He tells me that he was sure she had no idea what was going on, and did not deserve to be kept alive like this, she never would have wanted that. He empathises with neighbours in the assisted living facility who are losing their husbands or wives, telling me about one particular case which struck a chord with him: how one of his friends' wives is begging him to bring razor blades in with him each time he visits. Ed tells me that the cut-off point for himself is incontinence: if he has to be intimately cared for by someone else, then he does not want to continue living.

CHAPTER FIVE

Unmaking and remaking everyday lifeworlds: the fraying of life around the edges

It does not seem to me that people's lives are entirely derailed, all at once, when managing their heart failure. I rather see people shifting dispositions and bodily postures, like they are always trying to get comfortable with and in their lives. I imagine people to be carrying all these meaningful things in their arms, a precarious balancing act. Perhaps barely contained in some sort of sack or satchel, from which you might occasionally lose something, or be forced to remove it and put it aside. If life is spun and woven of gossamer threads, it might be this satchel. This hold-all which helps carry all the stories, memories, habits, routines, relationships, and things that populate a life well-lived. Heart failure does not immediately seem to irreparably rip or destroy this fabric, which would cause the chaotic loss of many things that make life meaningful all at once. I imagine, rather, as people walk on, the slow appearance of small holes in the hold-all. Where the loosening of threads fray the edges, or the seams, or wherever there is most wear. These holes might not readily be noticed, but soon they are numerous, and call for cutting and darning to make the fabric whole again. The hold-all might get smaller over time, even though it is the same fabric; forcing you to remove things or let them go as they fall away, choosing carefully what is possible to keep. What still fits. Until, eventually, perhaps one's ability and will to remake the fabric is undone by this insidious unravelling, this constant fraying of life around edges.

- Excerpt from fieldnotes, 25/03/2018

5.1. INTRODUCTION

This chapter is about how participants negotiate a life worth living through tinkering and layering compromises in the way they go about their daily lives, cultivating an attention to their changing bodies through which the world is perceived. Here, I elaborate the continuous processes of what I conceptualise as the 'unmaking and remaking of everyday lifeworlds', following Scarry's (1985) notation, summarised in Chapter 1. I started thinking about processes of unmaking and remaking part-way through my fieldwork, after spending the first few months with participants. Through getting to know them, I could start to see what sorts of changes were happening over time, and how participants were responding to and actively engaging with such changes.

By ‘changes’, I mean to encompass the entangled fluctuations in many intertwined aspects of the lifeworld; including bodies, routines, attitudes, family, medical events, technologies, structural changes to the home environments, as well as the engagement with these things. Most strikingly, it seems that a person must persistently make any number of smaller or larger adjustments to the way they go about their daily lives in order to maintain meaning-making activities and relationships that are important to them. These adjustments and re-adjustments seem geared towards making the kind of life that is worth living for a given person, in the face of changes that may call this into question again and again. In my fieldnotes (25/03/2018) in the excerpt above, I first described these adjustments as responses to the “constant fraying of life around the edges”. It is the work of making lives, indeed lifeworlds, recognisable.

This chapter is laid out to build on what was introduced in Chapters 1 and 2, elaborating the core characteristics of unmaking/remaking in this thesis. I first critically examine the work of Scarry, Mattingly, and Mol together in context of my research question, what these notions illuminate in the case of heart failure, and what they do not. I then apply this framework to participants’ own lives to further develop it. Conceptualising processes of unmaking/remaking firstly through literature and then through my own data in this way builds on, critiques, and extends understandings of how people continue living daily lives in cases of chronic terminal illness. As described in Chapter 1, my point of departure is taken from Scarry’s (1985) conceptualisation of pain as world unmaking, together with Mattingly’s (1994; 1998) narrative phenomenology and Mol’s (2015) tinkering as world remaking. Together, I use these theoretical perspectives to consider the nature of unmaking/remaking that is specific to heart failure patients living at home towards the end of life, in ways that extend theory.

In order to illustrate three key aspects of the unmaking/remaking complex, I present findings from fieldwork that concern bodily negotiation, attention, dispositions, and compromises. To this end, I explore participants’ experiences of: (1) having to sit down in the middle of daily activities; (2) attending (or ‘listening’) to one’s body; and (3) day-to-day fluctuations of

wellness. Here, I draw particularly on the phenomenological work of Leder and Csordas. In particular, Leder (1990) describes the absent body, i.e. how the body itself is absent in health, but becomes newly brought to attention in the case of sickness, where the body's dysfunction is brought to the fore. This forms the basis for describing, in the vein of Csordas' (1993) somatic modes of attention; the ways in which participants attend so readily to how they are feeling and what they are capable of doing in any given moment. Finally, there is a discussion that more explicitly interweaves theoretical perspectives with the data presented.

The bodily and mundane, or everyday, aspects of unmaking/remaking foregrounded in this chapter are but one piece of an exploration into how people (re)position themselves towards the end of life. This thesis presents unmaking/remaking as a core part of the ongoing processes involved in encountering one's life as worth living, or indeed no longer worth living. Chapter 6 goes on to consider the situated material relations involved in unmaking/remaking. Chapter 7 posits that the stilling of movement and certain kinds of story-telling signals the turning away from making altogether, and being done living.

5.2. THEORETICAL PERSPECTIVE

Elaine Scarry (1985) first wrote about 'the making and unmaking of the world' in her work on war and torture, *The Body in Pain*. With a primarily literary background, Scarry mobilises many diverse sources – including legal documentation, medical case histories, the New and Old Testament, and Marxist manifestos – in forwarding her argument that pain is exceptional in its capacity to unmake a subject's world; this unmaking further becomes a source of pain in a reciprocal cycle of unmaking. Demonstrating her argument through a structural analysis of torture and war in relation to bodily suffering, Scarry's work marks an important entrance of the lived, experiencing body into theorisations of pain in the humanities, which had been previously dominated by linguistic theories (Van Ommen et al., 2016:334). Scarry argues that pain is ineffable; pain uniquely "resists objectification in language" because "it is not *of* or *for* anything" in the way that we are 'hungry for' something, for example (Scarry, 1985:5, original

emphasis). Scarry thus highlights the inadequacy of linguistic understandings of pain on the basis that language is unable to capture lived bodily experience, rendering pain un-sharable with others.

> Physical pain happens, of course, not several miles below our feet or many miles above our heads but within the bodies of persons who inhabit the world through which we each day make our way […] it [pain] achieves its aversiveness in part by bringing about, even within the radius of several feet, this absolute split between one's sense of one's reality and the reality of other persons. (Scarry, 1985:4)

Focussing specifically on the extreme pain resulting from torture, she argues that this kind of pain collapses the perception of reality; meaning is drained as "the content of one's world disintegrates" (Scarry, 1985:35). With an indeterminate time-frame and uncertainty about the reasons for being tortured, the subject's world shrinks down to the room in which the torture is occurring. For this person, this kind of world-unmaking pain is "the most vibrant example of what it is to 'have certainty';" whilst for other people, hearing about a pain that is ultimately inexpressible is "the primary model of what it is to 'have doubt'." (Scarry, 1985:4)

The antidote to pain, according to Scarry, is imagination. Scarry defines imagination as human creation and above all a way of making meaning, an extension of the body and a representation of that person's being-in-the-world, e.g. artwork, meals, or conversations. Imagination is a kind of creative engagement that gives rise crucially to shareable worlds, counteracting the qualities of pain, which is otherwise acute and private. Although Scarry's argument is far broader – concerning the politicised nature of bodies in pain, and the dichotomy between 'body' and 'voice' – this is beyond the scope of what is relevant to this thesis.

It is the former conceptualisation of pain, rather than imagination, that has been predominantly taken up by later scholars (see Van Ommen et al., 2016). However, it is also a conceptualisation that has received much critique (e.g. see Harpham, 2001). In particular, a 2016 special issue of *Subjectivity* was dedicated to critically analysing and nuancing Scarry's notions of pain, war, and torture. Implicitly defining pain as 'suffering', as Scarry does, problematically renders all pain bad, an assumption that does not stand up to multiple other

real-world examples (A. D. Ross, 2012). There are similarly inconsistencies with the way that subjects are discussed, and bodies defined in opposition to language, which are stances easily critiqued from an embodied phenomenological perspective where the body-subject is not a "fixed identity but a *lived* modality" in constant flux (Bustan, 2016:375, original emphasis). Further, of particular note here, is Larocco's (2016) argument against the inexpressibility of pain. Rather:

> Pain seeks to speak to us, […] it troubles the body-subject, undoing a sense of utility, control, and social proficiency […], and articulates an alternative subject. (seen in Van Ommen *et al*., 2016:336)

However, most relevant to this thesis is a consideration of chronicity and ongoing suffering that is not so exclusively linked to pain, as in Scarry's torture example. Scarry (1985:109) only briefly references more lastingly injured bodies, where she describes the injury as having a "memorialisation function" that makes pain more enduringly visible and impactful, writing poignantly that "what is remembered in the body is remembered well." Scarry's notions have further been made relevant to chronic illness, applied in particular by Leder (1990) in his book on the phenomenology of the body in health and illness, *The Absent Body*.

Leder adopts Scarry's notion of unmaking, arguing that although pain and disease are not one and the same, they are intertwined and "disease tends to effect many of the same experiential shifts as does pain." (Leder, 1990:79) This extends unmaking to encompass other unpleasant and disruptive bodily sensations and experiences, such as those experienced by heart failure patients (e.g. fatigue, breathlessness). However, both authors spend less time considering processes of *re*making whilst suffering chronically. Whilst Scarry discusses remaking mostly when pain itself is gone, Leder too predominantly neglects how ongoing illness might be implicated in recovery and healing. It is here that I return, therefore, to Cheryl Mattingly's (1998; 1994) work with occupational therapists (OTs) and those with permanently life-altering illnesses (e.g. spinal cord injuries), who together imagine motivating futures.

Arguing that narratives structure lived experience itself, Mattingly documents the healing journey of people with life-altering illnesses through the co-construction of narratives between patient and practitioner. Mattingly's narrative phenomenology posits that narrative is centrally important to this kind of clinical work, as a manner of creating meaning, coherence, and future story-lines of normalcy and day-to-day living. These stories should be motivating for patients whose worlds have been unmade often in one catastrophic event, striving to make sense out of fragmented instances by incorporating them into someone's life as a whole. Prior to Mattingly's work, previous theorists generally studied narrative either as discourse, or performance (Desjarlais & Throop, 2011). Mattingly's narrative phenomenology works to transcend this dichotomy, encompassing gestures and told stories that patients and practitioners are involved in together.

As described in Chapter 2, OTs work to "emplot" clinical time and clinical encounters within grander narrative structures, so that the succession of many therapeutic events can be made sense of in relation to the shared plot of a given patient's life. There is a future orientation, an anticipation, an end-point of a life worth living for the person in question, where therapeutic tools have been integrated into daily life. In the face of many disjointed treatment regimens and only small, infrequent measures of progress, this process endeavours to make treatment meaningful to the person. Significantly, these kinds of narratives give space to the "unfinished, idiosyncratic, unpredictable, suspenseful qualities of life." (Mattingly, 1998:44)

Of most relevance to my data is Mattingly's analytical focus on narratives as including a particular end-point, a heroic structure of agency, and drama. For participants, processes of remaking seem to be more iterative, oriented towards multiple endpoints rather than one all-encompassing vision of a consistent new normal. Although Mattingly's narrative phenomenology may acknowledge and encompass multiple smaller aims and check-points, these are still bound within a grander narrative and vision. Instead, I suggest that participants continually renegotiate multiple endpoints. For example, Rosemary wants to continue cooking

for herself and aims to have her kitchen remodelled to better accommodate her deteriorating ability to stand (she sits on her walker); these changes would also accommodate a wheelchair, the eventual use of which Rosemary has come to understand is inevitable, yet she is firm that going into a wheelchair permanently would make her life not worth living.

Endpoints may thus be layered, relatively proximate or distant in time, framed positively or negatively, and multiple conflicting/contrasting endpoints may coexist at once. Over time and with different experiences, participants may realise that some endpoints are no longer possible, and engage in a kind of dismantling of these goals, as well as imagining and experimenting with further aims. Multiple endpoints are thus a feature of the lived bodily experience of unmaking/remaking: endpoints are iterative as people move through their lifeworlds in ways that continually challenge, recalibrate, and rework what is considered to be a life worth living. Further, this kind of work is not primarily done by clinicians, such as cardiologists, but rather must be motivated and/or experimented with by the patient and their family themselves, or other support services (e.g. occupational therapists, community matrons, etc.).

The construction of a single motivating storyline with a discrete beginning and end seems therefore somewhat incomplete when applied to my research: starting with a catastrophic event and finishing with a consistent 'new normal' from which to proceed does not resonate with the experiences of participants here. With a need to make space for the ongoing renegotiations of multiple aims, hopes, break-throughs, and set-backs, I thus turn to Mol's notion of tinkering. Mol et al. (2010:13) define tinkering as "attentive experimentation." This reframing can serve to nuance Mattingly's conceptualisation of co-constructed narratives, and further my consideration of iterative endpoints that are renegotiated according to diverse experiences within the lifeworld.

In their ethnographic book discussing the ethics of [good] care, *Care in Practice: on tinkering in clinics, homes, and farms,* editors Annemarie Mol, Ingunn Moser, and Jeanette Pols (2010)

make an argument for the continual 'tinkering' work that is necessary in various practices of care when incorporated into people's lifeworlds. Good care is seen as arising from "persistent tinkering in a world full of complex ambivalence and shifting tensions." (Mol, et al., 2010:14) The book itself emerged from an identified need to bring a broader and more nuanced notion of 'care' to the forefront of scholarly writing concerned with bodies and suffering. Previously, Mol et al. (2010:5-8) argue, this area has been dominated by largely sanitised and disembodied accounts of care that dichotomise public and private, good and bad, warm and cold care, the technological and the human. Blurring these boundaries instead, through a collection of chapters by diverse authors, the book edited by Mol traverses a number of different sites and participants, collectively (but not exhaustively) focussing on caring with and for those "who cope with disabilities." (Mol et al., 2010:8)

In the complex daily lives of real people, Mol et al. (2010:13) advocate for "local solutions to specific problems". Good care is something that is 'done' in practice. In this way, they argue not for one standard of good care, but instead for the acknowledgement of multiple different 'goods' that arise from different care practices. Different 'goods' refer to the values and priorities (e.g. quality or quantity of time left) of those being cared for and of different kinds of caregivers (e.g. OTs, cardiologists, palliative care specialists, family members, etc.). Fundamentally, these diverse practices reflect "different ways of ordering reality." (Mol et al., 2010:13) Such differences collide in the lifeworld of the patient, and must be productively dealt with together: "Care implies a negotiation of how different goods might coexist in a given, specific, local practice."

This negotiation is about "seeking a compromise between different goods" in ways that are not purely verbal; rather, they are "a matter of practical tinkering, of attentive experimentation." (Mol et al., 2010:13) In foregrounding the bodily dimensions that are so integral to the negotiation of daily living for participants, in this and later chapters, I mean to bring an embodied aspect to negotiating. This further nuances the negotiation of how

unmaking/remaking unfolds, without implying that these processes are purely physical or verbal, or unidirectional. Instead, this highlights how people may (re)negotiate with and through their bodies.

In defining tinkering as a practical undertaking of attentive experimentation, Mol et al. highlight the ongoing, and often inter-relational work that constantly unfolds as people go about their daily lives with changing bodies. Tinkering therefore seems to me to be specifically about the tangible, bodily aspects of continually renegotiating and striving for a life worth living: indeed, the very physicality of having to do something just a little bit differently every day. This kind of framing leaves space for complexity, for the ambiguities and messiness of the ways in which diverse people engage in living. In practice, this living is comprised of many imperfect solutions which are layered, again and again.

Each incomplete solution is oriented towards multiple different endpoints and goals, iteratively impacting one's being-in-the-world. Failure to reach a goal may thus not be a major problem. The ethics of care that Mol et al. put forward sets tinkering at the centre of caring practice: some things work, some things do not. Aiming high and experiencing experimental failures are therefore implicitly framed as encouraging for people to "try again, try something a bit different, be attentive." (Mol et al., 2010:14) In this way, tinkering supports multiple kinds of storylines, which much better reflect and accommodate the lived experiences of people with chronic illness towards the end of life:

> […] in care versions of the world, the hope that one might live happily ever after is not endlessly fuelled. You do your best, but you are not going to live 'ever after'. Instead, at some point, sooner or later, you are bound to die. Along the way, there will be unfolding tensions and shifting problems. Care is attentive to such suffering and pain, but it does not dream up a world without lack. Not that it calls for cynicism either: care seeks to lighten what is heavy, and even if it fails it keeps on trying. (Mol et al., 2010:14)

Experimentation in this way resonates with participants' experiences, as they continually (re)position themselves towards the end of life. Taken together, therefore, the combination of Scarry, Mattingly, and Mol's ideas culminate in a nuanced framework for thinking through how processes of unmaking and remaking unfold for participants, and what is at stake for them.

This chapter primarily establishes how I conceptualise and apply this theoretical framework, through the exploration of three themes from my data which illustrate specific aspects of the process of unmaking/remaking.

5.3. FINDINGS

5.3.1. "You just have to sit down until you can go again."

> *I watched as Ed shuffled his way in short, manageable steps, one and at a time with walking in stick in hand. I had slowed my pace to match his as we walked around the grounds of the assisted care facility. We were talking, but we were mainly focussed on our surroundings. It was a walk he was undertaking less and less often. My attention was particularly snagged by his breathing, not asthmatic-sounding like the air was too thick to inhale, as I might have expected. His breathing was rather short and sharp, somehow sore-sounding, pained. I spied a bench not too far away, and wondered whether he was aiming for it. When we were about to pass it, he leaned his head back and sighed before sitting down, announcing to me: "I just have to sit down for a minute until I can go again."* (Edwin, excerpt from field-diary, 15/08/2018)

The above vignette is a brief illustration of how life is interrupted by moments where participants have to stop what they are in the process of doing, and wait until they feel able to carry on again. It is a bodily experience permeated by "feeling exhausted" and "like you can't breathe" (Norma, Kent, Rosemary, Emily, amongst others). The responses from participants vary very little: "I've just got sit down, I've just got to!" (Rosemary, Visit IV, 13/03/2018) Having to 'sit down until you can go again' is thus a pervasive comment from participants, especially elicited when they are speaking of doing everyday, casual, and often household tasks: "Some days, even going to the bathroom, it just took all my energy," says Norma (Visit I, 20/06/2018), a fairly typical report from participants who had experienced particularly bad bouts of ill health due to their heart failure.

Walking to the grocery store or post office, getting dressed, vacuuming the house, doing other housework, gardening, or even making a cup of tea are all subject to interruption. These weekly or daily tasks are often done in set, methodical ways that are established over years of embodied, repetitive, habitual movements. These practiced movements begin to fall into a category of activity that does not generally require too much thinking to carry out; they are embodied in the sense that they are remembered in the body, they have become part of one's

corporeality, i.e. what Leder (1990:31) terms "incorporation". Participants intuitively know how long the activity generally takes, what to look out for, what they find difficult, and what they might need help with, for example.

However, participants are beginning to notice incremental changes; the familiar markers of their daily activities have begun to shift, detecting inklings of something different. When going about their daily activities in a state of health, participants would tend to continue without noticing, beyond the scope of what they usually experience, how they feel in their bodies. This is what Leder (1990) terms 'the absent body' (or corporeal absence): so much of what happens in and what we do with our bodies usually goes on without conscious awareness of the body itself. The primacy of the body in experiencing and responding to the world is clear; yet our attention rarely dwells on our own embodiment. For some of participants, feelings of breathlessness and tiredness begin to break through; they note aches and pains in their bodies, stiffness in their hands, as it becomes more difficult to do certain tasks; things begin to take longer than they used to. "It can get quite tedious," Emily (89) tells me, when speaking of how she can no longer vacuum her small house in one go any more (Visit I, 10/02/2017). "It's ridiculous, really frustrating," corroborates Norma (75), a clean and tidy person, when telling me of a similar issue of doing housework in stages, punctuated by having to sit down in between each small task. "It's so frustrating to not be able to do things like I used to." (Norma, Visit I, 20/06/2018)

For many of participants, it is this comparison to previous states of relatively better health that seems to exacerbate the unravelling of the familiar. Even if these changes are small, they are readily noticed by participants; there is a sense of pushing back against a new and imposed slowness, when they *have* to go slower in doing things they have done all their lives. As Leder (1990:4) describes, our body "seizes our attention most strongly at times of dysfunction; we then experience the body as the very *absence* of a desired or ordinary state, and as a force that stands opposed to the self." Some of participants experience and indeed almost measure the

absence of 'feeling able' through the frequency and length of time they have to be down for. These comparisons further fray the edges of their lifeworld, highlighting how they feel whilst doing these and other activities, as participants begin to pay more attention to their bodily states.

This attention becomes more focussed as participants' meaningful movement through their lifeworlds is forcibly and repeatedly slowed and, at times, grinds entirely to a (albeit often brief) halt. Attending to the body in this way consequently contributes to noting further declines in participants' constrained capacity to do not only the things they want to do, but also how they want to do them. It is this interruption of intentionality that is further disheartening to participants: to feel fine in one moment, to reach towards a goal, and to be thwarted in the next moment. Kent (88), who is predominantly sedentary due to severe heart failure and gout-affected feet, tells me:

> "The great irony and sadness of my life is that I look and feel, for the most part, perfectly well whilst sitting here in my chair – until I try to do something." (Kent, Visit II, 08/08/2018)

What Kent seems to express to me is how many of his bodily cues can no longer be trusted. It is not usually that participants are unable to do a task entirely, but it is that they are not able to do a task firstly, as they 'always used to'; and secondly, on their 'own terms'. Participants readily tell me about how they like and want to do things, but I observed again and again how they are foiled by the abrupt interruptions of having to take pause; and then of having to gather the effort to stand up again and take up the abandoned threads of what they were doing, even multiple times whilst doing the same thing. Some of participants find the need for multiple restarts, regathering oneself, and acute attention exhausting in itself: "Everything is a huge effort," Philip (91) says to me, a man who also spends much of his time in a chair due to severe heart failure, and arthritis that he describes as excruciating. "You get to a point when you don't really want to do most things." (Visit II, 19/06/2018)

Philip's utterance speaks to the creeping demotivation that is a core aspect of unmaking the lifeworld: not only do participants have to negotiate the barriers to accomplishing what they want to do, but these challenges tug persistently on their desire to do things at all. Especially with the more incorporated automatic tasks, participants experience a jarring disjuncture between their expected habit body and the challenges with which they are instantaneously presented upon action, as Kent expresses above. Heidegger (1996 [1953]:52) discusses this kind of pre-conscious bodily intentionality, which he terms 'comportment', and defines as a "directing-oneself-toward" that is "characteristic of [one's] everyday activity". Disruption on this level, on the level of one's very being-in-the-world, unravels participants' sense of their own bodies.

Experiencing interruptions to lifelong patterns, participants indeed speak initially of a disconcerting "little reminder" of poor health, "that you are not-quite-well." (Carol, Visit II, 21/09/2017) Leder (1990:76), following Scarry, asserts that the "disruption and construction of one's habitual world correlates with a new relation to one's body." On numerous occasions, participants tell me that the interruptions "make me feel old" (Rosemary, Emily, Carol, Norma) or "bloody useless" (Kent, Edwin). These interruptions, with how frustrating and saddening many of participants find them, niggle at their sense of wellbeing, fundamentally making them feel older and less capable. Participants have richly described their lives as full and busy, often with family and jobs, plans and day-to-day tasks; in lives that were predominantly characterised by activity, participants are now confronted with inactivity, to different extremes. The rest of life seems to flow from these interruptions, these moments of stillness where physical movement and activity is not possible. With so many punctuations in the flow of daily living, taking all these instances of stillness together, there is a profound sense that life – meaningful life – becomes pared down to consist of the small fragments in between periods where one has to sit down.

Yet, just as there is an imposed slowness in participants' daily living, I have also encountered an adopted and anticipatory slowness. Rosemary (83), for example, is an intensely social lady with a busy calendar, and also suffers from worsening heart failure complicated by a host of co-morbidities that present her with daily challenges. She tells me how she manages to keep going with the things that are most meaningful to her:

> "Just recently, I've taken to having a little lie-downs in the middle of my day now, just for an hour or so. I've got to, otherwise I can't get through the rest of my day, and everything I've got planned with everyone. And *that's* what's important, really." (Rosemary, Visit IX, 05/10/2018)

Of participants who are still predominantly independent, I have seen over the months I knew them that most of them adopted a designated period in the day where usual activity is suspended, and they plan to sit or lie down. They express to me that these moments of stillness may not strictly be the desired activity, but that they have realised it is necessary in order to continue especially with those things that are particularly important to them. Many of participants love to garden, including Nancy, who was enjoying her large and well-organised garden right until she passed away at 84. She told me: "I do what I can," because "I still like messing around out there", even though she hired someone in to mow the lawn (Visit I, 21/02/2018). She gave herself regular breaks, and just enjoyed being out in nature: it seems that this was a vital part of what made Nancy's life worth living, something she would rather have in her life than not, something that was worth the effort.

Through these kinds of accounts, I understood that stillness essentially can also facilitate participants persevering with the things that are meaningful to them, despite constraints: they have adopted the very thing that unmakes their lifeworlds as a key aspect of remaking. Stillness both frustrates and supports meaningful activities, and in this way participants demonstrate how life can be remade around these pauses, these excruciating moments of stillness that so disrupt their sense of wellbeing and the familiarity of how they have always lived their lives. This remaking may often require inventive work-arounds and dynamic solutions, which remake the lifeworld not in identical ways but ways that either are or become familiar. For

example, participants sometimes enlist support from family or others, as Nancy did, or use assistive technologies, which will be further explored in Chapter 6.

Although stillness was adopted in diverse ways, many of participants mention the risk that is introduced by unpredictable bodies: some of participants experience difficulty doing fine motor work, can no longer walk or stand unaided, and are also subject to the risk of sudden death characteristic of heart failure. Being still and in one place can also be protective, potentially avoiding accidents and hurting oneself: "I'm safe, upstairs, in bed where everything is soft." (Rosemary, Visit III, 01/11/2017) Some of participants also engage remaking through co-opting the time that they are still and safe, and do something they enjoy: "You can find me in my chair, knitting away, always been one of my favourite things, it doesn't hurt me to be here." (Emily, Visit V, 15/10/2018)

Some of the family members of participants, particularly those who live alone like Rosemary (83) and Emily (89), express worry about risks (e.g. over-exertion or falls), and are often relieved to find their loved ones sitting safely in a chair. Emily, amongst other participants, agrees that she does not want to "make trouble" for or "be a burden" on her children, well-documented in literature. This speaks to me to the twofold desire of some participants to neither be dependent, nor disrupt the lives of those who are meaningfully independent from them. Dependence especially on children may be deeply challenging to the familiarity of the lifeworld, where the flow of care is flipped between parent and child in ways that may be intensely unmaking. Yet, the tensions between risk, familial worry, and living meaningfully again highlight the profound sense that stillness in and of itself is not enough, it is not always worth it. As Jeanne said to me one day, having lived alone in relatively good health until she passed away at 96:

> "[My daughter] says to me: 'mum, go sit down! Go sit, I'll do all this, you're going to hurt yourself!' But I sneak a load of laundry in when she's not looking! [laughs] You can't spend *your whole life* in one chair." (Jeanne, Visit II, 10/08/2018)

There is therefore a careful balance to be struck, a dynamic equilibrium where the unmaking character of stillness must be mitigated by aspects that remake the fraying edges of the lifeworld, often into different yet recognisable patterns. A subtly different mode of being-in-the-world emerges; past states can no longer be cues as to how to go about current daily life. Indeed, Leder (1990:74) speaks of how the very disruption of someone's intentions to do something gives rise to bodies that are "no longer 'from' which one attends but 'to' which one attends." Participants' altered bodies become a site of uncertainty, demanding to be accommodated for in new ways that have never previously needed space. Attention is drawn to the body through the disruption of the vital flow of daily life, and the body demands to be listened to.

5.3.2. "You have to listen to your body."

> "I don't know what happened – I might have tripped over my feet, at any one time I don't know where these are [because my legs are numb due to my peripheral neuropathy] – and I just turned too quickly to pick the recycling up off the floor like I usually would have done. And I don't know, but I was suddenly on the floor. I really went a-whack. I've lost a lot of confidence now, and I don't think I can do things." (Rosemary, Visit IX, 05/10/2018)

As seen in the previous section, a different kind of bodily awareness is cultivated in participants as they spend more time with their changing ways of being-in-the-world. The body does not feel how it usually feels, does not do the things it usually does: participants describe a loss of confidence, as above, a lack of understanding of the boundaries of their capacity. Through a focus on dysfunction, there is the threatening potential for participants' lifeworlds to become entirely unmade, as Scarry's (1985) unmaking emphasises. However, the sick body also offers up ways of supporting remaking, offering new possibilities and sensations that participants must learn to attend, interpret, and negotiate as they go about their daily lives.

In discussing 'attention', I do not mean a psychologically-defined phenomenon that is predominantly cognitive and conscious. Rather, I mean to invoke Csordas' (1993:138) elaboration of attention as "bodily and multisensory engagement" with the "body's situation

in the world." These kinds of embodied attention are what Csordas (1993) refers to as 'somatic modes of attention'. He defines them as "ways of attending to and with one's body in surroundings." (Csordas, 1993:139) Phenomenologically (in the vein of Merleau-Ponty), the body is a generative principle; it is the primary mode through which the world is experienced (Morris, 2005). As such, attending *to* bodily sensations is merely part and parcel of attending *with* the body, i.e. attending to what gives rise to that sensation in the world (Csordas, 1993:138). Somatic modes of attention, therefore, denote a kind of bodily interpretation that transforms disparate sensations into embodied knowledge that makes sense of one's being-in-the-world. How participants learn to listen to their changing bodies thus emerges as a somatic mode of attention. In attending to and with their bodies, participants are engaged in the construction and deconstruction of embodied knowledge that is fundamentally implicated in unmaking/remaking lifeworlds. With this lens, it cannot simply be that illness unmakes the lifeworld whilst people remake it: instead, embodied persons living with heart failure continually unmake and remake their lifeworlds as they go about their daily living.

As bodily cues and sensations shift, some of participants experience a crisis of interpretation: they may realise that they may be no longer be responding appropriately to their changing needs. For example, Noémie (69) has spent all her life with a heart problem that quickly made her very breathless and red in the face during vigorous movement; when she was diagnosed with heart failure in 2013, she said she did not feel any different and any further symptoms were similar enough to handle in the same way. For the most part, Noémie found that she could basically ignore her heart troubles if she did not rush walking or doing things. In other words, over the course of her life, Noémie has learned what she can and cannot do within the constraints of her mode of embodiment. Recently, however, her heart failure is becoming more severe:

> "I have noticed I can no longer walk at my own pace any more. I get awfully huffing and puffing. When I was walking with others, and I never used to bother, but now – I cannot even go at my own pace. I don't know what will be next, I don't know what this means, really." (Noémie, Visit V, 25/09/2018)

She continues to worry about what this means for the way she chooses to live her life, and for how she will continue to care for her husband, Harry, who has multiple sclerosis. “I don’t care so much what happens to me,” she says, “but if I can’t do anything, then I certainly can’t look after him.” For Noémie, being alerted to new sensations and limits is part of listening to her body, yet also starts to unravel her peopled lifeworld at the edges of her reach, in a future for which she can now try to plan. She must give up, and unmake, her habit of pushing aside and through symptoms, presented with a number of new possibilities and problems which she encounters and negotiates little by little.

Many of participants are troubled by the worsening of their heart failure and other co-morbidities, yet through the ongoing processes of continuing with daily living, they learn how to probe their boundaries. “I am very careful to not overdo it,” many of participants say, highlighting to me the difficulty in negotiating what seems to be a fine line between ‘not overdoing it’ and being so wary that it becomes difficult to do anything at all. Emily (89) speaks of the shock she first felt when experiencing severe bouts of breathlessness: “It’s really quite horrible, you just feel like you can’t breathe.” Yet, her understanding also changed: “I know now, what it feels like, and what to do, I know now I’m not going to die.” (Visit III, 01/06/2018) In this way, somewhat demystifying the experience of breathlessness allays some of the unmaking potential of the sensation itself, and instead opens space for remaking. Once Norma (75), who is particularly prone to chest infections, had undertaken supervised gym sessions as part of a pulmonary rehabilitation programme, she said: “I learned I could do more than I thought. Every day, I walk a little bit further, and I can do it.” (Visit II, 21/08/2018)

Participants tell me that “it’s important to know your limits” (Baylee, Visit III, 30/05/2018). Indeed, there seems to be a certain amount of calibration that is necessary, learned through trial and error, going further and further (as Norma says) each day. When things change, incrementally, another layer of uncertainty is introduced about what is happening and what to do about it. This further dissolves the firm edges of participant’s shifting embodiment and

lifeworlds, which is all the more brought to the fore through the meticulous attention participants have learned to cultivate with respect to how they are feeling in any given moment. This is true both when participants feel worse, but also when they feel better: unsure of how long the feeling will last, or how far it will hold, some of participants take advantage of these moments. They push past boundaries in ways they would not have dared previously, when there was a certainty that they were "not feeling up to it". Emily (89), after discontinuing a particular medication, felt so much better that she mowed the lawn:

> "I really was feeling so rotten before, I would wonder to myself as I went to bed: 'will I wake up in the morning?' I didn't feel like doing anything […] I'm feeling so much better recently! I mowed the lawn the other day! I daren't do that before, but I just thought – why not try it? I went slowly and carefully, but I did it." (Emily, Visit V, 15/10/2018)

In this way, all kinds of sensations are built into the embodied knowledge that begins to restore some of the trust participants may have lost in their changing bodies. There is a certain amount of unlearning – of unmaking – that must be done in order to accommodate for such changes, yet concomitantly support and give rise to new potential for remaking. Rosemary (83), for example, has spinal spondylosis that causes blood to her brain to be cut off if she turns her head a certain way; she explains how the Alexander Technique has helped her with the issue:

> "I had to unlearn and relearn how to move my body to look left and right, so that I didn't accidentally set myself off – and it works beautifully! I was so impressed, it's not a problem, not at all, as long as I do things the right way." (Rosemary, Visit VII, 26/06/2018)

In experimenting with bodily postures and movements, facilitated by an acute awareness of bodily sensations (e.g. when she was moving in the 'wrong' or 'right' way), Rosemary negotiated both the construction and deconstruction of embodied knowledge in ways that offered up new possibilities for movement and continuing with her daily life. Indeed, in pushing boundaries, participants may both come up against further barriers, and may discover new possibilities. Effort is also made, in particular, in order to accomplish things that are of specific importance, from smaller to larger endeavours: chair-bound Kenneth (90) and his wife and full-time carer, Fran (78), always sit at the table to eat their meals; similarly chair-bound Kent (88) joins extended family at the dining room table for special occasions; Noémie (69)

goes travelling to far-flung countries. By paying close attention to how they are feeling, and making allowances that they have learned how to put in practice, these kinds of worth it activities to differing extents offer opportunities for participants to explore their boundaries. Norma (75), after an operation that ended months of feeling very unwell, finally felt well enough to go with her young grandson and daughter to a theme park, an offer which she had previously declined.

> "It was so worth it, just to see his [grandson's] and her [daughter's] face, to give them that. To go on that rollercoaster with them. He was so excited to go, and with grandma! […] And my daughter was terribly worried to begin with, she called me the day before, and said: 'Mum, I'm worried you won't cope!' And I just said to her: 'Well, if I'm not coping, you know what I'll do? I'll find a bench, and I'll sit down. At least I'll be out there with you, all of us together.' " (Norma, Visit II, 21/08/2018)

Emily (89) similarly began to feel much better after the discontinuation of one of her medications, and tells me she feels like knitting again: "I have a love affair with wool, it's an addiction!" Knitting, for Emily, is far more than the act of knotting wool together: it is a whole assemblage of meaning-making activities. She tells me about how she decided to make a cardigan for her youngest great-granddaughter, Faith, something Emily has not done in years since Faith was a baby.

> "I just thought, 'it's for Faith, so I'll make the effort'. […] We [my grand-daughter and I] walked – *slo-o-o-wly* – all the way through town. And there's this little shop that sells all sorts of things, and on the back wall, there is wool. Ooh, wool is like a drug to me [laughs], I see it and I've just got to have a look, I've just got to have it. I thought, I'll pick some out for her and make another cardigan. She needs another cardigan, and she's old enough now to know that nanny made it for her." (Emily, Visit V, 15/10/2018)

When asked about the potential risks or the reasons they decide to accomplish these things, many participants respond with something strikingly similar: "That's what life's about, really, isn't it?" Considering the associated 'risks', pushing the boundaries of what one feels able to do invokes a particular balancing act: if participants did not engage in this kind of meaning-making, would this render life not worth living? These vital activities therefore seem not to strictly follow lines of risk, but rather lines of meaning and hope; they represent goals worth aiming for. In some ways, pushing boundaries signifies a changing notion of risk for

participants as they negotiate what is or is not 'worth it', feeling through whether life is worth living or not. Whilst weathering the incremental and larger changes occurring, going through daily life as well as making a special effort for 'worth it' activities ultimately allows experimentation with (novel) modes of embodiment/being-in-the-world that furthers one's understanding of one's body. Pushing boundaries for worth it activities in ways that develop embodied knowledge indeed seems to qualify as a case of Mol's tinkering as 'attentive experimentation', nuanced by Csordas' particular conceptualisation of attention as attending both with and to the body.

Although it may hold different meanings and relevance for people, all of participants have at some point referenced the importance of "listening to your body". There is a sense that the body *knows*. Through losses of confidence, often due to encountering an unexpected barrier, one has to learn to trust the body again, to trust the sensation and interpretation: "I don't feel like doing anything," or "I thought I'd give that a go today". Viewed through the lens of somatic modes of attention, it is therefore not simply that the body-object signals and the conscious mind of the subject interprets; equally, unmaking is not exclusively the work of disembodied illness, nor remaking the conscious work of people. Instead, brought together in one's being-in-the-world, the lived body-subject engages in the construction and deconstruction of embodied knowledge; this embodied knowledge involves the closing down of some options whilst also being presented with new possibilities and reaching new understandings. Such processes are vitally implicated in unmaking/remaking the being in the lifeworld, in ways which importantly render unmaking/remaking thoroughly embodied in lived practice as people go about their daily lives.

5.3.3. "There are good days and bad days."

> "Well, of course, sometimes I feel better and sometimes I feel worse. But I know that if I don't feel well – my head is dizzy or my chest is bad or I just feel like something's a bit off – then I just pop myself back into bed! No problems. No qualms with doing that at all, just go back to bed and I'll get up again when I feel better. That's just life, isn't it, honey. Got to take each day as it comes." (Nancy, Visit I, 21/02/2018)

A key aspect of listening to the body is marking the good days and bad days. Well-documented in the heart failure and other chronic illness literatures, the ebb and flow of feeling well is highly disruptive, especially to planning and going about daily life. This kind of day-to-day fluctuation is discussed by multiple scholars of chronic illness, describing the episodic nature of chronic pain and illness that renders habituation nearly impossible; episodic pain is difficult to ignore, repeatedly disrupting life through many routes (Bury, 1982:180; Maynard, 2010:198; Leder, 1990:72). Partly due to this further layer of uncertainty, maintaining a recognisable flow to one's daily life becomes a particularly difficult task. Although participants represent a diverse spectrum of people, they all emphasise to me how difficult it is to plan: "You just don't know how you're going to be feeling on any given day." (Baylee, Norma, Emily, Rosemary, Kent).

The impact of these good days and bad days varies between participants, of course, and they speculate that these fluctuations might be triggered by any number of diverse things: poor sleep, pain from sitting in a chair for too long, family, feeling particularly breathless or exhausted. Mostly, participants do not seem to know from where the flux of their good and bad days stem, but they all describe these kinds of fluctuations nonetheless. In probing how they are first tipped off, those with spouses often say that their partner is the first one to notice: an off mood, a snappy comment, a slower pace even than usual. Despite this intangibility, many of participants seem to simply 'know' when there is a bad day outside of the usual spectrums, when something is more severely 'wrong'. "I could just tell," they say, "something was really not right." (Baylee, Norma, Rosemary, Emily, Kenneth) Indeed, some of participants have found they can somewhat calibrate their responses and act pre-emptively.

Norma (Visit II, 21/08/2018) tells me how the only viable response, for her, on a bad day is just to go back to bed and stay there: "Cancel the plans and go back to bed." Rosemary is also a very busy woman, who has particularly complex health issues and has had to cancel a number of our own meetings. She says she hates to cancel plans: "It's inconvenient for everybody –

what use is that to anyone, if I can't keep a date in the diary? And I'd never get to see some of my friends, they're also busy!" (Rosemary, Visit V, 13/03/2018).

In a lifeworld that is fraying around the edges of what is and when it is possible to plan, and see those plans through to fruition, in order to begin remaking it seems necessary to somehow make uncertainty a *part* of that lifeworld too. A characteristic attitude that participants almost unanimously adopt is, therefore, not to plan but instead somehow accommodate for the inherent unpredictability:

> "You just take one day at a time." (Nancy, Norma, Jeanne)
>
> "Take every day as it comes." (Philip, Edwin, Jeanne)
>
> "Just take it as it comes, what else can you do?" (Norma, Rosemary, Noémie)
>
> "Nothing to be done, you just see how you feel on any given day." (Kent)
>
> "Can't plan, you just take each day that is given to you as it is given." (Emily)
>
> "No use worrying about things you can't change." (Baylee, Kenneth)
>
> "You've just got to cope with what you've got and get on with it." (Nancy, Rosemary)

Although there are nuanced and subtle differences apparent amongst this collection of quotes, the thread I wish to draw out is what seems to be the underpinning pragmatic attitude of how to both accommodate for bad days and take advantage of good days. As certain activities are not deemed 'worth it', and fall by the wayside to make way for others, the flux of good and bad days encourages participants to let go of certain aspects of their lives. The attitude of 'taking each day as it comes' thus accommodates both for unpredictable unmaking and flexible remaking. In many ways, remaking occurs in and around the gaps that the unmaking of certain possibilities leaves; whilst the unmaking itself also gives rise to new possibilities that seamlessly form part of the work of remaking. For participants, there seems to be a kind of iterative dual movement of "bringing with and letting go" (fieldnotes, 30/01/2018), in ways that retain familiarity yet at the same time also create distance. As Nancy said of her garden in our final meeting before she passed away: although she did not garden much any more, she is

content to be able to just sit and enjoy it. I described this in my fieldnotes (10/04/2018), whilst thinking of the peacefulness I felt Nancy express, as a kind of "leaning back from living".

It is this characteristic attitude of 'taking each day as it comes' that primarily demonstrates how unmaking and remaking mutually constitute each other. There is unmaking in the remaking, and remaking in the unmaking, visible throughout this chapter through the entangled ways in which daily lives ebb and flow; participants feel better or worse; embodied knowledge emerges or is undone. This attitude is characterised by planning, or lack thereof; it involves carefully-attuned attention and responses, workarounds and letting go. Philip (91), who lives alone with a full-time carer, is particularly reflective about the unpredictable and flexible nature of his life.

> "I've got everyone checking on me all the time – my daughters, they call, and Lucy [my carer] is always here. They ask me how I am, which I know quite well by now, and they know that I'll tell them if I'm not feeling up to something, which I do quite often. It's never a problem, really, they're all quite good about it. What else can you do?" (Philip, Visit IV, 18/11/2018)

Philip's days are anchored by a habitual game of Scrabble with his carer (which he usually wins), and he tells me that the worst days are particularly memorable because he does not even feel like playing Scrabble. I end most of my visits with him by asking what his upcoming plans are, and to what he is most looking forward. He responds with a range of reflections (Philip, Visit II, 19/06/2018): "I had thought I might go [walk with my zimmer-frame] around the block again if my legs are up to it, like I did a few weeks ago, but I don't think really I shall be doing that again." On a subsequent day (Visit III, 14/08/2018), he says: "I am going to see my daughter for lunch tomorrow [at her house], which is good, I always enjoy that, and I didn't get to go last week because of my back." Through Philip's examples of enjoying doing what he can when he can, it becomes difficult to independently isolate which bits are unmaking and which bits are remaking. Instead, these aspects intertwine and collide in practice as participants experiment (or tinker) and see how they feel whilst doing things, or not doing

things. They are constantly shifting, and processes of unmaking/remaking emerge as an intertwined complex through which participants repeatedly negotiate a life worth living,

5.4. DISCCUSSION: Bodily Attitudes and Dispositions

During the course of this chapter, I have introduced and illustrated the theoretical framework with which I approach my thesis. The previous two sections showed firstly how I arrived at my theoretical framework of unmaking and remaking through literature, and secondly how I developed my specific conceptualisation through ethnographic data as well. When deriving the framework purely from the literature, I felt there was a tendency and temptation to dichotomise the processes of unmaking and remaking in a number of ways: to assume that unmaking is a negative, destructive process deriving from (uncontrollable) bodily pain and suffering (i.e. illness), and in contrast to think of remaking as a positive, hopeful process deriving from (controllable) conscious imagination and the creativity of people. As this did not resonate with participants' experiences, I instead sought to nuance unmaking/remaking in order to problematise such dichotomous thinking.

From the stories presented, it is not so much that things become de facto impossible for people; rather, in this chapter I explore the ongoing negotiation of how to do things differently, i.e. how world remaking arises from world unmaking, and vice versa. For example, the stillness that punctuates and so frustrates the activities that Norma, Rosemary, and Emily undertake was intentionally adopted in some circumstances to conserve energy and in fact accomplish certain plans. Learning to listen to and interpret their bodies anew, the way these women go about unmaking/remaking their lives around these limitations requires a continuous shifting of the very manner in which living is approached, in attitudes and bodily dispositions. Planning, for example, once enshrined in habit is instead strategically abandoned by many participants in order to increase flexibility that better accommodates the fluctuation of good days and bad days; avoiding disappointment, and capitalising where possible. Framing these processes as ongoing, intertwined unmaking/remaking highlights how participants must repeatedly

(re)negotiate how they approach and engage in daily living, as different kinds of challenges and opportunities emerge in the lifeworld.

As participants experiment with how to negotiate various aspects of daily living, world unmaking/remaking emerges as a recursive complex: as modes of being-in-the-world repeatedly change, ways of unmaking/remaking are similarly shifting to maintain lifeworlds as, if not the same, then at least recognisable. As Norma says, whilst still threatened by periods of poor health, understanding her body and negotiating her limits enabled her to reclaim her life and do what she wanted do when she wanted do it much more easily. This is something I initially captured in my fieldnotes (25/03/2018), which opened this chapter, as "shifting dispositions and bodily postures, like they are always trying to get comfortable with and in their lives." Throughout this negotiation, certain aspects and activities may fall by the wayside as participants alter and pare down their lifeworlds; yet certain things are also preserved. These are the things that participants tell me are 'worth it' or 'worth the effort'. Indeed, if they did not undertake whatever is particularly meaningful to them, then they tell me: "life wouldn't be worth living, otherwise, would it?"

The particularly impactful aspects of ill health that I observed with participants and explore in this chapter resonate with the lived experience of heart failure described in the literature; heart failure is characterised by chronic and fluctuating tiredness, breathlessness and physical weakness (a brief overview of this literature is given in Chapter 1). The experiences of changing bodies that I discuss here are well-described in literature as sources of anxiety, disruption, loss, isolation, and pain (e.g. see reviews by Greenhalgh et al., 2017:5-6; Jeon et al., 2010:4-5; Leder, 1990:68-106). Writing about the phenomenology of chronic illness more generally, Leder (1990) situates such symptoms and corollaries of 'dis-ease' as fundamentally bringing the dysfunctional body to the centre of one's attention and lived experience. Adopting Scarry's (1985) notion of unmaking, Leder (1990:74-75) thus argues that disease unfolds in ways that are profoundly disruptive to daily living. In this chapter, however, I show how these

experiences of changing bodies for participants may work to both unmake and remake the lifeworld, as people living with heart failure respond to unpredictable cycles of setbacks and adjustments that characterise their illness trajectories.

In considering the work especially of Scarry, Leder, and Mattingly, I found that unmaking and remaking were discussed as predominantly separate and separable. Each aspect was dealt with discretely, with the ultimate unmaking power of pain/suffering/ill health particularly emphasised. There was very little recourse to how unmaking and remaking might be interwoven in unexpected, hybrid ways that challenge or facilitate each other, such as in the example of the 'take every day as it comes' attitude. Unmaking is thus characterised as a gap, an absence, a dysfunction (to use Leder's word) that seems to me problematically totalitarian in outlook, shutting down any generative potential. Consequently in this rendering, processes of unmaking become strangely disembodied as things that happen *to* the body(-object), rather than a process in which the lived body-subject can also be engaged.

Although a simplification of their work, Scarry and Mattingly both essentially conceptualise unmaking to stem from catastrophic events that unmakes the lifeworld all at once, leaving it rather more static, almost passively ready for rebuilding. By contrast, participants have to deal with incremental changes under fluctuating circumstances. Changes may be sometimes bigger, sometimes smaller; participants shift back and forth, ebbing and flowing through wellness and illness in unpredictable ways that require dynamic solutions, and iterative and intertwined unmaking/remaking. The addition of Mol's tinkering thus offers a partial solution to the problematically discrete rendering of what unmakes and how one remakes. Re-learning how to inhabit and move through daily life in a changed or changing body is recognised in literature as part of adjusting to living with a chronic illness (Bontje et al., 2019; Bury, 1982; Mattingly, 2006; Sakellariou, 2015). With links to Occupational Therapy, they emphasise familiarity, 'normalisation' and storytelling in the face of disruption, the latter of which is explored in Chapter 7. Nevertheless, rather than a catastrophic disruption or persistent decline, it is the

consistent tug of sometimes being in poor health but sometimes feeling fine that seems particularly unsettling here. As Kent says, it is a great sadness in his life to be tricked into feeling he is fine.

In writing of the attentive experimental layering of solutions, Mol acknowledges this kind of incremental, imperfect work that must sometimes also be undone. In this way, melding the nuances of tinkering with an understanding of unmaking and remaking especially highlights how remaking is not only a calculated, reactive response to what is unmade (perhaps supported by clinicians, as in Mattingly's example), but remaking in fact emerges from unmaking, and vice versa. This chapter illustrates how similar experiences can in some circumstances be part of unmaking, whilst in others be part of remaking. This hybridity and uncertainty resonates with the complex ongoing nature of daily living that is only sometimes on an upward trend towards wellness. Participants are instead approaching the end of life, repeatedly confronted with the question of how they want to die, and under changeable circumstances renegotiate how they want live. Rather than the coherent overarching narrative that Mattingly's OTs and patients co-construct, participants are faced with shifting experiences that continually inform what constitutes a life worth living.

Taking an explicitly phenomenological approach, participants' changing bodies are centred as primary means of engaging with and experiencing the personal, historical, relational lifeworlds through which they move on a daily basis. I thus mean to explicitly highlight the experience of being-in-the-world whilst modes of embodiment are, sometimes quite radically, changing. With regards to defining and understanding the processes of unmaking/remaking, I have therefore elaborated unmaking/remaking as (1) intertwined, (2) embodied, and (3) recursive. Although each of the three examples illustrate multiple aspects of unmaking/remaking, one particular aspect in each is foregrounded for ease. I consider (1) how stillness punctuates the vital flow of daily living in ways that are both disruptive and facilitative, demonstrating how the same things can be both unmaking and remaking; (2) how attending and listening to one's

body deals in embodied knowledge, demonstrating how unmaking/remaking is not discretely linked to either bodily or cognitive processes but is rather a lived embodied practice; and (3) how the attitude of 'taking each day as it comes' both accommodates for unpredictable unmaking and flexible remaking, demonstrating how unmaking/remaking are mutually constitutive (i.e. there is unmaking in the remaking, and remaking in the unmaking).

Overall, I found that agency is difficult to locate in experiences of living with heart failure. I do not wish to imply that participants are passive victims of cruel and inevitable decline or the unravelling of their lives; yet neither do I wish to portray participants as having an artificially premeditated control over their lives and bodies. This framework instead allows for engaging with unmaking/remaking as processes fundamentally grounded in an embodied self, rather than in (or in opposition to) a disembodied mind. Instead of certain courses of action always being decided (as a purely mental function), unmaking/remaking is negotiated over and over again with and through the body. So much of what I have observed and intuit in participants seems to me to be a thoroughly embodied consideration of what feels right or wrong. It is a kind of embodied knowledge that is not necessarily articulable, about the ways in which they experiment with and negotiate their being-in-the-world. Although Mol disregards the term 'negotiation' as problematically evocative of purely verbal argumentation, I choose to write of bodily negotiation to denote processes of navigation and compromise that unfold with and through the body. I wish to invoke a physicality, a visceral dimension to negotiation that amalgamates its multiple meanings, culminating in the shifting postures and dispositions of participants that evidence how they repeatedly encounter their lives as worth living, or not. These ideas will be further explored and developed in the following chapters.

Bodily negotiation similarly foregrounds the difficulty in discussing bodies without reducing them to signals, signs, scripts, or performances; or defining bodies in opposition to language. Whilst Mattingly's narrative phenomenology does much to bridge the gap between discourse and performance, Scarry's original formulation entirely isolates the bodily experience of pain

from that of language and communication. In terms of mind/body divides, embodiment as a paradigm for anthropology has gone far in deconstructing such dichotomous conceptualisations, derived in part from Merleau-Ponty's phenomenology of perception and later developed by Csordas (discussed in more detail in Chapter 3). Embodiment also emphasises the need for a processual understanding and an appreciation of contingency when considering body-subjects rather than body-objects (Morris, 2005). In thinking about embodied knowledge, the basis for which is in the first instance is Merleau-Ponty's understanding of motor-intentionality as muscle-memory, I mean to accommodate for such process and contingency. For participants, embodied knowledge with heart failure and other comorbidities is constructed and lived through their daily lives and local lifeworlds. Participants seem to me to be negotiating a dynamic equilibrium, where they aim to intuit and respond to what they need: to sit or lie down, to make the effort, or even to lean back from living.

Interweaving ethnographic vignettes and utterances, this chapter unpacks the contrasting ways in which participants continue to go about their daily lives when, as so many have said on different occasions: "doing things is getting more and more difficult" and "some days are so much harder than others". As people living at home with varying stages of heart failure and other co-morbidities, participants generally seem to aim to maintain a lifeworld that is recognisable according to their previous experiences. I suggest that what is recognisable is not a question of ownership or identity, i.e. feeling that this life is mine, but rather to do with striving for a sense of 'normal' that is reflective of lifelong rhythms and routines that are disrupted in illness (Bontje et al., 2019; Bury, 1982). Further, unmaking/remaking thus unfolds in ways that give rise to questioning whether this is a life worth living or not: as some of participants have said, "I sometimes think – is it all really worth it?"

In constructing a theoretical perspective that is sensitive to what is meaningful to each person, I have elaborated at the bodily level how lifeworlds may be unmade/remade in iterative,

dynamic ways as people reposition themselves towards the end of life. For participants, a life worth living cannot, as is implied in particular in Mattingly's work, be a singular construction that is motivating in all circumstances. The tinkering unmaking/remaking in which participants engage reflects the shifting, back and forth nature of living at home with heart failure towards the end of life. Tinkering, however, does not only unfold on the bodily level but is also implicated in the ways participants navigate and move through their lifeworlds, and all the things encompassed therein. In the next chapter, I describe how material relations in the home shift during the fluctuating processes of unmaking/remaking, as participants negotiate a life worth living whilst dying.

CHAPTER SIX

Material extensions of the self: moving through everyday lifeworlds

"Don't help me!" Rosemary says emphatically, "my children know, now, and they feel terrible, but don't help me." Rosemary tells me that she wants to do it all on her own, and is particularly adamant that she shows me 'how she copes' with her daily shopping trip as if I were not there at all. She can no longer walk or stand without leaning on her walker, but she manages, meticulously. We are in her kitchen early in the morning, and she is preparing to leave the house. I try to keep out of her way, watching her as she narrates: everything takes a little while, and many things have been adapted somehow. The handles on the keys to lock the door with stiff hands, the floor-space in the rooms to easily manoeuvre her walker; a door taken off here, a ramp put in there, another walker waiting strategically, a bag replaced on the hook so there is always one available…a distinct back and forth, to and fro, of a life limited and facilitated by her body and things. *We leave by the back door, attended by a number of other small steps: putting her jacket on whilst leaning her back against the wall (she could not hang on to her walker for balance whilst getting her arms through the sleeves), gathering her list, purse, bag, and shopping bag into the hollow seat of her walker, going to the loo at the last possible moment and waiting to take her water tablets until after she came back so that she wouldn't be caught short at the shops; replacing her fingerless tight-fitting gloves that relieved some of the numbness with fully fingered brown leather ones. Ready. I walked down the ramp outside the back door, and waited whilst she turned to lock the door and spun again to manoeuvre herself down the ramp with a light touch on her walker. Inside the garage, things were orderly, labelled, strategically placed; we said hi to Henry the hibernating tortoise. The mobility scooter she uses, she tells me, is the smallest she could find, "narrow and nippy!" She has customised it for shopping by strapping a large rucksack to the back of the seat using the straps you'd usually fasten around your waist. She says that she often asks the check-out person at the supermarket to pack it for her. Arranging herself with her walker in front of her and buggy behind her, she sits heavily, and she's in. Pushing the walker away and pressing a button to open the new automatic garage door (I cannot imagine the effort it must have been before), she whizzes down the driveway and out onto the pavement beside the fairly busy main road into town, the garage door closing smoothly behind us. She lets me know that she'll go a bit slower for me – the top speed on her buggy is 4mph. I begin to pay attention to the width of the pavement, with different textures signalling bike or pedestrian, and we overtake several people. As we make our way together, I begin to notice anew the texture of the road surface, the closeness and loudness of the cars, the speed of other people, the height of the push-button to cross the street and change the traffic lights. We take small detours so that she can go down the sloping ramps built into the pavement to merge with the road, as we headed for a large local supermarket that would provide her with a mobility scooter of their own, if she called in advance. She preferred, however, to move around with her own; she was familiar with it and knew how hers worked, she said.* (Excerpt from field diary, Visit II, 01/11/2017)

6.1. INTRODUCTION

Where the previous chapter focussed on bodily attitudes and dispositions, this chapter is about bodies and things in motion together. Having elaborated unmaking/remaking as processes of bodily compromise, recursive and incremental, I now turn to observable material relations that are similarly implicated in these processes. In more explicitly considering how people (or body-subjects) move with objects through the lifeworld, I highlight the ongoing embodied, sensuous engagement with materials in the home. This is equally subject to change throughout the process of living whilst dying as bodies, circumstances, and priorities shift. Material relations are therefore important, as the movement of people with things is not arbitrary but meaningful and practical; participants move with objects as part of navigating a life worth living towards the end of life.

The introductory vignette for this chapter illustrates how people's lives and stories are bound up and made in movement. In getting to know participants, I began to see how people may radically restructure their home and its contents. The shifting and intertwined movement of people and things in and around the home sometimes includes dramatic changes to the structure of the home itself, and more often changes in routes through the home. Objects may be abandoned at the peripheries whilst others are brought with participants into the most used spaces. Focussing on moving with things highlights the changing ways in which participants occupy their lifeworlds, whilst also making this movement meaningful and maintaining a sense of familiarity. By 'occupy', I mean to encompass the physicality of inhabiting and moving through, but similarly how occupying is engaging oneself.

The chapter is organised as follows. First, I briefly summarise relevant literature discussed in Chapter 2 surrounding healthcare technologies and how these technologies are used by people or not in practice. Focussing on chronic self-management of illnesses at home, and mundane materialities beyond specific healthcare technologies, I present data that explore how participants: (1) alter the structural nature of their homes, (2) navigate different routes

through their homes, and (3) move with different materials, keeping some things close and leaving some behind in characteristic patterns towards the end of life. The subsequent discussion explicitly brings the theoretical framework of unmaking/remaking to bear through an analysis of shifting material relations in dynamic lifeworlds, in context of relevant literature.

6.2. LITERATURE SUMMARY

Digital health is currently a central technophillic discourse in healthcare, propagating revolutionary visions of increased efficacy, efficiency, and quality (Greenhalgh et al., 2012; Kaplan, 1997; Newton, 2014; Nicolini, 2006; Timmermans & Berg, 2003). As discussed in Chapter 2, technological innovations contribute to changing the nature of death and dying (e.g. Franklin & Lock, 2003; Kaufman et al., 2011; Lock, 2002). Technologies and relations with these materials are nevertheless increasingly recognised as profoundly impactful not only to the way care itself is provisioned and implemented, but also wider experiences of that care (Mol et al., 2010). Healthcare technologies may permeate multiple contexts and activities outside of the clinical, as remote care progresses, and more and more aspects of illness and pre-illness become medicalised through novel treatments and progressive classification of normal life processes as pathological (Kaufman, 1994; Lock, 1993; Oudshoorn, 2011). There is thus a move towards ongoing self- and home-management of chronic illnesses (Mattingly et al., 2011). This includes technology-enabled care, such as Assisted Living Technologies (henceforth ALTs), telehealth (i.e. remote medical treatment or monitoring) and telecare (i.e. remote social care services or monitoring) (Greenhalgh, et al., 2012:1; Oudshoorn, 2011; Webster, 2002). Home, however, is far from a blank canvas, emphasising the importance of place and place-making not only for healthcare technologies, but sensuous engagement and relations with many kinds of materials (Irving, 2007; Oudshoorn, 2012).

Whilst the organising vision of the digital health movement is often underpinned by discourses of modernism and technological determinism (Greenhalgh et al., 2012; Newton, 2014; Pols, 2012), as discussed in Chapter 2, health technologies are increasingly recognised as far from

neat stable fixes for neat stable problems (e.g. Newton, 2014; Nicolini, 2006; Oudshoorn, 2011). Considering how real people live daily lives, where these technologies are adopted, abandoned or adapted, highlights the specificities of local interaction between technologies, people, and places. Indeed, such technologies are bound up in wider social and material contexts that may be reorganised through the introduction of a novel component (Kleinman & Hall-Clifford, 2010; Nicolini, 2006; Oudshoorn & Pinch, 2005). In practice, particularly as STS scholars note, there is a vast amount of tinkering that is required in order to make these technologies work (Greenhalgh et al., 2013; Mol et al., 2010; Oudshoorn, 2012). However, as people go about their daily lives and self-manage chronic dying and/or illness, materials and assemblages beyond strictly healthcare technologies are also mobilised (Fox, 2016; Locock et al., 2016). This involves potentially taken-for-granted or mundane aspects of the lifeworld, such as architecture, ordinary household objects, clothing, and cleaning materials.

Set against the backdrop of this literature, which highlights both healthcare technologies and mundane materialities of everyday lifeworlds, this chapter explores how diverse materialities are fundamental to how participants navigate their lifeworlds with changing bodies, circumstances, and priorities. In the discussion, I therefore return to the literature summarised above and discussed in Chapter 2 to challenge technophilic and determinist assumptions, as well as the distinction between technology and care. I bring people, places, and things together through considering how unmaking/remaking implicates materials of all kinds in a situated, sensuous, lived bodily manner.

To do this, I reintroduce Ingold's making and dwelling (discussed in Chapter 1), nuancing conceptualisations of how technologies are made to work in different environments for different ends. This highlights how being-in-the-world necessarily involves feeling one's way through dynamic lifeworlds filled with things, unmaking and remaking emplaced relations with those things. Recasting materiality as that which is a dynamic part of lived bodily experience, implicated in moving and making together with lived body-subjects, this chapter

demonstrates how participants' sensuous engagement with the objects and structural aspects of their lifeworlds is part of unmaking/remaking a life worth living.

6.3. FINDINGS

6.3.1. Navigating structural change

Returning to the introductory vignette, Rosemary's morning routine is elaborate. Not only does she go shopping six days a week, leaving the house at 8am sharp every day, but there is a shifting sequence of movements that she goes through before she leaves the house. Increasingly using her walker to move around, Rosemary is particularly aware of how she has had to tweak her routine in order to wash, dress, eat, and be ready to leave the house on time. Coming from a farming family, Rosemary tells me that she is used to getting up early. When I first met her, she was getting up about an hour and a half before she needed to leave the house, rising at around 6.30am. Two years later, the critical mass of tweaking has added up to Rosemary having to wake up at more like 5am or 5.30am, almost three hours before leaving: "Everything takes me such a long time, now, and I have to take such care." (Rosemary Visit X, 10/12/2018)

In order to accomplish her morning routine, Rosemary shifts how she navigates through her home. She has moved things around to streamline her routine and support the new routes. For example, she has progressively moved all her toiletries and clothing to the downstairs bathroom and bedroom, so she does not have to use the stair-lift multiple times in the morning. She has generally pushed larger pieces of furniture to the peripheries of rooms to create more floor-space, particularly in the kitchen, where manoeuvrability of her walker is key for cooking. She strategically leaves a walker (hidden) outside her house for excursions with the car, and at the top of the stair-lift, to make sure that wherever she moves, she has support.

Rosemary shapes her lived environment through the movement of objects, as she unmakes/remakes the ways she navigates daily living. Nevertheless, working within the structural constraints of her house, Rosemary's movement is also shaped by the material

aspects of her lifeworld. Valuing her independence and concerned about what will happen "when [her] legs go," Rosemary worries how a wheelchair will physically fit into her lifeworld; how moving with a wheelchair through her daily life will render some activities impossible, and thus life no longer worth living. She exhaustively lists how a wheelchair might be simply too big to fit in her car, up some of the ramps, through doorways, around furniture, and in the kitchen. In contrast to her earlier persistent feeling that a wheelchair would entirely destroy her life, Rosemary seems to be preparing to accept this new bodily negotiation and is starting to explore different options for continuing to do the things that are most important to her. Rosemary is already finding it difficult to cook. Taking great pleasure in going out every morning to get her food for the day, despite the increasing time and effort, Rosemary insists on cooking for herself. Even whilst using her walker, she can no longer stand unaided and must therefore sit on it to cook. "It's just dangerous!" she tells me, "I'm stirring pots up here and bringing them down to check if things are done." (Rosemary, Visit 6, 02/05/2018)

With the help of an Occupational Therapist (OT), Rosemary is remodelling her kitchen (construction began February 2019). The OT aims to make the downstairs wheelchair-accessible, remodelling not only the kitchen but also the shower-room and bathroom. "That's not why I'm doing this," Rosemary tells me when I ask her how she feels about making her home wheelchair-accessible (Visit IX, 05/10/2018). "I know it's a good thing to be prepared and everything, so I'm glad about that, but really I just want to cook, and cook more safely now." Upon my last conversation with Rosemary in February 2019, however, she expressed how distressing the whole process of renovating her house is whilst she is still living inside it. She sounds doubtful that she will actually get to use her new kitchen how she always imagined: "I keep forgetting – I keep having to remind myself that I am 84! I can't do many things any more. And they're setting up the shower so I can be in there with a carer. So I don't know what's going to happen, I really don't." (Rosemary, phone conversation, 28/02/2019). Remodelling, in larger or smaller ways, speaks to processes of unmaking/remaking; these processes may

involve destroying even the built structure of the home, and remaking it in ways that open up new possibilities for movement.

Similar structural changes to the home are undertaken by others with financial resource, such as Kent and his wife Carolyn. During the extended bout of particularly poor health that preceded my first meeting with Kent in June 2018, Kent and Carolyn tell me that Kent was particularly unhappy with his life. He spent most of his time in a wheelchair or chair, due to extreme breathlessness and painful gouty feet. During the earlier stages of Kent's declining health, they were encouraged by healthcare practitioners to think about future daily life. Kent also loves to cook, so the couple began thinking about how Kent would move through their long, narrow home. They decided to have the kitchen redone to be wheelchair-accessible: the countertops were lowered, appliances were installed at the appropriate height, and cupboards opened easily in more helpful directions. Kent tells me, now, that he has never cooked in the new kitchen, two years later: "Got out of the habit," he says (Visit II, 08/08/2018), "it would be very difficult, now."

Initially, Kent tells me that not cooking was due to a combination of ill health and depressive feelings. This seems to have led to re-making a home-life that saw Kent become accustomed to being largely immobile. Later, he says, he realised that this was not only borne out of necessity but also personal decision. Both he and his wife express, separately, that "giving up" on these kinds of activities may not have been the best route, as it has led to Kent settling further into stillness (Visit II, 08/08/2018). Carolyn cooked for him whilst he initially rested and convalesced, and once these new habits had taken hold, the opportunity to figure out how Kent could cook again had slipped away. From the way our conversations on this topic swiftly move on, I get the impression that this option is rarely revisited now; the couple seem caught up in the flow of other important aspects of their daily lives, now.

During a visit (21/06/2018) where Carolyn shows me the kitchen, she chats with me whilst making jam on the stovetop, and tells me: "When Kent first got ill, and it was looking like he

might be in a wheelchair more permanently, we thought: 'Well we might as well do the kitchen.' But I'm the one that began using it and I'm the one that really uses it now." She stirs jam, made from the berries she picked yesterday when she went brambling with a friend, and smiles at me. "Well, it's perfect for me, actually – I'm five foot nothing!" Carolyn has made this reworked kitchen her place now, through accepting and engaging with the new materiality of the space; a kind of remaking with which Kent, on the other hand, has not engaged. The kitchen is no longer a space through which Kent moves at all, his quarters at one end of the narrow house and the kitchen at the other. Now, he rarely makes his way further than the adjacent dining room.

Often after visits with the couple, I would spend some time with Carolyn on her own, and she particularly expressed how difficult it was to know how to respond to Kent's ill health: with optimism and a new kitchen, or with acceptance and relinquishing a longer term future with him. She agrees that since the June I first met them, Kent's health and mood seemed to both be looking up, for the time being. However, Carolyn opines that he will still never use the kitchen the way they intended. Indeed, such structural changes to the home seem to work along a different trajectory of undone to redone than that of the chronically dying. Tinkering with smaller things may better allow for flexible negotiation that responds more readily to unpredictability. For both Rosemary and Kent, changes to the kitchen were borne out of a love for cooking, and a vision of a future where they would be able to continue navigating this space to achieve this familiar end, albeit in altered ways. However, a redone kitchen may not be enough to allow them to actually continue cooking. Participants' health status continues to shift, as do their priorities. Future movements are thus similarly subject to processes of unmaking/remaking, as possibilities are opened up, or let go.

Indeed, Kent and Carolyn take advantage of other kinds of structural changes. These changes had been instigated for purposes other than Kent's ill health, but nonetheless concretely shape Kent's movement through his daily life. As of mid-2017, when his health first declined, Kent

inhabits the annexe that they had originally built for Carolyn's mother many years previously. Moving downstairs before I met him, Kent and Carolyn tell me that they had decided on this due both to sleep and mobility issues. Given the age of the house itself, the winding and steep staircase was not a good candidate for a stair-lift. The annexe is attached to one of the short sides of the long house, and consists of an ensuite bedroom behind a small but separate living space. Carolyn's mother had only spent one night in the room before she passed away. Now, Kent and Carolyn are content with how convenient it is for them. Kent has outfitted his small living room with a large flat-screen TV and surround-sound, both controllable through one of his iPads, as well as an Amazon Echo, and an exercise bike he admits he does not like to use, even when his feet are not too bad. Kent's daily life now consists mostly of moving through these small but well-equipped spaces. Although mostly sedentary himself, Kent continues to move things around with him, unmaking/remaking, in order to content himself with what is in his immediate vicinity.

I encountered similar processes of navigating structural changes when spending time with Nancy, and her husband Dave, before she died in June 2018. "Never occurred to me that we'd be using them ourselves one day!" Nancy laughed, in response to my questions about the handrails I had seen in their WC, her husband agreeing with a nod.

> "I had my mum with me, and she was 88 and I looked after her as much as I could. I was, what, I was in my sixties then, so I looked after her. And we moved from the old house because we thought a bungalow would be so much easier for my mum then, but now it's so much easier for me. It's brilliant, absolutely brilliant." (Nancy, Visit I, 21/02/2018)

Nancy similarly drew attention to how her home readily shaped how she moved through her daily life, presenting both possibilities and limitations to how she might navigate her lifeworld with respect to her changing body and health.

> "My mum came to live with us, but before she did, we had an extension put on the side of the house so it was a double bedroom for them both [my parents]. But three weeks after they moved in with us here, my dad went into hospital. [We'd gone to see him, and] we'd been home an hour, when we got a phone call. He'd had a bad heart attack and was gone. Just like that. It was a shock. He was 86." (Nancy, Visit II, 10/04/2018)

Nancy and Dave later elaborated that soon after this, her mother died as well. It seems that these structural changes are not really used by those for whom they were unmade/remade. Whilst spending months preparing a space, that person's decline is often far swifter. Nevertheless, previously having made these changes may more readily present opportunities to tinker with the arrangement of things and how to move through daily life for others. For Nancy, she was glad of the things that were already at her disposal in the bungalow previously adapted for her ailing parents: no stairs, open-plan spaces, wide hallways, a self-contained annexe, and grab-rails in the bathrooms. This meant that Nancy continued to move through and use much of her home up until she died.

Indeed, larger structural changes take on an imaginative quality, telling stories of a future where an altered lived environment will better facilitate someone's meaningful movement. Yet somehow that person seems to rarely be the one to move through those spaces, once altered. Indeed, it is the layering of smaller changes to the lived environment, through moving things around or into the home, which seems to more readily enable the bodily navigation of the lifeworld.

6.3.2. Moving with and relating to things

Just as lifeworlds are subject to unmaking/remaking, the way people move through them is concomitantly unmade/remade in the recursive interaction of bodies and things. Kenneth with his wife and full-time carer, Frances, layer subtly different and sometimes seemingly small ways of moving bodies and things through the lifeworld. They do this with the explicit aim of achieving a life worth living for Kenneth. "Have we told you the saga of Kenneth's beds?" Frances asks during my second visit (17/08/2018). She begins to describe how Kent had been sleeping badly, and joint pain worsening, which prompted an OT to suggest that it was the bed.

> "So we got a new bed, but he slept on it for two days and everything got worse, and we both ended up in really foul moods, actually. So we decided that that was no good, it really was far too hard, one of those orthopaedic mattresses. […] Anyway, so after I had swapped the beds back and forth, we finally have got a new one – and it's brilliant, it really is, to sleep on. But [sighs, laughs once]. We've noticed that it's that little bit too

> high, so Kenneth can't get in and out of it very well at all, even with my help. So I've now fashioned a little stepladder!" (Fran, 17/08/2018)

This speaks to tinkering, the ongoing work of addressing smaller issues as they arise in a patchwork of care. These fixes are not static, holistic, or singular events but respond more readily to changes as part of ongoing processes of negotiation. This work shows how even smaller or simpler solutions to the way daily living is navigated must be consistently renegotiated through processes of unmaking/remaking, as people strive for a life worth living.

For Kenneth and Fran, their narrative demonstrates the minute toing and froing that must be done, the little adjustments that highlight how dynamic the lifeworld can be, presenting and accommodating new problems and solutions on a daily basis. The way daily living is navigated and made sense of is thoroughly bodily, part of the shifting process of getting comfortable. Fran, for example, responds to how things feel: how hard Kenneth's mattress is and how difficult it is for him to move in and out of bed. The strategic placement and reconstruction of things in the lifeworld is therefore part of an embodied navigation through daily life whilst dying with chronic degenerative illness. Material changes thus emerge as vitally important in this bodily navigation, but must be seen in context of the flow of daily living in local lifeworlds.

Many participants spoke of their resistance, initial or enduring or belated, to assistance in general, including the material relations in which they habitually engage. For Emily, she came to use her mobility scooter after initially not liking the idea very much at all. Emily lives alone, and has a very supportive family. One of Emily's favourite activities is being out and about in the neighbourhood to chat to people as she gardens or looks around the local shops. For longer journeys, such as to speciality wool stores or occasional church services, one of Emily's daughters or grand-daughters will take her. In early 2017, Emily's daughter Beverly tells me that she had driven past her mother's neighbourhood to see Emily struggling to walk back home with a cane and a bag of shopping: "She looked like she was coping, but it did look a struggle, and I don't want mum to struggle." With input from extended family, Beverly decided

that a mobility scooter would help Emily. During my visit, together they explained the story of how the 'buggy' was introduced to Emily, with good humour.

> Emily: "Mothering Sunday, went round to Diane, that's the grand-daughter with the two young girls – and Maisy, she's going to go to the senior school after the summer holidays – and so of course went round there on the Mothering Sunday and all met up and then she came out of the conservatory driving this little thing, and I said 'ooh lovely darling is that to take to the new comp school?' (Beverly laughs) and she said 'No,' she said. 'It's for you Nanny!' And I said, 'Ooh, I don't need that'."
>
> Beverly: "Her reaction was: 'well it's going to be a long time before I ride that up the shops' (laughs) – and I thought 'oh here we go'. And now we can't keep her off of it! […] You drove it home that day, with all the grandkids in tow, and that was that." (Visit II, 26/07/2017)

Beverly initially bought the buggy in response to her mother's feelings of breathlessness and struggle as she made her way through her daily life. The way Beverly introduces the buggy, in amongst a social family occasion, speaks to the sensitivity and understanding Beverly has for what her mother finds particularly important: family and community. The buggy is thus meaningfully and practically embedded in Emily's daily life, together moving from place to place, relating from person to person. The buggy emerges as an important facilitator for socialising, allowing Emily to get out and about. The buggy itself is familiar enough to Emily that she feels able to move with it, saying: "Mind, if I'd never driven a car, I would have been far more wary about driving in it."

Emily's account of the buggy is told through the activities that render her life worth living, and how these are meaningfully unmade/remade partly in relation to the buggy: "It's lovely – and so I'm still in touch with people, that's the main thing." Beverly, however, also speaks about the buggy itself as a piece of technology: "It's a great little thing […] it's a travel one, and pulls apart into five pieces." For Beverly, she is relieved that her mother can "jump on it and go […] under [her] own steam", and that she is not stuck, housebound and alone for long periods of time. Beverly herself lives far enough away that she cannot be with her mother at home or on

excursions quite as much as she would like; the buggy, therefore, eases the burden of the worry and care that she has for her mother.

Some participants describe more enduring resistance to assistance, despite their family's enthusiasm; perception is a key part of relating to things. A particularly poignant example is Philip's stair-lift. Philip lives alone in a small two-storey semi-detached home, returning there after an unhappy, short stint at a care home. Before the arrival of his full-time carer, his daughters insisted that he install a stair-lift, worried that he could not cope entirely on his own as he used to. Philip tells me (Visit II, 19/06/2018), however, about how he often used to crawl up and down the steep, narrow stairs, rather than use the stair-lift. The stair-lift was somehow not palatable to Philip as a way of moving through his lifeworld. In many ways, Philip let me know that his resistance was not about physical effort. This recasts stair-lifts as a mode of moving that involves more sitting and waiting, in a life already so still. As Ingold (2000:227) writes: "Our perception of the environment as a whole, in short, is forged [...] in the passage from place to place, and in histories of movement and changing horizons along the way." For Philip, using the stair-lift therefore might be more fundamentally unmaking of a life worth living, than if he simply minimises the number of times he uses the stairs, bodily crawling. This perception fundamentally shapes the way he relates to new technology in his lifeworld, leading him to reject the stair-lift, highlighting how innovations may not always be welcomed in the way designers intend.

This kind of resistance was similarly the case for Theo. Before he died in December 2017, not long after I met him, Theo had been house-bound for six months due to gout, arthritis, and severe heart failure. He spent most of his time sitting or lying on the living room couch, calling out instructions to his mildly dementing yet physically able wife and carer, Jeanne. Theo had access to a wheelchair. However, once a dancer, after using the wheelchair to move around his house for a short time, he told me that it felt so incongruous to the way he wanted to live his life that he abandoned the wheelchair altogether. Instead, I distinctly remember him telling me

how much petrol he had put in his car before his health had taken such a bad turn that he had become housebound.

This demonstrated to me how active he had been before this period. It seems that the toing and froing which Theo found most meaningful was outside his home. Theo seemed to perceive his house-bound life to be sub-par, seeing little improvement whether he moved in a wheelchair or remained on the sofa. Indeed, the couple had been professional ballroom dancers together, constituting a different kind of movement entirely. He described himself now as feeling "absolutely lifeless" (Visit I, 13/11/2017), suggesting that new technologies would be accepted perhaps only on the proviso that they restored some of the familiar kinds of movement Theo perceived as vital. Theo's experiences speak to me of how moving with things through the lifeworld is not a simple task of use or disuse, adoption or non-adoption of technologies. How one currently moves through their lifeworld is further bound up in lifelong movement. Sometimes, the prospect or act of moving differently, with different things, seems entirely too destructive or does not restore the kind of meaningful movement that is lost.

Indeed, equipped only with past bodily experience, it may be difficult to imagine futures where movement is fundamentally altered, or restricted. Chapter 7 explores when to wrap up one's life narrative, involving no longer looking to the future at all. Returning to Rosemary, she highlights the uncertainty of anticipating how she will react to moving permanently in a wheelchair. Sometimes she tells me: "I shall be dead!" Sometimes, she says: "Perhaps, once I am in it, I shall be glad." This signals her shifting perception of what is and is not an acceptable way to go about moving, making, and living. This also signals her shifting relationship with the materials (past, current, or future) that may both threaten these vital components, as well as facilitate them. This uncertainty highlights the need to balance potential unmaking/remaking aspects, requiring consistent (re)negotiation of how to bodily navigate the lifeworld. This involves making or rejecting smaller or larger adjustments accordingly. Such a patchwork approach is flexible, leaving space for people to change their strategies and decisions as the

perception of their environment shifts with similarly shifting bodily experiences of moving through it and being-in-the-world. In other words, as people move through their lifeworlds in different ways, these experiences inform understandings of what this feels like and means for their (future) daily lives. Although what is acceptable and meaningful to each participant varies, shifting material relations may offer up new possibilities for movement in amongst emerging understandings of what is no longer possible or desirable. A life worth living is thus thoroughly negotiated, reckoned, and realised through the relational movement of bodies with things in the lifeworld. Movement, therefore, is a part of the vitality that motivates people to continue living, rather than tell me that they are 'done'.

6.3.3. Keeping things close, letting things go

Relating to things is not only bound up in movement and perception because they help people physically move and realise different possibilities. Material relations are also bound up in movement because things are created, collected, and made sense of in movement. Things are part of stories, and stories speak of the toing and froing from place to place that people make meaningful. In telling me their stories, the people I spent time with entreated me to move with them to find and explore things. Noémie, in particular, has many exotic stories of her travels all over the world. Inspired by craftsmanship, she has returned home with many things. Demonstrating how these objects are essentially entangled in her lived experience, she continues to make meaning around these experiences through story-telling, which similarly necessitates movement through the lifeworld to go and find these objects in her home. We did this together often. Once found, these objects demonstrate to me something that I could not have understood from her words alone. "This is a jar of sand from Petra, Jordan." She says, speaking of her time in the Middle East and how she had, against the guide's insistence, collected her sample memento in a small jar from their hotel breakfast. The sand sits on the mantelpiece in her living room, where we usually took our tea whilst we chatted.

Transporting me back in time, she gets up to replace the sand and finds a diary of hers from her trip to Kenya in the early 2000s. Recalling China, she rummages in her loft to retrieve for

me a beautiful piece of decorative armour she had bartered for just outside the Forbidden City, the texture and clinking sounds of which evoked the colourful busy tours and markets I had only ever seen in photos. Seeking Egypt, she took me upstairs to the spare bedroom that had been taken over by her art things. Together, we sorted through old projects that had been inspired by all her travels, half-forgotten and half-finished in this room, whilst completed counterparts grace the over-crowded walls of her entire home. Wherever she went, however she moved through her home, it seemed, Noémie has made sure she could take her travels with her, through the many objects she had collected and created as a result of her movement through the world.

Many participants, however, begin to move in less diverse and far-reaching ways. Noémie herself most recently spoke of how she has begun to worry that she will not be able to go on so many trips in the future (Visit VI, 14/12/2018). This is partly due to her own declining health, as well as her husband's, who has MS. Although she has always sought advice from doctors before travelling, Noémie now realises that even walking on flat ground through Paris with her sister is more exhausting than usual. Noémie's worries speak to the shrinking area through which participants move over time. It is not simply that poor health leads to restricted movement. Rather, as this chapter argues, the world is diversely unmade/remade in manners that allow participants to make different ways through it.

Rosemary, for example, has found that splitting her day concretely into 'downstairs time' and 'upstairs' time allows her to accomplish everything she would like in a day, within the constraints of her health. Making sure her excursions and visits are done by 4pm, Rosemary gathers what she needs (diary, crossword, and a sandwich) and settles herself upstairs in bed for the rest of the day. As Rosemary and Noémie illustrate, patterns of movement in, out, and around the home change, sometimes profoundly, over time. With respect to declining health, the lifeworld must be navigated differently. People start paring down and streamlining their movements, retaining the things that are 'worth it', and dropping the things that are not. This

includes materials, and also stories, which are explored in Chapter 7. The nature and impact of what is kept close or let go is most starkly made to me through my observation of participants who were more, or less, mobile. This is in comparison both to each other, and also across their own patterns of fluctuating health.

Emily, for example, had an overall steady improvement in her heath and how she was feeling over the two years I spent time with her. Each time I visited with her, she would tell me how she felt well enough to go outside again and do some gardening; or ride her mobility scooter down to a shop or a friend; and more frequently went by car to neighbouring towns with a family-member when she was feeling up to it. The first time I met her, however, I remember being initially struck by the clutter of her home: I used phrases like "conservatory graveyard of toys and treasures" in my fieldnotes (10/02/2017) to denote the sheer volume of things in her home. However, it was not until she had a poor turn in mid-2018 that I realised how far the materiality of her home had changed. I had written initially of how she had surrounded herself with all the things that were important to her, immediate to her person, even though her house was so small that it would not be difficult to move to get anything one needed. In a vignette from our very first meeting, one I came to know as 'Knitting Love', I described the arrangement of objects that directly surrounded her:

> *Emily sits restfully with back straight against the armchair,* her *chair, I surmise, given its proximity to a mobile heater and some knitting needles. The needles are casually impaling balls of wool in a manner which suggests that knitting is a constant, somewhat unconscious habit. "Oh, yes," she confirms offhandedly when I mention the needles and the abundance of knit-wear adorning every available surface of the sitting room. "My children say I've knitted around the world!" She sits quite comfortably amongst a room that is overwhelmingly cluttered with THINGS. Things of all shapes and sizes, brand and provenance, age and air: knitting, trophies, books, photographs, paper, toys, trinkets, talismans. Lavishly cocooning, Emily has surrounded herself most intriguingly with everything that is meaningful to her: family things.* (Excerpt from field-diary, 10/02/2017)

At the time, I did not note the gradual de-cluttering of the space around Emily's living room chair. Instead, it was during a visit with Emily during a period of feeling unwell, that I became sensitised to how much more cluttered the space had suddenly become since my previous visit.

Her younger daughter, Diane, was staying at the time. That characteristic magnet-like clustering of materials around Emily in her chair was more evident. I did not stand with her in the kitchen to make tea, or kneel with her to look at a great-grandchild's drawing, but sat with her in her living room in a rather more siloed fashion. Diane had brought her portable spinning wheel with her, and the soft whirring of the pedal and the hoop provides gentle homely sounds in the background and the audio recording. Making us tea, Diane brings the mug and a box of tissues to put on the windowsill next to Emily's chair, saying: "I'll put those tissues there, mum, so you don't have to get up." (Visit IV, 04/07/2018)

This particularly struck me because in this action I can see the sensitive caring practices that contribute to the clustering of things around someone who is not physically moving through the world very much. However, I was reminded of this instance when Emily much later said to me: "The less you do, the less you want to do, and you can get quite stuck." (Visit VI, 21/02/2019) I do not mean to suggest that families' caring encouragements to safely stay put directly lead to the shrinking of people's lived, mobile, habitual spaces. Yet there is a sense that the process of preparing to settle in a particular place – more or less permanently – has important implications for what you bring with you, and what you let go. Spending time with people gave me the sense that this is not only about things that are simply used a lot, or placed there by others. Rather, these are things that have become bound up in the renegotiated ways that people choose to move through their lifeworlds, and thus support a life worth living.

Philip, who lives alone and recently with his full-time carer Lucy, offers a good example. Upon first meeting Philip, I immediately noticed the characteristic clustering of things around him; things that do not necessarily fit or belong together in any kind of linear narrative, and perhaps transgress the original or strictly intended use of the room. The story of these objects, and how they came to settle around Philip, meaningful and practical, lies instead in the story of his life, past and present. Of more or less note, there is a large-buttoned telephone, an empty mug, a

box of tissues, scrap paper and pencils, a book with a broken spine, half-read and facedown as if frozen in mid-flow, and Scrabble, amongst many other things.

Philip does not get out much any more independently, and told me on my last visit (18/11/2018) that he doubted he ever would again. As health changes and circumstances enforce the slowing of living, in particular Philip has let go of his desire to drive his classic car. He tells me he once prided his car, but he seems now to be letting go his desire to do many of the things outside his home that would require using it. He has therefore remade his world around where he has to be, in the chair in his living room. He continues to play Scrabble, something he has enjoyed with his family and friends over a lifetime. He plays with his carer, Lucy, every day; when he visits his daughters, he plays with them; when I visit, he plays with me – and Philip wins most times, he and Lucy assure me. The things that Philip chooses to bring with him, and settle around him, are predominantly not the kinds of technological 'innovations' that are hoped to redesign the future of healthcare. Rather, these things are the mundane objects that may have been a part of his life for many years, recalling the happy memories and rhythms of lifelong habits. In far smaller ways, Philip continues to move through the lifeworld in manners that unmake/remake the priorities and circumstances of his life, as he navigates and negotiates a life worth living, even whilst spending most of his time sitting in a single chair. This transitioning into stillness is further explored in Chapter 7.

6.4. DISCUSSION: Negotiating With and Through the Body

This chapter foregrounds how participants relate to and move with things through dynamic lifeworlds. The data I draw on illustrate how the people I spent time with (1) altered the structural nature of their homes, (2) navigated different routes through their homes, and (3) moved with different materials, bringing some with and leaving some behind in characteristic patterns towards the end of life. These aspects are intertwined in daily living. A central premise of this thesis is that unmaking/remaking is a form of bodily negotiation, where people negotiate a life worth living with and through their bodies. I take the notion of negotiate to

include both compromise and navigation. The negotiation focussed on in this chapter emphasises the visceral, observable aspects of unmaking/remaking as people navigate and accept shifting perspectives, challenges, and opportunities through their changing bodies and lifeworlds.

Taking Ingold's notion that in moving we make, and in making we live, navigation not only means moving through daily life, but feeling one's way through shifting lifeworlds in ways that mutually shape and are shaped by these lived environments. Bodily engagement and relations with material surroundings are necessarily entailed in the project of living. Ingold suggests that far from constructing environments and then inhabiting these static spaces, people are 'dwelling' in their lifeworlds. Dwelling, in Ingold's terms, is about making worlds. This kind of making, however, "is not a construction, governed by cognitive mechanisms of one sort or another, but an improvisatory movement – of 'going along' or wayfaring – that is open-ended and knows no final destination." (Ingold, 2010:S122) In emphasising the ambiguous and unfinished nature of living, these lifeworlds are therefore always coming-into-being through processes of unmaking/remaking as people move through them.

This notion of context is therefore vastly important to an understanding of how things work, move, and are made. These things, such as technologies, are not static objects in static lifeworlds. They are rather part of being-in-the-world, and therefore part of the ongoing processes of unmaking/remaking through not simply cognitive but sensuous bodily engagement. For Rosemary and Kent, for example, moving through the kitchen with changing bodies and various materials not only informed them of the inadequacies of the space itself, but what could be moved around to create new possibilities for movement. Even without structural changes, rooms in the home can be altered by (re)arranging things in ways that both reflect and shape someone's movement, and their stillness. Considering the varying ways people move with things thus highlights the dynamism and flexibility of lived environments.

Further, how these embodied relations with materiality also contribute to how people can reposition themselves to maintain standards of living.

Oudshoorn (2012:122), in STS perspective, states that contexts such as the home cannot be seen as a blank slate into which technologies can be simply plugged. She emphasises the importance of conceptualising place, rather than space, as that which is "not just physical but also involve[s] situated human intention with them." (Andrews, 2003, seen in Oudshoorn 2012:123) Making, moving, and living therefore does not happen arbitrarily in decontextualised space. Rather, a life worth living is realised in the intertwining of meaningful and practical toing and froing between places: grocery to sewing shops, church to family home; garden to kitchen. The importance of place-making is emphasised through Ingold's (2011:146) distinction between the "groundedness of place" and the "abstract sense of space." This distinction critiques 'space' as a way of describing the world that is "the most abstract, […] empty, [… and] detached from the realities of life and experience." Lived experience and bodily movement furnish space with a sense of familiarity and history, as people make their way through their lifeworlds, rendering place a "product of the body." (Casey, 1996; Ingold & Vergunst, 2014; Irving, 2007:206) Places, then, are unmade and remade through the social, material, and bodily relations which transform them on a daily basis. Places therefore mean something, in the way they are used, the memories that are made there, as well as the people and things that come and go through them with purpose.

However, given this co-constitutive and co-productive nature of bodies, things, and environments, in illness much might be thrown into unfamiliarity. Irving (2007:185) explores how those living with HIV/AIDS experience illness through an artistic project that maps their home city "through its emotions and memories rather than buildings and streets." Irving thus explores the experience of what he terms being-in-place, which may be disrupted in illness. As Philip shows in the case of his stair-lift, Theo's and Rosemary's wheelchair, people may no longer be able to move through their environments in the same way, and may therefore

experience these environments differently and perceive these experiences as unfamiliar. In a related way, Rosemary prefers to use her own buggy rather than the supermarket's one, as she has learned how her own buggy feels and how to manoeuvre it. As Irving (2007:206) similarly suggests, the body and one's lifeworld in illness may become "strange and alienated, requiring it to be re-inhabited and made familiar" again. Participants engage in ongoing place-making as part of unmaking/remaking a life worth living; navigating and accepting their changing bodies, lifeworlds, and priorities. Here, this engagement is partly through changing structural aspects, moving things around, and preserving what is most important whilst letting go what is deemed less important.

Entire rooms may be repurposed as essential items collect around individuals, not ending up there by accident but rather by intent, like Oudshoorn suggests. When living is being slowed, and places that people occupy shrink, people may strive to unmake/remake these places, perhaps populating them with what is meaningful and practical, tinkering to maintain a life worth living. Just as people do not simply construct environments that then house them in an unchanging manner throughout their lives, however, objects are similarly in flux. Objects are both agents of and subject to such changes, and in this way inform meaning-and place-making as things are brought with or left behind in people's movements through the lifeworld. Rosemary, for example, has let go of doing activities in the latter part of her day, instead bringing the essentials upstairs with her (telephone and dates diary) so she can lie down, resting, whilst still engaging in the meaningful social aspects of her life. Further, whilst Philip has relinquished much of what made his life worth living, settling into stillness for most of his time, he physically brought Scrabble with him to where he is settling as a meaningful component of lifelong enjoyment and comfort.

Making worlds is indeed a thoroughly material and bodily negotiation: participants and carers respond to how the world is felt, focussing on comfort and struggle in place, as well as in the pathways to and from place to place. This is illustrated particularly by Kenneth's saga of the

bed, or Rosemary's continuous stream of solutions to getting herself out the door on time each morning. Recalling Ingold's (2000:188) understanding of making, he highlights that the 'final form' of an object "is but a fleeting moment in the life of any feature, when it is matched to a human purpose, likewise cut out from the flow of intentional activity." As bodies and lifeworlds are continuously fluctuating, solving arising issues is not a singular event. Solutions, instead, must be layered again and again. As in the logic of tinkering, this means trying again until something works for you, and starting over when it no longer does any more, working things out as you go along. Ends and goals are thus recast as points on a journey. Objects, of many different kinds, including technologies, therefore cannot be understood as containing singular, static functions for people who are engaged in the bodily project of living, making, and moving. For people dealing with degenerative, chronic, terminal illness, this means that they are dealing with how their lives, bodies, environments, and priorities change.

Assistive technologies are often not designed with such specificities or co-operative needs in mind, and neither are they very often co-designed with users (Wherton et al., 2015). Indeed, Woolgar (1990) emphasises how technologies "configure the user", i.e. contain inscribed assumptions about who will use them, for what, and in what ways, which may be inappropriate. Technology designers, on the other hand, do not seem to have had Rosemary in mind when producing a particular technological solution, with her multiple co-morbidities and particular activities and needs that shape the specific way she engages and experiences certain technologies. Such technologies may therefore have perhaps a disembodied quality. This echoes Ingold's critique of 'materiality', used often as too vague a term that obscures many of the most important, sensuous qualities of materials themselves. He dedicates space instead to describing how these objects feel to the touch, how heavy they are, what they bring to mind, how they might be made, used, and transformed in practice.

Acknowledging the sensuous qualities of and embodied engagement with materiality is essential to understanding the way that problems and possibilities arise and are partially

solved in the lifeworld. Such as how Kent and Carolyn unmade Kent's bedroom upstairs and remade it downstairs. Or how Fran continually reworks her solutions to deal with the ongoing saga of Kenneth's uncomfortable bed, which ends up too high for him to easily get in and out of, something which is still important as he prefers spending his time in an adapted chair in the sun-drenched living room downstairs. As Greenhalgh et al. (2013:86) find, people engage in novel and innovative ways in *bricolage,* i.e. "pragmatic customisation." This involves the layering of multiple technologies in order to produce a customised and customisable solution to a local problem. Here, people and their carers co-produce a life worth living on a day-to-day basis (Procter et al., 2014). This echoes Mol's (2006) logic of care, how tinkering as attentive experimentation is a core part of repeatedly addressing issues in different ways. Tinkering gives space to the smaller or larger failures and successes that are continually renegotiated until some discomfort or suffering is alleviated. This kind of care "seeks to lighten what is heavy, and even if it fails it keeps on trying." (Mol et al., 2010:14)

Highlighting the practicalities, material and embodied aspects of caring (with technologies) in this way further dissolves the dichotomy between "warm care" and "cold technology" (Pols, 2012:23-25): the sensuous qualities of materials themselves and relations with these things are inextricably part of living, and part of caring. The warm care/cold technology dichotomy frames care as 'goodness', a nourishing gift, whilst technology is instrumental and interventionist (Mol et al., 2010:14; Pols, 2012:25). However, as demonstrated, there is necessary hybridity and complex interplay of technology and other kinds of care that come together to mutually shape local practices, so that they 'fit' the particular patient and situation (Pols, 2012). Technologies therefore rely on becoming incorporated into local caring practices to work, through the tinkering and adapting that is undertaken by real people (Mol et al., 2010:15). Embedded in these lived environments, technologies therefore not only mediate and transform contexts, but are also transformed themselves (Dant, 2005; Lock, 1993; Oudshoorn, 2011; Webster, 2002:447).

An essential part of this bodily negotiation are the concomitant perceptual shifts that transform how people relate to technologies or other kinds of (material) change; things that are met with initial rejection and perhaps eventual acceptance. In the cases of Emily's buggy, Philip's stair-lift, as well as Rosemary's and Theo's wheelchairs, they all initially perceived these technologies as unnecessary to the way they wanted to live their lives, and move through their lifeworlds. Whilst family members and healthcare practitioners were usually the champions of these changes, suggesting higher levels of safety whilst being mobile, not every technology was connected to the meaningful aspects of someone's life that would be augmented once adopted. Gawande (2014:157) points out, however, that living well is not just about safety, it is "about the reasons one wishes to be alive." He (2014:70) particularly highlights the different priorities people have, emphasising how "safety is what we want for those we love, and autonomy is what we want for ourselves." For many of the people with whom I spent time, the technologies introduced by their families fundamentally change the nature of their movement from place to place, and using them is therefore unmaking/remaking in myriad and uncertain ways. Negotiation is not only about having the adaptations, but accepting that they are needed, and incorporating them into one's changing sense of self and how it is acceptable to live.

Technologies therefore mediate between changing needs and shifting lifeworlds. Yet, technologies are not simply subject to adoption or non-adoption. Rather, they are incorporated into daily living in different ways, perhaps through bricolage or tinkering (Greenhalgh et al., 2013; Mol et al., 2010). They are sometimes layered together, innovatively used, and initially rejected, having not yet become part of processes of unmaking/remaking where they are made to fit with the fluctuating health, lifeworlds, and priorities of specific individuals. For those who use them, these technologies are rarely the centre of story-telling, but nonetheless become part of people's stories. Thus retaining a sense of familiarity, technological solutions and other kinds of material changes may be perceived as more acceptable when offering different possibilities. Yet, Philip and Theo both demonstrate how sometimes the prospect of using an

assistive technology is overtaken by the unmaking potential of moving with things that fundamentally alter the experience, meaning, and nature of that movement.

There are calls for technologies that are flexible and customisable to better accommodate the different needs of different users (e.g. Procter et al., 2014). However, far from modernist technophilic visions of plug-and-play, technological solutions are as much about the specific characteristics of the things itself as being subject to the changing perceptions of those who engage with them. Further, they must take heed of the dynamic, social, and co-constitutive nature of home environments that are consistently reinvented in smaller or larger ways as people move through them. Tinkering allows for relatively smaller changes to be incrementally fit into the lifeworld, experienced, and accepted – whilst larger structural changes, like Rosemary and Kent's kitchens, were abandoned by those for whom they were meant. However, those who tell stories of structural adaptations that they made in order to care for their parents, like Nancy's house and Kent's annexe, readily use these themselves even if they were too late for their parents. Already in place, these changes are already familiar and shape people's pathways through their homes, requiring less unmaking/remaking in the first instance.

Moving with people myself became critical to my understanding of their daily lives. In classical philosophy, movement is considered part of what constitutes vitality (Canguilhem, 2008). Vital movement is what sustains life, it is what signals that life is ongoing and happening. A sense of place contextualises vital movement, embedding the abstract concept in lived bodily experience of moving with and between different places, people, and things. Bringing vitality to an understanding unmaking/remaking underlines the powerful, crucial nature of what is at stake. Ingold and Vergunst (2014:3) write about walking with people as a mode of ethnographic enquiry, lamenting how much of ethnographic research is such that journeys get lost amongst a focus on destinations. In moving with people, I also became sensitised to the pathways that people navigate through their lifeworlds. For example, in the opening vignette

of going to the shops with Rosemary, I had not gleaned from her words the texture of the asphalt, the roughness and unevenness of the surface along which she travelled. I had not gathered how it felt to bump along, so much that her voice as she continued to chat to me vibrated with each small hurdle. In short, I had not understood that pathways must be negotiated, and that the easiest-looking direct route was not always an option. For her – and multiple others in this research - going about daily life, instead, seemed to be an experience of circumnavigation, of roundabout routes and circles.

For participants here, with their changing bodies and unpredictable prognoses, it makes most sense to focus on their processual and dynamic journeys between places, i.e. how they make their way. I felt that these experiences highlighted what is vitally important to each person, and the shifting day-to-day realities of how they strive to achieve these things. I thus gleaned a better understanding of what is at stake for them, over time, as well as for different family members (Mattingly, 2010). Rosemary, for example, sometimes spoke of solutions that her children suggest. She found online grocery shopping particularly unpalatable: "What then? My life won't be worth living if I can't go out every morning, to get exactly what I want, and see everyone!" (Rosemary, Visit II, 01/11/2017) This is what is at stake: vital movement that is meaningful and practical, borne out through the toing and froing from place to place that continually remakes those places, as well as one's situated relations (e.g. material, intersubjective) both with and in these contexts. This movement is negotiated, again and again, through processes of unmaking/remaking. What happens, however, when movement stills?

These considerations of situated, bodily material relations problematise and challenge underpinning determinist understandings of technologies. I also further work to collapse boundaries that are nevertheless conceptualised between technologies, users, and their lived contexts. This is done through building on current literature, incorporating foci on process, place, sensuous bodily engagement, and drawing inspiration from Ingold's insights into dwelling and making. People can thus be seen as engaged in the ongoing project of unmaking

and remaking their way through a lifeworld that is itself in flux, relating to a plethora of equally dynamic things. After such a dedicated focus on movement, however, the next chapter considers how moving with things settles, in the lifeworld, into stillness. I further explore how narratives trace this slowing and stilling, where imagining futures filled with movement gives way to a focus on the present, and the past. Eventually, telling stories almost exclusively about past experiences, remembering a life well-lived, moves one further and further away from making – unmaking or remaking – until people may turn away from making entirely. In the vein of comings and goings towards the end of life, Ingold writes:

> […] the stride is gradually shortened to a shuffle, and as the body loses its forward momentum, there is no longer any certainty of follow-through from one step to the next. Each becomes a separate movement. [….] coming home presages the decline of walking late in life […] With every step becoming more tentative, auxiliary means have to be improvised for getting around […] Time slows, and attention lowers from the horizon to the ever nearer to hand. (Ingold, 2014:16)

CHAPTER SEVEN

Looking back and settling into stillness

She was sitting there, a lone figure silhouetted in soft light, striking me as so small, and somehow almost ethereal. 87 years old, white hair, smooth sagging cheeks, and bright eyes. Huddled in a patchwork quilt, wrapped in layers of nightdress and dressing-gown, a box of tissues next to her on the arm of her sofa, packets and packets of pills scattered across the unoccupied cushion adjacent. "We used to go for an adventure every Sunday," she said. "We never used to plan anything – once, we even ended up all the way down on the Isle of Wight…" There was something other-worldly about the light of her conservatory-living room that shone so brightly in her hair; the warm sunshine on the cold day that separated us from the outside; the wind we could neither hear nor feel that took the trees gently by their branching shoulders, and shook them as if to wake them from a dream; the movement of birds in the garden that continued about their daily business, oblivious to the silent struggle inside her living room. Time seemed somehow viscous, when we were in that room with her. And something about it – the cocooning quiet, the seeping peace, the still absurdity – just made me want to cry. (Excerpt from field-diary, 04/02/2018)

7.1. INTRODUCTION

This chapter is about stories, stillness, and making decisions when life is no longer worth living. Here, I explore how movement follows narrative. Towards an ending, movement may give way to stillness. And making may give way to remembering a life lived, wrapping up stories rather than imagining and telling new ones. Making decisions, clinical or otherwise, requires such imaginative engagement. The excerpt above illustrates how I first took note of stillness and stories during my fieldwork. I was struck by these changes in movement through lived space whilst I was shadowing Heart Failure Specialist Nurses (HFSNs) during their home visits, in the exploratory phase of this study. Over the visits, which numbered 40 in total, I saw strikingly similar suspended tableaux, assemblages of bodies and things that had come to settle into stillness. The dynamic negotiation and sensuous engagement with the present and preoccupation with the future, discussed in the previous chapter, was no longer so evidenced.

It was the sheer visual impact of stillness – a sense that drags you to a halt with it – that prompted me to think about the nature of stillness as a manner of being-in-the-world where

making is no longer the core activity. Instead of striving to continue to do things, unmaking/remaking around stillness and other unpredictable changes, some participants stopped telling me about what they were doing or planning altogether. I wrote the above vignette in my field diary, entitling it 'reflections on a woman in the sun'. It is meant as a sensitising, poetic piece, highlighting my attempts to capture stillness. It seems to me that stillness may be far less easily apprehended than movement, action, or speech.

So often did I encounter these suspended tableaux that words began to fail me in my fieldnotes. Instead, I began to draw representations of the people I saw, with concentric circles radiating around them. I was trying to capture the strewn-out story that emerged in the embrace of these circles. The story of things left behind, left in between the lines, telling me of the toing and froing of past endeavours that was embedded therein. Pill boxes, tissues, empty plates, books, cards, pens, glasses, biscuits, telephones, diaries. These things seemed more adrift to me than those described in the previous chapter. They seemed no longer anchored by the intention of doing, or planning to do. It was difficult to keep track of the different people we saw, those sitting or lying in an adapted bedroom or lounge. They were surrounded by the paraphernalia of endings and existing that seemed to me to be no longer bound up in stories any more; or at least not stories that people found important to tell me. Instead, they told me stories from many years ago.

As I spent time with participants, I began to see the stillness, identifying characteristic patterns, of being done with living. I also began to understand the difficulty of settling into stillness. Specifically, healthcare practitioners or family members might call upon someone to make a decision: about treatment, about their future, about what to strive for now. Perhaps they are presented with the possible installation or deactivation of an Implantable Cardioverter Defibrillator (ICD), funeral arrangements, or a Do Not Resuscitate (DNR) order. Such decisions strike me as requiring unmaking/remaking, to imagine and take up present and future possibilities, as seen in previous chapters. Stillness here, however, seems to signal the shift

away from making entirely, and might therefore be less accommodating of making decisions. Settling into stillness is nevertheless equally a process of slowing: participants' health continues to fluctuate, and they may change their minds about things. Whilst the process of slowing and settling into stillness has core bodily and emotional components, this process is not simply about the stilling of movement, but also certain kinds of stories and meaning-making.

This chapter is structured as follows. First, I present a brief literature summary that contextualises and links the threads described above. Findings similarly reflect these themes, and therefore consist of considerations that are broader than stillness itself. The three sections explore how participants: (1) tell more stories of the past than present or future; (2) negotiate end of life decisions; and (3) encounter the difficulties of settling into stillness. Finally, the discussion considers these findings in context of barriers and facilitators of end of life decision-making; how such clinical encounters open up decisions about what Kaufman terms 'time left' and the value of life itself; and Mattingly's narrative phenomenology of practice, which weaves stories into bodily doings, and bodily doings into stories. I thus explore the nature and impact of stillness towards end of life.

7.2. LITERATURE SUMMARY

This chapter reflects on how the process of settling into stillness is part of distancing oneself from making, and how this changes storytelling and being-in the-world in ways that may impact decision-making. These decisions may be clinical in nature, the barriers to and need for which is discussed in Chapter 2. Briefly, as heart failure is treated as a chronic rather than a terminal condition, clinical end of life decision-making is made more difficult (Kaufman et al., 2011; Klindtworth et al., 2015; Steinhauser et al., 2011). This can contribute to a lack of patient understanding of diagnosis and prognosis, potentially unnecessary treatment, lack of planning for end of life care and events, and patient values being overlooked (Glogowska et al., 2016; Jones et al., 2017; McNamara, 2001; Östman et al., 2015). Healthcare practitioners cite a

number of difficulties to undertaking shared decision-making, including training and personal feelings, lack of palliative care resources for heart failure patients, balancing hope for recovery and fear of death, and patients changing their minds about treatment preferences (Clark et al., 2012; Hjelmfors et al., 2014; Hopp et al., 2010).

End of life decision-making is therefore complex and uncertain. Writing of those dying with chronic conditions, Kaufman (2010) suggests that making decisions about possible interventions and their outcomes opens up the category of time left. This future time is framed as partly under present control and action. Patients must decide the value of time left, and thus whether to pursue further potentially life-extending treatment and continue living. This is an imaginative endeavour: patients must engage in "imagining certain kinds of futures in which one's corporeality is central," in order to choose "among medical options in order to move toward one kind of future instead of others." (Kaufman, 2010:4)

As part of imagining these futures, people tell stories, as seen in the previous chapter. As Mattingly's (1994, 1998) narrative phenomenology of practice highlights, stories are not only verbally told but also enacted through the body. Narrative is therefore a practical accomplishment, similarly a form of imaginative engagement in which one's "corporeality is central," as Kaufman suggests. Mattingly describes the healing process for those who have suffered from catastrophic, life-changing injuries and illness. This process necessarily involves bodily action that sediments new ways of moving and living as part of lifelong tasks and narratives, such as relearning how to brush one's hair or walking. Mattingly suggests that these stories are thus emplotted into the overarching plot and narrative of someone's life, constituting a sense- and meaning-making, practical activity.

As goals and potential futures are brought under present action, narratives are "marked by change." (Mattingly, 1994:819) In other words, what motivates people and pushes plots forward is the movement of one state of affairs into a transformed state, from a beginning to an ending (Mattingly, 1994:818-20). Mattingly highlights how narratives of daily living are

therefore 'dramatic': they may "involve multiple characters, risks, suspense, and above all, a heightened sense that something is at stake." (Mattingly & Lawlor, 2004:30) As Irving (2017:3) states, writing of those who confront the world after being diagnosed with terminal illness: "The events that comprise our lives are continually being relieved, reimagined, and retold so as to interpret and reshape experience or inform future action." Narratives, therefore, are intertwined with everyday lived bodily practice and experience. They are about actively doing something, and what happens as a result. However, during bodily inaction, such events may no longer happening. In stillness, these are not being incorporated into the ongoing plot and goals of someone's life. Having linked stillness and storytelling, I now turn to the findings of my ethnographic work to explore this further.

7.3. FINDINGS

7.3.1. "I think I'm done."

> *Philip and I are preparing to have a game of Scrabble, and we are waiting for his full-time carer, Lucy, to put the laundry in before we start. Lucy and he have a game every day. This is my last visit with Philip, and I am glad to be invited into such a meaningful, habitual practice. Setting up the Scrabble board, Philip and I chat in our usual way about what he has been up to, and how his two daughters are doing. In particular, his younger daughter and her husband have a house in Spain which they visit whenever they can. I ask if Philip has ever seen it. "No, I can't manage that. Can hardly manage down to the shops, unfortunately. I'm ruled by my bladder, that's one of the main things." After exchanging sparse comments about the difficulty of balancing medications with what he still likes to do, he takes a brief pause, and tells me: "But, as I say, dear, I'm still breathing." Another pause. There is something in the way he nods, in his gaze, that makes me feel compelled to ask the follow-up question I can hear hanging between us: "Are you okay with that? Still breathing?" A final pause. He sighs. "Yeah," he sighs again, seeming to brush his thoughts away before he looks at me, and presses his lips together. "I must say, I've had enough." I nod in response, but say nothing, holding space for him talk. "I'm well-satisfied. When the time comes, I'll be glad to go. Thank you very much, it's been all very nice. I've had a good innings – for the last 80 years anyway," he adds with a smile. "But I shan't be sorry to go."* (Excerpt from field-diary, 28/11/2018)

From Philip's words, from his expression, from his posture in the chair he spends so much time in, I understood that Philip was 'done'. As he said, he has had enough. I have no other way to express the finality with which Philip conveyed that his interest in living – in continuing to move through active daily life – has waned to the point where he feels ready to stop. Philip is

not healing, the aspect on which Mattingly's work focusses. He is slowly fading out. Although Philip only said this to me in so many words in late 2018, I had the feeling that Philip had had enough from much earlier on in knowing him. Upon my second visit with him (19/06/2018), the first entry in my field diary was: "Remembering seems to be his primary activity." There was something about the combination of experiences and attributes that drew me to this conclusion: his stillness; the way he describes relinquishing daily tasks and decisions to his carer Lucy ("I let her do everything for me…") or daughters; and the conversations between us that barely skim the surface of his daily life now. Rather, Philip spends hours talking to me about his wife, who died in 2013, and his life working and raising children with her. To me, this reminiscence spoke to Philip's disengagement with his current daily life. Living for him now is primarily characterised by stillness and – at least when I was around – storytelling about the past.

Whilst Mattingly asserts that the drama of healing is fuelled by desire and risk-taking to achieve future goals, Philip's life seems rather to be the essence of non-drama. Reminiscing and ruminating on the past, whilst settling into a physical stillness, does not qualify. No longer moving, Philip is no longer making, enacting, or emplotting stories into the narrative of his life. Rather than engaging in imagining futures, he looks back to life as lived. I noticed the attendance of these two characteristics, storytelling and stillness, as I got to know other participants, and witnessed the ebb and flow of their feelings of wellness, motivation, and what I came to think of as their sense of vitality. "I spend a lot of time just daydreaming," Ed tells me, 98, who also lost his wife a few years previously (Visit III, 23/10/2018). Spending time with Ed saw us talking predominantly about his life and work as an aeronautical engineer, his interest in cars and firearms and gadgets that he had crafted and owned, and now sold. He spoke passionately, at great length and with great clarity, about the projects, deals, employees and managers he spent his time with; moving up and down the country, and diving into strange and exciting projects.

Now, Ed is struck by the loss of energy, idleness of his existence, and lack of motivating daily movement. Even though he still occasionally drives to take trips, and sometimes walks around the communal gardens near which he lives, there is something more pervasive that tugs at Ed's sense of a life worth living: "I don't always see the point, really, of carrying on […] but there's nothing else to be done." He elaborates, using frank language to describe how his very desire to do things has ebbed away:

> "There are times when you think: is it really worthwhile hanging on? Yes […] we're living far too long, and we're not making any sort of contribution any more. And I think, well, what's the point? You feel so utterly useless. I think this is the reason I feel it's not worth it. And probably the loneliness. Although I've got good neighbours, and I see them fairly regularly […] And the thing that gets me, I suppose, is I've become terribly lazy: I don't *want* to do anything. I've got a watercolour I've started and haven't got around to finishing. I've got a model car to build. I've got paperwork and pictures I haven't sorted out yet. Idleness. I nod off very easily, I get so tired, I don't know why. I wake up and I feel: 'Oh good lord, that's another day that's gone by that I've wasted.' I spend a lot of time just daydreaming. The past, mostly, things I've done or haven't done. When I think of the things I used to do, I wonder how I fitted them all in! I've got to be thankful that I had a good life, and enjoyed my job. […] I've been retired for thirty years now, and I don't know where the time has gone. (Visit III, 23/10/2018).

Speaking of loneliness despite company, stillness despite movement, telling me of the past rather than the present, Ed seems to be feeling his way around being done with living. For both Ed and Philip, even though there are things happening in their daily lives, both having access to cars and visiting family on a semi-regular basis, they prefer to talk to me about the past. This suggests to me that they have shifted their view: rather than looking forward, planning to do things and engaging with present in order to figure out how to get there, they admit that they do not particularly want to do anything. Neither seem to mark the changes that would move them forward, from one state of affairs to the next. They have instead shifted modes as they come to settle into stillness, making meaning through remembering rather than through planning and moving themselves towards motivating future goals. They are neither oriented towards nor anticipating futures in the way Mattingly finds necessary to motivate the action of remaking the world. Indeed, I interpret this as turning away from unmaking/remaking entirely; and by extension, turning away from making, moving, and living.

Jeanne similarly lived alone, spending time at her family's homes and having access to excursions by car when her family took her out, although she told me she could go out on her own any more. When I asked her how she saw herself moving forwards, Jeanne responded: "Well I don't really, to be honest." Before passing away in October 2018 at the age of 96, even during my first visit (05/07/2018), Jeanne bluntly told me, "I think to myself: I don't know if I'm going to put up with another winter." She expressed how she felt about her broadly sedentary existence, telling me that she does not feel any particular motivation to be alive for much longer, adding, "I don't think I should be sat [sic] here all the time, it does no one any good." No longer engaged in making new stories, Jeanne is similarly no longer engaged in making these a meaningful part of her lifelong narrative. The feelings of uselessness that Jeanne and Ed express seem linked to how their current bodily actions are not oriented to getting them to a desirable future. This is further intertwined with a coupled ebbing desire and ability to continue unmaking/remaking at all.

Exploring how she felt about her daily life, Jeanne told me reflectively: "I've had a lot of ups and downs in my life, and I've come out of it now." I wondered, in my fieldnotes, whether this reflects how content she has been with her life, but that she has finished her story now; and, having 'come out of it,' is looking back at the whole and is ready to be done with it. Our conversations mostly involved discussing her diverse life working as a cook, becoming a mother of five, a passionate gardener who grew most of her own food, and how this changed due to her heart failure. In the way Jeanne talks about her life, almost as a completed artefact, it emerges that she did not expect to live this long. She tells me it is a relief to talk about death with someone, so openly.

> "It seems as I've got older, my heart trouble has got worse – he [the doctor] said: 'You've got a partially blocked valve,' and he said, 'That'll do you for another 5 years,' he said. And I said: ''Oh good god, I won't be here then!' (laughs) 92 I would have been then." (Visit I, 05/07/2018)

For Philip, Ed, and Jeanne, they seem to express to me through their words about the past, and the stillness of their bodies and current daily lives, that they are – or are almost – done. These

characteristics seem to intensify for Theo and Nick, who were both predominantly bed-bound by the time I met them. Both died shortly afterwards. Neither spoke of their current situation or daily lives, leaving me to wonder in my fieldnotes (02/03/2018): how far does stillness lead to being done, or being done lead to stillness? As seen above, it seems that there is a pervading sense of not only being unable to do very much, but also not wanting to do very much. Perhaps this echoes the lack of motivating futures for which to aim, but also the reality of having to live within one's means, and finding this lacking.

Reflecting on lives lived seems to me to be a meaningful way to spend and occupy time as one settles into stillness. The less one moves through daily living, to and from meaningful places, people, and things, the less stories are grown or become subsumed into the lifelong narrative of one's living. This was starkly the case for Theo, who died at 86 in December 2017 shortly after my only visit with him and his wife. Theo used blunt language to briefly illustrate the current state of affairs. He swiftly turned the conversation back to his active, sociable past, where he and his wife had been professional dancers. His wife, at the time, was mildly dementing. Theo and I had the following exchange, in response to my asking how he was feeling day-to-day:

> Theo: I feel weak. Absolutely lifeless.
>
> Me: Okay. So you're feeling like you can't do much at the moment?
>
> Theo: I can't do anything. Can't do anything.
>
> Me: What sorts of things would you like to be doing?
>
> Theo: Well, I'd like to be dancing again. You know, like we did.
>
> (Visit I, 13/11/2017)

Theo left me with the distinct impression that the present was not worth dwelling on, or I could even phrase it 'dwelling in'. What happens now, it seems, is less important to emplot into Theo's lifelong narrative: it does not seem to qualify, for him, as meaningful living. "I haven't set foot outside this house in 6 months," he told me, without elaborating much further than to turn his attention back to the life he had lived. Through these brief, blunt interludes in his

stories of the past, Theo demonstrated to me how empty of meaning – empty of vital movement that was essential to making meaning – he seemed to find his current daily existence. Instead, Theo made meaning through reminiscing, and began to encounter his life as no longer worth living.

In expressing nostalgia and fondness for the past, these participants let me know not only how they enjoyed the things they have done and the people they have known, but also how they would like to be (and do) in that part of the life story again. Telling me how he would like to be dancing again, Theo seems not only referring to the activity of dancing, which he found so meaningful. Dancing for him is embedded in the memory and experience of being in the very midst of life, sensuously engaged in living; of having a body, lifeworld, and future trajectory that allowed dancing as it was experienced in his past. Much as Nick similarly says, Theo seems to desire his body and life to be 'put back' to the way it was back then. Whereas in his present, his desire to actively do things was weighed down by the stillness that was pervading his body and life. Turning away from making is similarly turning away from such bodily practices, no longer making sense of one's situation through the 'practical reasoning' that Mattingly describes. When meaning becomes predominantly domiciled in a different body, time, and life, there may come a point when the effort of doing things outweighs the payoff. This may contribute to feeling that things no long worth doing and perhaps, even, life no longer worth living.

I found this to be similarly, if even more blatantly, the case for Nick. Nick, 86, had had a prolonged bout of ill health for over three years since 2014, where he was unable to care for himself. For the final two years, he was predominantly bed-bound in the annexe of his daughter's home. "He had decided enough was enough," his daughter and primary carer, Linda, told me (18/06/2017). Both she and Nick's doctor, Dr Dee, explained how he had emphasised this, over the year before he passed away, by actively expressing a wish to die. "He just said 'if this is my life, I don't want to live it.' " I visited Nick once, going to see him in the nursing home

where he spent the few months of his life before he died in April 2017. I spent two hours listening to wonderful stories about his life as an engineer, across the world. I felt that the only acknowledgement of his current situation, bed-bound in the nursing home with 24-hour personal care, was when he responded to my question about how long he expected to stay in the home. Not without humour, he said to me: "Well, that's the million dollar question, isn't it?" (28/02/2017) At the time, as I had visited him before speaking to his daughter and doctor, I had not quite understood what he had meant. Now, looking back, one possible interpretation could be that he found his life to no longer be worth living, and had been waiting to die.

7.3.2. "Life became more worth living again."

Throughout my time with Emily, she discusses the difficulty of balancing what makes life worth living, with what unmakes it: "You never know the circumstances of what's going to happen." (Emily, Visit II, 26/07/17) She tells me about how she came to sign a Do Not Attempt CPR (DNACPR) order. This was during a visit with her heart doctor, where he suggested the order as a result of their conversation about Emily's quality of life: "He said, 'Do you want to, sort of, make arrangements if anything does happen?' You know, 'Do you want resuscitation, or not?'" Emily explains how she found it a difficult decision, filled with uncertainty about multiple possible futures. She says that she signed the order out of a desire to avoid certain futures, what she described as her wish to not "be left with half a life." She explains that this would be if she were "disabled and not able to do anything." She relates this desire to her mother's end of life, who "stayed sharp as a tac" and died quickly in Emily's care. "That's the way to go," Emily told me on a number of occasions. "Just quietly slip away, that would be just lovely." (Emily, Visit III, 01/06/2018)

Through further conversations between Emily and her daughters, however, I got the impression that Emily's poor health around the time she signed the DNACPR severely impacted her desire to continue living at all. Upon reflection, Emily later told me during a period of relatively good health (15/10/2018): "I really did feel quite rotten, I would wonder each night as I went to bed whether I would wake up in the morning." This intensely corporeal component

suggested that Emily was feeling so sick that it seemed to contribute to weakening her desire to continue living. Emily tells me of how she did very little during that time, and seemed to be settling into stillness, perhaps waiting to die. Yet, a few months after signing the DNACPR order, this all came to a crescendo in a dramatic story which Emily tells:

> "I'd had these *surges* through my body. And I would sort of sit and wait and it would sort of subside and go away, but it wasn't a very nice feeling, it was horrible. But then on this one particular Saturday morning, my grand-daughter was here and as I was talking to her I sort of caught the chair […] and with that, this quite big surge came and then it went away, and again, and again. […] I was in a poor state. My granddaughter said 'ooh nan, nan, you're not well!' So she rang 999 and this lovely, lovely paramedic girl came. But of course, I had signed a paper to say that I never wanted resuscitation. […] She did what she could, and eventually I came to. […] Five days I had in the hospital, then, didn't I? Three days in intensive care and then two days out. […] The doctor came one day, and he just looked at me and he said, 'You've signed a paper,' he said, 'Do you really want that paper?' and I looked at [my pregnant grand-daughter] and I said 'I would like to be allowed to live long enough to see that baby born'. He said 'right' so off he went and he came back and he said, 'I have destroyed the paper' […] He said, 'So now, whatever we can do for you, we will do.' ." (Emily, Visit II, 26/07/17)

In this excerpt, Emily is speaking of a time during April 2016. According to her GP and family, Emily was lucky to have survived the event. Her family had gathered around her in hospital, believing that she was going to die. What I found particularly striking about this story, is how Emily changed her mind about her DNACPR order. In combination with what her GP described as a near-death experience, Emily chooses to cite the future birth of her great-granddaughter as fundamental to making her life worth living again; perhaps suggesting to Emily that there is more of her life story that is yet to unfold.

After her great-granddaughter was born, Emily had an ICD (Implantable Cardioverter Defibrillator) installed. Feeling reinvigorated, she invested in protecting herself from future cardiac events, fighting for more time. She explains that she began feeling like she had more to do, and simultaneously invested in continuing to move her narrative forwards. "If my heart goes all over the place now," Emily tells me, "the defibrillator is supposed to kick in and stop your heart and then restart it again and keep a balance." She smiles and says to me, after a pause: "Sometimes I wonder, do we interfere too much?" Despite feeling more involved and

active in her life, Emily finds the same difficulty present in the ICD as with signing the DNACPR. When, she wonders, is it time for her to decide to turn the ICD off? "It's a job to know," Beverly, her elder daughter, agrees. It seems that the ICD brought about familiar questions and wider decisions about how far Emily found her future motivating, how far she imagined herself living it, and how far she found her life to be worth living then and now. This was first discussed with Emily at a hospital visit with a nurse during an ICD check-up. Beverly accompanied her, and describes what happened:

> "She [the nurse] had a chat the last time, didn't she? And she did say, you know, 'if there comes a time where you are terminally ill or something like that, or you know that you don't want to go on any longer' […] Then they can de-activate [the ICD] or whatever, and so then your heart would then just be normal, and if your heart wanted to slow down and stop, it could. Whereas at the minute there's a range, you know… It's just knowing when, isn't it?" (Beverly, 26/07/17)

This series of events partly traces Emily's negotiation of how to position, and reposition herself towards the end of her life. These decisions – which she must make a number of times over – are informed by a number of factors. Although clinical encounters, as Kaufman's work highlights, indeed do prompt Emily to consider interventions and possible corporeal futures, Emily's daily and past experiences similarly come into play. Emily is thus also informed by and understands her preferences through her own bodily and lifelong experiences. For example, feeling profoundly unwell, or being a part of the births and deaths of others, such as her mother and her great-granddaughter. This combination prompts her to sign a DNACPR to avoid living 'half a life'; but also to later install an ICD to see her great-granddaughter born.

Emily's bodily experience of movement, her feelings of vitality, are therefore linked with her life narrative, and vice versa. These connections influence how and whether Emily continues investing in her narrative in hope, or begins wrapping it up in stillness. "I don't ever want to feel like *that* again," Emily says, referring to her poorest experience of health (described at the beginning of this section). Drawing on past bodily experiences and imagining possible futures that inform her current decisions, Emily engages in narrative sense- and meaning-making. Indeed, she continues to engage in processes of unmaking/remaking. Whilst projecting herself

into the future, she considers how it is acceptable to live, and die. In doing so, she demonstrates how lifelong and bodily experiences fundamentally shape her reckoning of a life worth living, and a life not worth living.

Kent's story of how he changed his mind about his ICD may be interpreted in a similar way. Kent tells me how the combination of his improving health and the birth of his great-granddaughter contributed to improving his outlook on life. He subsequently had the ICD he had previously asked to be turned off, turned back on again.

> "Oh yes, I had my ICD reconnected. The girl who did it – she was nice – she said, 'I've turned a lot off, but you're the first one I've ever turned back on!' That's rather nice. Hasn't made any difference to how I feel, but it's only if the worst were to happen, you start to get some shocks that might just sort me out. […] Feels like a little donkey, kicking you." (Visit IV, 14/11/2018)

I first met Kent in mid-2018, where our first meeting was rescheduled due a minor car accident that Kent had had whilst driving. He stopped driving, after that, and sold the car. From later conversations, especially with Kent's wife, it seems that I arrived just at the tail-end of a bout of poor health, when Kent was progressively feeling that his life was no longer worth living. Amidst this period, Kent had had his ICD turned off. Kent explained:

> "Well, I was just – when I had it turned off, I was feeling a bit depressed, a bit fed up. I was getting fed up with these feet, and all the bits really. And [a healthcare practitioner] said: 'Well, have you thought about your ICD? Because if you are in the terminal stages, you're just on the point of disappearing peacefully (laughs) then you don't really want the donkey.' But then things started to look up. And I decided that, really, life *was* worth living. And so I decided I'd get it turned back on. […] Of course, I'm a great-grandfather, now, you see. We're both great-grandfather and great-grandmother. It was our eldest grandson and his partner, and they have a little girl, who was born in March." (Visit IV, 14/11/2018)

Kent similarly highlights the difficulty of balancing a life worth living with future considerations of a life that may no longer worth living. As a result, he is actively engaging in renegotiating his position through turning off and latterly turning back on his ICD. The ICD therefore becomes a part of unmaking/remaking a life worth living, implicated in both the possibly desirable extension of living, as well as the potentially inappropriate prolongation of

life. Indeed, many participants (including those who were relatively well) spent time considering possible future scenarios, particularly bodily states, in order to renegotiate the parameters that distinguish a life worth living from a life not worth living. "If I go into a wheelchair," Rosemary tells me, for example, "I shall be dead." Noémie tells me, "If I am unable to care for [my husband], we'll be done." Jeanne tells me, "If I'm left half alive and half dead and I'm just lying there, what's the point?"

Deciding between possible treatment options presents a powerful dilemma, seen above, as people position themselves towards the end of life. These kinds of statements express the difficulty of knowing when exactly to say 'enough is enough'. They similarly express the flexibility of experimenting with the conditionality of 'if' statements: people can change their minds. Participants renegotiate, unmake/remake, these parameters at least partly in relation to their own bodily experiences throughout their life narratives. This includes drawing on other people's stories to make sense of their own possible future narratives, and endings. In this positioning and repositioning, filled with the twists and turns of the dramatic, it seems that participants are feeling their way through how and when to settle into stillness, rather than continuing to strive to make decisions, make stories, make life worth living. In other words, they seem to be figuring out how and when to turn away from making, entirely.

Before she died in October 2018 at 98 years old, Jeanne told me (27/09/2018) that she ruminated a lot on those who lived and died around her when she was considering possible treatment options for her heart troubles towards the end of her life. She told me that she somewhat pre-emptively signed a DNACPR when she was first diagnosed with heart failure five years previously, saying: "It's no good leaving it." For her, signing the DNACPR earlier rather than later was essential. She reflected on those she knew who had refused treatment for terminal diagnoses (27/09/2018): "I would be the same, I wouldn't have any treatment if I had anything more wrong now." In definitively choosing to forego life-extending or life-saving treatment, I interpreted Jeanne's choices as part of signalling that she was no longer actively

making and securing an extended future for herself. Indeed, the possible futures that she had imagined and rejected, she had found to not be worth investing in living.

For Jeanne, being left entirely incapable would be unacceptable, "that would be it." She told me multiple stories of friends or family members for whom this had been the case, for years on end. In her words, not being able to do anything – not being able to engage in doing and making – is being 'half and half': "Half alive, and half dead." Poignantly and succinctly, Jeanne said: "You're just lying there, what's the point? It's not living, is it? It's no life." Although she spoke predominantly of those who had abruptly suffered severely impactful strokes and falls, Jeanne seemed to be highlighting the foreshortened future that accompanies this kind of stillness. In asserting that stillness is not strictly about living, Jeanne's words emphasise the absence of activity, engagement, and movement that are vital hallmarks of the project of living.

7.3.3. "We all knew it wasn't good enough."

When I spoke to Linda, Nick's daughter and primary caregiver, we were in her back garden after Nick had died. The annexe behind us was where Nick had lived only a few months previously, and I was visiting with her on a day that neither of us had originally realised was Father's Day. I sat with Linda in the sunshine as she cried.

> "I think he'd given up in early 2016, because he did so little. That's when he stopped eating so much, that's when he stopped drinking so much, he just...he was existing and he said, he said himself, that a lot of what he wanted to live for wasn't there. He couldn't drive, he couldn't do things for himself, he couldn't get up, he couldn't be focussed for long periods. He said to Dr Dee and he said to me: 'If you could turn the clock back five years…' And I said, 'what about three, what about two?' And he said, 'No.' And I know that the last one, one and a half years had been…not great." (Linda, Visit III, 18/06/2017)

Here in the final section of the findings, I wish to return to Nick and elaborate on his journey towards the end of his life. I mean this to be a final in-depth example of the provisioning that must be in place and continually negotiated in order for someone to be done with living. For them to no longer engage in decision-making about the future, to turn away from making altogether, and wrap up one's narrative whilst settling into stillness. Nick said to me once: "It's

bloody boring waiting to die." However, both Linda and Nick's doctor, Dr Dee, illustrated to me the struggle it was to negotiate Nick's end of life in practice. They both emphasised the difficulty of supporting him the best they could whilst understanding that his situation was not 'good enough': "It was the best we could do." (Linda, Visit III, 18/06/2017)

Nick lived in the annexe to Linda's house since his retirement, and when his health began to quickly deteriorate in 2014, Linda began caring for him. Linda tells me that she knew the circumstances of her father's life were inadequate: "He just hated it. And it was horrible, I know he hated it, I hated it." Nick, who she tells me stopped asking for her help when he fell or messed himself, told her one day: "I can't do this any more, bring me a plastic bag." Shocked though she was, and even though understanding that Nick was done with living, Linda had to work around her own circumstances, and was broadly unable to change anything. She worked a full-time job she was unable to leave for financial reasons, and Linda found the medical system to be set up primarily to support her in caring for him, rather than letting him die. Managing her competing responsibilities as best she could, when Linda could no longer cope at home any more, she checked him into the nursing home where I met him.

According to Linda and Dr Dee, Nick kept getting ill. It took her months to realise, Linda said, that similar medical issues kept recurring. With careful research and questioning multiple health professionals, Linda came to understand that the seesaw of poor to poorer health that Nick was experiencing was essentially the same things going wrong each time. The same things were failing, and being patched up, only to recur again a few weeks later. "He had decided enough was enough," she said. "So I stood by him and I said 'fine'. So I wrote to the GP and said: 'Dad's saying he doesn't want to do this any more'. You know, 'it's too difficult.' " With Nick's GP, Dr Dee, Linda sought a better understanding of how Nick's end of life would play out. "Dr Dee agreed," she tells me, "that enough was enough."

> "I said to him [my father]: 'You know, you've wanted to give up for a long time, this is now your time to say 'no more and no medicines.' […] We could stop all the medication and offer him what he really solely needed and just let nature take its course, and that's

> what he decided […] It was just a question of time, but the twisted intestine came back, and the nursing staff had wanted to take him in again [to hospital], um. And he had said 'no', and they phoned me and they said, you know, 'it's come back again, we feel we need to…' and I said 'we need to respect his wishes.' So I phoned 111 and I spoke to a really nice person and she said, 'I need to take your number, I'm going to get somebody to get back to you.' And a really nice lady, I can't remember her name, but she phoned me back about 20 minutes later and we were on the phone for ages and she was brilliant and she said to me that if the nursing staff were to need to ring anybody, they had to ring 111 and ask for their um...god, um…their palliative team. It wasn't an ambulance, she said if an ambulance comes, they will take him into hospital. […] But she said [if they call the 111 palliative team] 'we'll send someone out and we'll nurse him and do what he needs.' But she said if you call 999, they will send an ambulance and he'll go to hospital. […] We talked for a while and she talked it all through, you know, she'd never met my dad, she didn't know anything, she was probably able to see a bit about him on the screen and I'd given her a bit of a picture but she was just really lovely. She said it straight-ly and nicely." (Linda, Visit III, 18/06/2017)

Linda's discussion of her experiences of her father's end of life, illustrated by the excerpt above, emphasises how the process of dying is not only a bodily experience of an individual, but also a practical matter that must be negotiated by those around them. Even whilst someone is fading, having already decided that their life is no longer worth living, there is much that requires (rapid) organisation around them. When they are no longer making and negotiating and positioning themselves, this unmaking/remaking may fall to others, who do the best they can. However, talking with Linda particularly highlighted for me how this inherent difficulty was ongoing right up until Nick's death. Discussions of how and whether to go down different pathways towards different futures were still happening until the end of Nick's narrative.

It seems, in part, that participants were less able to settle into stillness when clinical support is invoked towards end of life. They are moved around, possibly to hospitals, when in crisis (e.g. Emily, Nick, Rosemary, Kenneth). They are asked to consider future preferences such as DNACPRs (e.g. Emily, Rosemary, Kent, Jeanne). They are sent healthcare practitioners who enquire about (and help with) funeral arrangements (e.g. Rosemary, Philip, Jeanne). I do not wish to pass a value or moral judgement on these proceedings. I only wish to point out how potentially interruptive these may be. Further to this, highlight the amount of material *stuff* that must be in place for someone to be done. In other words, end of life comprises many

practical undertakings, involving family and carers and multiple kinds of other healthcare practitioners, networks, and systems. In many ways, the unmaking/remaking that these activities imagine and aim for are future- and possibilities-oriented. There seems to be an underpinning forward-motion to these considerations: to keep on keeping on, to continue moving the story onwards. Sometimes, however, it seems that this is not what the people at the centre of these stories are trying to do.

7.4. DISCUSSION: Away from Making

This chapter explores the links between stillness, storytelling, and decision-making (including changing one's mind). Settling into stillness emerges as a process that centres around turning away from unmaking/remaking. The data presented above illustrate how stillness is a state where participants no longer (wish and/or are able to) engage in imagining, experimenting, tinkering, and repositioning. Stillness may therefore be considered an important indication of someone being done with living. Those who are still rather engage in remembering a life lived, reminiscing, and retrospective storytelling. They are no longer investing in future-planning, and moving their life narratives forward. They are instead wrapping their narratives up, and in so doing are finding an ending which they deem acceptable. Nevertheless, clinical decision-making, as well as other practicalities of caring at and dealing with end of life, require some movement and imaginative engagement. In considering movement and stillness in the unmaking/remaking of a life worth living, end of life becomes not so much about death as also about being done with living. This discussion thus further considers how the nature of movement, stillness, storytelling, and unmaking/remaking towards end of life might contribute to shaping clinical practice.

Lived bodily experience is intertwined with life narratives. In moving, making, and experiencing feelings of vitality, participants are actively engaged in unmaking/remaking their present and future living. Drawing on Mattingly, as above, this movement pushes narratives forward, marked by change that is made meaningful and motivating. Whether continuing to

make in hope or settling into stillness in being done with living, as seen in the previous chapter past and present bodily experiences inform participants as to which futures they wish to strive for – or whether they feel they need to stop striving altogether. Feelings of vitality in movement might motivate participants to continue imagining and creating stories, plans, and futures. Further to this, however, feelings of having had enough, the effort of struggling to move to achieve less and less meaningful outcomes, might rather suggest to participants settling into stillness and beginning to wrap up their stories.

Finding an acceptable ending is also, therefore, about how participants want to live (or do not want to live), rather than strictly how they want to die. Multiple participants have said to me: "I never want to feel like that again," and so engage in unmaking/remaking around avoiding these potential futures. Equally, taking stock of how one is currently living, and how one has lived, may highlight how current states of being are no longer enough to make life worth living. As Theo and Nick both said, they would rather their bodies and lives be "put back" to how they were many years ago. Looking back on life as lived, as experienced through the body, is a key part of making sense of narratives as wholes (DelVecchio-Good & Good, 1994:856). Endings are thus highly important, as they partly determine the meaning of a narrative. Even though the inevitable and unimaginable ending of death may continue to be surrounded by uncertainty, and has not yet occurred, the wrapping up of narratives before this is part of how participants feel their way to an ending they deem acceptable. This is done partly through retrospection in stillness, and constitutes an important aspect of living towards the end of life.

As people try to finalise the form of their life narrative, through retrospective reminiscing and storytelling, priorities shift as making is colonised by remembering. As laid out previously in this thesis, the hallmarks of unmaking/remaking concern tinkering, layering, and experimenting with respect to the body, and relations with the material and circumstances in participants' lifeworlds. This entails smaller or larger shifts in how one attends, interprets and responds to their body, navigates and alters their lived environment, seeks compromises and

negotiates their priorities for how they want to live. As Arthur Frank (1998:187) suggests, illness disrupts old stories and new; "people [feel] submerged in stories they cannot change, and people [try] to tell new stories that are part of a project of living."

It seems understandable to me that these iterative, ongoing, relentless activities might come to settle into an ending that is characterised by stillness. This stillness manifests the turn away from making which demonstrates that enough is enough. In the turbulent case of heart failure, participants already suffer with fatigue, exhaustion, breathlessness, and discomfort. The effort and desire to continue making, moving, and living might eventually be put aside, as that effort is no longer worth being a part of all the meaningful things in one's life. In other words, life is simply no longer worth living. These processes, through which the distinction between a life worth living and a life not worth living is negotiated, are emergent to living, with all the ambiguities and messiness this entails.

I do not see being done with living a certain way as the same as wishing to die. Neither being done or wishing to be done, I would argue, should always be seen as symptomatic of an underlying pathology. Indeed, non-pathological wish to die seems under-studied (e.g. Rurup et al., 2011; van Wijngaarden et al., 2015, 2016). Most commonly, wish to die is explained as stemming from a disorder such as clinical depression, the core risk being that a patient might feel differently about their lives if they were not depressed. Contrastingly, conceptualising being done with living as a gradual process of settling into pervasive stillness and retrospection stems from having had enough of expending energy unmaking/remaking; negotiating and renegotiating with and through the body, one's circumstances, priorities, and lifeworld. Far from depressive, stillness thus offers a context in which life narratives can be meaningfully processed and people can engage in making sense of an ending. This kind of slowing towards an ending is fundamentally about how one wishes to live, and finding one's current state (and potential futures) wanting, rather than wishing to die.

Making, moving, and living entails a future orientation and prospective perspective that engages with investing in futures, plans, and goals. Stillness is therefore not only a physicality, but a mode of being-in-the-world that no longer involves looking to or imagining these potential futures. In this way, decision-making is about unmaking/remaking, not about settling into stillness. For clinical decisions, such as the DNACPRs and ICDs that multiple participants discussed with me, people are asked to imagine the possible futures with and without these provisions in order to ascertain which direction to move towards. This as much about avoiding certain corporeal futures as maintaining others. Indeed, end of life decision-making especially in heart failure seems to be particularly difficult. In particular, heart failure carries with it the risk of sudden death. The options available to patients, set out in a white paper review about end of life care for those with heart failure, include advanced directives, electing to "forego therapies or procedures perceived as burdensome, or to deactivate devices that were implanted earlier in the disease course." (Whellan et al., 2014:121) However, for heart failure patients, conversations occur less often and patients are found often to "not acknowledge the seriousness or severity of the disease." (Barclay, et al., 2011; Klindtworth et al., 2015:125)

Clinicians particularly cite difficulty having discussions and making decisions in the case of heart failure. Through the insights given here, these discussions may be timed and framed to better accommodate making, moving, and meaning. Difficulties are compounded by disease characteristics, such as the chronic and fluctuating nature of trajectory/prognosis, rendering the end of life difficult to isolate; as well as the lack of palliative resources available to those with heart failure (May et al., 2016; Whellan et al., 2014). Indeed someone might die before they have come to settle into stillness. Yet, stillness might offer a partial answer to the difficulty in isolating end of life, and the trouble of changing minds when people begin to feel better or worse. Stillness, in many ways, signifies the ending of someone's life, in the wrapping up of their narrative and emphasis on retrospection rather than prospection. They do not want to engage in making decisions any more. For Philip, by the point at which he had settled into stillness, he had already abdicated responsibility to make these decisions, having given power

to attorney to one of his daughters. For those already settled into stillness, being presented with clinical decisions might therefore be a jarring experience that calls for a kind of movement, intellectual engagement, and exertion that they are no longer interested in, or even perhaps capable of, making.

For those who change their minds, like Emily and Kent, they were still considering the future and had not wholly settled into stillness and retrospective storytelling. Kaufman's (2010:2-3) category of time left asserts that the timing of death is partially under "clinical individual control," opening up the novel question of "how much more time do I want to try to live?" This invokes the difficulty of knowing when 'enough is enough', particularly as Emily discusses. Kaufman (2012:3) poignantly puts it that "the value of the amount of 'time left' and the value of life itself must be weighed against each other." Yet these decisions are not simply about corporeal futures and time left: they are about the meaningful and personal reasons one wishes to be alive, such as seeing the birth of a new family member. Time left is therefore about meaningful, inspiring futures – what stories are left to be made, still to be told?

Control – personal, technological, and/or clinical in nature – are appealing companions to the inherent uncertainty of these kinds of decisions during this kind of dying (Exley, 2004; Kellehear, 2009a; McNamara, 2001). However, stillness is partly about relinquishing control and purview over the future, rather than seeking to further one's agency within it. Approaching heart failure prognosis through the lens of unmaking/remaking that may eventually give way to stillness mirrors the oscillating, unpredictable trajectory of heart failure. The ebbing and flowing of these oscillations, as with making, similarly gets smaller and smaller towards the end of life. Unmaking/remaking highlights the lived experience of how these fluctuations require flexible responses and experimentation with respect to uncertain futures. As the illness progresses, someone's willingness and ability to invest in these activities might wane, and they might come to the conclusion that they have had enough of living like this. This approach may therefore flexibly inform expectations for patient and clinician, without being

unrealistically prescriptive; and without perpetuating fear of death, nor hope of survival, nor either pathologising the wish to no longer live.

Decision-making and caring towards the end of life might therefore take heed of the gradual action of bringing with and letting go that may lead to settling into the kind of stillness that signifies 'enough is enough'. Acknowledging that there may come a time when people are done with living, moving, and making, healthcare practitioners might more easily and appropriately respond to this shift at the end of life. This is a shift perhaps comprised of turning from making, moving, and living – to remembering, stilling, and dying. As Nick's case particularly illustrates, there is rather a dominance of movement and doing in caring activities. As Mol et al. (2010) state in the logic of care (and as I have discussed earlier in this thesis), care is about doing, tinkering, continuing even through failures. Although I do not wish to escalate this sentiment ad absurdum, there is still a sense of the predominating importance of continuing to move forward, doing, even though death is imminent.

For Mattingly too, movement and storytelling are measures of healing, seen as tools (for healthcare practitioners and patients) in the journey towards the future goal of health. We move towards healing. Stillness, however, is about coming to an end, and is therefore potentially lost in this rendering. Its importance may be overlooked, as caring might entail tinkering beyond the point at which people are done with tinkering themselves. With the difficulty of deciding what and when enough is enough, cues as to how care progresses could be taken not only from what the patient signs and says – but also from what they do not say, the stories they do not tell any more (e.g. about plans to which they are looking forward). Where possible, attention should be paid to their lifeworlds, and their manner of being in and engaging with it: making or remembering, movement or stillness, living or waiting to be done.

Although I am not concerned specifically with reckonings of a 'good death', sociologist Beverly McNamara (1994:1501) writes of the realities of accomplishing dying, highlighting the "complex set of relations and preparations" entailed. However, she emphasises concerns that

the institutionalisation of the good death has led to the "encroachment of mainstream medicine and medical technological imperative to treat." (McNamara et al., 1994:1501) In response to the inherent uncertainty of end of life and what makes a good death in practice, as well as what is possible at the time, healthcare practitioners may default to prioritising a hierarchy of physical management of symptoms and other medical aspects. This highlights that even in cases where patient wishes and holistic wellbeing are sought and emphasised, these aspects seem to still find difficulty being accommodated. At home, with disparate healthcare practitioners, family members, and carers involved in one person's end of life, these priorities may similarly (if not more easily) become lost and disrupted. Stillness, at other periods of life, might signify convalescence and risk-averse safety. As a signal of waning vitality towards the end of life, however, stillness may be overlooked.

Anthropologist Carolyn Smith-Morris (2010:34) suggests that research focusses on "the 'disrupted' portions of life" because these are most visible. This results in these periods being over-emphasised. She (2010:34) rather calls for researchers to refocus on the "connecting sinews between diagnosed and undiagnosed periods of life […] to produce a more holistic discourse about lifelong health." Lifelong narratives are part of these connecting sinews. They are multi-vocal, practical accomplishments. Although narratives are in many ways dependent on different kinds of movement, stillness is nevertheless an important facet of storytelling. Stillness represents a period of life that focusses on taking stock of these narratives and investing – instead of extending these narratives further – in finishing them, of a fashion. Stillness, however, is less visible than the disrupted periods of life; periods through which one is meant to move, rather than settle into. Yet, for the people with whom I spent time, they are not healing. They are living whilst dying.

CHAPTER EIGHT

Reflections and Conclusions

'Life. Death. Whatever.' It was an art exhibition put on by a collaboration of artists in 2016. The installations were hosted by Sutton House, a Georgian-era National Trust property in London. I was immediately intrigued, drawn to this sense of home and responding to how I felt the artists sought to re-embed death and dying into the home – as a journey and context through which people must move. With each room the domain of a different artist, as visitors we are asked to make our way through the house and engage with whatever was offered: fleshy statues shrouded in rags crowding the parlour; bloodstained sheets wrapping evocative shapes hanging from the ceiling, suspended amongst swarms of paper butterflies; coffins painted in blackboard paint on which to draw, filled with children's colourful balls in which to lie; an empty room filled only with the sound of one artist's sonic ruminations on his emotions surrounding death; a bedroom where, lying on the bed, one is offered headphones which project a poetic meditation that elucidates in exquisite detail the progression of the body's decay. Although not engaged in the everyday doing and being of our own lives, we are all called upon to interrogate and encounter our thoughts and feelings, evoked by the strange, familiar, and sometimes disturbing reframes offered by the artists of what it might be like to die.

8.1. SUMMARY: Expressing the Inexpressible

The act of making one's way through the exhibition at Sutton House as a visitor, sensuously engaging with and transforming what one finds emplaced therein, resonates with the hallmarks of unmaking/remaking that I develop in this thesis. The narrative that unfolds through the process of moving from place to place in Sutton House is one of sense- and meaning-making, and unmaking/remaking in general. One artist, Claudia Bicen, created life-size graphite portraits of people in hospices whom she had interviewed about their lives' regrets and successes. Inscribed in each line of her drawing, she transcribed the dialogue from over fifty hours of interviews. The artist said that what she learned from other people's life stories was that meaningful living "does not come from consumption, but creation." Bicen highlights the centrality of making in how lives become meaningful and are woven into narratives, not only for her as an artist, but for those who reviewed their lives with her.

This exhibition struck me in contrast to the scholastic literature and dominant narratives of the clinical in end of life, which focus instead on technological intervention and the inevitable deterioration that happens to bodies. In this thesis, I describe and develop my own observations in each of the findings chapters that do not presuppose or rely on such narratives. Taking a phenomenological approach allowed a kind of embodied enquiry (Sheets-Johnstone, 2009; Todres, 2007) into dying. Additionally focussing on positive aspects of living meaningfully and well at home, this meant that I developed my understanding of dying through attending to vital movement of the body embedded in everyday living, and cultivating an appreciation of what is at stake for people.

In this thesis, I illustrated that the process of living and dying are equally processes of making, something people engage in throughout their lives. In the face of change (perhaps rapid and extreme, perhaps slow and subtle), participants in the study strove to maintain familiarity in their lives, and continuity in their lifelong narratives. These processes partly inform what is worth making the effort for, and what is not. In heart failure, dying is not the action of one great disruption that alienates and disembodies one's life. Rather, it is a series of slippages, smaller interruptions and disjunctures, that require experimentation and consistent tinkering in order to sustain meaningful continuity and familiarity.

In particular, Chapter 4 highlighted and embedded people's everyday experiences of dying in context of lifelong experiences, vicissitudes, and successes. Chapter 5 illustrated how unmaking/remaking is implicated in attending to and interpreting the body in new ways, in order to make the most of living whilst dying. Chapter 6 discussed how sensuous engagement with materials allows people to both explore and extend their lifeworlds, capabilities, and priorities in ways that inform how they wish to live, and die. Finally, Chapter 7 focussed on the way movement and narratives intertwine as people settle into the kind of stillness that may signify that they are no longer looking to or planning for imagined futures, but are rather done with living, moving, and making entirely. Throughout, I showed that processes of

unmaking/remaking towards end of life are about actively negotiating, navigating, and compromising with and through the body.

These considerations – of movement, stillness, vitality, and meaning-making throughout living – are conspicuously absent in many accounts of dying in literature. Death and dying were once considered hidden and taboo, in-articulable as the 'unimaginable other' (Ariès, 1975; Bauman, 1992; Kastenbaum & Moreman, 2018; Strauss & Glaser, 1977). Later, death and dying became sites of social activism in response to medicalisation (Broom et al., 2016; Green, 2008; Lawton, 2000; Lofland, 2019; McNamara, 2001; Woodthorpe, 2007). More recently, biomedicalisation fuels the urge to continually reach for the next treatment, intervention, and technological fix (Clarke et al., 2003; Franklin & Lock, 2003; Kaufman, 2010; Kaufman et al., 2006). I am wary of what is typically lost or silenced in these endeavours: the everyday, the mundane, the personally-meaningful, the relational, the human. This is what anthropologists, amongst others, particularly highlight with a view to challenging assumptions and reframing understandings, in ways that open up possibilities.

I am reminded of the explosion of artistic and literary work that Susan Sontag and others (e.g. Sontag, 1986; Treichler, 2012) discuss, partly when HIV/AIDS became more chronic in character after the introduction of anti-retroviral medications. I see potential parallels with the increasingly chronic character of dying in general. As I drew towards the end of my project, finally finding the headspace to consider wider scapes beyond my own world of data, I sought current examples of how people express what might otherwise be inexpressible about death and dying. Writing of "human becomings" and how anthropology can access such ongoing experiences at the nexus of global influences and local specificities, João Biehl and Peter Locke (2010:337) state:

> Continually adjusting itself to the reality of contemporary lives and worlds, the anthropological venture has the potential of art: to invoke neglected human potentials and to expand the limits of understanding and imagination.

In a recent BMJ Opinion article, Alan Kellehear was reported to emphasise that "action with the dying and the grieving is not in hospitals, hospices, or primary care clinics but in homes, workplaces, schools, golf clubs, parliament, and the community." (R. Smith, 2019) Kellehear went on to advocate for public health strategies and interventions which build strong, compassionate communities that go beyond awareness-raising, towards social support. He suggests a spectrum of activities, including art exhibitions, short story competitions, dedicated book clubs, public forums, community round-tables, recognition for 'caring architecture' and relevant dissertations. These examples resonate with me, and the findings of this thesis. These, I immediately thought upon reading the article, are how people are communicating and together grappling with unmaking/remaking around dying. They immerse me in a tradition that seems to intuitively reach for the importance of movement, meaning, and making in the project of living.

The following discussion introduces some aspects of public discourse and popular culture considerations of dying, embedding my findings in wider context. I highlight throughout how processes of unmaking/remaking, movement, and stillness interweave through dialogues of different forms. I particularly consider how this serves to challenge dominant narratives of dying prevalent in much academic literature. Going beyond more formalised settings like Death Cafes, support groups, and clinical encounters, I focus on how people communicate feelings, ideas, and complexity about dying. This is not only verbal, but includes engagement with news articles of scientific prowess and technological innovation. Building on this, I then consider the implications of my research in terms of potential future directions. Finally, in an Epilogue, I reflect on my commitment and responsibility to participants, how I undertook self-care throughout this project, and dealt with saying goodbye to the people I came to know.

8.2. DISCUSSION: Questioning Dominant Narratives

Starkly contrasting the human, relational accounts evoked in the art exhibition at Sutton House – coming crashing down from the level of community and communication to the cellular – a

BBC (2019) article boldly proclaims that "heart breakthrough could save thousands of lives." The article briefly describes a new "pumping heart patch," only a few centimetres in diameter and made up of "living, beating stem cells" that could be sewn to damaged human hearts to "regenerate existing heart cells." With respect to heart troubles that are "incurable" and "debilitating […] making everyday tasks incredibly difficult," the article quotes the primary investigator, who says: "If we can patch the heart up and help it heal, we could transform the outlook for these people." Despite the mention of daily living, this new piece of biotechnology is not entirely free of the determinist, modernist visions which so often attend technological innovations in health (Franklin & Lock, 2003; Greenhalgh et al., 2012; Mol et al., 2010).

The pumping heart patch, which is now ready for human testing, is an incredible feat of biomedicine and indeed may one day offer routine treatment after heart attack or for those with heart failure. However, I am struck by the image of this isolated, synthetic, futuristic piece-of-a-heart that is grown in a lab from patients' own cells – that can then be stuck almost like a plaster it seems into someone's body. I am left to wonder about the person themselves: how far might they have already turned away from making, their life already so changed by their ill health? I wonder how disruptive and difficult it might be to work one's way back towards making, once having started to settle into stillness?

I think of Norma, whose cardiac stent aided in the partial recovery of her energy and overall health – but also the work she undertook to renegotiate her way back to moving, making, and living meaningfully. Unmaking/remaking is about finding one's limits and how to negotiate a life worth living around these, whether or not it is considered a positive or negative change in the first instance. Having already learned wariness and slowed her life down, Norma had to unlearn and relearn all over again, finding the energy and the motivation to do so. The timing of such interventions may therefore be important in shaping how impactful they can be. The intervention itself is further embedded in lifelong experiences that are similarly impactful; Norma told me that she wished to never again return to the state of ill health she experienced

before the stent, that she would rather be dead. Interventions act on the body, but they do not automatically heal or reconstruct the lifeworld. Such lived bodily experiences are lastingly impactful. Norma wove her fluctuating ill health into her life's narrative, translating this into priorities and positioning of how she wished to approach end of life. These experiences and decisions took time to renegotiate after her stent operation.

One's eventual death – even if potentially delayed – is conspicuously absent in the pumping heart patch article. The impact on someone's daily life, conceptualised as suddenly restoring physical capacity, glosses over so much of the practical and visceral work, including but beyond the physical, that must be similarly and perhaps more slowly undertaken. Technologies are never total solutions, as the issues they attempt to solve are never static: technologies take work to work, and must be tinkered with, layered, and reconfigured in local practices (Mol et al., 2010; Nicolini, 2006; Oudshoorn, 2011; Pols, 2012). These contexts, including the biological body, are equally transformed by the introduction of different materials in potentially unanticipated ways (e.g. Greenhalgh et al., 2013; Ingold, 2013; Oudshoorn, 2012). Such interventions may further require some kind of preparation, provisions, and groundwork which prime and support later uptake. With an understanding of the gradual slowing, and unpredictable ebb and flow of wellness that occurs throughout life, larger or more pervasive changes may be more difficult to make successfully later in life.

Having an eye on the importance of timing, and multiple endpoints, renowned 'green' architect Sarah Wigglesworth tells the story of how she sees her life and capacity changing in the future. She has recently undertaken home renovations to support these ends, even though she is currently healthy and capable at 62 years of age. An *Evening Standard* article (Field, 2019) describes how she concretely considers the "comings and goings of everyday life" in the design and functional flow of her home not only currently, but when her body and priorities change in the future. There is potential for a lift in her home, but in anticipation of avoiding stairs and potential falls, she installs a downstairs bedroom. Anticipating forgetfulness and further

mobility difficulties, she adapts the kitchen so she does not have to stoop or reach to cook, reducing overall risk of accidents. She thinks not only of how she moves through these spaces, but also the additional provisions needed for those who might care for her, as she and her husband have no children.

In making these changes earlier rather than later in her life, whilst she is capable of and interested in making them, Sarah is trying to maximise the benefits she might reap from these adaptations in the future. Sarah is engaging in unmaking/remaking, starting the process of paring down the things she does in her lifeworld at home and their material counterparts. She does this by considering what she can adapt and preserve, and what she can let go, in order to maintain the most meaningful aspects of her life as she negotiates how to continue going about living. She maintains many of the 'green' aspects to her home, but says goodbye to her composting toilet, which would require too much physical input for the positive outputs. Finally, she brings in the essential characteristic of joy into her considerations. Sarah thus emphasises the importance of these practices being meaningful, supporting the life she particularly wishes for herself in a future which is uncertain, but for which she can start to provision early.

Sarah's preparations are not the work of advanced directives, and decisions about when to implement or discontinue interventions, in order to assure a particular kind of death. This is the work of making a life worth living up until that end, and ensuring that this kind of living is not entirely derailed along the way. "Future proof your home," the headline of the article reads, which makes me frown slightly. It reminds me of the sentiment to 'child proof' one's home, but this is not about blocking off potentially harmful areas or equipping homes to be resistant to our future bodily shortcomings. Unmaking/remaking is about the opposite: it is about opening up possibilities in ways that allow the most to be made of them under uncertain circumstances. These processes are about supporting whole people (as lived body-subjects) in moving through their lifeworlds, to and from place to place – from kitchen to bedroom to living room

to bathroom. These are the sites of emplaced experiences, memories, and habits that may become unfamiliar and need to be renegotiated, reconfigured, and re-inhabited when one's body, circumstances, and priorities shift (Casey, 1996; Dahlberg et al., 2009; Irving, 2007). As part of being-in-the-world, and being-in-place, people engage in ongoing place-making to maintain the familiarity and continuity of lifeworlds across the life-course.

Far from restricting movement as child- and future-proofing evokes, unmaking/remaking is about facilitating emplacement and practically negotiating what stays, or goes, when options are limited. These processes of course involve compromise. Although there is space for a lift, Sarah might decide to not install one. She would then relinquish moving through her upstairs world, just as she already considers letting out her office to provide extra income when she can no longer work. Unmaking/remaking involves tracing the patterns of comings and goings throughout the day and figuring out new routes through, new ways of achieving similar things in order to continue living whilst dying at home.

Home modifications themselves, as with other kinds of interventions, may not be practical by the time they are possible. This is particularly illustrated by Rosemary and Kent, when they do not use their adapted spaces in the ways they initially imagined. There is a sense, therefore, that these adaptations may come too late, or may be somehow out-of-sync with the oscillations of unmaking/remaking. Although some needs and desires cannot be anticipated, there are multiple barriers and different groundwork needed in order to ensure the smooth uptake of interventions that are meaningfully impactful in people's lives towards the end of life – when energy, motivation, and time itself may be limited.

Partly due to the socioeconomic cross-section of those who participated in my study (see summary table in Appendix I), only a handful of people built extensions or redid parts of their homes. In reading about Sarah's refurbishment, it strikes me that some people – I would surmise most of those who participated in my own study – may not be able to financially afford such structural changes. Indeed, this is raised by Sakellariou (2015) when investigating home

modifications and living well with Motor Neurone Disease. He focusses on a couple living in Wales, Marion and Dave. When Dave could no longer manage the stairs, they could no longer sleep in the same room together as they had all their married life. Finding this an essential part of their relationship, yet unable to afford the modification themselves, the couple applied for financial assistance in the form of a 'disabilities facilities grant' from the local government. Dave and Marion, however, were found not to be eligible for funding assistance, as healthcare professionals did not see their desire to sleep together as an essential need; when compared to other interventions and their outcomes, it was therefore found not to be cost-effective.

This example speaks to the negotiation between different goods, and versions of good, that both Mol (2006) and Mattingly (Hunt & Mattingly, 1998) discuss when considering the best course of action in treatment. Different ideas about what is best and why collide, reflecting the diverse rationalities and priorities that healthcare practitioners, patients, and families hold and advocate. As McNamara highlights in the Australian practitioners' statement of the good enough death, however, in practice these multiple goods are not on equal footing. When difficult to realise in clinical contexts, the ideal of a good death may be replaced by biomedical imperatives and a hierarchy of physiological needs that trumps others. The good enough death becomes the good that is aimed for. There are further potential power differentials between these actors, needs, and priorities, as well as influences beyond the individual and institutional that impact resource distribution between different people, places, and causes (Exley, 2004). These difficulties and differentials speak to the diverse value systems forwarded by different people, and how challenging these are to realise together in practice (Gawande, 2014; McNamara et al., 1994). There are daily collisions between patient-centred care, wellbeing, safety, and risk-aversion, amongst many other priorities (e.g. Borgstrom, 2018; Boyd et al., 2009; Kaufman et al., 2006; Klindtworth et al., 2015; Mattingly, 2010).

Living, moving, and making are what people do every day. These processes are described in accounts of dying, but seem to have not yet been codified in ways that can be put into practice

effectively. People find different ways of expressing these experiences, part of lifelong narratives in which people engage daily. In focussing on living whilst dying, end of life is no different a struggle to live, move, and make than any other part of living – until the point at which people turn away from making, and settle into stillness. This stillness seems a more appropriate way of identifying dying or end of life, in that it may signal the stilling of multiple hallmarks of being engaged in the project of living. The importance of moving, making, and stillness seems to become lost in the biomedical negotiation between different goods.

Contrastingly, these themes seem to be highlighted as prominent considerations in my reading of popular semi-autobiographical accounts, books, and films relating to dying. These works describe lived bodily experience of patients and their loved ones, where moving emerges as part of making sense of and meaning through these unpredictable experiences. Resonating with my own experiences during fieldwork, these works represent artistic engagements with imposed stillness on the body, and the struggle to continue moving through lifeworlds in meaningful ways.

As brief examples, the film *Breathe* follows the story of a polio victim in the late 1950s whose wife's efforts to support him in making his life worth living revolved around physically moving him out of the hospital, back into his world, and continuing to travel. *The Diving Bell and the Butterfly,* a memoir written one blink at a time by Jean-Dominique Bauby whilst suffering from locked-in-syndrome after a stroke, illustrates the movement of his mind 'like a butterfly' across the stories of his life and (im)possible futures. In *The Salt Path*, Raynor Winn (2018) autobiographically narrates how, when her husband was diagnosed with a terminal illness and they are left homeless, they together walk the UK South West Coast path as part of "looking back, looking forward or just looking for something that was missing." She writes:

> Drawn to the edge, a strip of wilderness where we could be free to let the answers come, or not, to find a way of accepting life, our life, whatever that was. Were we searching this narrow margin between the land and the sea for another way of being, becoming edgelanders along the way? Stuck between one world and the next. Walking

> a thin line between tame and wild, lost and found, life and death. At the edge of existence. (Winn, 2018, p. 112)

In telling stories about finding new ways to live, making is not complete until those stories no longer look to the future in some way, and movement is stilled.

Many considerations of stillness do not arise from studies of end of life specifically, but rather disabilities and occupational therapy literatures (e.g. Cole, 2006; Mattingly, 1994; Maynard, 2010). In these accounts, those who have suffered catastrophic illness and are perhaps paralysed (e.g. as in Cole's account of spinal cord injuries) seek to make a life worth living nonetheless. As I have shown through close consideration of Mattingly's work throughout the thesis, these studies are oriented towards getting out of stillness as part of rehabilitation and healing, not settling into stillness as part of dying. Whilst healing, the goal is to return to a point of normalcy, a dynamic equilibrium that is then unmade and remade accordingly. This is not the case for the dying. There are multiple endpoints that must be renegotiated throughout the undulations of wellness. Rather than moving forward towards these future goals, moving slows as the horizon shrinks, and the unmaking/remaking of multiple endpoints comes to stop.

Making is something which involves embodied engagement in ways that grow and transform knowledge of being-in-the-world (e.g. Canguilhem, 2008; Hallam & Ingold, 2014). Nothing is ever static. Artefacts of many kinds, including lifelong narratives, are always shifting as they are unmade/remade. Stillness as turning away from making therefore emphasises the subtle differences between stillness that gives way to movement as in occupational therapy literature, and stillness that gives way to death. Stillness thus seems most often overlooked, thinly observed in institutional settings (e.g. Broom, 2015; Lawton, 1998; McNamara, 2001) where being still may be associated with being safe, a core part of convalescence. Immobile bodies in hospital or hospice beds are the norm, but the existential meaning of this immobility is lost.

The notion of settling into stillness does not depend on or invoke cognitive and/or bodily deterioration and decay. These are important aspects of death and dying, but less so when

focussing on meaningful living towards end of life. There is therefore an important difference between conceptualising the slowing and stilling of making, rather than the inevitability of decline and weakening. Whilst the latter foregrounds the inescapable disintegration of a person, the former highlights positive capacities and meaningful intentions in one's life. Settling into stillness, and realising that one is done with living, might thus be respected.

Being done with living is often pathologised, cast as a depressive state that requires treatment (e.g. van Wijngaarden et al., 2015, 2016). Rather than something that happens to the body, settling into stillness is a gradual process of bodily, material, contextual, perceptual, and narrative change. It involves being-in-the-world and engaging with it, and eventually drawing away from this. In many of the literary and artistic accounts of living meaningfully until death, there comes a very human point of having had enough. Being done can be seen as a legitimate endpoint for a person, where many of the hallmarks of a life worth living are absent, as the motivation to continue moving, making and living – vitality itself – ebbs away.

8.3. IMPLICATIONS and FUTURE DIRECTIONS

Many have described the necessary reordering of life when illness strikes (e.g. Bury, 1982; Frank, 1998; Garro, 1992; Kellehear, 2009a; Kleinman, 1992; Mattingly, 2006; Mol et al., 2010). I have collected and drawn inspiration from this rich literature, and theorised through a focussed consideration of making and movement in the case of those with heart failure living whilst dying at home. As part of living and dying at home with chronic degenerative illness – when the trajectory produces unpredictable changes in the body, when decisions must be made, and life must continue to be lived in meaningful ways – people continuously unmake and remake their worlds as life frays around the edges. My contribution is to reframe dying to highlight the active and incremental ways in which people negotiate how to live and position themselves towards the end of their lives, taking account of intertwined relations with one's body, surrounding materiality, and lifelong narrative.

I therefore offer an understanding dying of that conceptualises a way of making an ending, coming to settle into stillness. I do this without relying on narratives of deterioration to conceive of end of life, or pathologising being done with living. Unmaking/remaking accommodates uncertainty in ways that do not prioritise discrete, predetermined aspects of living and being well, nor imply a mind/body divide. In this way, I hope that what I write resonates with practitioners, patients, and people of all kinds as experiences that are recognisable, and relatable. Although I cannot generalise the specifics of my own data, the theory of unmaking/remaking can be explored further in diverse contexts in order to produce novel insights.

Understanding health through the dynamics of movement and stillness in the lifeworld does not invoke a mind/body divide. Mental health, for example, may similarly manifest in the movement and stillness of bodies, things, and stories. Movement is already important in understandings of dementia, with researchers sometimes 'wandering' with participants (e.g. Wherton et al., 2019). Attention is similarly being paid to ways of living and moving with schizophrenia (e.g. Pinto, 2016). Finally, lack of interest and participation in daily activities is cited as a core determinant of clinical depression (e.g. American Psychiatric Association, 2013; Tolentino & Schmidt, 2018).

Foregrounding bodily movement as an example, the wandering of those with dementia may take on a different kind of significance; schizophrenia may involve a kind of disordered movement; and in depression, there may be no movement at all. This suggests to me that in understanding the nature of movement, we can better understand the nature of ill health. Care might then be framed as ways of restoring the rhythms and flow of daily life that partly constitute 'dis-ease' and render ill health so disruptive to a life worth living. This returns to the work of Dahlberg et al. (2009), Smith and Lloyd (2006) discussed in Chapter 1, where notions of vitality worked to recast health, illness, and person-centred care as informed by movement through the lifeworld.

In terms of future directions in cases of heart failure, I thus see the potential for pursuing impact in clinical settings and the way caring is undertaken, including technological interventions. The uncertain trajectory and prognosis of heart failure contributes to difficulties for healthcare practitioners, patients, and their families (Glogowska et al., 2016; Jones et al., 2017; Östman et al., 2015; Steinhauser et al., 2011). Expectations, worries, and hopes might be better managed through considering the oscillating movement of unmaking/remaking, the constant shifting and repositioning to become comfortable. Returning to the question posed at the very beginning of this thesis, dying with heart failure could be explained as feeling like gradual slowing down. This would involve explaining the need to consistently seek compromises for small changes as life is pared down, and forward-planning becomes more and more limited.

Recast in this way, priorities of care become about supporting the most meaningful activities, and understanding that these priorities are also subject to change. Whilst these hallmarks of heart failure are described in the heart failure literature, they are not usefully brought together as a manner of understanding the nature of dis-ease in a way that informs care. Rather, they are seen as symptoms that inform treatment. This subtle difference may have an important impact on how it is possible to continue living daily life and how dying is approached for those with heart failure.

With respect to the upturns and downturns of unmaking/remaking, my findings suggest that interventions may be more or less successfully implemented and adopted depending on the particular point at which they are introduced. ICDs, DNACPRs, home modifications, and mobility devices in this study have all been shown as successfully integrated into someone's life, as well as unsuccessfully. This is potentially due to not only to how they are introduced into someone's life, but when. In the process of leaning back from living and settling into stillness, these interventions seem far less likely to produce the desired impact. By this point, people are no longer striving to unmake/remake; interventions and decisions which require

unmaking/remaking are therefore more likely to be abandoned. Embedded within narrative and meaning-making, and an understanding of how people go about unmaking/remaking, these interventions should therefore be framed around a focus on the priorities of living towards end of life, as much as priorities of how to die.

What I have tried to emphasise is that these considerations are so much more than about quality of life – they are about vitality, and what makes life worth living. Where quality of life is predominantly a functional measure that separates domains of wellbeing, vitality evokes an ineffable sense of not only being alive, but being actively engaged in the project of living. It interests me to explore whether the signals I have identified here are robust enough to become markers, and therefore be translated into clinical practice. These markers may be indicators of where someone is along the oscillating trajectory of unmaking/remaking, and coming towards stillness. For example, if people are no longer telling stories about recent happenings or their plans for the future, then it may be reasonable to conclude that that person may not be interested in living for much longer. This may therefore inform what kinds of caring activities and decision-making to undertake next, and how to plan for the eventuality of death when that person becomes no longer interested in making life worth living.

A theme that emerged in my fieldwork, but that which I was unable to give space to in this thesis, was how similar end of life may seem to depression with respect to stillness, lack of motivation and creativity, and finding life no longer worth the effort of living. Although I think much of care towards the end of life would benefit from an understanding of the vitality of movement, and therefore supporting that movement, there is a sense of risk in allowing people to settle into stillness. 'Can we change their minds?' a doctor once asked me. In the risk averse context of biomedicine, letting someone settle into stillness when their minds could be changed about whether life is worth living is a large risk to take. In combination with the reportedly high rates of depressive feelings towards end of life and prescription of

antidepressants (e.g. Breitbart et al., 2000; Damron-Rodríguez & Carmel, 2014; Steinhauser et al., 2011; van Wijngaarden et al., 2015), this seems a fruitful area of future exploration.

Finally, whilst I have not focussed strongly on the power dynamics at play, there are unexplored nuances of interventions and medications in the old and dying that interface with literature on biopolitics, biopower, and bare life (e.g. Mbembe, 2003; Rose, 2007; Russ et al., 2005). In questioning the dominant narratives of how dying is conceptualised as a debilitating phenomenon of bodily decline, the assumption to always reach towards the next treatment option is similarly problematised. However, an added political dimension highlights how these treatments and technologies are intertwined with imperatives to care for one's own health, and preserve one's capacity as an active member of civil society. Beyond quality versus quantity, I find the need to further question what kind of life is being extended. There are impactful differences that require highlighting in diverse circumstances between a life bare of meaning and political significance, and a life that is worth living. It is a life worth living – reckoned through what each person makes meaningful in the emplaced movement of the everyday – that I have highlighted here. There are myriad factors that influence how this living is and can be unmade/remade. These processes unfold as those with uncertain or precarious circumstances, priorities, and bodies engage in living whilst dying – and slowing, potentially through multiple kinds of disruption, to finally come to settle into a dénouement of stillness.

EPILOGUE

Saying Goodbye

Given the immersive nature of ethnographic fieldwork, the close relationships I built with many participants, and the emotional labour specific to end of life research, I wanted to give space here to how difficult I found drawing the research to a close. I wanted to do this in a sensitive way that also honoured those relationships beyond the fulfilment of a research project, partly echoing the discomfort others have written about when receiving a PhD based on research about the lives and deaths of the people we have known (e.g. Borgstrom & Ellis, 2017).

I found it sad to do what felt like saying goodbye to many participants, knowing that I would probably not see them again. I similarly wished to give participants the chance to feed back regarding my preliminary findings, and amend any of my impressions as they saw fit. The strategy I decided upon, after discussing with colleagues and supervisors, was a personalised 'thank you' card and enclosed summary of findings with my contact details, entreating people to correct me; I followed this up with a debrief phone call or final visit. The thank you card contained a short (edited) excerpt from ethnographic vignettes I had written to introduce each participant in this thesis, a thick description of them (which make up the bulk of Chapter 4). My very first participant was also the last person I visited, and she called some of her family to come say goodbye, those I had met and also spent time with over the course of two years.

Having worked so hard to establish informal personal relationships, where I would check in regularly with participants and they would let me know when things went wrong (or right), I felt the difficulty of disentangling myself. I reflected in my field diary how I felt sad and guilty about exiting the lives of people who sometimes felt more like friends. Prior to debriefing, therefore, I systematically mentioned months in advance that I was coming to the end of my research, and what they should expect. Although I felt that I never lost sight of my experiences

as fundamentally part of a research project, I thought of this as shifting myself back into 'researcher mode'; gradually moving our relationships from more personal to more professional, and thus enabling me to distance myself.

In order to maintain this division throughout the project, and taking heed of others' previous experiences (e.g. Woodthorpe, 2009), I used grounding self-care techniques to not become overwhelmed with the subject-matter of my study, the vicissitudes and endings of participants' lives. I reflect on these practices more concretely in an instructional blog, 'Sound(e)scapes: singing as a self-care tool during fieldwork at home' (Pilbeam, 2019). This is published online as part of the Somatics Toolkit project, which aims to provision first-time ethnographic researchers with techniques to manage the stresses of longer-term immersive fieldwork.

I still reflect on my ongoing commitment to participants, as their lives come in and out of focus, and my memories of them are sometimes shadowed by the quiet question: are you still alive? My emotions throughout this study have been complex and certainly not guilt-free. I worry about creating dependence on my presence, wonder about refusing the offers to come for tea after the study was done, and remember all the times I was horrified at myself for being a day or two later than I intended when calling participants for a chat. These experiences and reflections highlight to me the human-ness of research, and its potential failings; and remind me that what I write here means something. It is important that I am rigorous, reflexive, and honest. I am the prism through which these people's lives come to light, and potentially inform better practice for future people struggling to continue living, whilst dying.

It seems to me that these kinds of relationships with participants are always-unfinished. Whilst I have been going over the same material, considering it anew and continuing to write about it, hearing their voices on audio-recordings or seeing their faces in memories and illustrations, I do wonder what and if they ever think of me. I was delighted, and touched, to have received an email from Emily a few months before completing my thesis. Interested in her impressions, but also how she continued to give me an update much as she would in person, I include it here

as part of an epilogue. In a way, the email offers an open-ended reminder of these relationships which, although I have distanced myself from, continue to come in and out of my – and sometimes also participants' – thoughts.

> Hello Caitlin at last I have remembered to ask one of the family to show me how to get your name into my iPad , never too old to learn !! Do hope all goes well for you , thankyou for your letter , your studies have all been varied from so many people , we are all a bit different for sure , I expect through the years different memories will go through your mind as you continue with your work , I'm still pottering on , had a few set backs with the cold bug , then ". Old age " got into my back for couple of weeks , but it was kidney infection ,so antibiotics seem to have settled it , I'm still looking for the energy pills to give me a bit more " go" !! I wish you all the best as you continue with your career , enjoy all life has to offer you, it all slips away so fast , I cannot believe , if all's well I will be 90 in August , my head still thinks I'm younger , I wish you a Happy Easter , hoping too we have a dry sunny weekend , take care of yourself , fond memories from Emily x
>
> Sent from my iPad

- Email from Emily, 17/04/2019 in response to the debrief letter I sent summarising themes and thanking everyone a final time for their participation (unformatted)

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11.1. APPENDIX I: Fieldwork Logs

	Date	Activity	Duration	Emergent Themes
1. Rosemary (83)	20/02/2017	Life history interview in home	2 hours	• Health challenges threatening to derail the way she lives her life currently (specifically mobility challenges) • Anticipating & ameliorating impact • Importance of routine
	03/10/2017	Chat at home, home tour	1 hour	• Compromises & adaptations to lifestyle & physical spaces in the home • Adoption of a pragmatic attitude as necessary to 'keep on keeping on'
	01/11/2017	Shopping trip to local shop as part of PAW's everyday routine, PAW in mobility scooter	2 hours	• Navigating & negotiating movement in/out of everyday spaces & provisioning for new challenges (physicality of negotiation) • Meaning-making through activities that meet a number of needs & desires (social/food/out) even if the mode of engagement has to change (e.g. using mobility scooter in lieu of walking)
	24/11/2017	Clinic visit to the podiatrist and pharmacist in the car, PAW drove, recovering from recent home invasion & burglary	2 hours	• Independence • Risk • Perseverance – just because something is difficult does not mean you should not do it
	13/03/2018	Chat at home about recent health issues/holidays, hidden ramp up to front door of home	2 hours	• Distinction between adaptations that enable living & those which prevent harm (e.g. hiding the ramp which signals disability) • Preparedness & being well-informed
	02/05/2018	Gardening at home, planting potatoes, chat, kitchen plans to redesign to accommodate wheelchair/no standing	2 hours	• Pace of doing things has to slow down • 'Worth the effort' • Teaching & passing things on to next generation (meaningful) • Family support (even when not asked for)
	26/06/2018	Gardening at home, harvesting potatoes, new planters from son, garden tour, family temporarily staying with her	1.5 hours	• Family supporting meaning-making activities (e.g. raised planters for gardening whilst sitting on her walker) • Reminders in current lifestyle of previous occupations (miss them/pleased to remember)

	06/08/2018	Gardening at home, various vegetables, pottering in the kitchen, upstairs tour	2 hours	• Tired • Seasons • Friend's death and funeral – everyone dying around you
	05/10/18	Chat at home, pottering about the house, showing photos	1 hour	• Getting worse, noticing that she has to do different things in order to accomplish the same tasks • Still motivated to change kitchen
	12/12/18	Phone call due to postponed meeting (Romary's ill health)	1 hour	• Funeral last week of close family member in the farming community • Feeling very unwell, everything slowing down, not much more doctors can do • Wearing her down (forget she's 83)
	NOTES: Frequent phone conversations, about once every 2 weeks, often cancelled appointments due to bouts of ill health (mainly kidneys, urine infection, one stomach flu); one burglary; once house was struck by lightning; a couple of rescheduled or 'emergency' hospital appointments; she is often waiting for GP to call with blood test results or for an update (closely monitored)			
2. Emily (89)	10/02/2017	Life history interview at home (GP (CA) present)	1.5 hours	Pragmatic attitude 'take each day as it comes' • Heart failure for half of life – fades into background • Worry that after death then family will not be held together • Motherhood & role of mothering in family
	26/07/2017	Chat at home together with eldest daughter, home tour	1.5 hours	• Transition from carer to being cared for • Importance of having 'own' lives in a family • Family support (even when not asked for) • Taking 'unnecessary risks' create more a problem long-term • Change & accepting new technology into life (e.g. mobility scooter enabling meaning-making)
	01/06/2018	Chat at home, made tea, great-grand-daughter visited (3 years old) dropped off by grand-daughter	2 hours	• Lit up when family came around (suddenly made a bit more sense to me) • Reciprocal engagement – family engages with her/she actively engages with family • Slowing down – things take much longer but are worth doing (e.g. hosting/making tea/knitting)

	04/07/2018	Chat at home together with younger daughter, showed me how to spin wool on a spinning wheel and knit, upcoming holiday being taken by daughter to her home	1.5 hours	• Remembering & reminiscing together (as part of meaning-making) • Planning for activities • Being flexible & fitting in with others' plans (feeling less central/less important?)
	15/10/2018	Chat at home, tour of the garden	2 hours	• Getting better after taking herself off a pill • Change in how she's feeling has triggered her to talk about "really how rotten" she was feeling, and how she hid that from everyone whilst not knowing every night she went to bed whether she would get up the next morning • Cycle of life – births and deaths all around, but also people falling in and out of love
	21/02/2019	Chat at home with tea, daughter (A) stopped by to say goodbye to me	2 hours	• Changing feelings of wellness since I've known her • Thinking about the future (doesn't want to leave home) • If you stop doing things then it becomes harder to do things, spiral
	NOTES: Got much better after medication change September/October 2018, admitted that she hadn't been telling her daughters quite how unwell she had been feeling, started gardening and knitting again, talking much more about her family again, but she doesn't tell them when she does the more risky things. Watching a lot of her friends die or go into homes (Emily herself is adamant she doesn't want to go into a care home, rather stay in her own home) – but sensitive to people not being able to do all the things that need doing, and can't "keep up"; says to her kids "if I get to the stage where I can't do anything anymore, just leave me in the bed and give me a glass of water and that'll do, just let go. Because the thing that I think about now, I can still do my knitting and things – what you do all day in a home when none of it is your own possessions, and you see all these people sat round in chairs…and to me that is so awful! Some of them must be content." (last interview) "if these people that go into a home like that, they do pick up a little bit and feel a bit better, and wish to go back home – no turning back, their home's gone. Difficult." Lack of discussion about death.			
3. Nick (86) – deceased 04/2017	28/02/2017	Life history interview in care home	1.5 hours	• Depression & 'done' with current state of living • Missing previous life/occupation/health • Lack of meaning-making highlighted by lack of new/current stories
	13/06/2017	Interview with GP (CA) about MM's death and end of life care at NDPCHS	1 hour	• 'Best death we could manage' • Doing right by everyone involved • Importance of offering options & being transparent but finding this difficult • Being aware of biomedical will to fix brings worry into whether right decisions are being made

	18/06/2017	Interview with daughter (KW) about MM's death and end of life care in her/MM's home	1 hour	• Fight with system • Negotiate with other family members & medical system but also finding support here • Limits on what is possible • Coping & dealing with death in a 'healthy' way
	NOTES: Co-morbid with Parkinson's			
4. Carol (74)	12/09/2017	Semi-structured interview at home in MK	1 hour	*(CPi not present, interview conducted by CPa)*
	21/09/2017	Life history interview at home in MK	1.5 hours	• Boredom • Feeling well most of the time but consistent reminders of illness • Intolerable circumstances & changing minds • Retirement & no children/grandchildren close
	NOTES: Initial interview and ethics for the OTQS trial			
5. Theodore (86) – deceased (12/2017)	13/11/2017	Life history interview at home, home tour, kitchen pottering with SA's wife (JA)	1 hour	• Husband & wife complementary team • Tired & had enough – depressive feelings & focus on what is no longer possible • Lack of doing & feeling of waiting • Central meaning-making activity no longer possible
	22/02/2018	Interview with District Nurse (KS) who was in attendance at SA's death, at NHS District Nurse offices	1 hour	• Processing the shock • Idea of a 'good death' • Importance of being surrounded by family • Problem of acceptance – wife with dementia realised repeatedly that her husband was dead (what is best for her?) • 'Feeling' that something is wrong immediately
	NOTES: Theodore's wife ended up living in a care home, decided by family members who are very supportive in the ways they can be			

6. **Nancy (84) – deceased (06/2018)**	21/02/2018	Life history interview at home, husband (CB) came home halfway through, kitchen pottering, home tour	2 hours	• Lots of current stories from meaning-making • Slowing down & pottering – breaking up activities into manageable chunks • Things seem less important & strict now (e.g. keeping everything spotlessly clean) • Listening to own body • Husband & wife team – doing together
	10/04/2018	Chat at home, tea and biscuits, photo albums, garden tour, poetry & diary reading, CB there	2 hours	• Still enjoying being but less doing • Letting go & not planning so much anymore/actively investing • Caring for others & self as essential role of family
	NOTES: Phone conversations with CB once every two-three weeks after this point as MB got severely ill (too ill for me to come over), and I checked in to see how she was doing before she died late June 2018. Saw her husband CB walking around a few times as I've been seeing other people around the village.			
7. **Noémie (69)**	26/02/2018	Life history interview at home, husband (HT) present but not involved, drifts in and out, met the cat, silver tea service	1.5 hours	• Living with heart issues whole life – fade into the background • 'Do what I can' attitude • No grandchildren is upsetting still – feels missing something from life
	27/03/2018	Chat at home with tea, home tour (newly painted kitchen), art & lace paraphernalia shown, showed me how to make lace	2 hours	• Making meaning in interim periods where certain activities are not possible through active remembering & creativity around these things (e.g. when cannot travel, do photo albums & art & artefacts) • Some things seem no longer 'worth the trouble'
	25/04/2018	Chat at home with tea, travel diaries & exotic objects shown, husband around, craftsmanship	2 hours	• Challenges & pressures of caring for husband • Responsibility • Negotiating the limitations of what is currently possible
	18/07/2018	Chat at home with tea after travels (and illness) to India/Rajasthan	2 hours	• Travel and making new friendships • Old/new • Leaving husband – guilt

	25/09/2018	Chat at home with tea, saw the back of the house and garden (extension where DT husband lives)	2 hours	• Heart not the same as it has always been – changes in the body and feeling old • Incompatibility with her husband's illness progression → looking to the future and don't know how manage • Friends and being content with what you have/being alone/contact • Could care less about herself and her health, but worries about husband and the compatibility of their ailing health
	14/12/2018	Chat at home after trip to Paris	1 hour	• Recent trip visiting sister in Paris • Lots of walking highlighted worsening health – "not much anyone can do" • Recent hospital appointments and MRI
	NOTES: Phone calls with participant once every 2-3 weeks, asking how things are going, surprisingly chatty on the phone, told me about what she'd been up to (usually someone who was staying or some sort of home improvement – kitchen/fridge)			
8. **Baylee (67)**	12/03/2018	Life history interview at home, downstairs home tour (kitchen, fridge, garden), tea, met the dog (Louis)	2 hours	• Recommendations & 'doing what I am told' (trying to find meaning in this – going through the motions?) • Importance of treat & cheats that make life worth living
	09/04/2018	Chat at home, with tea (same mug I chose last time), talked a lot of current affairs and updated ourselves on news	2 hours	• Depression – trying to convince himself there is nothing wrong with his life • Remembering – active regret & 'what if' thinking • Lack of meaning-making highlighted by lack of current stories • Search for meaning without engaging/doing (i.e. lack of active *making* meaning)
	30/05/2018	Chat at home with tea, cleaning lady (carer and/or companion) also present (Mylie), revamped garden tour	2 hours	• Negotiating & maintaining meaningful relationships with family & non-family • Up & down trajectory • Entertainment versus meaning-making (superficial changes/doing)
	27/07/2018	Chat at home with cool drinks, garden tour because new garden since he accidentally burnt half of it down since last time	1 hour	• Lonely, not a lot to look forward to • Gossip from the town – in the loop, when I ask about him • Routine disrupted by weather and heat – hyper-awareness of body • Depression medication fixed – 'feel nothing then it's working'

	10/12/2018	Chat at home with tea	1 hour	• Everything has been going smoothly • Stopped walking due to weather • Gaining a bit of weight and drinking at night
	NOTES: Taking prescribed anti-depressants; intermittently teetotal; several appointments between October-December due to researcher illness			
9. Philip (88)	04/05/2018	Visit with heart failure nurse (RH) at home, met OB & full-time carer	30 mins	• Up & down trajectory • Some more physical movement due to feeling so much better, encouraging
	19/06/2018	Life history interview at home, carer on a break & out food-shopping, downstairs home & garden tour (he did not get up), phone call with daughter checking on him	1.5 hours	• Role of wife as companion & carer • Formal carer not the same • Remembering as a primary activity • Lack of current stories • Support from family • Doesn't want to be in as much pain as he was previously with arthritis
	14/08/2018	Further life history interview, met carer (Lucy), had tea, laughed a lot, demonstrates pendant alarm for me (test)	1.5 hours	• Power of attorney given to daughters for financial reasons • Worried about finances (not daughters) • Gets 'fed up' occasionally (not bored) • Pain as suffering/life not worth living • Misses getting out of the house more • Friends dead, outlived most, but won't really talk about his plans for his own death, no plans?
	28/11/2018	Chat at home, Scrabble with him and carer (beat us both hollow!)	1.5 hours	• He is done, doesn't want to continue but won't tell anyone/worry family • Still enjoys a game of Scrabble
	NOTES: Seemed to get tired of me….felt a bit bad, like I had asked one too many questions about the more depressing stuff, doesn't seem to want to see me too many more times, despite my efforts to get him to think about playing Scrabble with me, which he finally did accomplish at his insistence on the last visit			
10. Norma (75)	20/06/2018	Life history interview at home, downstairs home & garden tour	1 hour	• New lease on life ☺ previously very unwell • Re-invigorated after feeling life not worth living • Attitude of take each day as it comes – uncertain why/how long feel like this
	21/08/2018	Chat at home with tea, kitchen pottering	1 hour	• Continuing to feel better every day • Family is my world but I don't live for them • When feeling horrible, don't have any motivation to do anything – don't even want to do anything (not going back to feeling like that) • But living each day as it comes and enjoying SOMETHING about each day

	06/12/2018	Chat at home with tea, showed me photos and grand-kids art-work, looking through old puzzles	1 hour	• Learned so much over the last two years about her body and herself, now knows how to deal with the symptoms of heart failure • Take every day as it comes, nothing matters too much to be done tomorrow • Family chat, super-prepared for Christmas • Gained back confidence • Not too worried about future – take each day as it comes, what happens happens
	NOTES: Periodic chest infections, gone through pulmonary rehabilitation, positive upwards trajectory, continuing to feel a lot better most of the time, although arthritis (has had for 14 years) drug (methotrexate) is an immunosuppressant (only told in November during a chest infection), does not want to get ill again like before, worries a bit about the winter; loves puzzles and gave me 3 puzzles on my last visit with the insistence that I give them away once I am done with them ☺			
11. Kent (88)	21/06/2018	Life history interview at home, wife (BPe) present, home & garden tour, silversmith shown & original art *(rescheduled visit due to car accident previous week)*	1.5 hours	• Lack of doing & lack of wanting to do (unsociable but not in a self-sufficient way) • Husband & wife team – very optimistic wife • Unable to meaning-make in any of the ways previously engaged with – the 'non-negotiable' & the unacceptable • ICD – turned off but now maybe turn back on?
	08/08/2018	Chat at home with tea, met daughter-in-law and grand-daughter, spoke with wife on her own afterwards, demonstrates Alexa for me	2 hours	• Worried about wife's creeping illness • Tech-savvy, fascinated by gadgets, use to augment life and keep mind active • Wife struggling with caring, wonders whether caring for him is a bit like giving up
	12/09/2018	Chat at home with wife and tea, a bit quieter than before	2 hours	• Changes – past and present, changing attitudes and behaviour • Delighted to have saved his toes – but would have chopped them off at doctor's advice • Differences between husband and wife, ailing health and dealing with it differently
	14/11/2018	Chat at home with tea and wife	1.5 hours	• Wife getting more and more unwell • Feet much better, almost back to healed, which makes a huge difference • Had his ICD turned back on
	NOTES: Neuropathy and a bit of Parkinson's and arthritis, cannot really use hands and feet anymore, spends most of time sitting and feels mostly okay, but cannot get across the room on his own or really at all, has his own little suite in the house			

12. Jeanne (96) – deceased (10/2018)	05/07/2018	Life history interview at home, photographs shown, home & garden tour	1.5 hours	• Had enough, thought she would die a while ago, a bit done with kids too, worried at night, don't know if can face another winter (lonely, dark, cold) • Growing disinterest in things that previously held • Supportive family but she is unable to do much if they do not support – frustrating but attitude of must accept • Happy enough to continue but also air of waiting
	10/08/2018	Chat at home with tea, shows me properly around her kitchen whilst she makes tea, shows me a lot of old photos	2 hours	• Relief to talk about death • A lot of friends and family dying – most stories oriented in time in relation to a death or a birth, circle of life • Family caring for family
	27/09/2018	Chat at home with tea and biscuits, kitchen and plant tour indoors, I found it to be a very comfortable atmosphere	2 hours	• Memory (short-term not so good) • Content enough • Lonely in the winter and doesn't like the dark • Has to rely on others to go out
	NOTES: See quite a few similarities with the themes for IM as with OB (although OB doesn't seem to want to talk about death as much as IM does). One of her daughters and her heart failure nurse let me know that she had died, peacefully in the night in October; made me think about how Jeanne had told me that she did not want to see another winter.			
13. Kenneth (90)	06/07/2018	Life history interview at home, wife (LPo) present, home tour, met neighbour's cat	1.5 hours	• No kids & no family • Husband & wife team ('*we* will go out of here in coffins') – silent husband & chatty wife • Need for support for carers • Lack of current stories – no ability to meaning-make in ways previously engaged with • Air of waiting
	17/08/2018	Life history interview at home with wife, got to talk to him a bit on his own	2 hours	• Not really engaging with living – says he prefers sitting in silence and ignoring everything, but when given the space told me about the things he misses • Growing old means that everyone else dies around you
	23/10/22018	Chat home with tea and biscuits, wife and next-door's cat present	1 hour	• Upward spiral at the moment (after reduced dosage of some medication), unwilling to think about what could go wrong when feeling so much better (they don't seem to be questioning the upward swing?) • Nothing else really changing, happy to keep puttering along

	NOTES: Very much a team, quite well-matched in their health issues (complementary)			
14. Edwin (98)	23/07/2018	Life history interview at his new home, a not-quite-assisted-living space in a park home estate with a nursing home on-site	2.5 hours	• 'It wasn't so much my illness as my wife dying that changed my life' (died 2 years ago, married for 62 years) • Estranged daughter – nature/nurture • Victorian ideas of gender roles • Engineering – mechanical minded
	15/08/2018	Interview and walk around the grounds	2 hours	• Sitting day-dreaming much of the time • Tired • Wife's illness and care before she passed away, friends going through similar things, intolerable ways to live
	23/10/2018	Chat at home with tea, showing me old letters and photographs	2 hours	• Feeling older, not very useful, very lonely, despite being surrounded by people; feels like he is wasting time • Not sure 'what the point is' anymore, but manages to keep himself occupied for the most part nonetheless, 'nothing else to be done' • Did some travelling to see family/old friends (assisted by his house-lady) – everyone so old
	NOTES: Lives alone and independently in an assisted living facility; an old friend and house-lady comes to see him once or twice a week to clean the house and keep him company			

11.2. APPENDIX II: Participant Information Sheet (V2)



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

PARTICIPANT INFORMATION SHEET (PATIENTS)

OXFORD TELEHEALTH QUALITATIVE STUDY: "THE WAY WE LIVE" PhD Project

Hello, my name is Caitlin, and I am a doctoral student at Oxford University. I'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information, and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask me or the person who invited you to consider the research.

What is the purpose of the study?

I am an anthropologist and PhD student at the University of Oxford, part of a research team that is working with doctors and nurses at the John Radcliffe Hospital and Oxfordshire Clinical Commissioning Group. As part of a wider study on how best to support people with heart failure, I am researching what it's like for a person to live with heart failure. There has been a lot of research done on drugs and technologies for heart failure, but much less research on how this condition affects people's everyday lives away from the hospital. This is an opportunity for you to help us understand the best way to support people with heart failure at home.

What is the purpose of the study?

To capture the experiences of people with heart failure, their family and/or carer(s), so we can develop more appropriate technologies and services to better support people with heart failure.

Why have I been invited?

You have been chosen either because you have expressed an interest in using new technologies/services to help manage your heart failure or because your doctor, nurse or carer has identified you as someone who might wish to do so.

Do I have to take part?

No, taking part is entirely voluntary and you can withdraw at any time if you later change your mind, without giving a reason. Withdrawal will not affect your clinical care.

What will happen to me if I decide to take part?

You will be given one week to think about whether you wish to participate (and longer if you would like more time). After that, I will ask you to sign a consent form agreeing to take part. I would visit you at home on up to four occasions. One of these visits will include me interviewing you about your illness and your experiences of heart failure. With your permission, I would like to tape record the interview. The recording can be stopped at any time if you become uncomfortable, and all data will be anonymised and confidential.

In the interview, I would like to know about your illness, your experiences of heart failure, as well as your daily life and how things have changed as a result of your illness. I will ask you to talk about places, people, activities, and/or things that you find particularly meaningful or challenging in your life. You can talk about anything that you find important.

In addition to the interview, during the visits I would be very interested to see your home and neighbourhood, and understand how you go about your daily life. If you would like to walk out from your home to show me a place you usually go (e.g. shops, church, park), and if you are well enough to do this, I would like to accompany you to discuss the meaning that this place holds for you. Additionally, if there is an activity that you enjoy doing and that I could be helpfully involved in at home or out (e.g. baking/gardening/an excursion), this would be a great opportunity for developing further understanding. With your permission, I might like to document photographically anything that helps you live as you currently do (e.g. adapted technologies); if people are included in photographs, they will be anonymised, and I will ask you to approve the use of any photographs.

The first visit will last about an hour, and any subsequent visits can be much briefer at your convenience. You do not need to commit to all four visits, you can choose any number and any activity, and withdraw at any time with no stated reasons.

What should I consider?

The main thing to consider is whether you are comfortable with me asking you questions and/or observing you in your home. Some people enjoy the opportunity to share their experiences, whilst others may prefer to keep things more private.

Are there any possible disadvantages or risks from taking part?

The main disadvantage of the study is that I am asking you to commit some time and will ask questions about your personal life and medical details, which will be written up as part of the wider research.

What are the possible benefits of taking part?

The main benefit of taking part is the opportunity for you to contribute to improving researchers' understanding of what matters to people with heart failure. Findings from the study will be used to inform changes in the heart failure service. If you raise issues about your personal experience of the service we will feed these back to the service team and it may be possible to improve your own experience, though we cannot guarantee this.

Will my General Practitioner/family doctor (GP) be informed of my participation?

Yes, unless you ask me not to tell them.

What will happen to me if I decide to take part?

You will be given one week to think about whether you wish to participate (and longer if you would like more time). After that, I will ask you to sign a consent form agreeing to take part. I would visit you at home on up to four occasions. One of these visits will include me interviewing you about your illness and your experiences of heart failure. With your permission, I would like to tape record the interview. The recording can be stopped at any time if you become uncomfortable, and all data will be anonymised and confidential.

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Will my General Practitioner/family doctor (GP) be informed of my participation?

Yes, unless you ask me not to tell them.

Will my taking part in the study be kept confidential?

Yes. All data from the study (tape recordings/photos/fieldnotes) will be made anonymous (unless you would prefer us not to blur your face, for example).They will be kept on a secure, non-networked computer at the University of Oxford. In those stored data, you will be referred to only by a code name ('pseudonym'). We will keep a separate paper record in a locked cabinet of participants' real names and corresponding code names. All photos and audio recordings will be destroyed at the end of the study.

Responsible members of the University of Oxford and the relevant NHS Trust(s) may be given access to (anonymised) data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

Will I be reimbursed for taking part?

No, and since the visits will take place in your home, we do not anticipate you incurring any travel or expenses. If you would like us to provide you with printed copies of some of the photos we have taken, we can do this.

What will happen to my data?

We will keep the research data for up to three years after the end of the data collection, to allow us to analyse it all and write papers and reports. Once these are completed, all data will be destroyed. Anonymised transcripts of interviews and consultations may be kept for up to 15 years.

What will happen if I don't want to carry on with the study?

You can stop at any time. Participation is voluntary and even if you originally said yes, you may change your mind at a later stage. If you withdraw from the study, unless you state otherwise, any interview or photographic material that has been collected whilst you have been in the study will be used for research as detailed in this participant information sheet. You are free to request that your data are destroyed at any time during or after the study. Withdrawal will not affect the care you receive from the NHS now or in the future

What will happen at the end of the study?

I will analyse the data, along with other members of the research team, and write some papers and reports (including my PhD thesis), including a 'lay summary'. We will provide you with a summary of the findings if you would like us to.

You will not be identified from any report or publication placed in the public domain. I may wish to use quotes from your interview, or some other materials collected, in a conference presentation or teaching session, but you do not have to agree to this. If you are happy for this to happen, tick the relevant box on the consent form.

What if you find something unexpected?

If anything you tell us in an interview has a bearing on your clinical care (for example if you disclose to us that you have a new symptom), we will inform the GP and/or your heart failure nurse, as appropriate.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study. NHS indemnity operates in respect of the clinical treatment which is provided.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Professor Trisha Greenhalgh whose details are given below, or Professor Richard Hobbs (Professor Greenhalgh's line manager, same address). Alternatively, you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224, or the head of CTRG, email ctrg@admin.ox.ac.uk.

How have patients and the public been involved in this study?

People with heart failure were involved in helping design this study. People with heart failure have also checked this information sheet and consent form.

Who is organising and funding the study?

The study is funded by The Wellcome Trust. It is part of the SCALS (Studies in Co-creating Assisted Living Solutions) research programme, which aims to improve the fitness for purpose of technology-supported health care and monitoring for people with medical conditions. The study team is led by Professor Trisha Greenhalgh, a GP who works at the University of Oxford; she is also custodian of the study information.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Oxford C Research Ethics Committee.

Further information and contact details:

Please contact the following individual if you would like further information.

Professor Trisha Greenhalgh (Chief Investigator)
Nuffield Department of Primary Care Health Sciences
University of Oxford
Radclilffe Primary Care Building
Woodstock Rd
Oxford OX2 6GG
01865 617835
trish.greenhalgh@phc.ox.ac.uk

Thank you for considering taking part.

11.3. APPENDIX III: Participant Consent Forms

UNIVERSITY OF OXFORD

NUFFIELD DEPARTMENT OF PRIMARY CARE HEALTH SCIENCES

CONSENT FORM (PATIENT PARTICIPANTS)

OXFORD TELEHEALTH QUALITATIVE STUDY

"THE WAY WE LIVE" PhD Project

Name of Researcher: _____

If you agree, please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I know that the research will include the following [delete anything you don't want to do]: - The researcher will interview me about my heart failure and other health condition(s) - The researcher will ask exploratory questions about my lifestyle and wellbeing - The researcher will ask about places / activities / people / things that are particularly meaningful to me - The researcher will audio record some of my interviews - The researcher may take photos, give me a camera and / or scrapbook to record some of the important things that are happening in my life - The researcher may accompany me on a short walk outside	
4. I agree to audio recording and the use of photographs and anonymised quotes in research reports and publications (delete words from this section if you would prefer not to share particular aspects of your data in this way)	
5. I would like identifying details (e.g. my face) to be blurred in any photograph to make sure I am not recognisable.	

6. I agree to photographs or quotes being used to illustrate talks about this research at conferences or for teaching purposes. (Delete words if you would prefer the material not to be used in this way.)	
7. I agree to my General Practitioner being informed of my participation in the study.	
8. I understand that the information held and maintained by the Health and Social Care Information Centre (or amend as appropriate) and other central UK NHS bodies may be used to help contact me or provide information about my health status.	
9. I agree to take part in this study.	

Name of Participant	*Date*	*Signature*
Name of Person taking Consent	*Date*	*Signature*

**1 copy for participant; 1 copy for researcher site file; 1 (original) to be kept in medical notes* (if participant is a patient).

11.4. APPENDIX IV: Interview Guides

INTERVIEW GUIDE – PATIENT PARTICIPANT

We are here to talk to you about the things you enjoy in your life. I am interested in exploring how people live well with chronic disease, how they live lives that are full of meaning despite symptoms and diagnosis, so I am here for you to talk about whatever you find important. (Explain consent forms/pilot study/informed consent/right to withdraw at any time.)

Tell me about…

1) Your health
    a. How did you first realise something was wrong?
    b. How have you managed up to this point?
    c. How does your illness affect your life?
2) Daily life
    a. Routine?
    b. What sorts of activities do you enjoy?
    c. How long have you been in this house?
3) Attitude towards life
    a. How do you feel day-to-day?
    b. Do you feel you're living the life you want to live?
    c. How do you see yourself moving forward, living your life in the future?
    d. Do you ever feel overwhelmed? How do you cope with this?
4) End of life talk
    a. Conversations with doctors/other health professionals about illness/trajectory/what changes to expect?
    b. Conversations with family about end of life care?
    c. Have you made any preparations or arrangements – will/funeral?
    d. How do you imagine you'd feel and/or cope with deterioration in your condition?
5) Medication & medical devices
    a. What sorts of care do you receive?
    b. What sorts of things do you do to care for yourself (not restricted to medication)?
    c. What sorts of compromises have you had to make/how has your life changed?
    d. How far are you willing to make further alterations to your life?
6) Meaningful places/things/activities
    a. Would you mind if I did an activity with you?
    b. What sorts of things/places are important to you? Would you like to show me?
    c. If you could take me somewhere, where would you take me?

INTEVIEW GUIDE – FAMILY MEMBER

We are here to talk about your father/mother/etc., and your experiences of living and coping with their health needs in the family. I am interested in exploring how people live well with chronic disease, how they live lives that are full of meaning despite symptoms and diagnosis, and how this might be experienced by those involved in their lives. (Explain consent forms/pilot study/informed consent/right to withdraw at any time.)

Tell me about…

1) Your family member
    a. How did you first realise something was wrong?
    b. How does your family member/family member usually deal with ill health?
2) Diagnosis
    a. Tell me about how diagnosis happened
    b. What kinds of things were worrying/comforting?
3) Chronic illness
    a. How did your life change, what sorts of arrangements did you make to cope with your family member's condition?
    b. How are these arrangements decided upon with your family member?
    c. How do you think their life was changed?
    d. What role did you have in their life?
    e. How do you communicate and coordinate with others?
4) End of life
    a. How has end of life care (planning) been discussed?
    b. *(If deceased)* Tell me about your experience of your family member's end of life care and planning, what sort of care did they receive?
    c. How are/were you involved?
    d. How are/were decisions about their care made?

INTERVIEW GUIDE – HEALTHCARE PROVIDER

We are here to talk about your patient, X, and your experiences caring for them and how you understand them to be living and coping with their health needs. I am interested in exploring how people live well with chronic disease, how they live lives that are full of meaning despite symptoms and diagnosis, and what role healthcare provision might play in their lives. (Explain consent forms/pilot study/informed consent/right to withdraw at any time.)

Tell me about…

1) Your patient
    a. How did you meet them, how long ago?
    b. How well do you feel you know your patient?
2) Clinical encounters
    a. What sorts of things do they bring up in consultations, what do they talk about?
    b. What do you think about their quality of life?
    c. What do you know of their life outside of the clinic?
3) End of life
    a. How have you spoken with them about end of life care?
    b. How do you discuss prognosis and treatment preferences, does your patient ever bring up end of life preferences?
4) Medications & devices
    a. What sorts of medications are they being treated with?
    b. Any medical devices – how was this decision made?
    c. What sorts of issues/challenges/triumphs have they had with these aspects?
5) Illness management & daily life
    a. How well do you think they are coping with their illness?
    b. How well do you think they are managing their illness clinically?
    c. What sorts of problems have you encountered with them?
    d. What do you feel you can offer them?

11.5. APPENDIX V: Ethical Approval

NHS
Health Research Authority

South Central - Berkshire Research Ethics Committee

Bristol REC Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

21 April 2017

Prof Trisha Greenhalgh
Professor of Primary Care Health Sciences
University of Oxford
New Radcliffe House, Walton St
Oxford
2 Newark Street
London
OX2 6GG

Dear Professor Greenhalgh

Study title:	**The Oxford Telehealth Qualitative Study (Case 3 in the SCALS - Studies in Co-creating Assisted Living Solutions - study).**
REC reference:	**15/SC/0553**
Amendment number:	**Substantial Amendment 1**
Amendment date:	**22 March 2017**
IRAS project ID:	**186971**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*

NHS
Health Research Authority

Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 1	22 March 2017
Participant information sheet (PIS) [New PIS and consent form for ethnographic study (patient)]	1.0	17 March 2017
Research protocol or project proposal [SCALS protocol on official template Clean 2.1 210317]	2.1	21 March 2017
Research protocol or project proposal [SCALS protocol on official template 2.1 210317 MARKED]	2.1	21 March 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/SC/0553:	**Please quote this number on all correspondence**

Yours sincerely

Arun

pp

Mr David Carpenter
Chair

E-mail: nrescommittee.southcentral-berkshire@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Heather House, Oxford University Hospitals NHS Foundation Trust*
Ms Heather House, Oxford University Hospitals NHS Foundation Trust

NHS
Health Research Authority

South Central - Berkshire Research Ethics Committee

Attendance at Sub-Committee of the REC by correspondence

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr David Carpenter	Social Scientist	Yes	
Dr Mike Proven	Coordinator for QA in Research	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Sadie McKeown-Keegan	REC Manager

FW: IRAS 186971. Confirmation of Amendment Assessment

Trish Greenhalgh
Sent: 23 May 2017 14:18
To: Caitlin Pilbeam

You may need this as an appendix to your DPhil. It's HRA approval.

From: "TOTENHOFER, Ashley (HEALTH RESEARCH AUTHORITY)" <ashley.totenhofer@nhs.net>
Date: Tuesday, 23 May 2017 at 13:51
To: Trish Greenhalgh <trish.greenhalgh@phc.ox.ac.uk>
Cc: "heather.house@ouh.nhs.uk" <heather.house@ouh.nhs.uk>, "TMA, Ouh (OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST)" <ouhtma@nhs.net>
Subject: RE: IRAS 186971. Confirmation of Amendment Assessment

Dear Trisha

Further to the below, I am pleased to confirm that HRA Approval has been issued for the referenced amendment, following assessment against the HRA criteria and standards.

The sponsor should now work collaboratively with participating NHS organisations in England to implement the amendment as per the below categorisation information. This email may be provided by the sponsor to participating organisations in England to evidence that the amendment has HRA Approval.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Ashley

Dr Ashley Totenhofer | Technical Assurance Officer
HRA Centre Manchester
3rd Floor, Barlow House, 4 Minshull Street, Manchester, M1 3DZ
E: ashley.totenhofer@nhs.net | T: 0207 104 8017
www.hra.nhs.uk

Would you like to receive the latest updates on HRA work? Sign up here

For more information on the HRA Approval process Click here

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

From: nrescommittee.southcentral-berkshire@nhs.net [mailto:nrescommittee.southcentral-berkshire@nhs.net]
Sent: 06 April 2017 11:25
To: trish.greenhalgh@phc.ox.ac.uk
Cc: heather.house@ouh.nhs.uk; ouhtma@nhs.net
Subject: IRAS 186971. Confirmation of REC Validation and Categorisation of Amendment

Dear Prof Greenhalgh,

IRAS Project ID:	**186971**
REC Reference:	**15/SC/0553**
Short Study Title:	**Oxford Telehealth Qualitative Study version 1.2**
Date complete amendment submission received:	**05 April 2017**
Amendment No./ Sponsor Ref:	**Substantial Amendment 1**
Amendment Date:	**22 March 2017**
Amendment Type:	**Substantial**

Thank you for submitting the above referenced amendment. I am pleased to confirm that this amendment has been submitted to the REC for ethical review. Please find attached a copy of the validation letter.

Categorisation of Amendment

In line with the UK Process for Handling UK Study Amendments I can confirm that this amendment has been categorised as:

- **Category A -** An amendment that has implications for, or affects, ALL participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the three conditions below, you will be able to implement the amendment at your participating NHS organisations in England **35 days after you notify them of the amendment.** A template email to notify participating NHS organisations in England is provided here.

Subject to the same three conditions, you will be able to implement your amendment at participating NHS organisations in Northern Ireland, Scotland or Wales on 10 May 2017.

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion, (for participating organisations in England, this includes receiving confirmation of HRA Approval for the amendment). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England, plus to local research teams at any participating NHS organisations in Northern Ireland, Scotland or Wales*.
- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.
- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.

Note: you may only implement changes described in the amendment notice or letter.
If you receive required regulatory approvals (for participating organisations in England, this includes confirmation that the amendment has been granted HRA Approval) after the 35 days have passed, you may then immediately implement this amendment at all participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study.
There is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35 day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.
* Where the study involves NHS organisations in Northern Ireland, Scotland or Wales, the HRA will forward regulatory approvals to the relevant national coordinating function to distribute to their research management support offices.
Please do not hesitate to contact me if you require further information.
Best wishes,
Lucy Roberts
REC Manager
(on behalf of)

Sadie McKeown-Keegan | Research Ethics Committee Manager
South Central – Berkshire
Health Research Authority
Bristol HRA Centre, Level 3, Block B,
Whitefriars, Lewins Mead, Bristol BS1 2NT
E: nrescommittee.southcentral-berkshire@nhs.net | T: 0207 104 8043
www.hra.nhs.uk | HRA: 0207 104 8056

IMPORTANT – Click here for details of significant changes to the REC booking and submission process

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

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This message may contain confidential information. If you are not the intended recipient please inform the sender that you have received the message in error before deleting it.
Please do not disclose, copy or distribute information in this e-mail or take any action in reliance on its contents:
to do so is strictly prohibited and may be unlawful.

Thank you for your co-operation.

NHSmail is the secure email and directory service available for all NHS staff in England and Scotland
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NHSmail provides an email address for your career in the NHS and can be accessed anywhere
For more information and to find out how you can switch, visit http://support.nhs.net/joiningnhsmail

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