At home in a nursing home: on movement and care

Angela Rong Yang Zhang

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A note on pseudonyms

I use pseudonyms throughout the thesis.

Abstract

This thesis follows the everyday movements of a group of elderly Australians, to critically examine how they came to experience a sense of home while living with bodily and cognitive impairments in a nursing home. In tracing their steps and the minutiae of their day-to-day activities, this research illustrates how nursing home residents experience 'home' as a sense of 'rightness' of being through doing the most mundane activities of walking, transferring position and eating. Examining care through the lens of home, I analyse how home, bodies and movement are reconfigured through multiple contexts of care. I argue that it is only in constellations of care that produce movements that residents attempt to make, but are unable to make on their own, that the potential to become at home is made possible.

Based on 12 months of fieldwork in two nursing homes in metropolitan Adelaide, South Australia, this research attends closely to the sensory extensions (Dennis 2007) and restrictions of residents' bodies *vis-à-vis* their engagements with other people and things. From the taste of a home cooked meal, to the touch of staff and family members, medications, handrails, carpeted floors and walking aids, residents' ageing and declining bodies respond to, and may resist, assistance to walk, stand or eat. Care plans, staff and equipment, as this thesis will show, can also restrain residents' bodies, inhibiting their movements and their becoming at home.

This thesis draws on Deleuze and Guattari's (1977, 1988) theories of becoming and desiring production to expand Jackson's notion of home (1995, 2002) and 'existential imperative' (2002, p. 14) to propose that home is a matter of becoming-at-home-in-the-world. Key to my argument is how residents experience an innermost drive to move, and in examining how their urge to move is responded to, I demonstrate the multiple and at times contested forces that can propel residents to sit, to stand, or to put one foot ahead of the other. It is through this Deleuzian approach that I detail the multiple persons and things that enact and produce assemblages (Deleuze & Guattari 1988) of care.

In so doing, I demonstrate that an ethically responsive care, or the care that was communicated and experienced as 'right' by residents, requires tinkering (Mol, Moser & Pols 2010) to achieve a balance between inclusion and autonomy (Rapport 2018). From moment to moment, and day-to-day, as bodies age, decline and eventually die, each resident requires different assemblages of care to move and to become at home.

Examining the varieties of experience for nursing home residents through the theoretical lens of becoming at-home-in-the-world, this thesis provides new knowledge about the interrelations between movement and care, and the generative and productive affects of walking, standing and eating in residents' lives. I argue that this ethnographically informed understanding of the sensibilities and potentialities of movement presents a challenge to clinical constructions of bodily and cognitive impairment and is at odds with aged care discourses and practices that may render the lives of nursing home residents inactive or meaningless and thus further constrain their existential and bodily potentials.

Thesis declaration

I, Angela Rong Yang Zhang, certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

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I Introduction

1 (Re)locating home

‘Going home’ to the nursing home

In the initial stage of my fieldwork, I often walked with Mr Harris. Sitting opposite the main entrance of the facility, Mr Harris would routinely fix his gaze at the front entrance from which people constantly came and went. Every resident leaving the facility was accompanied by someone else, a staff member, a family or friend, a volunteer or visitor, who would unlock the door using a security code—a string of numbers and letters on a piece of printed paper in small-sized font posted on the wall next to the security lock. Printed on this poster was a reminder: “Close the door behind you to prevent the residents from absconding.” With a grave look, Mr Harris whispered to me, “This is imprisonment.” He then told me that he would ask his daughter to get him out of this place when she came to visit. “I want to go home”, he sighed as he slowly held on to his walker, stood up languidly and walked away. A few days after my chat with Mr Harris, I discovered that he was ‘out’ as he had wished—his daughter came to take him for ‘social leave’ to spend the weekend with her family. I felt happy for him—he could have a break from routinised nursing home life and spend time with his family. Yet, in the late afternoon before tea was served, and to everyone’s surprise, Mr Harris was back inside the facility. Distraught and exhausted, his daughter explained the situation. After a car trip to the beach and a fun family feast, Mr Harris became restless, walking up and down the house looking for his own room. When she told her father that he would spend the night in a spare bedroom in her place, he grew more distressed and insisted that he should go back before it was too late. Confused and heartbroken, his daughter sent him back to the facility. After joining other residents in the dining area for some soup and bread, Mr Harris looked his usual self. Pushing his 4-wheeled red walker, he was back on his feet walking again.

How can we understand the perplexing experience of Mr Harris, who wished to go out of the nursing home but chose to go back to it while being away? Mr Harris clearly voiced his resentment over the constraints of living in a secure care facility and yet, he also found relief and comfort in the assistance provided in its purposefully designed and built environment. Referring to his institutional life as being a prison, did Mr Harris find great similarity between a nursing home and a jail, a total institution in Goffman’s

sense (1961, p. 4)? In the field I was confronted with the question about where home was located for people like Mr Harris. In leaving his daughter's family house for the care facility, did Mr Harris feel more at home in the nursing home? In conducting 12 months of fieldwork in two residential aged care facilities in metropolitan Adelaide, South Australia and writing up this thesis, I traced the multiple and shifting experiences of home in the day-to-day lives of residents, and I attended to the minutia of what they said and did, recording how people moved and events evolved. In this thesis I examine how frail residents came to feel 'at home' and I attend to how this was made possible through walking and moving in the nursing home.

Many times in the field, I witnessed elderly residents' profound sense of loss and sadness when they longed to return to their own homes. Yet, if home is to be understood as the place where they lived before moving into a nursing home, many had no home of their own to return to. As I learnt from staff, Mr Harris had, like most of the other residents, sold his property and possessions before moving into the facility, to pay for the Refundable Accommodation Deposit (RAD).[1] In expressing his wish to go home, Mr Harris was not referring to his previous household or house. In nursing homes, residents' appeals to return home are understood by people around them as expressions of longing, reminiscence, expectation, or imagination of home in institutional settings. In her autoethnography, Janelle Taylor recounted how she came to the realisation that, in expressing her wish to go home, her mother, a nursing home resident with dementia, 'was trying, in her own way, to hold on' to her loved ones (Taylor 2008, p. 332) and longing for a sense of connectedness with the world. Residents often expressed their wish to go home especially in the process of adapting and adjusting to the nursing home. Time and again they criticised the surveillance measures that restricted their movements in their new abode. Confronted with locked doors, security codes and the watchful eye of care staff and management, Mr Harris struggled to feel at home. In wishing himself to be out of the institution and to go home, Mr Harris revealed that the nursing home was a place in which he felt constrained—he explained that he did not feel 'right' there and he wished he was free to leave. For Mr Harris and residents like him, home is less about a concrete place, but more a sense of being 'all right' living there—moving around as one likes to do and to feel at ease.

[1] Residents entering aged care on or after 1 July 2014 can choose to pay the accommodation payment in full as an up-front lump sum, known as Refundable Accommodation Deposit (RAD).

This thesis follows the lives and bodies of people who, like Mr Harris, are frail and elderly. It attends to their lived experience of physical and cognitive impairments and their need for assistance with everyday movement. For frail elderly people living their last stages of life, moving into a nursing home is rarely perceived as a choice that they willingly make on their own. Mr Harris was admitted into the aged care facility due to the progression of his Parkinson's disease. When his wife died, he lived alone but after having frequent falls, tripping over rugs and his own feet, Mr Harris and his family realised that living alone at home was no longer an option for him. He hated the idea of living in a 'Home' but, given his bodily condition, there was, he told me, no way to fight it. Though he entered with his own consent, he was forever resentful about being institutionalised. In nursing homes, many residents had been hospitalised for injuries from falls, or for terminal diseases, before their admission into an aged care facility. This is a common pathway for the one in twenty elderly Australians who live in residential aged care facilities, according to the Australian Bureau of Statistics 2015 report on disability, ageing and carers (ABS 2015). In the current aged care system, Home Care Packages and high-level residential aged care provide senior Australians with nursing care and daily life assistance.[2] Yet, residential aged care becomes the last resort for care and support with daily living if assistance from family carers is not available.

Staff often remarked that residents seemed to be able to settle down as time went on, despite the experience of loss due to nursing home placement; as one service provider (whose affiliating facility hosted this project) proudly stated on the organisational website, residents: 'feel at home in our care homes'. Similarly, in chats and interviews residents often expressed a sense of acceptance, contentment and belonging. Mrs Joyce explained: "This is the best place to be if I have to live in a place like this." And Mrs Simmons once told me: "I live here. This is my home now." Their accounts conveyed a sense that they are in the right place for them. Some other residents, like Mr Harris, refused to call a nursing home 'home' constantly voicing distaste towards its practices. Yet, they could find comfort and convenience in a purposefully designed, furnished, equipped and staffed environment with features that aided their comfort, like central heating and cooling and the convenience of the onsite café (see Plate 1), gift

[2] This program supports older people with complex care needs to live independently in their own homes. The support is funded by the Australian Government and provided through a Home Care Package—a coordinated mix of services (Department of Health 2020b).

shop (see Plate 2) and hair salon (see Plate 3). They also benefited from housekeeping services, aiding devices and around the clock nursing care. From their serviced and temperature-controlled rooms, residents could from time to time feel at ease.

Plate 1: Onsite café

Plate 2: Onsite gift shop

Plate 3: Onsite hair salon

As I came to learn, being at ease in a nursing home required more than housekeeping, amenities, or suitable heating and cooling. A crucial requirement was when residents' need to move was responded to, such as when an arm lent out to support them to stay upright, or a walker was conveniently placed in reach, or a staff member took the time to get them dressed gently—all instances where *vis-à-vis* attentiveness and care from others allowed residents to do the things they wanted to do but were unable to do independently. On these occasions, when concerns had been taken care of, residents spoke of things "working out all right" and of feeling "just right", despite the ongoing difficulties and discomfort with their bodies, communal living and institutional practices. Feeling just right and at ease—a sense of being in the right place, among the right objects, with the right persons, or being assisted at the right time in the right ways—was an everyday part of the vernacular of the nursing home; it was at the core of how residents feel, think and talk about being at home in the nursing home. This research found that residents experienced home as a sense of 'rightness' in being with others in the nursing home.

Becoming at home through movement and care

The sense of rightness experienced by nursing home residents resonates with what Michael Jackson, a phenomenologically oriented anthropologist, describes as 'a sense of existential control and connectedness' (1995, p. 154). In his work *At Home in the World*, Jackson uses the term 'home' to describe people's experience of a reciprocal

person-world relationship whereby one has some control over and connectedness with the world. For Jackson, feeling ‘at home in the world’ emerges ‘when what we do has some effect and what we say carries some weight’ (1995, p. 123). Being at home is thus approached as a metaphor for the experience of trying to strike a balance between acting and being acted upon, and it is considered within a relational framework in which people can assert themselves, to varying degrees, in the world. Of critical importance to Jackson’s notion of home, is the positioning of the need for a sense of connectedness and control as fundamental to human life. ‘Home’, in Jackson’s sense of the term, is thus an ‘existential imperative’ (2002, p. 14). Following Jackson, I reflect on what home is for residents in nursing homes, and I similarly approach home as involving connectedness with other people and things.

My fieldwork suggests that residents experienced a sense of being at home when they felt all right and at ease in the nursing home. However, unlike Jackson’s informants, participants in this study lived this existential struggle through ageing and dying bodies. They experienced the ‘existential imperative’ (Jackson 2002, p. 14), not as a need for some modicum of choice and some sense of control over the course of their own life, but primarily as an innermost drive to move. This thesis follows their footsteps and traces their attempts to move and to act in the world despite shifting states of bodily and cognitive decline. Accordingly, I extend Jackson’s (1995, 2002) notion of home and the existential imperative to consider the everyday experience of nursing home residents with physical and cognitive impairments. Moving beyond Jackson’s assumption that persons share similar experiences of being physically or cognitively intact, I turn to Deleuze and Guattari’s (1977, 1988) theories of becoming and desiring production. For Deleuze and Guattari, there are no beings, only becomings. Instead of considering the world as composed of relatively stable entities of things and beings, everything is in a state of motion, a process of becoming, a multiplicity (Deleuze & Guattari 1988). Becoming is thus not about what is already constituted—subject or object, body or mind, wish or will—but the shifting generative potentials made possible through desiring production. Approaching bodily and cognitive impairments as productive potentials, this thesis poses a challenge to medical discourses, which portray ageing and dementia as a loss or lack.

In this thesis I draw on Deleuze and Guattari’s theories of becoming, their notion of a productive desire to destabilise deficit models of ageing. Productive desire offers a useful analytic lens to examine how residents’ stiff and sore bodies were propelled to

move, becoming set in motion, such as in walking, standing and eating. Using their term ‘desiring machine’ (Deleuze & Guattari 1977), I describe how bodies and things come together in the processes of desiring-production. A mouth and an edible thing, a pair of feet and a surface to walk on, are approached as ‘desiring-machines’ simultaneously affecting and affected—coupled in connective syntheses—inducing different movements and feelings. In walking or eating, the feet and the carpet, the mouth, the edible and the cutlery, respectively, come together as one, co-functioning in an assemblage (Deleuze & Guattari 1988). Assemblage is a key concept for Deleuze and Guattari (1988) to seek to account for change in becomings in which objects, beings, events, processes and discourses of heterogenous natures co-exist as multiplicities (Deleuze & Guattari 1988) through metamorphosis. Thinking about home in nursing homes, I find Deleuze and Guattari’s (1977, 1988) notions of productive desire, assemblage and multiplicity useful to consider residents’ innermost drive to move as a productive desire, which attracts and arranges other things and persons into an assemblage that supported residents in becoming mobile and feeling at home. In short, I propose in this thesis that home is a matter of becoming-at-home-in-the-world and I explore how becoming at home occurs through shifting and entangled movements and potentials made possible through assemblages of multiple things and persons.

This ethnographic study details how bodily impairments affect the ways that people could create a sense of home. With the passage of time in the field I noticed how the loss of sensory capacities, motor coordination, balance and strength made residents’ bodies numb, weak slow and unstable, and thus limited the possibilities for them to become at home in the nursing home. Yet, despite the pain, discomfort and risks posed by walking, standing and eating, many frail and aged residents felt an urge to move and continued to do so, exerting themselves by attempting to move daily. It was often through the most mundane everyday activities of changing position from sitting to standing, walking and eating that residents could, despite bodily decline, feel at home. These were occasions such as: when Mrs Wilson could stand up on her own from an adjustable chair; when Mrs Brie could eat from a lipped plate, and when Mr Harris had his Parkinson’s medication ‘on time’ and, with the aid of his walker, could move around the facility. It was when persons and things came together in ways that generated the movements that residents wanted to make, that a sense of home was made possible. Examining movement through the lens of home, this thesis will show how day-to-day

movements, of walking, of standing and of eating, with other things and persons could open up potentialities for residents to feel at ease despite bodily dis-ease and to become at home in the nursing home. Home, as I will demonstrate in this thesis, was a matter of moving and of being moved, of shaping and of being shaped by one's body and one's world, and it was intimately connected to other people and things in an assemblage (Deleuze & Guattari 1988).

It is important to introduce the variety of things that can comprise these assemblages and which are centrally placed in the day-to-day lives of nursing home residents. Some physical things, such as a 4-wheeled walker and handrails installed in hallways, could play a pivotal role in supporting residents' efforts to move. A 4-wheeled walker (see Plate 4) is designed to provide balance to users when walking, which makes it easy for residents who have issues with stability, to get around. An adjustable chair can provide optimum hip support and assist in standing and transfers with design features of modifiable seat height and angle and comfortable padded armrests (see Plate 5). An inner-lip plate with built up rims and ridges allows residents to catch the food on their fork or spoon (see Plate 6). It works well for residents with low vision or difficulty grasping and moving eating utensils.

Plate 4: 4-wheeled walker.

Plate 5: Adjustable chair

Plate 6: Inner-lipped plate

Technologies such as nursing call-bell and sensor mat alarm systems are widely used in nursing homes to facilitate connections between residents and staff. A nursing call-bell system allows residents to alert staff when they need assistance. A call-bell can be wired and installed in resident rooms (see Plate 7 Middle and Right) or wireless and worn by residents (see Plate 7 Left). The call-bell system displays the room number on staff deck phones, monitors in nurse station and LCD screens in corridors when a resident presses the button.

A pressure sensitive mat is a rubber mat with embedded electronic wires. It is used in nursing homes as a fall prevention strategy to alert staff of residents' movements and need for help (see Plate 8). It is placed either at the sides of the resident's bed or in

front of their chair. When the resident, in bed or in a chair, puts their feet on the mat and stands up, the pressure is detected and an alarm is sent to the paging system in the facility. The resident's room number is exhibited on both the staff deck phones and the LCDs installed underneath the ceilings in the corridor. Staff are required to give a quick response to sensor mat alarms by attending immediately to the resident. If care staff cannot give an immediate response to the alarm by pressing the reset button, the registered nurse on duty will receive a message from the system so that she can contact care staff for prompt action. The sensor mat alarm system is often integrated into the call-bell system to use multisensory media—buzzer bell, LCD display and vibration on staff deck phones—to communicate resident need for assistance to staff.

Plate 7: Left: A wireless call-bell; Middle: The control panel of a wired call-bell on the wall in a resident's room; Right: Wired call-bell

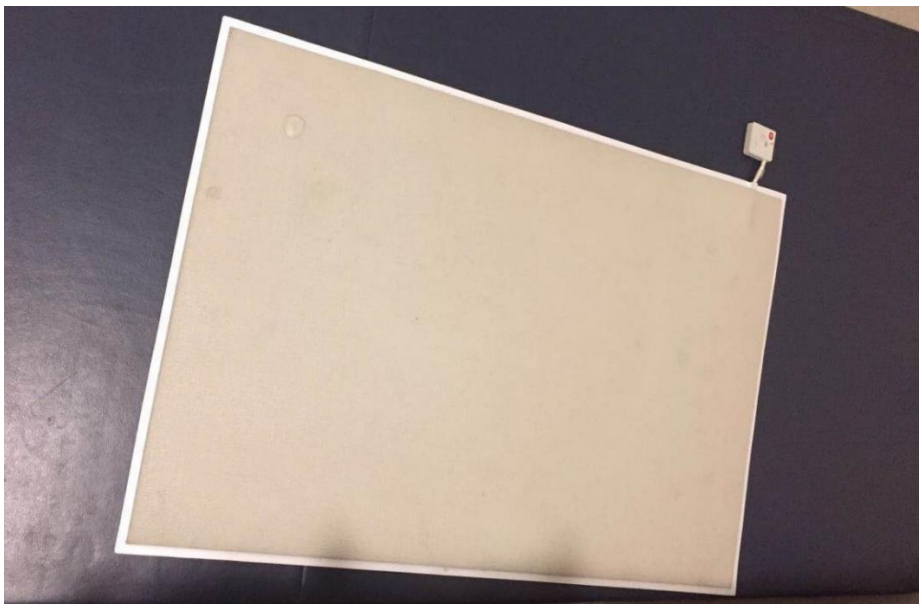

Plate 8: Sensor mat on the floor alongside resident's bed

Alongside this diverse range of technologies, nursing home residents spent the majority of their last years or months with personal care workers. These workers played a critical role in assisting residents to stand, walk and eat. Their job is physically demanding and it calls for their own bodies to move in response to residents' movements. The concept of assemblage is useful in analysing how residents' movements articulate with these multiple persons and things in ways that could sensorially extend (Dennis 2007) residents' bodies in correspondence (Ingold 2017). In an arm reaching for a handrail, a shaking hand joined by a steady hand raising a spoonful of food and a care worker attending to a resident in response to the call-bell, residents' movements are joined with the attentive and responsive movements of assistive things and staff. In examining how these people and things come together, this thesis will show how a sense of home comes from residents' moving, walking and becoming in touch, familiar with and intimately entwined in the relational social world of the nursing home.

These assistive devices, medications and staff assistance that support residents to move are considered as the provision of care service in nursing homes, which is routinely delivered within the limits of care plans and aged care funding instruments. As this thesis will show, while staff, medications and aiding equipment can be assembled to support residents to move, they can also restrain residents from moving. Because residents' efforts to walk were a struggle, residents were more often seated in 'princess chairs' (see Plate 9), pressure-cushioned chairs that are designed with a curved backrest to provide extra postural support and comfort for residents sitting for long hours. Bodies, left sitting for long hours, could thus be restrained from making movements or, in turn, engaging with other people or things in the nursing home. In their duty of care, nursing home staff regularly sought to reduce the risk of injury, particularly through falls, that may occur in those small critical time windows when residents lose their footing or transfer from one position to the next. Residents were prescribed sensor mats as a means of preventing falls, by warning staff of their attempt to stand up from a chair; staff could then act to prevent them from moving on their own. Safety-oriented care-planning often led to the use of Fall Prevention Plans to keep residents safe; however, despite the good intentions represented in these plans, reducing residents' movements also limited sensory extension (Dennis 2007) and reduced the potential for residents to step out of their rooms, to meet others and become at home. Using the concept of assemblage, in this thesis I will analyse how

elderly residents' movements articulated with multiple persons and things, including: staff, medications, walking aids, assistive utensils, adjustable beds and chairs, as well as aged care policies, assessments, care plans and falls prevention programs. I will show how some productive compositional elements are assembled to produce the movements residents wished to make, and conversely, how other assemblages of care comprised counterproductive components, e.g. discourses of risk and agitation, which could restrain and further inhibit bodies. In this thesis, I explore the tension between how 'right' care is conceived and practised according to policies, care plans and procedures, and how residents could be assisted to make movements that they could not make on their own and which felt 'right' to them. Following Mol (2002, 2008), care is approached in this thesis as multiple and, at times, contested, even though care is considered as a definitive moral practice (Kleinman 2009, p. 293) aiming 'to make life better than it would otherwise have been' (Mol 2008, p. 86).

Plate 9: Comfort chair (nicknamed 'princess chair' in nursing homes)

Thinking about care through the notion of home (Jackson 1995, 2002), this thesis will demonstrate that residents' sense of home in the nursing home could not be disentangled from their being supported by an assemblage (Deleuze & Guattari 1988) of care to move all right and feel just right. This thesis extends Mol, Moser and Pols' approach to care as 'a negotiation about how different goods might coexist in a given, specific, local practice' (2010, p. 13) within a logic of care (Mol 2008). Care is understood in this thesis as multiplicities—different assemblages of care—some of which were productive and responsive to resident effort to move, and others were less

productive, or even restricted residents from being able to move and have a sense of rightness of being in the world with others. I approach the former as 'right assemblages of care.' As I will detail in this thesis, assemblages of care that are right for residents require shifting arrangements of people and things coming together to 'step in' or 'lend a hand'. I draw on Mol and colleagues' (2010) work of care as a practice of tinkering, and Rapport's (2018) notion of care as a balance between inclusion and autonomy to show how care, if it is to rightly assist residents to have a sense of home, must be enacted differently as multiplicities, depending on the situation and on the residents' changing conditions and circumstances across different points of their life course.

The inclusion of residents with a range of physical and mental disabilities (due to various forms and stages of dementia) enables me to analyse the varieties of experience of residents as well as to critically reflect on the operations and ethics of care. In his conceptualisation of a social ethics of care, Rapport draws on Jackson's (1995) notion of home to emphasise the importance of caring for the elderly to achieve a sense of being-at-home-in-the-world (Rapport 2018, p. 256). He points to the tension between being for oneself and being for others' with the insight that, while being cared for, the elderly may be constrained from exercising their free will (Rapport 2018, pp. 255-256). He thus argues that care needs to be a matter of preserving the 'personal preserve' of the elderly and 'caring that their autonomy is not infringed: that [is] so far as possible, and for as long as possible' (Rapport 2018, pp. 255-256). As this thesis will show, Rapport's argument that care needs to be a matter of protecting the elderly's autonomy is critical to thinking about care for people with dementia. Yet, with an emphasis on cognitive capacities in his conception on 'personal preserve', Rapport's (2018) conceptual framework of social ethics of care is too limited to facilitate discussions on care for residents with cognitive impairments due to later stages of dementia. Drawing on ethnographic materials, this thesis argues that resident autonomy needs to be understood beyond conscious choice and autonomous action and that there should exist no limits to how elderly people can be rightly cared for across their time in care. To extend anthropological analyses on care (Mol 2002, 2008; Mol, Moser & Pols 2010; Rapport 2018) through the notions of home (Jackson 1995, 2002) and assemblage (Deleuze & Guattari 1988), this thesis considers that a right assemblage of care is pivotal to residents becoming at home in the nursing home. In examining care as multiplicities that come together to support residents to stand, to walk and to eat, this study foregrounds the productive potentials of movement.

Approaching movement in relation to home

Writing from different disciplinary and theoretical perspectives, ageing and care-related studies are frequently seen to draw on the concept of home for an understanding of older people's lives. The etymology of the word 'home' in both German and English shows close association between house, or a dwelling place and home (Bowlby, Gregory & McKie 1997; Giddens 1984; Hollander 1991) in the material sense. The association between house and home was found to be consolidated in English case law in the early seventeenth century (Rykwert 1991, p. 53). Many authors assert that contemporary white Western conceptions of home privilege a physical structure or dwelling (Bowlby, Gregory & McKie 1997, p. 344; Giddens 1984). On the other hand, home is also seen to be conceived as a haven, a confined space that offers freedom and control (Darke 1994), security (Dovey 1985), intimate context for close, caring relationships and scope for creativity and regeneration (Allan & Crow 1989; Bachelard 2014; Cooper 1974; Finighan 1980; Korosec-Serfaty 1984). Related to this view of home is the idea that it is an enclosed, private and domestic space clearly differentiated from public space and removed from public scrutiny and surveillance (Mallett 2004). This idea of home as a comfortable, secure and bounded space prioritises the conceptualisation of home as a singular place.

Unlike the notion of home as a pure domestic space, nursing home is conceived as a contested cultural space 'composed of elements drawn from oppositional spheres of meaning: home and hospital' (Stafford 2003b, p. 121). Nursing home is indeed an intriguing name given to this type of institution for the aged. What is provided, and where it is provided, are represented respectively using two concepts: the practice of nursing and the place of home. The combination of a medical institution with a residential facility is thought to have created a categorical ambiguity for people living and working there. While the concept of 'home' has the connotations of private property, independent living, domestic setting and intimate relationship, the concept 'nursing' is associated with the fragility, disability and decline of aged bodies, and the 'bed-and-body work' (Diamond 1992; Gubrium 1975, p. 123) involved in an institutional care setting. This contradiction in meaning is seen by Stafford as 'the chief problematic of the nursing home—its *inherent cultural ambiguity*' (2003a, p. 8 Italics original). Extending Stafford's (2003b, p. 121) illustration of nursing home as possessing the dual character of home (in that older persons are residents) and hospital (in that older persons are patients), Bland (2007, p. 941) claims that nursing homes have two

additional characters: hotel (in that older persons are customers) and hospice to those who are dying (Dekker 2018). Seen in this way, the institution is a hybrid of all four characters.

Researchers often frame their nursing home studies, explicitly or implicitly, within the relations between home and nursing home and tend to focus on the *movements of people* from the home to the nursing home, which is about a *transition* from one place to another. Some researchers consider moving into residential care a rupture, 'a transition from "doing for" to "being done for", as well as a transition from independence to dependence' (Higgins 1989, p. 141). In the analysis of the transition as a rupture and displacement from home, home and nursing home are conceived as two oppositional concepts, domains or sociocultural spaces (Stafford 2003a). The focus is often around the structures and practices on the institutional level (such as the care culture, routine practice and built design), which are seen as having significant influence on residents' lives (Ryvicker 2009; Willcocks, Peace & Kellaher 1987). The transition from home to the nursing home is considered as involving multiple forms of loss—the displacement from the family home (Milligan 2003), dispossession of the pre-loved objects and dissociation with the loved ones—leading to an overwhelming sense of loss experienced by elderly people in developed countries (Fiveash 1998; Iwasiw et al. 1996; Nay 1995) as well as in developing economies (Adamek & Balaswamy 2016; Dutt 1998). The loss incurred in the transition to nursing home life is often thought of as irreversible since these elderly people can neither recreate a home in nursing homes (Stafford 2003a) nor return to their own homes (Vesperi 2003). The majority will eventually die in nursing homes (Kinley, Froggatt & Bennett 2013) with increasing dependence upon assistance, tools and facilities (Kofod 2008). A sense of sadness is portrayed in the research on nursing homes, which documents experiences of residents who often yearn to go back to homes that were permanently lost (Laird 1979; Vesperi 2003). Residents who have everything done for them by staff in the nursing homes, are portrayed as feeling helpless and lacking in control (Willcocks, Peace & Kellaher 1987).

The notion of home and nursing home as a fixed and finished structural given is increasingly questioned in research (see for example, Milligan (2000) and Milligan and Wiles (2010), writing about the changing context of placing care at home). Some researchers position home and the nursing home not in opposition but as relational concepts held in tension. They highlight potential continuities of life before and after

the move into the nursing home by incorporating what was in the residents' prior existence, including personal histories, possessions, family and social relations, into their existential present (Cram & Paton 1993; Gubrium 1993; Lamb 2009; Perkinson 2003; Robbins 2013; Rowles 1993; Shield 2003). With a shift of focus from rupture to continuity, researchers increasingly understand home as a *sense of home* and describe how home is felt and thought of. For theorists on home, a sense of home is not only made through social and discursive constructs as meanings (Gurney 1997; Somerville 1992), but also through lived experience as senses and feelings (Ahmed 1999; Gurney 1997; Jackson 1995; Somerville 1992). As life goes on, a sense of home may evolve over time. It can be felt as a sense of orientation through production (Ahmed 1999), a sense of security, stability and belonging (Latimer & Munro 2009; Samanani & Lenhard 2019); it can also be experienced as a sense of defence, protection and autonomy, which is conveyed in the nineteenth century saying, 'The Englishmen's house is his castle' (Rykwert 1991, p. 53). The domestic environment is conceptualised as providing elderly people with an important sense of control (Paton & Cram 1992; Stones & Gullifer 2016; Whitmore 2001) where elderly people can interact with long-term possessions.

Nursing homes, as the following chapter details, have evolved into a more home-like environments, through their built design and environment modifications (Bradshaw, Playford & Riazi 2012; Lee, Yu & Kwong 2009). Residential aged care facilities encourage residents to bring personal possessions with them (Lovatt 2018, p. 366) as an initiative to create continuity of life before and after nursing home placement. During transitions between homes and institutions, elderly people are found to engage with material possessions, such as cherished books, in creative ways to sustain social personhood (Luborsky, Lysack & Van Nuil 2011). It is assumed that the objects from their former homes can help to transfer a sense of personal identity (Cram & Paton 1993; Rowles 1993), home and belonging to their lives in the new rooms in an unfamiliar institutional setting so that they can feel at home. Considering home and nursing home as material surroundings filled with objects and beings (Nord 2013), this material culture approach opens new possibilities of seeking potential continuities across the settings of home and nursing home through the *movement of objects* from one home into the other. As shown in the literature, these nursing home studies are continuously framed within the concept of transition—the movement of elderly people from home into nursing home. It is important to note, a notion of rupture—a

discontinuity of life at home—is inherent to the concept of transition. Seeking to account for continuity of life and a sense of home while living the discontinuity—transition from home to the nursing home—researchers often attempt to identify the objects, beings, or relationships that are *of home* and *moved with people* from home into the nursing homes.

Arguing that objects are not just passive symbols representing a sense of home, Lovatt attempts to show that it is not the objects from previous lives but the interactions between residents and these objects that lead to residents' feeling at home while 'doing home' (2018, p. 366). By the term 'doing home', Lovatt identifies a particular set of regular practices and routines including 'acquiring new things—as well as displaying existing possessions—and also through interacting with mundane objects in everyday social and relational practices such as cleaning and hosting' (2018, p. 366). With a shift of focus away from the place where elderly people live and the objects that they possess, researchers increasingly posit their foci of study on resident effort to adapt and adjust to the new nursing home environments (Brooke 1989; Lee, Woo & Mackenzie 2002; Lovatt 2018; Wilson 1997) so that they can recreate a sense of home in nursing homes. Nursing home residents are portrayed as being able to settle into their lives in nursing homes with a sense of peace, stabilisation and satisfaction (Lee, Woo & Mackenzie 2002; Lovatt 2018). As Minney and Ranzijn convey in their study on a South Australian nursing home, a resident is reported to claim that, despite the loss of my "beautiful home, I think I'm happier here" (2015, p. 919). With a life that is as close as possible to that lived before admission, elderly people, according to these studies, 'regain normality', maintaining their individual 'sense of biography, of self and of belonging' (Nolan et al. 1996, p. 271).

In describing residents' practices of 'doing home' (Lovatt 2018, p. 366) and in emphasising residents' efforts to adjust to their new life in nursing homes (Brooke 1989; Lee, Woo & Mackenzie 2002; Wilson 1997), researchers seek continuity in *what residents do* across changing settings of home and nursing home. This approach views the transition from home to nursing home as the process of becoming at home (Allan & Crow 1989, p. 11; Lovatt 2018, p. 366). Drawing on Allan and Crow's theory of 'becoming at home' as 'essentially an active process which involves "housework" in the broadest sense of that term' (1989, p. 11), Lovatt suggests that a feeling of belonging and a sense of control 'came from the work that residents did in incorporating the objects into a new sense of home' through routine practices which 'demonstrated

their control of, and belonging in, the materiality of their rooms' (2018, p. 374). Taking a material culture approach, Lovatt locates home in the interactions between nursing home residents and the physical objects in the material environment of resident rooms. Here, 'house work' (Allan & Crow 1989, p. 11) and practice of 'doing home' (Lovatt 2018, p. 366) are identified as what are *of home* and *moved with people* from home into the nursing home. Lovatt further argues that being at home in a nursing home need not be so different from being at home at other stages of the life course and in other settings (Lovatt 2018, p. 375).

Nevertheless, as this thesis will show, although residents with severe physical impairments or cognitive impairments due to later stages of dementia could no longer carry out the routine practices that Lovatt names as the practice of 'doing home' (2018, p. 366), they could still experience a sense of home in the nursing home. Associating a sense of home with a particular type of practice, limits the scale of investigating how residents with different bodily conditions (e.g. with or without cognitive impairments) and in different stages of life (e.g. with a terminal disease or not) could feel at home in the nursing home. As shown in Lovatt's (2018) research, seeking to account for residents' sense of home through the lens of transition often leads to an approach which treats life across home and nursing home as ruptured and discontinued. While researchers seek continuity and a sense of home in objects, beings, relations and practices that are of home and move with people from home into a nursing home, a sense of home is inevitably understood and represented through these types of objects, beings, relations and practices.

Departing from this approach, I shift my focus from the movement of elderly people from home to nursing home as a life transition to the *everyday movements* that residents make within nursing homes. I hold the view that life continues across home and the nursing home *not* because of particular possessions, persons or practices, but because people continue to live their everyday lives in nursing homes through walking, standing and eating—the day-to-day movements that are a fundamental mode of being (Barbaras 2008; Ingold 2011). I attempt to explore a sense of home as the senses and feelings that are intrinsic to one's being-in-the-world by attending to the minutia of the movements of bodies in the nursing homes to understand residents' movements as their ways of becoming at home.

To return to Jackson, home is not associated with any particular property, place, possession, person, or practice. His term ‘being-at-home-in-the-world’ (Jackson 1995, p. 123) describes a particular way of being and feeling in the world as having ‘a sense of existential control and connectedness’ (Jackson 1995, p. 154). According to Jackson, to have a sense of connectedness and control is a fundamental human need—an ‘existential imperative’ (2002, p. 14) that underlies all human strategic movements. Following Jackson in considering home as a matter of ‘being-at-home-in-the-world’ (1995, p. 123), I understand ‘home’ in a nursing home as how residents can exert themselves into the world and become connected through sensory extension (Dennis 2007) and correspondence (Ingold 2017).

Reproducing home

As Lovatt points out in her study, key to the routinised practices of ‘doing home’ are the interactions between residents and objects in habitual ways through which persons and objects become closely connected (2018, p. 366). She argues that residents feeling at home comes from the process of doing home in which feelings and meanings of home can be generated (Lovatt 2018). Reflected in this approach is the understanding that a sense of home is experienced as relational and processual.

Nonetheless, in emphasising habitual interactions and routinised practices and addressing the question of what residents do to feel at home (Lovatt 2018, p. 366), Lovatt (2018) focuses on *naming* what residents do, feel, think and talk about. She generates concepts of ‘doing home’ and ‘feeling at home’ from what residents do, such as cleaning and hosting, and feel, such as a sense of belonging and a sense of control (Lovatt 2018). She conflates residents’ feeling and doing home in a symbolic construction of home. In mostly reporting what people do (naming the practices), not how they do it (describing the processes), Lovatt (2018) does not provide the ethnographic materials that support her key argument that home is processual.

In conflating ‘doing home’ with ‘feeling at home’, Lovatt’s (2018) research overlooks the difference between what one may say, and do, and what one may experience. What people do (practices) and what they feel (experiences) can be different even in the situation where people engage in the same kind of practice. Lovatt concludes that being at home in a nursing home need not be so different from being at home at other stages of the life course and in other settings (2018, p. 375). For this to be true, the way people feel and do home, through experience and practice, would have to remain

largely the same across different stages and settings of life. My ethnographic study, however, shows that residents' efforts of doing mundane everyday activities are affected over the course of their lives by their bodily conditions and situations. Bodily deterioration accelerates at the last stages of life. In failing to consider how ageing affects our bodily conditions over different stages of life, one dimension of continuous and constant change is ignored. Lovatt's (2018) study focuses on the experiences of eleven residents who do not have dementia and are relatively physically able and though residents' 'limited capabilities' (Lovatt 2018, p. 374) are observed, their impact on how home could be done and felt differently remains unexplored. Although other research suggests that physical disabilities do not necessarily prevent residents from living active lives through engaging with their material surroundings (Nord 2013), its impact is captured in other anthropological nursing home studies and conveyed using residents' narratives. In a conversation with the ethnographer, T. D., a North American nursing home resident, asserted that the residents 'could do better [with helping themselves] if they could get walking' and 'be happy' (Vesperi 2003, p. 88). Lily Robinson, a nursing home resident interviewed by Jaber Gubrium, contrasted her experience as a 'whole being' at home, with her sense of 'being partial' living in nursing home with her loss of capacities and her inability to 'take care of everything' after the amputation of her legs (1993, pp. 128-129). These diminished capacities not only impact on what residents can do, but also how they do it. While the word 'cleaning' can be used to typify what residents do using a *CarpetMate* cleaner, it cannot signify how Susan, a resident sketched in Lovatt's study, could manoeuvre around the room with the cleaner in one hand and her walking frame in the other (2018, p. 372).

Residents' efforts in doing mundane activities are also affected by their material surroundings. What material things, e.g. an electric kettle and a toaster, can be made available to which resident (with or without signs of cognitive impairments), and how these material things are provided (temporarily or permanently), and used (supervised or unsupervised), vary in different settings and situations. Though the opposition between home and nursing home is itself a cultural construct, the particularities of domestic or institutional material environments can hardly be ignored. Similar to the multidimensional home as a site of caregiving (Milligan 2000), a nursing home is a multidimensional institution, a site of contestation and complexity (Stafford 2003a), constitutive of residents' 'regular practices, routines and interactions with their material surroundings' (Lovatt 2018, p. 372). While, in Lovatt's study, residents could exert

control over what and how certain material things are made present in their individual rooms in the nursing home, their acquisition of these material things is made possible with the support of facility management and assistance from staff. Assistance provided in its varied forms and styles, or the lack of it, may impact on residents' recreation of a sense of home in the nursing home. Individual efforts to recreate home are always made in relation to the presence and participation of supportive other material things and persons, such as aiding devices and staff.

This thesis attends to the lived experience of residents' declining bodies, and the care provided to them to enable them to move. As this thesis will show, ageing impacts on bodies; thus living out the final stages of one's life in a nursing home is not the same as living earlier stages of one's life course. Residents in this study often recreated a sense of home through the most mundane everyday activity of walking beyond the physical boundaries of their individual rooms. Instead of interacting with objects within their rooms, residents who walk daily are in constant touch with material things located in communal areas, such as handrails in the corridors, or the tables and chairs in the lounge and dining areas. By conceptualising being at home in association with 'housework' (Allan & Crow 1989, p. 11) which exclusively involves objects within residents' individual rooms (Lovatt 2018, p. 366), Lovatt risks the danger of systematically overlooking how residents could recreate a sense a home in other ways and places through connecting with non-personal objects, such as carpeted floors, grab-rails and corridors. As this thesis will show, it is not what individual residents do (for example, cleaning their room and hosting visitors) that makes becoming at home possible in nursing homes. Rather, becoming at home emerges in the lived experience of being cared for to do home (Lovatt 2018, p. 366) through not only residents' bodies but other bodies and material things that support and respond to residents' attempts to move, in ways that lead to their feeling all right living in nursing homes. It is precisely at this point that this thesis takes a departure from the existing literature on *what* doing home means to individual residents, to foreground instead the relational and embodied experience of *how* home is experienced in a nursing home.

How is home experienced in a nursing home?

Barbaras (2008), a French phenomenologist, suggests that how a person relates to their world can be thought of in two modes of being—a 'living being' in the transitive sense and 'lived experience' in the intransitive sense. How a person relates to the world is fundamentally different in the modes of living being and lived experience. In the

mode of living being, the world is filled with persons and things objectified through observation and contemplation. On the other hand, the mode of lived experience describes how 'the feeling or experience of something' (Barbaras 2008, p. 3) is preconsciously constituted, yet, not caught in reflective thinking and known to the person. In this sense, there exists no conscious experience in this mode of lived experience apart from its constitutive process. Other phenomenologists, including Jackson (1996), Merleau-Ponty (1962) and Heidegger (2010), make a similar distinction. Key to an understanding of the processual nature of residents' feeling and doing home, their experience of a sense of home needs to be thought of as constituted through lived experience. While their feeling and doing home are consciously felt, thought and known (to a living being), the constitution of what is felt, thought and known is preconscious and prepersonal.

For Merleau-Ponty, our perceptive experience is preobjective, which is to say that 'objects are a secondary product of reflective thinking; on the level of perception we have no objects, we are simply in the world' (Csordas 1990, p. 9). In referring to the routinised practices of 'doing home' as the 'interactions between residents and objects' (Lovatt 2018, p. 366), Lovatt can hardly describe the process of residents doing home simply because a constitutive process is preconscious and preobjective. Both residents and the material objects in their rooms only become existent in the process of residents doing and feeling home. An example of how people and physical things, such as musical instruments, can become connected preconsciously is described in Dennis's (2007) ethnographic work on rehearsal and performance.

Distinguishing Merleau-Ponty from Husserl, Heidegger, Sartre and Schutz, Dennis points out that 'Merleau-Ponty's elimination of the boundary between mind and body comes into its own, for within his work, the body can be understood as the grounds of all perception and can include within its bounds such a thing as "the mind"' (2007, p. 33). Dennis follows Merleau-Ponty (1962) in that she takes the body to be the ground for all perception and the sensuous life of the body to be at the heart of thought (2007, p. 34). Following the lead that Abram (1996) took in his ecological and philosophical explorations, Dennis explores the person-world connectedness and control not on the conscious but on the preconscious sensual-perceptual level. Drawing on and extending the critiques that Michel Serres (2014) made of Merleau-Ponty's phenomenology, Dennis (2007) demonstrates how in multisensory processes, music players and musical instruments connect with one another preconsciously through

sensory extension and incorporation in different modalities. This notion of sensory extension and incorporation is central to an understanding of what Latimer and Munro consider as the relational extension (2009)—establishing person-world connectedness through routine practices and creating a sense of belonging.

A living body is not only 'the ground of perceptual processes that end in objectification', but also a 'general power of inhabiting all the environments which the world contains' (Merleau-Ponty 1962, p. 311). For Merleau-Ponty (1962), bodily motility is primarily experienced as basic intentionality—our way of being geared towards the world. The physical things and spaces can be incorporated into self on the motile-sensual-perceptual level. Life as such must be understood as movement in a radicalised sense, in which the living being is no more the subject than the product (Barbaras 2008, p. 3).

For Barbaras, the distinction made between the modes of living being and lived experience is conceptual and artificial, and is rooted in the ambiguity that is 'the mark of a primary sense of life' (2008, p. 4). The original sense of being, before any analytical distinction, is simultaneously a living being and lived experience in the intransitive sense. To understand life as the original unity of the living being and the lived experience across the conscious and preconscious levels, Barbaras proposes a third mode of being that extends one into its world without objectifying oneself into a living being (2008, p. 8). He suggests that movement is the manifestation of life of a living being 'as it is a moment of accomplishment [which] passes into exteriority because it is only realized through concrete movements' (Barbaras 2008, p. 14). Barbaras argues that movement is this fundamental and irreducible mode of being (2008, p. 9).

Ingold (2011, 2017) also considers that being alive is a mode of moving through the world with others. He coins the term 'correspondence' (Ingold 2017, p. 9) to describe the dynamic processes of engaging with other material things and beings in and through movements. Correspondence, according to Ingold, 'is the process by which beings or things literally answer to one another over time, for example in the exchange of letters or words in conversation, or of gifts, or indeed in holding hands' (2017, p. 14). In the context of this thesis, correspondence can be seen as the process in and through which residents' efforts to move were joined by other supportive material things and persons. Ingold's notion of correspondence describes the processual formation of connectedness, through the exchanges of linguistic expressions between persons, or engagements between persons and things in co-movements such as walking together.

Thinking about home in the nursing home through the concepts of perception (Merleau-Ponty 1962), sensory extension (Dennis 2007), movement (Barbaras 2008) and correspondence (Ingold 2017) enables an attendance to the varieties of experience for residents with different states of bodily and cognitive decline. This thesis considers two aspects as crucial in seeking further information about the processual nature of residents creating a sense of home. One aspect describes people's conscious experience of a sense of home as a modality of being while the other aspect speculates on the constitutive processes underlying the conscious experience of a sense of home. To do this, I turn to Jackson's (1995, 2002) notion of home for a theoretical framework on conscious experience of a sense of home, and Deleuze and Guattari's (1977, 1988) theories of becoming for extensions and expansions on Jackson's notion of home so that the constitutive processes of a sense of home can be illuminated and understood. In doing so, this thesis re-examines and problematises established conceptions and theories symbolising what are felt, thought and known consciously, including subject, object, body, mind, need, will, purpose, choice and action. With a shift of focus from conscious experience of a sense of home to its constitution in the preconscious productive processes, this thesis extends Jackson's (1995, 2002) notion of home to propose that home is a matter of becoming-at-home-in-the-world. Exploring the constitutive processes of a sense of home has methodological implications and poses a methodological challenge. In the next section I will draw on staff accounts and relevant literature to discuss these implications and challenges.

Movement as methodology

In the pre-fieldwork stage, I considered this study as mostly epistemological and methodological—the objective was to *know* the everyday experience of nursing home residents using appropriate research methods. The conventional methodology of qualitative study on experience is centred on linguistic expressions in verbal and written forms. The research participants are expected to produce narratives in interviews. These narratives are taken as being representative of what has been lived in the participants' lives. While an individual participant's narrative is inevitably personal and bound to his or her own situation, the number of participants in the research becomes important as the explanatory power of the given research relies on the high degree of similarity shared by a large group of participants. The methods of interview and text analysis are at the core of this research methodology. The underpinning assumption is that the knowledge about other people's experience—the subjective

meanings of what has been lived—can be gained through communication in linguistic forms. A high proportion of previous nursing home studies on residents' experience followed this research convention to collect narratives, extract themes and draw conclusions based on their synthesis and analysis of interview transcripts (Bergland & Kirkevold 2005; Bradshaw, Playford & Riazi 2012; Lee, Yu & Kwong 2009).

With an emphasis on the narratives of research participants, the validity of research is thought as closely associated with the effectiveness of the tool—the interview questions—and the number of participants. This can be seen in how the Human Research Ethics Committee of the University of Adelaide raised some issues during the review of my ethics application concerning: the 'adequacy and rigorousness' of the schedules of interview questions; the pilot testing of these questions; and the numbers of residents, staff and family members who would be interviewed. I was also advised by the facility management to commence my fieldwork in a particular area where the residents were considered as cognitively competent in giving informed consent and capable of expressing themselves in interview. Reflected in these concerns with this project on residents' experiences is the emphasis on the participants' capacities to reflect, articulate and communicate what they have lived through.

Nevertheless, one of the most devastating effects of bodily decline is cognitive impairments. The great majority of nursing home residents suffer cognitive impairments to varied degrees, which affect their capacities to reflect upon and articulate their thoughts and feelings. Residents who could be included in the research by giving informed consent are neither representative of the residents in the two facilities where I did my fieldwork, nor of the entire nursing home population, in Australia or elsewhere (Olsen et al. 2016; Palm et al. 2016). The practical significance of this research would be severely compromised if most nursing home residents are excluded from this study.

One of the two facilities where I did my fieldwork regularly hosted research projects in disciplines ranging from speech pathology to gender studies. Staff in this facility openly expressed their reservations on using interview as a primary research method for nursing home related studies. One personal care worker said: "Most of them [residents] can't talk properly. Not sure how many of them can understand your talking." In contrast to the university Human Research Ethics Committee members who favoured the method of interview to that of fieldwork, staff in the field found the ethnographic method

of participant observation “interesting” and one staff member remarked that is was “not too different from how we have learnt about the work and the residents”. A care worker once used the terms ‘participation’ and ‘observation’ to explain how nursing and care staff get to know the residents through two separate modes of working in the nursing home settings. She said: “Aged care is actually about hands-on work. But the nurses spend a lot of time watching and writing.” As a personal care worker herself, she is mostly involved in practical activities with residents, which demands close-up interactive bodily movements and constant intimate human touch. Alternatively, nursing and allied health professionals are trained to ‘name’ the bodily conditions and capacities through non-engaging observational assessments using medical knowledge.

What intrigued me is how the care worker related these two modes of working in the field to the issue of *knowing* and claimed that the nurses would have known the residents better if they could walk with them rather than watching them walk. She said:

> I told them [the nurses] they would know the residents better if they could walk with them instead of watching them walk. They said what they did was objective observational assessment of the residents’ mobility. They could know the residents better if they are *not* involved in the residents’ walking.

She emphasised on the word ‘not’ with an expression of disapproval, and added: “I don’t know how to put things into words [to describe and define], but I know how to help residents with their walking.” What is illustrated in this account is her experience of acquiring a *tacit* sense of knowing through doing and undergoing—moving together with another person—while assisting residents with walking. It is distinctively different from producing representations of others’ experience through observation and interpretation (Schutz 1967) of residents’ walking. A close look at this account reveals three distinctions made between the nurses’ knowing by watching the residents walk and the care workers’ knowing by walking with the residents.

First, the two modes of knowing that she made distinctive between nurses’ non-engaging observation and care workers’ participatory assistance with residents’ walking are phenomenologically different. According to Schutz, it is the acts of typification of the other person’s lived experiences for the former and the ‘genuine understanding’ of the other person in a face-to-face situation and a ‘we relationship’ for the latter (1967, pp. 163-167).

The second distinction that she made cannot be explained using Schutz's framework of intersubjectivity: while she claimed that she could know her residents better by taking care of them, she could not tell *what* she knew other than what she described as a 'feel', and she could not explain how she knew it. Her experience is by no means unique among care staff working in a nursing home. So often during my fieldwork, the care workers could not verbalise what they did, but offered to show me the ways of doing it. They could demonstrate what they knew in *action* but not in *explication*. As Polanyi (1958) noted, although language is a vital tool for sharing knowledge, we can often know how to do things without either explicitly knowing or being able to articulate to other persons why we know what we do. The sense of knowing of care workers comes from a 'feeling', which is acquired through years of doing care work with residents.

The third distinction that she made is about the relations between knowing and doing. Unlike nurses and researchers who are engaged in observation and interpretation with the purpose of producing explicit knowledges about residents' experiences, personal care workers are committed to the hands-on work of 'doing'. A sense of knowing is how they feel when they assist residents at the right time, in the right place and in the right ways so that residents start walking all right and feeling just right in walking well. In more exact words, what care staff have acquired through caring for the residents is an *understanding* constituted in the process of walking with residents.

Merleau-Ponty's analysis on perception reveals a distinction between the perceptual and reflective levels of experience. On the perceptual level, the body is 'a certain setting in relation to the world' (Merleau-Ponty 1962, p. 303). With an emphasis on our perceptual experience as preobjective, Merleau-Ponty suggests that subjectivity is 'all I see … by being this body and this situation, and through them, all the rest' (1962). In this sense, the constitutive process of lived experience is ontological to our embodied being-in-the-world. Senses and feelings on the perceptual level can be consciously experienced as an *awareness* of one's own being-in-the-world. In and through the process of staff walking together with a resident, both residents' bodily feeling of just right while walking and what staff described as a tacit *understanding* of how residents could feel just right in walking are constituted. Nonetheless, according to Schutz (1967), what is preconsciously lived through sensing and moving can be consciously felt on the perceptual level but not thought and known to the person unless they engages in reflective thinking. In short, without staff reflecting upon what they have

experienced, their understanding of residents' experiences of walking remains a tacit sense of knowing.

The discussions so far have shown that, exploring the constitutive processes of a sense of home has methodological implications and poses a methodological challenge. The challenge focuses on the likely limits of articulating what is preconsciously lived through as *immersive participation*. Non-engaging observation, like what nurses do for the purpose of assessments, may aid in articulation; yet, by being observant *to* the resident, the deeply embodied and situated dimensions of being immersive in walking *with* residents is missing.

How can the anthropologist meet this methodological challenge so that residents' experiences of feeling at home in the nursing home can be illuminated *not* as a static being but a dynamic becoming? How to reveal what is in the deeply embodied dimensions 'as intercorporeity and through the five senses as introceptivity' (Jackson 1998, p. 12), which is elusive to the conscious attention but hidden in a tacit dimension of feeling as knowing (Polanyi 2009 [1966])? To what extent can anthropologists gain access to the experiential dimension of other people remains a question. Referring to the work of Hallowell (1955) with the Ojibwa people of north-central Canada, Ingold asserts that the endeavour of doing anthropology is characteristic of the constant awareness of alternative ways of being (2010, p. 239) with the objective to acquire a comparative and critical understanding of human beings in the one world we co-inhabit (2010, p. 229). The alternative ways of being can be understood in a varied mode of living, such as dreaming, as in the case of the Ojibwa people. Hallowell's Ojibwa mentors told him, the world remains the same, in waking or dreaming, while your experience of the world becomes different:

> You perceive it with different eyes or through different senses, while making different kinds of movements—perhaps those of another animal such as an eagle or a bear—and possibly even in a different medium such as in the air or the water rather than on land. When you wake, having experienced an alternative way of being in that same world in which you presently find yourself, you are wiser than you were before (Hallowell 1955: 178-181 as in Ingold 2010, p. 239).

According to Ingold, while co-inhabiting in the one world in an altered mode of living, such as 'being there' as an anthropologist in Geertz's (1988) sense, the alternative ways of being can be understood through dwelling in place, doing the activities,

sensing the difference and reflecting on the experience, and making sense of what is felt as different. ‘It is not a question of going native,’ states Geertz, ‘It is a question of living a multiplex life; sailing at once in several seas’ (1988, p. 77). To do anthropology is therefore, as Ingold (2010) argues, to experience the altered ways of being and self-reflect upon such experiences—to dream like an Ojibwa.

Doing anthropology or not, we are all exploratory probers while inhabiting the world. The probability of me knowing anything at all comes first and foremost from my experience as a self-conscious and reflective prober in my environment. This happens by facilitating my body to reach out to sense and feel, to attend and respond, to observe and describe, and to constantly suspend my assumptions at any given moment and ponder upon what is happening. What distinguishes anthropologists from other members of a given social environment is *not* their experiences of ‘being there’ (Spry 2001, p. 710) but how their being there and their self-reflections of being there become a research tool while ‘being here’ (Spry 2001, p. 710). By ‘being there’ (Spry 2001, p. 710), the body becomes ‘a certain setting in relation to the world’ (Merleau-Ponty 1962, p. 303) on the perceptual level. Fieldwork is inscribed into the body of the researcher in particular ways as senses and feelings that are experienced as a *different* ‘feel’—an awareness of one’s being-in-the-world in certain *alternative* ways. Then, by ‘being here’ of the research’s own scholarly reflection (Spry 2001, p. 710), the subjective meaning of the foreign feel and the ethnographic insights into the alternative ways of living become accessible to the researcher. The Ojibwa people do not think about themselves and other beings as distinctively separate and individualised entities. They gain insights of life by exploring altered modes of living, e.g. moving like a fish, smelling like a bear and seeing like an eagle. To do anthropology like an Ojibwa, an anthropologist needs to use herself as a principle research tool.

Many anthropologists draw on their own fieldwork experiences for ethnographic insights. Christine Helliwell (1996) reaches an understanding of Gerai experience of sociality through her own experience of living in the Dayak Longhouse. Conducting fieldwork in North and West Africa, Paul Stoller draws on his experience of becoming ill and suffering various misfortunes to call for a more ‘sensuous scholarship’ to ‘eject the conceit of control in which mind and body, self and other are considered separate’ (Stoller 1997, p. xii). Both Stoller’s *Sensuous Scholarship* (1997) and Sarah Pink’s *Doing Sensory Ethnography* (2015) argue that rather than being caught in a web of

reasoning and metaphysics, anthropologists need to make connections with people, material things and the surroundings through sensory and affective ways.

According to Barbaras (2008), the original sense of being before any analytical distinction is simultaneously a living being and lived experience in the intransitive sense. To understand life as the original unity of the living being and the lived experience across the conscious and preconscious levels, Barbaras proposes that movement is the fundamental and irreducible mode of being in which one:

> gives itself in exteriority without being developed as an object, that nevertheless affects itself without enclosing itself in immanence—and whose interiority calls for, rather than excludes, an exteriorization' (2008, p. 8).

In this sense, movement is a process of becoming-moving and simultaneously becoming-feeling just right with moving—the actualisation (or, 'exteriorization', in Barbaras's sense) of many physiological (or, 'internal', to use Barbaras's term), perceptual and preconscious processes. To follow this chain of thoughts, how residents move is to be considered as ontological of their experiencing a sense of home in and through moving, and how care staff move with them is to be considered as methodological of their acquiring a tacit sense of knowing residents' experience of home. In the situation of nursing staff, how residents experience walking is materialised into movements, which is observable in the process of actualisation.

Taking a phenomenological stance, this thesis uses movement as the methodological vehicle and aims to acquire an *understanding* of how elderly Australians could feel at home in a nursing home at the last stages of life. The word 'understanding' refers to the ethnographic insights gained through experiencing the altered ways of being and self-reflecting on such experience, which is by nature processual and experiential. Key to the use of movement as the methodological vehicle in this thesis is for the anthropologist to undergo a multifaceted ontological process—a sensorially immersive 'process of gradual familiarisation in practice' (Hastrup & Hervik 2003, p. 8). This provides 'the occasion, the pretext and the locus of the drama that is the source of anthropological reflection' (Hastrup 1990, pp. 45, 51), and a continuous process of observation and reflexivity in which the observed and reflexive are isolated and objectified. In taking the alternative roles of: walking like residents; walking with residents; observing residents and staff walk: and making up a care plan to prescribe

staff-assisted walking and transfer for residents, the anthropologist is cultivated, both sensorially and affectively, for producing ethnographic insights.

Plate 10: The ethnographer learning to walk with a walking frame and assistance from a physiotherapist

As shown in the picture taken during my fieldwork (see Plate 10), I learnt to walk with assistance from a physiotherapist and a walking frame. Meanwhile, I sought to videorecord how I walked with assistance and I walked to assist residents, to visualise the movements and processes. In watching the movements in these contexts, I could relate how I felt while moving with what I observed while watching, to reflect upon the process and make explicit what was tacitly felt through descriptions and understandings. In nursing homes, videorecording of resident movement was difficult. Residents who were able to give informed consent declined my invitation to participate. Residents who had a diagnosis of dementia could not participate in the videorecording because they were considered unable to give informed consent. I was thus unable to record how I assisted residents to walk.

With permission from the facility management and support from staff, I videorecorded how I was assisted to walk, to transfer from bed to chair and to reposition in bed (in the roles of different residents in varied bodily conditions). Before filming, I conducted multiple interviews with two physiotherapists about their professional training, their perspectives and understandings of their work of mobility assessment, and the routine

practices of staff assisting residents to move. To give staff ideas of the context, I made Mobility Care Plans for the residents whose bodily conditions and ways of walking and moving I aimed to experience. The care plans were developed using the templates that staff used in their daily work. I showed drafts of care plans to the registered nurses, enrolled nurses and care staff with whom I made the acquaintance to seek their comments. Their feedback was written into field-notes and used to revise the care plans.

Seven video clips were recorded, with one on walking, two on repositioning in bed (conducted by two pairs of staff members and recorded in two occasions) and four on transferring from bed to chair (recorded in one occasion by the same pair of care workers; see Plate 11). The physiotherapist who assisted me to walk and two care workers who assisted with the repositioning in bed (first recording) and transfer from bed to chair were invited to watch the videos, and they reflected upon and talked about their experiences in interviews. One registered nurse and one care worker who were not involved in making these videos in the first occasion were invited to an interview to watch the videos, comment on the ways that I was assisted to move, and demonstrate how I could have been assisted with more ease and comfort in the second recording of the repositioning in bed. I also played these videos to six residents, who did not have dementia, either individually or in a group. Their comments were recorded in field-notes.

Plate 11: The ethnographer assisted by two care workers with transferring from bed into a princess chair

In this process of immersive participating, observing, reflecting, describing and communicating, staff-assisted residents' movements were felt, seen, thought through and discussed. The entire process made it possible for me to have different experiences (being assisted by different staff members in different contexts), draw different perspectives (of residents, physiotherapists, nurses and personal care workers) and combine different practices (assessment, care-planning and staff-assisted walking and transfers) into my understanding of how residents are assisted to move in the nursing homes. When I was assisted by the same pair of staff with transferring from bed to chair, I was 'manually handled' and talked about differently in different circumstances. When I was more responsive towards staff assistance, we could move together with ease and they described me as "helpful". But, when I appeared to be reluctant to respond and move, and staff had to lift my legs to assist, they described the situation as "difficult". I also found that different staff used different manual handling techniques with me, according to their experience with residents and understanding of the resident's bodily condition described in the made-up care plan.

This multifaced open-ended process is pivotal in my fieldwork as it led to the understanding that, as an everyday practice in the nursing homes, staff-assisted walking and transfer of residents, was undergone, practised, contemplated and communicated not as one, or as multiple practices. Rather, it is a multiplicity (Deleuze & Guattari 1988)—a becoming moving and feeling that is emergent from the actualisation of a highly routinised practice in ever changing circumstances. Revealed in this process is how residents moving rightly and feeling right at home in the nursing home involved the entanglement of multiple objects and persons such as aiding devices, other equipment and staff, and the interplay of diverse forces and discourses (e.g. funding schemes, work efficiency, staff workload and resident risk and safety). Conducting fieldwork as such, I may not be able to *know* the experience of being a nursing home resident *as if* living elderly men and women's everyday lives. Instead of seeking to know what it is like to be a nursing home resident, this research seeks to acquire an understanding of residents' ways of inhabiting nursing home environments.

Methodologically, this study aims to shift attention from typifying the bodily-felt senses and feelings of residents or interpreting the subjective meanings of these senses and feelings, to describing residents' movements as multiplicities. Examining movements ethnographically by walking and moving with residents, I aim to offer new insights into

how the elderly live their everyday lives in the nursing homes and to challenge health perspectives on ageing and dementia.

Reframing biomedical approaches to ageing and dementia

In his Introduction to *Thinking about Dementia* (Leibing & Cohen 2006), Cohen (2006) states that the aim of the book is to organise conversations around senility as opposed to organising them around dementia. By senility, he means the perception of deleterious behavioural change in someone understood to be old, with attention to both the biology and the institutional milieu in which such change is marked, measured, researched and treated (Cohen 1998). This thesis is my attempt to join the conversations of social scientists on reframing biomedical approaches to ageing and dementia. I will do so with a focus on resident movement. In describing residents' movements of walking, of standing and of eating, I will problematise and critique biomedical constructions of these residents' lived experiences as psychological and behavioural symptoms of dementia and challenge resulting aged care discourses and practices that can constrain or limit resident movement.

It has been argued that the status of old age is of 'cosmological ambiguity' (Hazan 2002, p. 327) within the context of a 'capitalistic, death-denying, immortalist-oriented, individualistic culture' (Kearl 1996, p. 338) in the West European and North American societies (whose fundamental cultural values are shared in Australia). The temporal image of old age marks an abrupt and much detested interruption of the progress characteristic of life stages from birth to adult. The aged are culturally constructed as 'symbolic others whose representational codes are nebulous, unknown, or threatening' (Hazan 2002, p. 327). The widespread equation of old age and disease (Estes 1979; Sankar 1984) led to the 'medicalization of old age and death' (Kearl 1996, p. 340) through which the aged are viewed as frail, mentally impaired and otherwise limited in their human capabilities (Adelman et al. 1990; Cohler 1993; Thomasma 1991). As Kaufman points out, 'Old age-as-disease has become a more compelling "truth" than old age as one of several normal developmental processes' (1994a, p. 432). As part of the process of medicalisation of the institution for the aged, an increasing number of bodily processes are subject to medical scrutiny, control and technology, whose power 'reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and every day lives' (Foucault 1980, p. 39).

The biomedical framing of old age limits our understanding of elderly people's bodily condition and life situation. Defined as 'older adults or aged individuals who are lacking in general strength and are unusually susceptible to disease or to other infirmity' (Bergman et al. 2007, pp. 731-732), the term 'frail elderly' becomes a constructed medical concept associated with disease and disability. Culturally conceived as retrogression, old age is made equivalent to decline. This is most obvious in how residents' difficulties with moving and walking are medically constructed into a lack or loss of bodily sensitivity, flexibility, tolerance and coordination. Nonetheless, as revealed in Kaufman's discussion of frailty beyond instrumental definitions, frailty is a lived problem which is socially constructed as a parameter of risk for institutionalisation (1994b, pp. 54-56).

The mental losses associated with age have been among the most deeply stigmatised conditions in human history (Cohen 2006). Yet, the contemporary sociocultural construction of age-related cognitive changes is seen as a thoroughly medical one (Ballenger 2006, p. 106). Since German physician Alois Alzheimer first discovered the dramatic shrinkage and abnormal structures in the brain of his patient Auguste D. in 1906, what was coined as Alzheimer's disease by psychiatrist Emil Kraepelin in 1910, dementia has come into being through biomedical discourse. In biomedicine, dementia is conceptualised as a highly disabling neurological condition that is, according to the Australian Institute of Health and Welfare, not curable by medical intervention (AIHW 2007). In her compelling book, *The Alzheimer Conundrum*, Margaret Lock (2013) gives a provocative account of why Alzheimer's disease is such a puzzling mix of scientific hypotheses, research agendas, pharmaceutical interests, funding objectives and theories of aging. She highlights just how much we do not know, from problems with Alzheimer's pathology, testing and diagnosis to the search for a drug treatment. Nonetheless, with its genetic, diagnostic and predictive uncertainties, the biomedical discourse of Alzheimer's disease affects how people perceive, approach and understand the experiences of those who are affected. Within the logic of dementia diagnosis, people use such references as the 'gothic and zombie stories' or the 'horror of Alzheimer's' (Taylor 2008, pp. 317, 324). People with dementia are conceived as suffering a loss of mind and self and are not accorded recognition as persons who are capable of sensible communication and maintaining reciprocal relationships (Taylor 2008). What Cohen (1998) terms as 'senility' has been 'reduced' to a medical

problem—a progressive and terminal cognitive disease—within the logic of dementia diagnosis and care (Cohen 2006, p. 3).

The logic of dementia diagnosis is to focus on brain pathology and symptoms of cognitive decline, which highlights the impairments. These include: lack of capability in logical reasoning, planning and focusing on intentional and purposive activity; decreased ability to be attentional, reflective, and to form short-term memory and retrieve long-term memories, such as autobiographical memory; and inability to effectively communicate using language. Constructing dementia as a cognitive disease, the biomedical discourse of dementia poses a threat to the traditional concept of personhood, which is cognitive-centred. In this model, one relates to other things and beings as a 'self' through a mind where meanings—symbolic representations of objects, events and relations—are generated in linguistic forms for reflection and communication. A mind is considered central to a meaningful existence of someone in their relationships with others in the world. Thinking about dementia in terms of brain pathology and symptoms of cognitive decline, dementia is equivalent to a loss (Brown 2016, p. 1), of mind, of self and of a meaningful existence in relations with other things and beings.

In nursing homes, residents with later stages of dementia are often described by some staff as "dementia full stop", a term that indicates silliness, uselessness and hopelessness. In this version of dementia, personhood is thoroughly disintegrated and eventually dissolves into disease itself. Drawing on Erving Goffman's (1961) conception of *mortification*, Neil Henderson suggests in his ethnographic work on a dementia unit, that the institutional 'induction process designed to kill the prior social self and remake the person into another entity congenial to the goals of the new environment' indicates the social death of the person (2003, p. 154). This is the *first burial* (Kayser-Jones 2003, p. 66; Stafford 2003a, p. 17) before the person's biological death.

The logic of dementia diagnosis leads to the disease-centred dementia care where lived experiences of people with dementia are approached, perceived and understood as symptoms. Focusing on a loss of mind, their utterances and movements are deemed to be behaviours, which are void of meaning. In the situation where their meaningless behaviours are thought to be excessive, persistent or harmful to other people and themselves, those behaviours are further constructed as behavioural

problems—the Psychological and Behavioral Symptom of Dementia—that require pharmaceutical treatment or psychological intervention. While the lived experiences of people with dementia are medically constructed into symptoms that are pathological and abnormal, these constructs affect how these people are cared for. This thesis will show how discourses of 'mindless' bodies, or 'meaningless' movement promote the restrictive practices of falls prevention that use bodily restraint on nursing home residents.

By examining the sensibilities and productive potentials of movement, I argue for the ethnographically informed understanding of resident movement as one relates to other things and beings through sensory extension (Dennis 2007) and correspondence (Ingold 2017) where senses are constituted into feelings. Demonstrating that bodily and cognitive impairments could be the productive potentials for residents to move, extend and feel at home in the nursing homes, this thesis presents a challenge to biomedical assumptions and clinical constructions of bodily and cognitive impairments. This research provides new knowledge about how people with dementia can still relate to others *not* cognitively but sensorially, and how a sensible approach to care for those people needs to support them to have a sense of rightness in moving among others and feeling at home.

Overview of parts and chapters

This thesis follows the everyday movements of a group of elderly Australians, to critically examine how they came to experience a sense of home while living with bodily and cognitive impairments in a nursing home. Through the central analytic of becoming-at-home-in-the-world, I examine how a sense of home is achieved in everyday activities of walking, changing position from sitting to standing and eating. This thesis consists of nine chapters and is divided into four parts. Part II is dedicated to the theme of walking while Part III is primarily on care.

As has been detailed, this thesis draws on Deleuze and Guattari's (1977, 1988) theories of becoming and desiring production to extend Jackson's (1995, 2002) notions of home and existential imperative to consider how bodily impairments affect the ways that people could create a sense of home. Examining movement through the lens of home, this thesis will show how day-to-day movements, of walking, of standing and of eating, with other things and persons could open up potentialities for residents to feel at ease, despite bodily *dis*-ease, and to become at home in the nursing home. The

concept of assemblage (Deleuze & Guattari 1988) is useful in analysing how residents' movements can articulate with multiple persons and things in ways that could sensorially extend (Dennis 2007) residents bodies in correspondence (Ingold 2017) with movements of other things and persons, to create a sense of home.

Part I introduces and orients the reader to the theoretical framework and to the field, inviting them into the historical sociocultural contexts in which this research is conducted. This part consists of two chapters. This introductory chapter has detailed the theoretical perspectives on home (Jackson 1995, 2002) and assemblage (Deleuze & Guattari 1988) that make becoming at home possible in and through the productive process (Deleuze & Guattari 1977, 1988) of movement (Barbaras 2008; Ingold 2011; Ingold & Vergunst 2008) and care. The second chapter aims to contextualise the thesis by briefly analysing the historical origins of the nursing home and its contemporary fashioning as an aged care facility. It details the multiple contesting socioeconomic structures constitutive to the material realties of a nursing home and the entangled processes of care. Chapter 2 also provides information about my fieldwork sites: the two aged care facilities that I named Auxilia and Dulce Domum, and the residents and staff living and working there. I use fictitious names in this thesis to keep the institutions, the residents, their family members and staff anonymous.

Part II on walking consists of Chapters 3 to 6. Tracing residents' movements and their entanglements with other persons and things, I examine how residents are assisted to walk. Part II aims to develop an understanding of how bodies are constituted through their striving to become mobile and, key to the theme of this thesis, to become and to feel right at home. It demonstrates that a right assemblage of care can create new possibilities for residents to move all right; however, it also takes time and resources. In the time-pressured environments of nursing homes this can create tensions, posing a challenge to service providers and staff. Chapter 3 will illustrate how frail elderly people with physical impairments like Mrs Casey come to feel at home in a nursing home through careful and routine walking. In watching each step, Mrs Casey experienced her body as simultaneously 'mobile' and 'minded'. Chapter 4 will demonstrate the process of becoming at home for people with cognitive impairments due to dementia like Mrs Sage, revealing how she came to feel at home in the nursing home through 'wandering'. In the process of wandering, as I will show, Mrs Sage becomes immersed in and connected to the world in ways that are far more in correspondence (Ingold 2017) with other people and things than the Diagnostic and

Statistical Manual of Mental Disorders (DSM) criteria of dementia imply. Chapter 5 turns to how those with movement disorders, like Mr Harris with Parkinson's disease, feel at home in the nursing home through a medication schedule and a staff-assisted walking routine. This chapter details the productive potential of an assemblage of care that, as staff said, works "all right" in unblocking residents' urge to stand up and move to feel just right in and through walking. Chapter 6 will use the example of Mr Dixon, a resident with dementia with Lewy bodies, to explore residents' experiences of sitting and living in tension between walking and not walking. It will demonstrate how residents' attempts to move can be responded to by other people and things in different assemblages of care; some support them to feel right at home, and some prevent them from walking.

Part III extends the analysis on walking to other movements and it foregrounds the multiple and contested understandings and practices of care, particularly for residents with later stages of dementia and those who are approaching the end of their lives. Attending to residents' movements, I reveal the complex and shifting interplay between bodily impairments, material surroundings, aged care discourses and daily practices in the nursing homes. Chapter 7 will demonstrate that care can be conceptualised, positioned, practised and experienced differently by different people (staff, family and residents themselves) in aged care facilities and across different stages of the life course. In following these intersections, I show how residents' experiences of care can conflict with and contradict institutional approaches to care. Chapter 8 will use the example of Mrs Brie closing her mouth to food to demonstrate that, at the end of life, a desire to move and to become alive comes to an end. Dying residents live in tension between the struggle to live and to move, and they seek relief from their painful and declining bodies. A right care for dying residents is a matter of taking time to care and to respond to their shifting situation and circumstances, assisting with their departure by reducing suffering.

In Part IV I conclude this thesis by discussing the ethical implications of the findings in this study. For frail residents living their last stages of lives to feel at home in a nursing home, an ethical care needs to be understood as always relational, responsive to their productive potentials and creative in achieving a balance between inclusion and autonomy (Rapport 2018). Drawing on the Deleuzian concept of assemblage (Deleuze & Guattari 1988) and Mol's (2002, 2008) critical framework of care as multiple, I suggest that, as an ethical form of care, right care is what works best and what works

will be different for different residents across different stages of their life course. Right care can enable residents to move by attending to their urge, their propulsion towards, or away from, other people and things. It is an attentive and immediate response to residents seemingly small efforts to move, to stop, to withdraw and to die contributing to their having a sense of rightness of being as they transition from life to death.

2 The field of nursing homes

Nursing home: what is in the name?

During my visit to a facility seeking permission to conduct this research project on residents' experiences of living in a nursing home, I was told by the facility manager that the name 'nursing home' is no longer used today. "This is the first thing for you to learn if you want to research aged care," she said. This change in name was part of a broader shift in how residential aged care was designed, funded and packaged for an ageing demographic. Many things, according to the manager, had changed for the better, including the name. "Nowadays, we call this place a 'residential aged care facility'", she said. I wanted to know why the name 'residential aged care facility' is better than that of nursing home, what had changed over time, and how the changes may have contributed (or not) to residents' experiencing a sense of home. Before I could raise my questions, she explained that she started working in this facility more than thirty years ago as a carer.

> You didn't know what a nursing home was like back then. Six people shared one big room. There were only curtains to provide the residents with some privacy. When we attended to one resident, everyone else could hear what was going on. It was awful. Now, all the resident rooms are single-bedded, or double-bedded for couples. The whole facility is newly renovated and uplifted to make it look more spacious, bright and cheerful. Though the residents are older, sicker and more fragile, the aiding equipment, such as the lifters, wheelchairs and hospital beds, makes the work so much easier. Back in the old days, working as a carer was a heavy physical job. I almost broke my back!

This account spoke to a view that was shared among management, that the name nursing home was no longer representative of what a facility is or of the people who live and work there. Accordingly, the term 'nursing home' is no longer used in contemporary aged care policy and industry. Nowadays, the organisation delivering care for elderly people is an aged care service provider and the physical setting providing accommodation and care for the aged is a residential aged care facility. However, in the field, residents, family members and care staff routinely used the terms nursing home and nursing home residents, and, in following the language used by these participants, I also use their terms in this thesis. But in doing so, I reflect on these multiple and contested meanings of the nursing home and the names that have come to define and redefine it. This chapter thus attempts to trace the making and the unmaking of the nursing home over time and the associated diverse forces impacting

on it, including: government funding schemes, social ideologies of medicine and multiple bureaucratic processes and daily practices to provide a social and historical context to how residents become at home in nursing homes. In the next section, I will start by briefly reviewing the emergence and evolution of the institution for the aged to reveal the constitutive and differentiating forces that have produced the many material realities of nursing homes in Australia.

Contested cultural space

The name 'nursing home' reveals the contested ideas and practices entangled in the institution of care for the aged. While the concept of 'home' has acquired the connotations of private property, independent living, domesticity and intimate relations, 'nursing', by contrast, may evoke more clinical associations. This contradiction and ambiguity in the meaning of the term nursing home is captured by anthropologist Phillip Stafford in his introduction to the collection of ethnographic nursing home studies conducted in the United States, *Gray Areas: Ethnographic Encounters with Nursing Home Culture*. Stafford attributes the collective discomfort with the nursing home to its 'ambiguous status in the cultural order, owing to its being composed of elements drawn from oppositional spheres of meaning: home and hospital', which renders it a 'contested cultural space' (2003a, p. 10). Yet, as this section will show, in the Australian context the contestation goes beyond the imperatives of medicine and domesticity to include the combined forces of government funding and capital investment from the private sector. Over time, the interplay of these forces has led to the increased complexity which has rendered the name and purpose of the nursing home ambiguous.

Home for the homeless and aged: funding care

Prior to 1900 in Australia, charitable assistance from benevolent societies was the primary means of relief for people who could not support themselves (ABS 1988). The Benevolent Asylums (known as the 'Destitute Asylum' in South Australia) were institutions established throughout the colonies of Australia in the nineteenth century to house the homeless. Victoria had 9 Benevolent Asylums in 1857 (Hull et al. 1863) while in 1860, there were 11 Benevolent Asylums in New South Wales (The Sydney Morning Herald 1860). The Destitute Asylum in Adelaide, South Australia was established in 1851 (George & George 2011). The inmates were not all old people. They took in the poor, destitute, disabled and aged, but many mainly focused on children and pregnant women.

As the population aged and the presence and needs of old people (mostly men) who were ill and destitute were increasingly recognised, the Melbourne Benevolent Asylum (see Plate 12) was built in 1851 (Kehoe 1998) as a social institution for the aged and sick. At the time of its origin, it stood at the periphery of society as a charity, mostly developed through Christian charitable organisations and financed by a government grant and charity money. In its founding years, Melbourne Benevolent Asylum was 'filled to repletion with aged and infirm persons, many of them labouring under complicated diseases' (Whitehead 2018). More Benevolent asylums were built in the following years in Melbourne. These institutions received maintenance subsidies for pensioners from 1909 to 1963 and their residents were provided with the protective shelter, food and water that were desperately needed by the socioeconomically disadvantaged at that time.

Plate 12: Melbourne Benevolent Asylum, North Melbourne, 1900 (http://localhistory.kingston.vic.gov.au/htm/article/302.htm as downloaded on 15/12/2017)

During the Second World War, Australia under a Labour government created a welfare state by enacting a series of national schemes for unemployment, sickness, and special benefits for the socioeconomically disadvantaged (ABS 1988). The nursing home became a mainstream and federally funded social welfare institution when the Commonwealth Government stepped into the aged care field in 1954 with the *Aged Person's Homes Act*. The Act provided subsidies to approved charitable organisations

to provide essentially self-contained, hostel accommodation. Most of the rapid growth in the number of nursing home beds occurred between 1962 and 1972 following the introduction, by the Menzies Government, of a 20 shillings ($2) per day nursing home benefit per patient in approved nursing homes (Guen 1993) . The private sector was quick in seizing the opportunity for profit. In the five years between 1963 and 1968, the number of new nursing homes grew by 20 per cent and the number of beds added to existing homes grew by 48 per cent (Parker 1987, p. 14). In 1982, the residential aged care sector provided some 140 beds for every 1000 Australians aged over 75 years, and was rated as one of the highest (in terms of number of government-funded beds per 1000 people) in the world (Guen 1993, p. 1). However, with its undesired association with age and death, the nursing home was the last resort in the provision of everyday accommodation and support to old and sick people in Australia. This is still the case for many Australians today. Yet, as the facility manager described, nursing homes back then were not the domestic haven that the word 'home' represents today.

The status of the nursing home as a social welfare institution was re-examined in its booming years due to the changing socioeconomic situations of the country, as well as its ageing citizens. The problem of shortage of accommodation for the aged in the early 1940s was seen by the McMahon Commonwealth Government in the early 1970s as being replaced by the new problem of uncontrolled growth of private nursing home accommodation and a very rapid rise of expenditure on Commonwealth nursing home subsidies (Guen 1993, p. 4). The Government's solution to the growth of government expenditure on aged care was to support elderly people who were socioeconomically disadvantaged, but not retired taxpayers and owners of private homes.

For the poor and disadvantaged, special supplements, as specified in Section 11-3 of the *Aged Care Act 1997*, were in place to provide care. These included: a Homeless Supplement to support aged care homes that specialise in caring for people with a history of, or who were at risk of homelessness; a Hardship Supplement paid on behalf of care recipients in financial hardship who were unable to pay their aged care costs; and an Accommodation Supplement for those unable to pay all or part of their accommodation costs. With the provision of shelter through a broader range of public housing measures (e.g. through the South Australian Housing Trust), a change of focus from 'housing' to 'care' emerged and moving from the home and into a nursing

home was deemed unnecessary if an older person was not in *need* of nursing care.[3] Instead of being a home for the homeless and aged, the nursing home was increasingly a place of nursing practice, which led to a pivotal shift in federal government aged care policy and funding.

Since the beginning of the Hawke Commonwealth Labour Government in 1983, the notion of a nursing home as a bounded physical site gradually dissolved due to the continual reforms of government funding policy on aged care (Guen 1993, p. 4). In the 1990s, hostel beds providing low-level care, and nursing home beds providing high-level care, merged within the one facility so that older people could move more easily between the two as they became frailer. Nursing care was also established in the community for those in need of care but who remained at home (Guen 1993, p. 37). Furthermore, as the term 'nursing home bed' was coined in aged care policy, an abstract 'nursing home place' was constructed, which referred to a status of eligibility for government-funded care in a residential facility. Instead of referring to a concrete, physical and bounded residential setting for the aged to be accommodated and cared for, the name 'nursing home' increasingly became used as a signifier of federal government aged care funding and resource distribution.

Alongside the construction of 'nursing home place' and 'nursing home bed' in policy, the term 'nursing home care' was produced in the context of policy change with an emphasis on the provision of nursing practice. Before the 2012 aged care reform[4], the term 'nursing home' primarily referred to high-level care and the residential setting where this type of care was provided. One of the aims of the reform was to provide more support and care at home.

High (nursing home) care: medicalising needs

The construction of 'nursing home place' in policy and funding schemes aimed to differentiate older Australians who were considered *in need* of nursing care, from those who were not. Only those assessed as in need of care and eligible to take up a nursing

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[3] In 1936 the South Australian Parliament established Australia's first state housing authority, the South Australian Housing Trust. The Great Depression had accentuated the need for adequate housing and the Trust was required to provide low-cost rental housing. Following the end of World War II, its role expanded to become a large-scale developer and public housing authority (State Library of SA 2015).

[4] The 2012 aged care reform, also referred to as the Living Longer Living Better reforms, was announced by the Gillard Commonwealth Labour Government in response to the *Caring for Older Australians* report, prepared by the Productivity Commission in 2011.

home place are admitted into residential aged care facilities. The medicalisation of needs and care was used in this process of differentiation. In Australia, one crucial step to medicalise the arena of aged care was the introduction of the medicalised aged care assessment in 1972. The approval of a medical practitioner was required prior to an older person's admission to a nursing home so that a nursing home place was provided to someone who was in need of it (Guen 1993, p. 14). The medical practitioner's certificate was also required to be endorsed (or rejected) by a Commonwealth medical officer. The federal government announced in August 1986 that a comprehensive health assessment was necessary to help older persons avoid unnecessary nursing home admission. The assessment was made by teams of specialists who became known as Geriatric Assessment Teams. The name was changed to Aged Care Assessment Team (ACAT) in 1992 because large numbers of older people objected to the negative connotations now associated with the term geriatric (Guen 1993, pp. 5-14).

Medicalised eligibility assessment was the initial step leading to further medicalisation of the social welfare sector of aged care. Both the welfare state and the ageing citizens as nursing home residents are constituted through the process of practising medicalised assessments of care needs. As part and parcel of the ‘medicalization of old age and death’ (Kearl 1996, p. 340), medicine dominates in the arena of aged care, especially in the institution for the aged. Stafford (2003a) suggests that the nursing home is primarily a medical institution in which the ideology of medicine, as a set of organised ideas, is in full play. As ‘the individual patient’s “problem” is seen as a health problem (disease) that needs treatment’ (Stafford 2003a, p. 6), nursing home residents are categorised and conceived of through their diseases. In the Australian Institute of Health and Welfare 2012 report (AIHW 2012), residents are represented using disease categories and incidence rates, such as circulatory system diseases (24%), diseases of the musculoskeletal system and connective tissue (18%), endocrine, nutritional and metabolic disorders (8%) and cognitive impairment with dementia (52%). Eligibility assessment focuses on the presence or absence of disease and extent of pathology which defines who can or cannot access nursing home care and residential accommodation. In turn, ongoing care level assessments determine the availability of aiding devices and equipment to residents, as well as funding to facilities.

Aged care industry: commoditising care

Under the accumulative pressure of government budget deficit, the once heavily government-subsidised aged care system evolved into a profitable service industry in Australia and other developed Western countries.[5] In Australia, the co-contribution funding model launched as part of the 2012 aged care reform further accelerated the process of commercialisation in this business sector. In the context of policy and industry, residential aged care refers to a type of commoditised service providing accommodation, everyday living support (meals, laundry and cleaning), nursing and personal care services. It is subsidised by the federal government, charged for by a service provider and paid for by residents and their families. The services categorised as 'care' are central in residential aged care. It is the element of care which gives the name, shape and form to the sector of residential aged care. While everyday living support with meals, cleaning and laundry are provided under the category of housekeeping and itemised separately, they are essential to the daily delivery of care.

The word 'care' is used in the context of 'care practice' to refer to the organised activities aimed at maintaining a liveable everyday life for older people. There are two main types of care practice in residential setting: nursing care and personal care. Nursing care (or 'health care' as it has been more recently called), including: medication management, continence and catheter care and wound treatment, is available any hour in the week from qualified nursing staff. 'Personal care services' include varying levels of assistance with bathing, toileting, eating, dressing, mobility and managing incontinence (Productivity Commission 2011, p. 25). Personal care is mostly delivered in the form of assisting residents with their Activities of Daily Living (ADLs), which is both a nursing and an industrial term.

There is a hierarchy of work in nursing homes with the 'dirty' personal care work, namely, cleaning body waste, showering and toileting, at the bottom and the 'clean' office paperwork at the top. Nursing care and personal care are delivered by different staff—with different qualifications and positioned differently in institutional hierarchies. While care staff spend most of their shift time engaging intimately with residents doing

[5] Importantly, population ageing is an international issue that has led to increased care needs for the elderly in many non-Western countries, as well. One prominent example is China, which has seen significant growth in the aged care industry. By 2018, as reported in Xinhua, a Chinese state-run news source, China had 28,000 registered nursing institutes for the elderly and more than seven million elderly home beds (https://gbtimes.com/china-has-28000-registered-nursing-homes viewed on 15 April 2020).

dirty hands-on care work, nursing, medical and allied health professionals often spend substantial working hours doing paperwork. There is a parallel hierarchy of employees in nursing homes corresponding to the hierarchy of work. As is widely acknowledged in the aged care system, the more educated and trained the staff, the higher the rank they will be and, in turn, the further away they are from daily care practice for the residents. The institutional power is always initiated from the top of the hierarchy—the 'office' where the executives and administrators conduct their daily work—to the bottom of the hierarchy—the 'floor' where the residents live, and daily care work is carried out.

Institutionally organised staff assistance permeates the everyday lives of nursing home residents and often gives the care facility its institutional look and feel. Based on covert ethnographic research undertaken as a certified nursing assistant or 'nursing aid' (or, in Australian terminology, a 'personal care worker') in three different nursing homes, Timothy Diamond's (1992) *Making Gray Gold: Narratives of Nursing Home Care*, offers an insider's view and interpretation of nursing home life. He places the nursing aids' hands-on caregiving activities and the institutional accounting of that activity, the text, at the centre of his analysis, showing how daily care practice is structured by institutionally prescribed and documented tasks such as the two-hourly repositioning of bedridden residents. His observations reveal the parallel existence of the lived realities of residents and nursing aids, and the institutional structures that emerge from the capitalist system of labour and service commodification, which governs the nursing home. The assertion that an economic imperative is central to nursing home operation is confirmed by more recent nursing home research that demonstrates that the organisation of work in nursing homes is 'geared to "getting done" with the maximum economy of human resources' (Baker 1983 as in Bland 2007, p. 942).

Moving into a nursing home is a life-changing and, for many Australians, a financially prohibitive event. For people who have no or low assets and need financial hardship assistance for residential aged care, their choice may be limited to low cost facilities. In recent years, in response to the demands of the retiring prosperous generation of 'baby boomers', increased competition and innovation has entered into the residential aged care industry. There is now an aged care measure called Extra Service Status, which is to enable service providers to charge more money for higher standards of accommodation (Department of Health and Ageing 2012b, p. 43). Situated in an affluent suburb of Adelaide, the care facility, Dulce Domum, had a face-lifting renovation with new investment after a change of ownership and became affiliated to

a large multi-state aged care service provider in the private sector. All beds were approved by the government for Extra Service Status and the service provider advertised the facility on its corporate website as ‘a major investment’ that is ‘genuine value for money’.

In the Australian aged care system, the accommodation fee is set by the aged care provider according to the standards of accommodation. There are three possible fees that the older person or the family may be required to pay: The Accommodation Fee, the Daily Care Fee and the Means Tested Fee.[6] The Accommodation Fee is set by the facility. The other fees are set by the federal government. The following table (see Table 1) is made using data extracted from the documents openly provided on the website of the Auxilia Aged Care Facility. Auxilia is also situated in an affluent suburb in Adelaide. It is one of seven fully accredited residential care facilities owned by a South Australian not-for-profit organisation. As the table shows, the pricing is structured by the size and design of living quarters.

[6] Residents entering aged care on or after 1 July 2014 have the choice of how to pay for their accommodation (set by the facility), which will be a Refundable Accommodation Deposit (RAD), or a Daily Accommodation Payment (DAP), or a combination of both. Residents can choose to pay the accommodation payment in full as an up-front lump sum, known as RAD, or the daily payment for accommodation in an aged care home, known as DAP. Maximum Permissible Interest Rate (MPIR) is the maximum interest rate chargeable on accommodation deposits as determined by the Government.

The Government pays the Daily Care Fee to the care facility for services delivered to the resident. The maximum daily care fee is approximately 85% of the single basic Aged Pension: Single: $944.30 per fortnight (approximately $24,554 per year), which is reviewed every March and September by the Commonwealth Government.

The Means Tested Fee is a supplement paid by residents who exceed the limit set by the Government’s assets and income test. Since the Daily Care Fee does not cover 100% of the actual costs incurred by an aged care facility in providing its services, the Commonwealth Government pays a subsidy to each facility to help cover these costs, based on the number of residents it looks after. If a particular resident is deemed to have the financial means to contribute more to the cost of their own care, they are required to pay a Means Tested Fee back to the government. The amount payable is determined by the level of income and/or assets held by a resident, but in any case, there are maximum limits to the amount a person pays per year and in their lifetime.

Table 1: Categories and pricing of accommodation in Auxilia Facility

Area*	Room name	RAD**	DAP***	50% RAD + 50% DAP****
A1, A6, A7	Deluxe single with private ensuite	$510,000	$94.32	$255,000 RAD + $47.16 DAP
A1, A2	Deluxe suite with private ensuite	$550,000	$101.71	$275,000 RAD + $50.86 DAP
A1	Companion with shared ensuite	$325000x2	$60.10	($162,500 RAD + $30.05 DAP) x2
A4	Standard with private ensuite	$400,000	$73.97	$200,000 RAD + $36.99 DAP
A2, A3	Deluxe room extra services	$550,000	$101.71	$275,000 RAD + $50.86 DAP
A2, A3	Deluxe suite extra services	$750,000	$138.70	$375,000 RAD + $69.35 DAP
A7	Studio room with private ensuite	$550,000	$101.71	$275,000 RAD + $50.86 DAP

* Capital letter 'A' and numbers 1 to 7 are used to refer to the seven areas in Auxilia
** Refundable Accommodation Deposit (room)
*** Daily Accommodation Payment (person/day)
**** People moving into the facility may choose to pay half of the RAD plus half of the DAP

The new policy and fee structure provide more flexibility in a business model for residential aged care and encourage the sector to be more market-led and competitive. Older persons and their families become customers, and in accord with a neoliberal policy agenda, they are responsible for making choices about what they want and how much they will pay to receive it. Driven by growing competition in a customer-centric market, it becomes a strategic priority to remodel and renovate aged care facilities, to attract affluent residents by meeting their preferences. Nursing home accommodation can thus be modified and upgraded for people who pay additional fees for increased amenities and services, may they be elderly people themselves or families who pay for their loved ones. The following descriptions and images (see Plate 13 & Plate 14), showcased on the Auxilia website, detail such extra services:

> 'The extra service deluxe suites vary between 28–31 m^2 in size and include a single room with an ensuite and a separate private lounge area within the living quarters. The extra services standard single room is 16m^2 in size and includes an ensuite. These premium rooms are beautifully appointed with designer selected superior decor and fittings and floor coverings and overlook gardens, the courtyard, or attractive views. Residents are able to access a range of services and goods as part of their service and accommodation charge. These include beauty treatments, daily newspapers, a la carte three course menus, complimentary snacks and beverages, a choice of dining venues, functions and events held weekly, private garden areas and rooftop garden access. Visiting friends and family can access the overnight stay apartment.'

Plate 13: Deluxe suite bedroom

Plate 14: Deluxe suite lounge

Extra Service Status approved by the government enables service providers to charge more money using an ‘extra services agreement’. It involves the provision of ‘hotel-type services, such as better accommodation, food and services’ to residents who are entering an extra services room (Department of Health 2020a). Deluxe rooms and a la carte menus afforded by the Extra Service Status make it possible for residents to accommodate visiting family and friends, to entertain, share food and enact domesticity in a home-like environment.

Auxilia is a large facility with 160 beds. All residents have access to a wide range of amenities including a community centre, cafe, hair salon, library (see Plate 15), chapel (see Plate 16), internet cafe and outdoor BBQ area. With elements akin to hotels, such as a grand lobby, refined interior decoration (see Plate 17), ‘deluxe’ rooms, and an emphasis on the etiquette and manner of staff, the commoditisation of care is increasingly built into the residential aged care industry in Australia.

Plate 15: Onsite library

Plate 16: Onsite chapel

Plate 17: Living area

Nevertheless, elderly Australians admitted into aged care facilities that are located in less affluent suburbs may (and often do) live in material environments that are different from those exhibited in this thesis. The ‘standard’ living condition in a nursing home

can be quite basic with resident bedrooms furnished with a single bed, a wardrobe, a locker and a chair, and residents may share toilet and bathroom facilities. Residents living in other facilities may not have access to the many onsite amenities that are presented in this thesis. While attempting to accurately represent the two aged care facilities where I did my fieldwork, descriptions in this thesis are by no means representative of all aged care facilities in Australia.

Home-like environment: domesticising everyday experience

While contemporary nursing homes are ostensibly designed and promoted as catering to individual needs and preferences, care homes are portrayed in research as 'placeless spaces' (Twigg 2000, p. 78) or 'nonplaces' (Milligan 2016, p. 118). Coined by Marc Augé (1995), 'non-places' conveys the uniformity and standardisation of architectural structures like hotels and airports and the impact that their superficiality and transience has on social relations and interactions. In her ethnographic study in two Australian residential aged care facilities, Fiveash (1998) reveals the uncomfortable experiences of residents that emerge from the public nature of nursing home living. As one of her participants said: "I have no private place of my own" (Fiveash 1998, p. 169). Much of the distress experienced by residents in this study arose from the involuntary sharing of rooms and space (Fiveash 1998, p. 168). This is in line with the facility manager's accounts that I cited at the beginning of this chapter illustrating how these crowded nursing homes of the past stood in stark contrast to the residential aged care facility of today.

With the word 'home' replaced by the more clinically oriented term, 'facility', service providers are increasingly drawn to the cultural imagination of home to change the institutional ambience, appearance and feel of facilities. In a care facility that I visited in Melbourne, which provides specialised care for elderly Australians from a Chinese cultural background, Chinese cultural elements such as the statue of Maitreya (also known as the Big Belly or Laughing Buddha; see Plate 18, image on the left) and the poster with the upside down Chinese character 'Fu' (a pun indicating the befalling of happiness; see Plate 18, image on the right) are used to decorate residents' living rooms and doors.[7]

[7] With permission from the facility management, I visited an aged care home in Melbourne as part of my fieldwork and conducted interviews with the director and manager of the facility, which provides specialised care for elderly Australians from a Chinese cultural background.

Plate 18: Interior decoration in a Melbourne care home for elderly Australians from a Chinese cultural background

Residential aged care service providers seek to provide a home-like physical environment and, through the built design, interior decorative features, aiding devices and technologies, attempts are made to provide residents with their own space in which to feel comfortable and at ease. In the two facilities where I did my fieldwork, each resident had their own room, a private bathroom and storage space, with each room either single-bedded for individuals or double-bedded for couples. Upon admission, residents are encouraged to personalise their bedrooms using their own furniture (depending on the size of the room), souvenirs and photos of families and pets (see Plate 19). Research shows that creating and decorating a home-like environment within the layout of the facility, or bringing possessions from home into the nursing home have significant impact on the quality of residents' lives (Barnes 2003; Bradshaw, Playford & Riazi 2012; Nord 2013).

Plate 19: A resident interviewed in her room in the aged care facility

However, as shown in my earlier discussion on material approaches to 'home' in nursing homes, while researchers consider a move from home into a nursing home through the lens of transition, they tend to associate home solely with the physical objects that are of home and moved with people into the nursing home. As Stafford reports, 'Many professionals state that a nursing "facility" can't be home, but an attempt is made, nevertheless, to create a simulacrum' (2003b, p. 123). The public nature of nursing home living may render the efforts of environment modification of a nursing home (Lee, Yu & Kwong 2009, p. 123) a superficial 'home-like' presentation. Indeed, as I will show in this thesis, 'some institutions have taken on the trappings [of home] … without fundamentally questioning the presumptions of care and basic human needs' (Stafford 2003a, p. 20).

The constitutive and differentiating forces revealed in this section produce the many material realities of nursing homes in Australia. Although these multiple, and sometimes contested, forces, ideologies, discourses and practices heavily affect how elderly people live their everyday lives, none of these components could determine how nursing home residents could feel at home in nursing homes. Home, as this thesis will show, is not to be considered as solely associated with physical things, persons,

material environments, or practices. While these physical things from home do have associations with home, none of them could singularly produce home. As this thesis shows, it is in the coming together of multiple things and people into right assemblages that home is made possible for residents. Shifting my focus away from the forces, discourses and practices, I seek to understand home as deeply entwined with the movements of nursing home residents and their relational and sensory engagements with other people and things in assemblages. In the next section I will turn to the research design and detail the research methods that I applied in this study to gain an ethnographically informed understanding of home.

Research design: focusing on movement and care

This ethnographic study attempts to understand the everyday experience of nursing home residents, with an emphasis on how in coming to feel right and at ease they can become at home in the nursing home. Considered within the conceptual framework of becoming-at-home-in-the-world, it attends to how a sense of home is assembled in material surroundings, living bodies, daily practices, bodily movements and everyday experience. This thesis aims to acquire an understanding of residents' everyday experience through a reflexive and participatory engagement with their altered ways of walking, standing and eating.

The central focus of and research methods used in this ethnographic nursing home study went through multiple iterations in the process of conducting the 12-month period of fieldwork. Residents' movements only became obvious, explicit and represented in this thesis through the processes of fieldwork and writing up. In the original design of this ethnographic project on nursing home residents' everyday experiences, I was interested in the discourse of challenging behaviour as the entry point to exploring the embodied and situated dimension of residents' experiences. Challenging behaviour is widely formulated in public health policy and other practical texts as 'actions and incidents that may, or have potential to, physically or psychologically harm another person or self, or property' (SA Health 2013, p. 3). Individual idiosyncratic events, such as residents kicking, punching or slapping staff while being assisted with such things as showering, toileting and taking medication (Vesperi 2003, p. 83), are conceived in the institutional setting as 'challenging behaviour', being 'non-compliant' or 'refusing care' (Crombie, Boyd & Snell 2008). The discourse of challenging behaviour reveals the contrasting and contradictory ways that residents' behaviours are understood and responded to—medically constructed as symptoms requiring treatment, politically

framed as funding problems requiring special subsidy, and institutionally positioned as risky and in need of intervention. Two assumptions underpinned my choice of residents' challenging behaviour as a strategic entry point for this ethnographic study. The first assumption is that the everyday experiences of nursing home residents are largely shaped and formed in the nursing home environments by the institutional practices. What is conceived through the sociocultural construct of challenging behaviour is in effect part of how residents experience the place of nursing home and its institutional practices. The institutional *shaping* of residents' experiences can be revealed through the normative, discursive and governmental regime of the nursing home and its impact on residents' experiences. This leads to my second assumption: by deconstructing the *making* of residents' challenging behaviours in these contexts, what these behaviours *really* are—residents embodied and situated experiences—can be illuminated. With the aim to reveal the nursing home as a multidimensional place and its practices, I started fieldwork.

My fieldwork in the first three months mainly involved four approaches: following staff in care work; conducting interviews with residents, staff, families and friends; collecting documents on policy, industrial and organisational rules, regulations and the working texts that staff used in daily work; and, collecting data on workflow using the facility call-bell system and a purchased tracking device (Fitbit Zip). During this period I witnessed how the repetitive occurrence of the individual idiosyncratic events, such as when a resident continuously calls for help or attempts to exit the facility without staff supervision, may lead to a process of assessment in which residents' eccentric behaviours or spontaneous movements are constructed *not* into residents' needs for staff assistance but the Behavioural and Psychological Symptoms of Dementia, which require medical treatment or intervention. Data collected in the field reinforced my assumption that residents' everyday experiences are *primarily* shaped by the institutional practices.

This assumption was however challenged by Mrs Joyce, a resident who had difficulties with walking, and yet followed a daily walking routine. Although she relied on her walker and staff assistance for support, she withstood the pain and made her own efforts to continue to walk. Once, after a painfully slow walk from the dining area back to her room, Mrs Joyce told me that she felt at home in the nursing home. Despite her expression of content and relief, I could not believe what she said truly conveyed her experience. Given her ailing body, and the long and difficult walk through the corridor

of the facility, I was shocked and I wrote in my fieldnotes: “It can’t be true, especially for an elderly lady with terminal cancer who is cared for every hour of the week in a nursing home.”

In reflecting upon the first three months in the nursing homes, it became clear to me that my fieldwork was not so much about the constitution of residents’ experiences but the making of care as a set of institutional practices: how the care needs of residents are assessed, funded by government and priced by the service provider; as well as, how care activities are organised, delivered, documented and reflected on by staff. In demonstrating the making of care in daily practices, the normative, discursive and governmental regime of the nursing home could be revealed, but not the experiential dimension of residents. The large volume of generally available data reflecting the governmental and organisational power over care provision, and staff control over actual care delivery, did not reflect how nursing home residents experience their everyday lives.

Examining how I felt towards Mrs Joyce’s remark and my assumptions underlying the research design, I found that, at the core of my assumption was my preconceptions of the place of nursing home and its residents. For me, at that time, nursing home could not be home to its residents as, due to their disabilities and impairments, they are passive care recipients depending on institutionally organised staff assistance for daily living. It was no surprise that I had collected little data of residents doing daily activities. The ways in which residents made their own efforts to continue to move had not been the focus of my fieldwork.

The moment when Mrs Joyce shared her feeling of being at home constituted a pivotal shift in my thinking on the potential for elderly people to experience a sense of home in nursing homes. It marked a turning point in this nursing home study, challenging my assumptions about how elderly people could experience their nursing home lives and leading me to a novel methodological approach focusing on residents’ experiences with an emphasis on their own efforts. This led to the second stage of my fieldwork and to the shift in focus from the governance and funding of the institutions to how care is practised around residents’ efforts to move.

Extending my original focus on challenging behaviours, I turned towards more mundane everyday activities—walking, transferring position such as when one stands up or sits down and eating—to explore the deeply embodied and situated dimensions

of residents' movements. A central characteristic of these types of activities is the involvement of residents' bodies. Residents need to use their bodies to make their own efforts to move; they get involved. Some daily activities, like cooking and housekeeping, are undertaken by staff and do not necessarily involve the residents' efforts to move. The difference between eating and cooking or walking and being pushed around while sitting in a wheelchair is that, in walking and eating, residents themselves are active participants—making their own efforts to move despite physical and cognitive impairments. Without residents opening their mouth or taking each step, staff could not walk or eat *for* the residents even with the most caring attitude.

When describing residents' movements in this thesis, the word 'effort' is preferred over 'behaviour'. The word 'behaviour' implies that individual acts are discrete symptoms to be treated, isolated from a person's sociocultural context, and so, the term is only used in this thesis as a descriptive one in medical or psychiatric contexts. The word 'effort', however, represents the experiential dimension that is embodied and situated, allowing for a phenomenologically oriented analysis. As this thesis will detail, the emphasis on residents' own efforts to move is key to the understanding that elderly people's living in a nursing home is an ontological process of desiring production (Deleuze & Guattari 1977, p. 30) in which residents' efforts join together with other people and things—material surroundings, living bodies, daily practices, and movements (like those involved in walking), to enable their bodies to do what they want to do but are unable to do on their own. As I will argue, it is in these everyday experiences and productive movements that residents' sense of home can be created. This new design of tracing residents' desire to move through their own efforts in activities like walking is crucial for this nursing home study on residents' experiences, as it foregrounds myriad ways that residents are affecting and not solely affected by other material objects and persons in the nursing home.

Research methods: tracing residents' movements

To sense, feel and find the differences in ways of moving, I used the method of comparison. I was given permission to conduct my fieldwork in two different care facilities with different organisational structures, management styles, built features and staff and resident composition. This provided me with the opportunity to walk and work in the places differently through varied modes of 'being there' (Spry 2001, p. 710). These differences were lived through doing participant observation and becoming

immersed in the nursing homes operations, leading to different understandings of residents' experiences.

Two sites

The two residential aged care facilities, Auxilia (Site A) and Dulce Domum (Site B), hosted this research project.[8] The following table presents information in terms of business status, location and capacity to accommodate and care for residents with different care needs, including dementia care and extra service status (see Table 2).

Table 2: General information about the twin sites

Item	Auxilia (A)	Dulce Domum (B)
Business status	Not-for-profit	Private
Location	Inner northern suburb	Eastern suburb
Number of ward	7 areas	7 areas
Capacity	160 beds	76 beds
Dementia area	2 (19/23-bed)	1 (13-bed)
Extra Service Status Area	7 (76-bed)	2 (22/14-bed)

Other than business status and physical settings, these two sites were also different in terms of organisational structures and management styles. The facility manager in Dulce Domum is the sole representative of the organisation authorised to grant research approval. The facility manager gave me permission for access right after the ethics application for this project was approved by the Human Research Ethics Committee of the University of Adelaide in November 2014 and I started my fieldwork there two weeks later. In Auxilia, my experience in negotiating permission for entry was quite different. Navigation of a complex multilevel governance structure within the organisation was required for the purpose of research and student placement. Following many pre-fieldwork site visits (including once with my two supervisors as requested by the organisation), and discussions, the key contact person from the organisation's research department then referred to and followed multiple lines of communication with the CEO committee and the directors and managers of various internal departments to reinforce his points in conversations about the importance of

[8] Another two aged care service providers in Adelaide declined my request to conduct a research project in their facilities. Aside from the 12-month fieldwork conducted in Adelaide, I also visited an aged care home in Melbourne which provides specialised care for elderly Australians from a Chinese cultural background.

always seeking permissions while conducting fieldwork. In addition to the ethics application submitted to the university's Human Research Ethics Committee, I was required to submit a separate ethics application to the Human Research Ethics Panel of the organisation. The organisation could thus oversee and influence researchers' activities in the facility. In the case of my fieldwork, this shaped my own movements within the nursing home, including access to the site, the hours I could spend there, my designation as a 'volunteer' and access to written and computerised documentation, which directly and indirectly impacted on the fieldwork process.

Residents

Based on the lists of names of residents that I collected from the two care facilities, my observations and communications with staff, I extracted some basic demographic information of residents including gender, ethnicity and marital status. Consistent with the aged profile in the two affluent suburbs in which this research was undertaken, residents were mostly Anglo-European, had middle-class backgrounds, had been married, and there was a higher ratio of women to men. There were around 230 residents living in the two care facilities where I did my fieldwork. I only met two residents who were not from an Anglo–European background. These two residents were both female, one was originally from Vietnam and the other was from Bangladesh. Most of the residents spoke English, yet some of them had difficulties with finding words and making meaningful sentences due to cognitive impairments. Some residents had lost their English proficiency and switched back to their mother tongue, e.g. German. Out of 128 residents living in 6 areas of Dulce Domum, eight had never been married and during my fieldwork four heterosexual couples shared a Deluxe suite with private ensuite.

Most of the residents in the nursing homes are from affluent suburbs of relatively high socioeconomic status. As aforementioned, this study is thus not reflective of nursing homes and nursing home care across Adelaide and Australia. The table below summarises residents' information in terms of gender ratio, number by gender and care level in all the divisional areas in the two care facilities (see Table 3). The source data of the numbers shown in the table are from the residents' Allocation Sheets in the divisional areas collected approximately in the period from 16 to 27 February 2015. The numbers were accurate at the time and date of collecting. However, an occasional re-visit to some of the areas made me realise that the numbers were changing constantly due to death of current residents and the admission of new residents. The

termination of life is part and parcel of everyday life in a nursing home. As shown in the table, neither facility was, in the words of staff, a “full house”. The regular death of residents ensured vacant rooms and it usually took one week to complete due procedure for the next person on the waiting list to move in.

Table 3: Resident numbers and gender ratios

Site	Area	Care level	Residents	Female	Male	F/M ratio
Auxilia (A)	A1	Mixed	29	22	7	3.14
	A2*	Low	22	20	2	10
	A3*	Low	14	12	2	6
	A4	High	21	13	8	1.63
	A5	High	22	18	4	4.5
	A6	Dementia secure	19	17	2	8.5
	A7	Dementia secure	23	10	13	0.77
Total			150	112	38	2.95
Dulce Domum (B)	B1*	Mixed	8	3	5	0.6
	B2*	Mixed	8	5	3	1.67
	B3*	Mixed	8	3	5	0.6
	B4*	Dementia secure	13	6	7	0.86
	B5*	Mixed	10	6	4	1.5
	B6*	Mixed	13	9	4	2.25
	B7*	Mixed	13	9	4	2.25
Total			73	41	32	1.28

* Extra Service Status area

The composition of residents in a unit may affect the general atmosphere as well as how each individual resident could move among other people in the nursing home. A significant difference in gender ratios was apparent in the facilities. While there were nearly three times more (2.95) older women than older men in Auxilia, the numbers of older women and men are closer (1.28 women per man) in Dulce Domum. The two dementia secure areas in Auxilia have provided a gender comparison during this period of fieldwork. In area A6, the great majority of residents were older women (17), and the older men are the apparent minority (2). On the contrary, there are more older men (13) than older women (10) in area A7 and there were also more counts of resident incidents in area A7. The term ‘resident incident’ was used by staff to denote events that involved a resident in a situation with the potential for injury to the resident themself, other residents or staff, or families and visitors. A resident incident can be

verbal or physical aggression towards staff or other residents, falls, or other problem events. In contrast there were much fewer resident incidents in A6. The area A6 is widely commented on by both staff and visitors as being more pleasant, calm and placid. In spite of the many differences in building design, environmental features, overall care level and allocation of staff, the positive image of A6 is made in comparison to A7 and its positivity is attributed to the presence of the many older women. In one particular case, a wandering older woman was moved from A7 into A6 to save her from constantly being pushed and scolded by the male residents in A7. Although her wandering also attracted complaints from the residents in A6, she was deemed as safe from physical abuse of other residents.

Staff composition in the two facilities was quite different in terms of gender, age and ethnicity. In Dulce Domum, staff were mostly young or middle-aged female migrant workers, while in Auxilia the staff cohort was older (a small proportion was close to retirement age and several were still working casually after retirement) and more gender-balanced. There were significantly more middle-aged, both male and female, workers from the local communities in Auxilia.

Fieldwork

My experience of fieldwork in the two sites was very different. I spent more fieldwork time in Auxilia since I was permitted to be on site from 7am to 5pm during weekdays, which meant that my fieldwork hours could cover the entire morning shift (from 7am to 3pm) and part of the evening shift (from 3pm to 11pm). According to the ethics approval granted by the Human Research Ethics Panel of the organisation to which this facility affiliates, I was restricted from participating in delivering direct personal care to residents. Nevertheless, during the meeting held in the Research and Development Department, the project manager of Research and Student Participation made it clear that I was expected to actively participate in the everyday activities as a volunteer helper. I usually helped by making the residents' beds or feeding the residents. As time went by, my non-engaging observation grew into active participation by playing a role as a member of the community when care staff drew me into their doing of care work. After a few weeks, the morning shift care staff became used to my being there and they remarked that they were happy to see the "student helper" who had been "shadowing" them. I learnt about care work and staff opinions on care delivery in the contexts of working alongside care and nursing staff. Brief conversations about their experiences were exchanged while the work was done. These contextual

communications were valuable in developing an understanding of care work in the facility. Another place to engage with staff in reflective conversations is the staff room. I usually spent my lunch break hour chatting with staff about their work and the other things they happened to talk about, such as how their family life was affected by what happened at work. I made acquaintances with some staff members both 'on the floor' and in the staff room. Aside from staff handovers, I attended staff training sessions and resident and family meetings. When opportunities arose, I observed physiotherapists, speech pathologists or others performing specialist assessments. I also conducted formal interviews with staff. To understand care work from a staff perspective, I used a tracking device (Fitbit Zip) to extract, record and compare their daily levels of physical activities in terms of calories burnt and steps taken. With residents' permissions, I also sought interview opportunities with their families and friends. It was obvious in my 3-month fieldwork report that my fieldwork was more fruitful in Auxilia than in Dulce Domum in terms of collecting data, e.g. work sheets, and conducting interviews.

Yet, as my research direction turned towards the activities of walking and the transfer of residents, the focus of my fieldwork also shifted. Instead of following staff in their delivery of care work, I spent more fieldwork time in the communal areas, such as corridors, lounge and dining areas, walking with residents and observing how they walked. With this shift of focus, I started to see what was previously invisible to me—the walking and wandering of residents. This shift of fieldwork focus led me to see residents, not as passive care recipients waiting desperately in their individual rooms for staff assistance, but as people who could make things happen—affect other things and persons around them through bodily movements, such as walking.

It was a different story in Dulce Domum. I was not allowed in the facility before 11 o'clock in the morning. When I arrived and walked from unit to unit, most of the care work was done. The highlight of the day was lunchtime. I helped in the main dining area by arranging tables and delivering dishes. After lunch, some residents retreated to their rooms and some fell asleep while sitting in the lounge. Time went by slowly in Dulce Domum.

In Dulce Domum, participant observation often involved sitting with residents. Staff commonly commented that I was with "the ladies sitting in the communal area". Participant observation also entailed walking with residents, with staff remarking on my accompanying "the wandering man in the hallway". I collected floor plans of buildings

and pictures of interior settings. I used partial images of floor plans to illustrate some spatial features of how residents move in the environments. They were especially useful in my thinking, describing and communicating with other people, including personal care workers, nurses and physiotherapists about the contexts of residents' movements. My understandings of the residents' movements were deepened when their movements were visually and graphically recorded and demonstrated. To explain this research method, I will use the examples of "the wandering man in the hallway" and "the ladies sitting in the communal area".

The name of the lonely wandering man is Mr Harris, the resident who I introduced in the opening vignette of this thesis. He walked persistently throughout the day with his red walker, along the hallways in the facility. In walking alongside him, we were connected through the carpeted floor, the light from the ceiling in the hallways and the occasional breeze coming from the front door while it was opened. We were also connected through our movements together. My own walking was in a continuous alignment, tension, exploration and negotiation with his, while we both proceeded, slowing down, taking a pause in correspondence (Ingold 2017), with other people around us, as well as with the floor, the handrails, his walkers and the furniture.

Plate 20: Hallway leading from the front entrance to the 'roundabout'

I found that his walking followed a set route, which always included the 'roundabout' seat opposite the main entrance of the facility. He usually sat down at the roundabout and watched people entering and exiting the facility through the front door, which is guarded by a security lock. The picture above (see Plate 20) shows the hallway in front of the main entrance to the facility and the roundabout seat in the distance, which is indicated on the floor plan with a red-yellow star in a brown circle (see Figure 1). Mr Harris' room was in area B2, indicated by a red-yellow star in Figure 2. He always walked along the corridors between the two rows of resident rooms in area B2, turning left or right, and towards the roundabout area. The red arrows in Figure 2 show his daily walking routes.

After walking together for several weeks, one day, when we both sat on the 'roundabout' seat, he took a deep sigh and said to me: "This is imprisonment. I want to go home." After all the silent hours of walking together, his simple utterance, as depicted in the introduction in this thesis, made a powerful impact on me and my fieldwork. Examining residents' walking at a micro level, I traced the openings, paths and ruptures of desiring production in residents' walking to yield ethnographic insight. One way to do so is to examine cartographies of nursing home environments, like the figures that I presented here, to illustrate, record and consider how residents and other persons assemble and move.

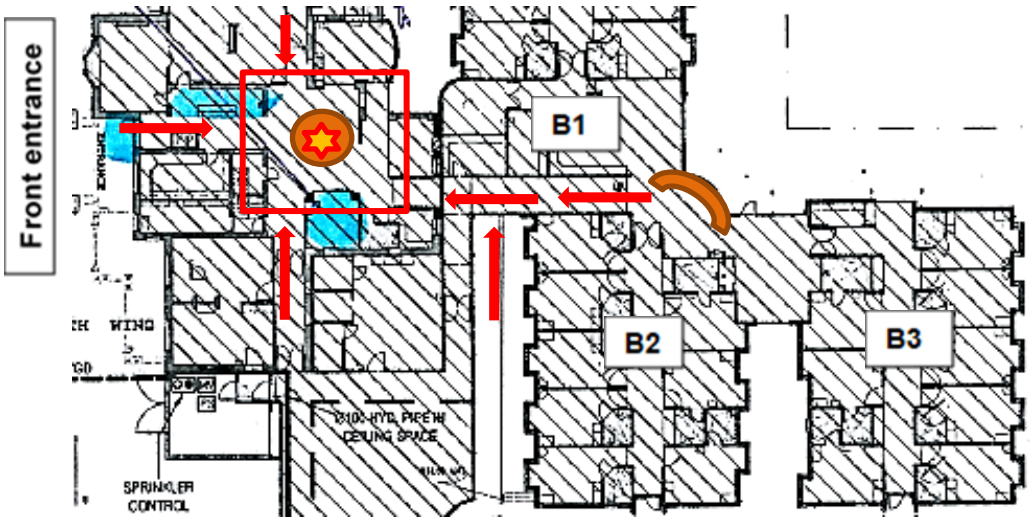

Figure 1: The 'roundabout' on the ground floor. The brown circle with a red-yellow star marks the seat in the middle of the roundabout; the red square marks the roundabout area; the red arrows show people's walking routes towards the roundabout.

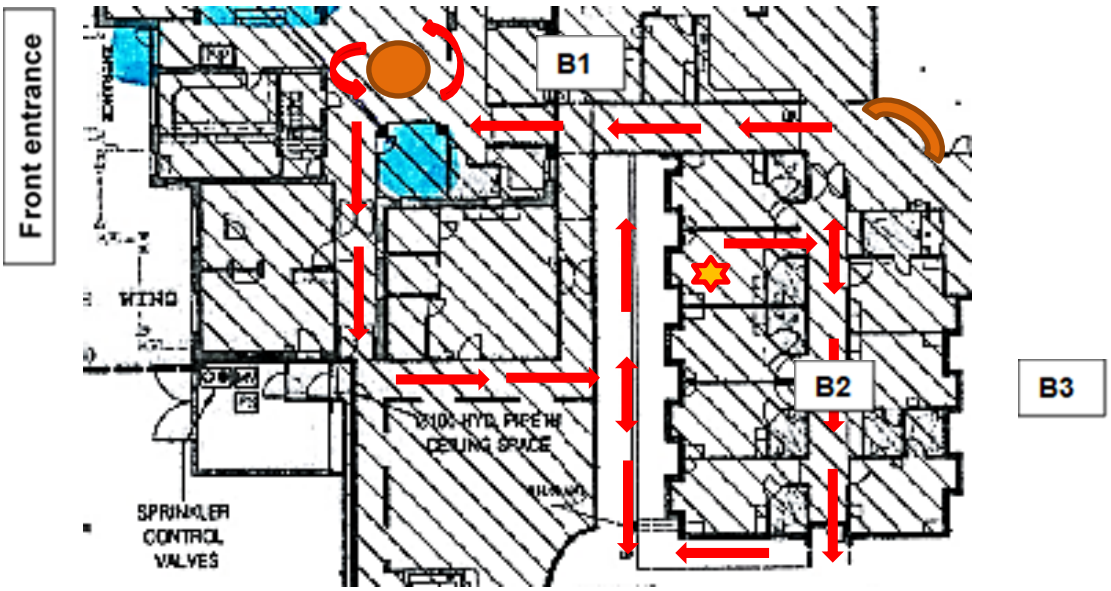

Figure 2: Mr Harris' daily walking routine. The brown circle marks the seat in the middle of the roundabout; the red-yellow star marks Mr Harris' room; the red arrows show Mr Harris' daily walking routes.

Another example is "the ladies sitting in the communal area". The same group of elderly women always sat together in the couches located in the communal area from morning teatime (10 am) to the late afternoon (4 pm). They seldom talked to each other but sat quietly one next to the other. Their gathering was routinely interrupted by lunch (12 pm to 1 pm) and occasionally interrupted by trips to the bathroom, called 'self-toileting' or 'staff assisted-toileting' in the everyday vernacular of nursing home staff. Their sitting together in the communal area was described as a "strange behaviour" by staff as they closely watched people coming and going. From time to time visitors complained about being "glared at" and saying they felt "weird".

Spending hours and hours sitting with these residents, I became kind of like them: instead of trying to start a conversation, I tended to watch people passing by. Using the floor plan that the facility manager provided upon my request, I marked the location of the lounge area to contextualise their sitting, making transfers of position and walking. The picture below (see Plate 21) shows the communal lounge area in Dulce Domum, which is indicated by a red-yellow star in Figure 3.

Plate 21: The lounge area where a group of female residents sat daily

A careful reading of the floor plan gives clues to the understanding of this group of female residents' daily gathering. As this lounge is situated at a central crossing point between areas B1, B2 and B3, a large amount of traffic, including residents, staff, visitors, move in and out of the area (see Figure 3). Instead of sitting within the four walls of their individual rooms, these residents sat amidst the flows of movements of staff, sounds, visitors, trolleys, the passing breeze and wafting aromas. They were watching, hearing, smelling and feeling, while being seen. They seemed to have mingled with others in their movements while remaining seated. In sitting with these female residents daily, I came to understand that their sitting was not simply a state of being immobile and inactive, and nor was it a "strange behaviour". There exists an innermost drive in residents to connect and to be in touch with others and the world. They were doing this by sitting.

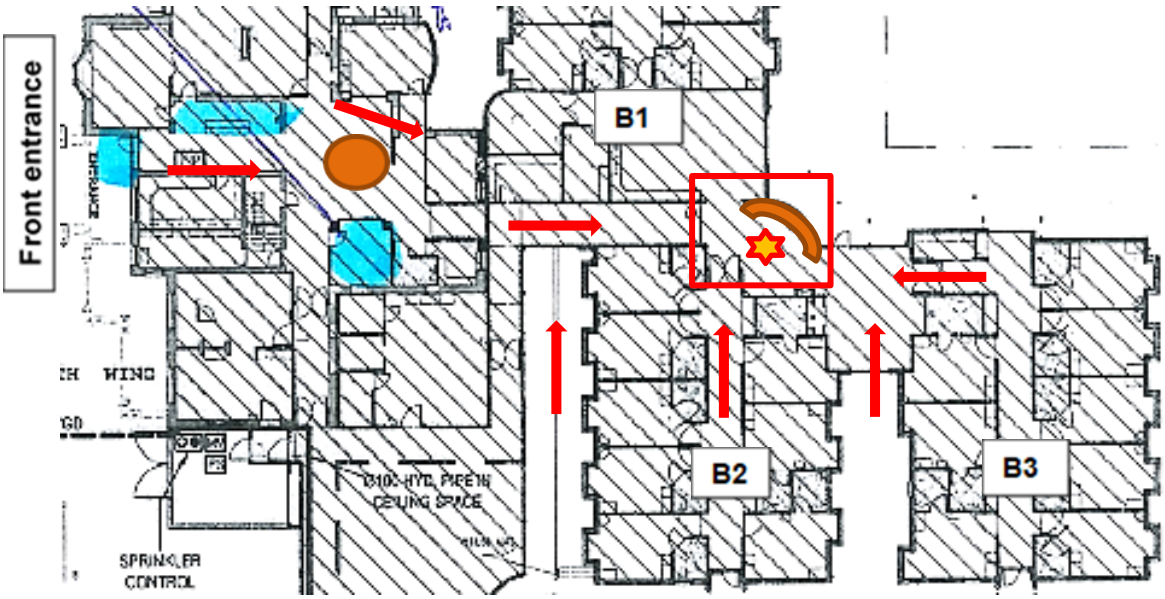

Figure 3: Location of the lounge area and people's movements around it on the partial layout of the ground floor. The brown semi-circle with a red-yellow star marks the couches in the lounge area; the red square marks the lounge area; the red arrows show people's movements around the lounge area.

This process of doing fieldwork—immersive participating, observing, communicating and reflecting—plays a pivotal role in developing an understanding of residents' walking and sitting. Drawing on ethnographic examples in the next part, I will in Chapters 3 to 6 critically examine how, despite living with varied bodily and cognitive impairments, residents came to experience a sense of home in the nursing homes in and through walking.

II Walking

Introduction

What is walking? Is it an ability developed when we grow and lost when we age? Is walking an intentional action, like walking on a tread mill for fitness or rather a motor activity supportive to an intentional activity, such as walking to school or work? Is walking a behaviour with no definite intention, or as Ingold (2011, p. xii) suggests, one modality of moving, which is a fundamental mode of human embodied being-in-the-world? Such questions may sound strange to ordinary people living their everyday lives as walking is largely something that we just do without thinking about it. Ingold and Vergunst suggest in their edited book on the ethnography of walking that walking is a quintessential feature of what we take to be a human form of life (2008, p. 1).

Yet, following the steps of nursing home residents, I learnt that age-related bodily deteriorations may lead to balance and gait impairments as well as attention and cognition deficits that significantly impact on walking, rendering it a difficult task of daily living. Part II of this thesis attends to the everyday walking of residents, to critically examine how they came to experience a sense of home while living with bodily and cognitive impairments in a nursing home. Tracing the footsteps of residents and the responsiveness of other bodies and objects in their path, I analyse how home, bodies and walking are reconfigured through multiple contexts of care—assemblages (Deleuze & Guattari 1988) of different things, persons, discourses and practices. I draw on Deleuze and Guattari's (1977, 1988) notions of becoming and productive desire, to extend Jackson's (1995, 2002) notions of home and existential imperative, to explore residents' walking as a process of becoming at home in the nursing homes.

This part will describe varied modalities of walking from an everyday routine (initiated by residents or staff), to what was deemed as 'excessive' as in the case of the wandering residents, or 'agitated' such as in the persistent failed attempts to transfer position. Chapters 3 to 6 will demonstrate that residents in the nursing homes often felt unable to walk safely, as they attempted to do, due to their impaired bodily conditions. In capturing the 'diabetic feet' of Mrs Casey, the 'frozen gait' of Mr Harris, the 'loss of mind' of Mrs Sage and the 'roller coaster of cognition' of Mr Dixon, this ethnographic study details how bodily impairments affect the ways that residents could create a sense of home when their reduced sensitivity, flexibility and coordination affected their walking. Despite their impairments, as these ethnographic examples will demonstrate,

there exists an innermost drive to move leading to residents' persistent attempts to walk. I approach their bodily impairments as the constitutive and differentiating forces that propel bodies to sensorially and relationally extend through other people and things.

To explore how bodily articulations and entwinements create productive assemblages of care, I examine how these assemblages (of residents bodies, walkers, medications, handrails and the helpful hands of care staff) generate the movements that residents attempt to make but require assistance to make on their own. The key argument conveyed in this part is that multiple persons and things need to come together to enable residents to find firm ground, to move in the world, despite their ailing bodies, and to become at home in the nursing home.

Chapter 3 finds that it is possible for frail elderly people with physical impairments, like Mrs Casey, to feel at home in the nursing home through a careful attention to walking and a daily walking routine. In watching each step, Mrs Casey experienced her body as both 'mobile' and 'minded'. Her cognitive capacities are constituted in the process of walking in which her diabetic feet are not just an impairment but also a productive force. Chapter 4 will demonstrate that it is possible for frail elderly people with cognitive impairments like Mrs Sage to feel at home in the nursing home through wandering—which is understood in the nursing home as walking that is excessive, persistent and careless. In the process of wandering, Mrs Sage remains immersed in and connected to the world, which challenges dominant conceptualisations of cognitive decline. Chapter 5 finds that it is possible for frail elderly people with movement disorders, like Mr Harris with Parkinson's disease, to feel at home in the nursing home through his Parkinson's medication schedule and a staff-assisted walking routine. Chapter 6 will use the example of Mr Dixon, a resident with dementia with Lewy bodies, to explore residents' experiences of sitting and living the tension between walking and not walking. Chapters 5 and 6 will demonstrate how residents' attempts to move become entangled with multiple material things, persons, practices and discourses. Their wish to move can be responded to by a right assemblage of material things, technologies, staff attention and assistance that supports them to feel a sense of rightness in walking and living in the nursing home. In tracing the movements of these residents, this part of the thesis will demonstrate how a body becomes walking with other material things and beings, undergoing a process of *in*-habiting nursing home environments through sensory extension (Dennis 2007) and correspondence (Ingold 2017). A sense of home,

as will be demonstrated, can be constituted in this productive process (Deleuze & Guattari 1977, 1988) when residents walk all right and feel just right.

Examining walking at the last stages of life in nursing home settings, I ask, is there a limit to frail residents continuing to walk and having a sense of home? For Ingold and Vergunst, ‘Just as no definite point marks where we start to walk’, they write, ‘so there is no point, on homecoming, at which we come to a stop. …Barring accident, older people do not, of an instant, stop walking’ (2008, p. 16). Nonetheless, for the frail nursing home residents, walking is always a becoming-walking in which tensions between walking and not walking are continuously negotiated. In Chapters 5 and 6, I also turn to situations where residents were not assisted to walk as they wished, to pave the way for my discussions on the topic of care in Part III. While care is understood in this thesis as a dimension of walking, Part II foregrounds walking as a way for residents to become at home. In Part III, I shift the focus from walking to other activities of standing and eating to explicitly describe and analyse the prominent role of care in residents’ movements and in their becoming at home in the nursing home.

3 Watching each step

Sore legs and numb feet of Mrs Casey

In her ethnography on barefoot running, Warnock describes how barefoot runners experience pleasure as they 'feel the world through their feet' (2013, p. 96), but which differs from shoed runners and walkers, who may still feel the world through their feet, but do not experience 'pleasure from the sensation of the ground' (2013, p. 96). While people can run and walk through bipedal movements no matter whether they are barefoot or shoed, Warnock (2013) identifies how our feet get *in touch* with the ground and how this may *differentiate* our feelings and senses of running and walking. A sense of pleasure is related to the heightened sensitivity produced from the feet directly touching the ground.

Our feet are the only area of the body that has direct contact with the ground as we stand and walk. Walking, running and standing become impossible if our feet are off the ground. Each time we take a step, we preconsciously activate our nerve endings on the soles of the feet. Without conscious attention, we accommodate our terrain by putting pressure on various parts of the feet and adjusting our position. Whether we are standing up from a chair, walking on a flat pavement, or climbing up a slope, similar physiological and neurological processes are involved—we adapt preconsciously by changing how we ground the feet and so does the body. That grounding, or lack thereof, affects our overall posture, movements and stability. Being barefoot or wearing shoes affects one's grounding and overall experience of running and walking. Meanwhile, how people encounter the world is also affected by their environments. Warnock's (2013) research reveals how barefoot runners are careful with the trails that they choose to run. Running with bare feet on a rocky road is not pleasant but painstaking. Running on a sunbathed red dirt trail may be felt as bouncy and uplifting—every tiny bit of the soles stretches itself in the recurrent rhythmic vibrations; yet, once the resonance is interrupted by the sharpness of rocks, the steps become uneven and the runner is off bounce and balance.

While the feet play a crucial role in grounding the person, we are not ordinarily aware of our feet touching the ground while running and walking. Walking is an accomplishment of the whole body in motion (Ingold & Vergunst 2008, p. 2). We do not experience walking as separate bodily movements, such as putting one foot in front of the other, but as a concerted natural flow of movements. According to Polanyi, all

bodily movements involved in walking are in the subsidiary awareness, which is the instrumental attention that gives us a tacit *feel* of our positions and movements in relation to others around us (1958, pp. vii, 91). It gives rise to our experience of walking as 'carefree'—little attention is paid to the path on which we walk or the position and movement of legs, spine and ankles. People and objects in the environment are incorporated into one's self through the working of subsidiary awareness, which gives the appearance of our natural way of walking. The other type of awareness that Polanyi suggests is focal awareness (1958, pp. vii, 91) which works to make walking part or supportive to the practical activity in which we engage. While I have a conversation with a friend when we both walk, my focal awareness is on talking and listening. I keep walking without being aware of how my centre of weight is shifting all the time, and my pace adjusts automatically when I am ascending a slope. It is not my conscious act to know about the degree of ascending of the slope or the extra efforts of climbing up. The subsidiary awareness of my moving through place is merged into focal awareness of my conversing while walking (Polanyi 1958, pp. vii, 91). Material things, such as the surface of the footpath and my bodily parts become indistinguishable in the movements, through the coordinated operation of subsidiary awareness. As this brief discussion shows, how my awareness operates is interconnected with other material objects and beings in a changing environment. The very fact that I engage in a conversation while walking shows the unity of my whole-body functioning. The feeling in the feet, propelling of the legs, rotation of hips and swinging of arms all contribute to a person's way of walking. What Polanyi conceptualises using the terms of subsidiary awareness and focal awareness is how, through the organic *synthesis* of many conscious and preconscious processes, we relate to the world through sensual incorporation and perceptual objectification—an originary sense of being alive in and through movement (Barbaras 2008).

Yet, with ageing and bodily decline, the ordinary way of walking can be drastically interrupted, and without grounding the feet one will lose their footing. Mrs Casey, a nursing home resident with type II diabetes, is such an example. Mrs Casey could not feel heat, cold, or pain in her feet, even when they are badly squeezed by her shoes. The nerves in her lower limbs, including her legs and feet, are damaged due to her

long-term diabetes, which leads to her condition of ‘sensory diabetic neuropathy’.[9] She only has a faint sensation from her soles when she walks. Meanwhile, the muscles of her feet do not function properly, because the nerves that make the muscles work are damaged. Consequently, her feet do not align properly. To make her situation worse, the neuropathy causes severe leg pain. On bad days, she could hardly get out of bed, and was all consumed with sharp pains and pins and needles in her legs. On these occasions Mrs Casey would stay in bed, crouched in the fetal position, moaning.

Her weak and insensitive diabetic feet could barely get in touch with the world; unable to receive the proprioceptive information integral to walking, she struggled to maintain posture, gait and balance while standing and walking. Both the sensation of pain in her legs and the insensibility of her feet interrupted the unity of her whole-body functioning and her pre-diabetic usual way of walking. What was usually in the subsidiary awareness—the movements of her feet and legs—was starkly brought into her focal awareness through pain, and the flow of movements broken down into a sequence of distinguishable slow and separate motions of bodily parts. At times Mrs Casey was so engulfed by excruciating pain that she ceased walking.

Desire to walk

For a short period after moving into the care facility, Mrs Casey avoided walking. For her, walking was painful and risky. She told me that it was “not the right thing to do” as it could induce a large amount of pain, discomfort and a fear of falling. Yet, she soon realised that her nursing home life could be miserable if she stopped walking altogether. Without walking she was confined within her own room; she rarely saw or talked to anyone other than the staff who delivered meals and pills. Increasingly bored, sedate and isolated, she put on weight and had frequent mood swings. She started missing the feeling of being able to walk, having lunch in the dining area and meeting people for a chat. The longer she was alone in her room the stronger her wish to walk again; she told staff that she wanted to resume walking.

Mrs Casey’s idea to resume walking was supported by her doctor and the care management team in the facility. Walking, the clinical nurse explained to Mrs Casey, is the most effective way to reduce her diabetic pain and potential complications.

[9] Sensory neuropathy occurs if the body's sensory nerves become damaged. People with diabetes have an increased risk of neuropathy as high blood glucose levels over long periods of time can damage the nerves.

Recollecting her experience of relearning to walk, Mrs Casey talked about how her experience of pain in her legs became different after her conversation with the nurse. She used to feel dreadful, with overwhelming pain, including pain from severe tissue damage to her legs, and with the gloomy prospect of having an amputation. She was greatly relieved to know that walking would do no harm to her legs and would help to get her diabetes under control. This new understanding of her bodily condition and situation fuelled Mrs Casey's desire to resume walking. With the belief that her diabetes would be under better control if she could continue to walk, Mrs Casey took steps to relearn to walk and established a walking routine.

Walking was intense and potentially risky for Mrs Casey and she often had mixed feelings towards walking—prior to each walk she feared losing control of her body and injury from falling. Yet, after each walk, she felt a sense of contentment and peace. Instead of a tedious task that she undertook daily, she considered walking as a therapy, something she could do to get healthier and feel better. As she continued to walk daily, Mrs Casey experienced a sense of rightness in walking—being able to stand on her own feet and walk again is understood as a sign of improvement and control. As she said, "feel right if I walked just fine" and, "feel something undone and not well" if she missed a day when her legs hurt. While residents often feel, as Mrs Casey said, that they "can't do much" after living in a "home", being able to walk and feeling good and right in walking is at the core of how she feels, thinks and talks about "feeling at home" in her nursing home.

An innermost drive to move underlies residents' walking, and for residents with physical disabilities and cognitive competence, like Mrs Casey, this innermost drive to move not only manifests itself in their own efforts of relearning to walk, but also in cognitive activities, such as choosing to relearn to walk over sitting in a wheelchair, or a decision to establish and follow a daily walking routine. It is from this key understanding of residents' innermost drive to move as a preconscious, impersonal and productive desire (Barbaras 2008; Deleuze & Guattari 1977, 1988) that this chapter illuminates the walking of Mrs Casey as a productive process leading to the actualisation of movements and a sense of *becoming-at-home* in the nursing home.

The first phase of Mrs Casey relearning to walk was to recondition her painful legs. Under the supervision of a physiotherapist assistant, she stood in front of the handrail in the corridor out of her room and held on to it. With her feet apart and pressed firmly

into the floor, she transferred her weight to her right foot and slowly lifted her left leg off the floor. Holding that position for a few seconds, she slowly put her left foot back onto the floor. Transferring her weight to her left foot, she slowly lifted her right leg. She tried to disregard initially troubling sensations of pain while exercising: “It’s not that bad. I’ll get better if I can walk.” Gradually, the pain in her legs was no longer as sharp. After her legs were attuned to the concerted movements of the body, Mrs Casey could shift her focal attention to experiment with taking steps.

With help from the physiotherapist, Mrs Casey learnt to use her sight and conscious attention to monitor the movements of her feet. She carefully placed her left foot on the floor in line with the left wheel of the walker while bending herself forward from her waist up to see her own feet moving. Under the normal functioning of our proprioception, ‘The body ‘knows’ … where all its parts are without being able to see them in objective space’ (Spurling 1977, p. 158). Yet, in the case of Mrs Casey, she must see how her feet move in objectified space to know how to take the next step. Having learnt to adjust her attentional mode through practising, Mrs Casey could substitute the preconscious proprioceptive perception—sensation from under her soles—with the conscious proprioceptive awareness through sight. In feeling her way while seeing her feet moving, visual perception of her even strides was synthesised with her proprioceptive perception of balanced posture and gait. With time the walking of Mrs Casey appeared sluggish yet rhythmic and fluent: being balanced, steady and moving, she felt just right.

From feeling not right to just right with walking, the process of Mrs Casey relearning to walk is also the process in which a walking body is gradually and repetitively constituted despite the bodily impairments. This cannot be explained within the dominant conceptual framework for understanding residents’ walking. In aged care discourse, the walking of nursing home residents is conceptualised as ‘ambulation’, a modality of resident mobility, which is the ‘ability of older individuals to move within their environment performing functional tasks’ (Ouellet & Rush 1996). Within this framework, health professionals and nursing staff tend to understand the walking of residents in terms of their individual capacity to walk, and its partial or total loss. The assumption that one’s functional capacities are bounded within the body proper underlies the aged care discourse on capacity. Two central points are key to this conceptualisation on capacity as a natural and innate given, which this thesis finds reductive and problematic.

First, the acquisition and loss of capacities are thought as the natural outcome of development and decline. A direct association is made between old age and the loss of capacities. Difficulties with daily life activities and normal functioning, like walking, are understood in physiological research as the result of the aging process (Milanović et al. 2013, p. 8), characterised by reduced 'functional capacities' (Borkan, Hults & Mayer 1982, p. 182). In this singular attention to biological aspects of aging, decreased function is foregrounded, and it is presented as natural and inevitable. Older people are seen by health professionals and care staff as struggling with the limits imposed on bodies: declining bodies, damaged bodies, bodies that are painful, insensible, slowed down or in stasis. As the process of deterioration is irreversible, aged bodies will unavoidably fail to function and fall. Yet, this direct association of bodily decline and loss of capacities with old age erases the complexities of walking that I observed in the day-to-day lives of nursing home residents. What is missing in this perspective is how elderly people can actively adapt and adjust to bodily changes in their real-world environments. Individual capacity to walk thus cannot be conceived as a given, fixed innate entity.

Second, taking a reductive approach, the capacity to walk is considered in terms of the respective function of body parts which is assessed through measures of gait, pace and stride. As detailed in Chapter 2, an individual resident's capacity to walk is measured using standardised tests to indicate the highest possible level of functioning of that individual. Mobility care—as one category of the institutional practice of service delivery—is organised around this notion of resident mobility. The decrease of functional capacities is investigated in physiological research as the reduction of physical fitness, including strength, endurance, agility and flexibility (Riebe et al. 2009). Difficulties with walking are reduced to deteriorating body parts, or systems, such as the reduction of muscle strength in lower limbs. The solution to this problem is therefore, to 'slow down the loss of functional and physical abilities' (Milanović et al. 2013, pp. 8, 555) through exercises targeting failing body parts or systems (Gault & Willems 2013).

In the field however, the assessed mobility capacity of a resident is not predictive of how the resident would move during daily activities. In real-life environments, residents assessed as incapable of walking could in effect walk on their own under staff supervision, or with the aid of an assistive device. This observation is in line with the findings from research conducted by Giannouli and colleagues (2016) on mobility of

older people living in the community. Their research shows that mobility performance, measured in daily-life environments, is not solely a matter of functioning within the limits of capacity to move. Rather, how elderly people move reflects how they are actively exploiting their capacity to be mobile in everyday lives (Giannouli et al. 2016, pp. 11-12).

Mrs Casey described a process of “feeling just right in walking”, having increasing confidence in standing up from a reclining chair, and being “less and less worried” before setting off on her lunchtime walking routine. When residents change from feeling crippled to feeling just right, understanding their movements can be aided by Canguilhem’s conceptualisation of normativity (1998, p. 127). In a general sense, normativity may be defined as the power of establishing norms. From the particular standpoint of medicine, normativity is defined by Canguilhem as the organism’s power to create different and more or less stable ways of functioning according to various normal or pathological states (Debru 2011, p. 2). In the case of Mrs Casey, she attempted to establish a new functional norm—a careful way of walking—by navigating the limitations produced by diabetes.

In relearning to walk, Mrs Casey was ‘deploying [remaining] capacities of attention and response that have been developmentally embodied through practice and experience’ (Ingold 2011, p. 11) so that the whole-body could set in motion in exercises, such as sit-stand with handrail and wall push-ups, despite its local impairments. Through individualised and scheduled physio exercises, Mrs Casey worked on her core muscles, back, butt and hips to improve her balance and mobility. In this sense, the sore legs and numb feet of Mrs Casey became the constitutive force in her relearning to walk, thus demonstrating that bodies are not lived as fragmented collections of parts but as multiplicities that hang together to ‘present various forms of coordination’ (Mol 2002, p. 55). In a field where the dominant discourse is about disability and impairment, relearning skills and expanding the body’s capacities are often seen as unrealistic, if not entirely unthinkable. But as demonstrated by Mrs Casey’s deliberative and adaptive response to bodily decline, relearning to walk was made possible. Relearning a movement is in effect a matter of ‘growth’ (Downey 2011), expanding one’s capacity into a new bodily condition so that the person continues to move.

Walking aid: the best walking companion

The process of Mrs Casey re-learning to walk also involves assistance from other material things and persons. Her ‘wheelie walker’ played a pivotal role aiding her to eventually place one foot firmly in front of the other. Mrs Casey was initially assessed by the physiotherapist as needing ‘1-staff physical assistance with transfers and locomotion’, which meant she was prescribed the help of one personal care worker to provide support either by holding her back or arm when she gets out of bed, stands up from a chair, or walks. Over time, she required more support, as ‘1-staff physical assistance’ was not enough to get her moving. As Mrs Casey is heavily built and overweight, it did not take long for her and the staff to realise that, one care worker could do little to effectively help her with transfers and walking. Besides, Mrs Casey expressed her dislike of the physical contact from staff, such as a hand on her lower back, which gave her an uneasy feeling and distracted her from walking. The physiotherapist then prescribed a 4-wheeled walker to assist Mrs Casey with her walking. A 4-wheeled walker is designed for users who can walk reasonably well but would benefit from extra support over longer distances. However, in the case of Mrs Casey, the support from her walker is crucial and indispensable. “You can’t walk without your best friend, Mrs Casey!” staff would often joke in reference to her walker. The word ‘right’ was frequently used by staff to refer to situations, such as these, when residents were observed to be able to move. The walker provided the right type and amount of assistance and was hailed as “just right for Mrs Casey”.

But it could take time for the right fit to emerge between residents and walking aids. According to Mrs Casey, the walker felt strange when she first took hold of it. Its plastic handlebars were cold to touch. Its wheels were either too fast or too slow to respond to her manoeuvres. “I didn’t feel it would fit me when I first started,” Mrs Casey said. Yet, as time went on, she could incorporate the walker into her movements. She tried to lower the handlebars to push using her hands and later raised the handlebars to push using her elbows. She pushed it to stand up, pulled it to sit down or leaned on it to take a breath.

With time and practice, as staff commented, the walker increasingly fitted, aiding Mrs Casey’s posture, gait and balance. In observing that Mrs Casey was able to walk with the walker, staff documented in ‘progress notes’ that it was ‘right’ for Mrs Casey. The right assistive technology differed from person to person. It was something that had to fit with residents’ bodies. This fit was apparent in two unique ways. First, in contrast to

standard usage, which requires the person to hold the frame at a comfortable position in front of the body, usually with a 15 to 30 degree bend at the elbow to facilitate standing in an upright position, Mrs Casey did not hold the handlebars with her hands or take an upright posture. Instead, she bent herself forward from her waist up, leaning on the walker using her elbows. In bending forward heavily on her walker, her upper body was positioned at a 100 degree angle. The centre of gravity was therefore out of the walker's base of support and her body proper: it rested in between Mrs Casey and her walker. Only in this way could she move her feet: part of her body weight was transferred onto the walker. The walker provided both additional support and a wider range of stable centre of gravity positioning. Second, by directing body weight through her elbows and the walking aid, lower impact and static forces were transmitted through her arthritic knees and ankles. The walking aid and her arms could substitute for the muscles and joints of the spine, pelvis and legs in the generation of dynamic forces during walking.

Once she felt the walker fitted her, the way that her walker came to her aid required no conscious attention. She did not look at either the walker or the positions of her elbows while she walked and pushed the walker forward. Her elbows rested on the handlebars of the walker with ease. When I once tried the same posture, my body became tense as I concentrated in order to remain steady and not lose my balance: my neck hurt when I looked up from a much lower position; my back cracked when I kept bending to a right angle. It was such an awkward and nerve-racking posture to me! Yet, the walker came to Mrs Casey like a handy hammer to a ready hand—tacit knowing through touch.

In contrast to healthy adults, the walking of residents often involved the use of an aiding device, such as the wheelie walker, or assistance from staff. Walking was therefore not a matter of moving alone but moving alongside together, which calls for the *attunement* or *synergy* described in Ingold's case of sawing (2011, p. 17). Using the example of sawing through a plank of wood, Ingold (2011) explores how sawing, a rhythmic activity requiring manual dexterity involves attunement, which calls for intense concentration. The concentration, as Ingold demonstrates, 'is that of a consciousness that is not confined within the head of the practitioner but reaches out into the environment along multiple pathways of sensory participation' to 'bring into phase an ensemble of concurrent movements, both within and beyond the body' (2011, p. 18). Following a walking routine may become a ritual-like performance for residents like Mrs Casey,

which brings the person into a particular state of being. After personally experiencing the Warlpiri ceremony in central Australia, Jackson was convinced that:

> a sense of home is grounded less in a place *per se* than in the activity that goes on in a place … concentrated activity is experienced as a quickened relationship between oneself and whatever one works upon. The object comes to embody the life of the worker. This means that before Warlpiri recognize a metaphorical fusion between person and place, this fusion is felt in bodily praxis (Jackson 1995, p. 148).

What is achieved as fusion between person and place through ceremonial dancing in Jackson's case is forged as 'the synergy of practitioner, tool and material' (Ingold 2011, p. 17) in Ingold's skilled sawing activity.

As the descriptions demonstrate, in relearning to walk, Mrs Casey could *attune* to her declining body, and meanwhile *connect* with the right things (e.g., a suitable walking aid) and persons (attending staff members) to establish *adaptive* new forms of walking. To further illustrate Mrs Casey's walking as a way of feeling right at home in the nursing home, the next section describes how she could manage to walk safely—taking each step with care—relating to her surroundings with sensibility and responsiveness.

Watching each step

As has been demonstrated, Mrs Casey walked in a unique manner, bending herself forward from her waist up and leaning on the walker using her elbows. There is a special reason for this gait: it was crucial for her to see her own feet moving to ensure she placed one foot on the floor and that its position was right in relation to the position of her walker. She would not have been able to lift her other foot up and swing it forward if the positioning of the supporting foot did not look right. "I must watch each step of mine", Mrs Casey once told me, explaining how she managed to walk safely. Unlike able-bodied healthy adults, walking becomes a highly concentrated activity for residents like Mrs Casey. This modality of residents' walking can be described as 'careful'—taking care with each step in a slow pace—so that they will not trip over, lose balance and have a fall. This section describes how Mrs Casey could feel just right, having a sense of control in walking safely through watching each step while walking.

Mrs Casey was very focused once she started walking. She did not look ahead or around but down at her own feet moving on the floor. She was surprisingly steady with each step, yet painfully slow. After four steps, she might stop walking and look around: Mrs Casey only responded to people around her at such moments. While walking, she

simply ignored whoever passed by and said “Hello!” to her. I once asked whether she needed some help when I met her in the hallway. She paid no attention to me until she came to a full stop. She turned her head to the side where I was standing and looked up: “No, leave me alone. It’s better to let me do it,” she answered and slowly resumed her gait, proceeding with her walking. Annie, a veteran care worker later told me not to talk to Mrs Casey while she was fully engaged in her walking:

> Better leave her to concentrate on her walking. When they age, they cannot cope with more than one task. Mrs Casey would feel overwhelmed to have a conversation with you while walking.

After having seen Mrs Casey walking in the hallways for a few months, I started developing an understanding of her unique way of walking. Her walking was characteristic of a sequence of slow-motion movements of her feet, a rhythm of a four-four beat (four steady strides) then rest (stop to look around), and a style marked by an arching posture over her walker and a large-range rotation of her hips. Unlike the ordinary way of walking, Mrs Casey maintained an intensified focal attentiveness towards that which usually evades conscious attention, leading to a lower level of fluency in her movements. Being attentive towards each step, Mrs Casey walked carefully: any interference might have disrupted her walking.

I turn now to examine three key features of Mrs Casey’s careful walking in some more detail. First, she largely relied on visual perception to monitor the position of her feet and to control the movement of her legs. Her close watching of her feet and their every movement indicates that there are perceptual processes, including comparison of positions, judgement on distance and decision on fine-tuning the movements involved. Second, it takes Mrs Casey’s full visual concentration to control her movements while walking. Mrs Casey could undertake no more than a single simple motor activity, like walking on carpeted floor. Multi-tasking such as talking while walking would distract her and prevent her from being in control of her movements. Finally, such a careful way of walking is time and energy consuming. Her speed was slow. The fact that the movements of lifting-up and swinging of her lower limbs were consciously monitored and controlled slowed each step down. Mrs Casey needed to stop after every four steps to regain her energy. Her course of walking (from her room to the dining area) was short, and the frequency (twice a day) low because of the mental effort and energy required.

As a kinaesthetic form of activity, walking is often experienced by healthy able-bodied adults as fluent and effortless; bodies move on their own with little conscious awareness. Yet, walking became an intensive activity for Mrs Casey. She had to make extraordinary efforts to follow a daily walking routine. This leads to the question that is key to the investigation and argument of this thesis, namely, in what ways could feeling right in walking enable a sense of feeling at home if it involved so much effort? Seeking answers to this question, the next section attends to the walking routine of Mrs Casey as a sensory extension (Dennis 2007) through which she became familiar and at home, and step by step inhabited (Ingold 2011) the nursing home.

Becoming at home in a walking routine

Personal routines reflect residents' concerns, interests and preferences. How elderly residents could *adjust* to the institutional ways of life and *inhabit* the nursing home environments are affected by how they are assisted to establish and follow everyday personal routines. Research on residents establishing daily routines in a Hong Kong nursing home demonstrates that routine is neither the exact same activity that one experienced before, nor does it refer to a completely different form of activity which has no relation to past experience. Newly admitted nursing home residents in Hong Kong are found to attempt to 'fit in by repatterning their lifestyles and daily routines as much as they could' (Lee, Woo & Mackenzie 2002, p. 671). Doing home in the nursing home, or 'regaining normality' (Lee, Woo & Mackenzie 2002, p. 673), to use Lee's term, is a process of reformation in which residents actively fit home habits and routines into nursing home environments, so that new habitual interactions and routine practices emerge.

My observations in the field reveal that, to *fit* home habits and routines *into* nursing home environments, residents undergo a process of *in-habiting*—entering continuous and uncertain processes of doing undergoing (Ingold 2017, p. 9), which is by nature 'the evanescent reality of movement' (Sheets-Johnstone 2011, p. 126). Establishing a walking routine, as the example of Mrs Casey shows, involves movements that are not merely repetitions (Latimer & Munro 2009) but also circumstantial modifications (Dennis 2007). For anyone who is learning or relearning to walk, the process involves a large amount of repetitive practice, which is to establish 'habit' as a movement in which both we and those who move with us, and to whom we relate, will in-habit together in the world (Dewey 2015). Adolph and colleagues' (2012) research details the immense amount of practice involved in learning to walk: on average, 12 to 19-

months-old toddlers took 2,368 steps and fell 17 times per hour. Despite the apparent differences between infants learning to walk and elderly residents relearning to walk, they share in common repetitive practice. Both the very young and the very old experience bodily changes in and through the movements they carry on and the postures they take. Learning or relearning a movement takes place in the environments that are at once physical and sociocultural (Jackson 2016). Infants not only grow into walking, they grow into the expected ways of walking, which are shaped by the material things that they walk upon, through and with, as well as the persons with whom they walk alongside (Adolph et al. 2012). Relearning a movement is not only about the particular movement *per se*. While walking becomes an everyday routine activity, selected material things and acquainted places are regularly and consistently incorporated into self through sensory extension (Dennis 2007). In relearning to walk, Mrs Casey reconfigured her bodily capacities to see and feel, push and pull, attend to and respond towards the material things and persons in her day-to-day life. Over a period of more than two years, Mrs Casey always lived in the same room but by regularly walking she becomes engaged with life beyond her individual quarters. It is the keeping up of routine engagements that matters to people, as Latimer and Munro argue, because it brings about a regular, mundane affirmation of what it is that they care for (2009, p. 324), and for Mrs Casey she cared to keep in touch with her surrounds through walking.

It is important to note that, while residents' daily walking is regarded as 'established routines' that are 'always sedimented and repeated' (Knappett 2011, p. 48), it is in effect an open-ended improvisatory forwarding process: 'guided by the past but not determined by it; heading into a future that is essentially unforeseeable' (Ingold & Hallam 2007, p. 11). To familiarise herself with every inch of the hallways linking her room to the dining area, Mrs Casey was always careful observing what was around her. She stopped to watch or ask if she saw any changes in the surroundings: a crack on the floor, a sharp turn around the corner, or a new piece of furniture. Mrs Casey knew that, if she happened to step on a crack on the carpet, she could not adjust her posture to stabilise herself and she would trip over and fall. Walking was for Mrs Casey a process of exploiting the dynamics and potentials of becoming 'upright' in walking. In being spontaneously repetitive and improvisatory, she could experience greater sense of control over walking in and through her surroundings.

Over time Mrs Casey became woven into the 'meshwork' (Ingold 2008, p. 1809)—organic interconnectedness—of the nursing home and grew to know her surroundings. She naturally turned to the other side of the hallway to avoid the crack on the carpet. She stopped to watch for the coming traffic before making a turn at the sharp corner. While she was careful with her steps, the sensory and tangible properties of the material things, like the colours of the red carpet and bright yellow wooden floor, became responsive to her movements through perception and proprioception. Constituted in her careful way of walking was her sense of home—a sense of permanence and security in a 'dynamically unpredictable world' (Sheets-Johnstone 2011, p. 126). For residents like Mrs Casey, a personal walking routine enabled a processual becoming at home in the nursing home.

Achieving a balance: the becoming of a walking routine

For Jackson, being is 'living the tension between acting on one's own will and being acted upon by others to which one has no control' (2002, p. 14). In Jackson's theorisation on home, what is considered as acting—one's own choice and efforts—plays a central role in one's having 'a sense of existential control and connectedness' (1995, p. 154), creating a sense of being-at-home-in-the-world (1995, p. 123), and shaping one's own course of life. In his Afterword to the articles collected in *The Australian Journal of Anthropology* special issue 'Moralities of care in later life', Nigel Rapport proposes a social ethics of care for elderly people with an emphasis on 'caring that their autonomy is not infringed' (2018, p. 256). He draws on Jackson's notion of home to suggest that elderly people may not be able to have a sense of home while living the tension between being autonomous and being included by others with the insight that, while being included by other people through the provision of care, they can be constrained from exercising their free will (Rapport 2018, pp. 255-256).

Researchers find that the institutional routine practices of care, when strictly followed, constrain the people who live and work there. As an exercise of the institutional regulatory power (Harnett 2010), the routine practices of care 'are driven more by a desire for organizational efficiency than the comfort of residents' (Bland 2003, p. 187). Conveyed in this research is the seemingly overwhelming control of the institution over its passive members, residents and staff alike. While Vesperi (1983) considers the paternalistic management of older people's lives as the outcome of cultural influence, Gubrium (1975) points to the structural insulation between those who manage the lives of the patients and those who are managed. The administrators who make decisions

for the patients do not understand the complexity of care processes from the perspectives of patients and caregivers. A focus on the imposing power of the institution often highlights how elderly residents have little control over the ways that they are cared for.

Other researchers have investigated residents' adaptive efforts while living within the constraints of institutional life. Kayser-Jones (1981) finds that the adaptive capacity of residents is shown in their efforts to reciprocate with staff in different ways, including being compliant with staff demands. Research has also demonstrated how residents attempt to garner back some small vestige of power within the constraints of the institution (Harnett 2010). To exert subtle influence on the maintenance of institutional routines, residents in a Swedish nursing home make 'efforts, such as asking staff for a change of bedtime, to carve out some autonomy or fulfil personal preferences in everyday lives' (Harnett 2010, p. 292).

In contrast to the research findings that residents have little control over their daily activities, Lovatt suggests that residents' routine practices 'demonstrated their control of, and belonging in, the materiality of their rooms' (2018, p. 374). Using data collected through participant observation and in-depth interviews in an English nursing home, Lovatt shows that residents cultivated a sense of home in their individual rooms by establishing regular practices, routines and interactions with their material surroundings (2018, p. 372). In considering residents' routine activities, such as cleaning and hosting, as their *own practices* of 'doing home' without staff participation and engagement, Lovatt suggests that residents exert choice and effort, or what can be thought of as 'acting' in Jackson's framework. In showing that residents 'do' or act with a sense of control, Lovatt depicts these lives as far from constrained.

Nonetheless, what I observed in the nursing homes revealed the nuances of routine practices as *multiplicities*—becomings of daily activities which lay beyond any singular notion of control. I found that the ways in which Mrs Casey could relearn to walk, establish and follow a walking routine was not an example of walking as simply doing (for oneself) *or* being done (by others), but rather striking a balance 'between engagement and inclusion on the one hand, and a preservation of autonomy and personal sovereignty on the other' (Rapport 2018, p. 250). The term 'balance' is used in Rapport's social ethics of care to describe 'an appropriate proportionality to

autonomy and inclusion' (Rapport 2018, p. 250), which indicates a balance is to be achieved in processes of doing care for each different bodily condition and situation.

A daily walking routine was first and foremost Mrs Casey's initiative and efforts. She was strategic with developing a walking routine. After relearning the skills to walk safely with her walker, she slowly increased her walking distance and negotiated between routes that are easy to navigate and those that have a steady flow of trolleys, wheelchairs and staff rushing from place to place. In a progressive manner, she became familiar with the environment and became more at ease with her careful walking. She took care to always walk at the same time, once before lunch, and the second time after lunch, and took the same route: from her room to the dining area and back. From taking each step to following a daily routine, Mrs Casey was taking control of her own movements as well as her course of life.

Nevertheless, in nursing homes, what is considered by staff as residents' *personal* routine, such as the walking routine of Mrs Casey, does not involve solely the residents' own choices and efforts. Walking is never just a matter of resident choice. Walking is contingent on multiple factors. Mrs Casey did not make and act on her own choice free of external influence and control. Her decision to relearn to walk and follow a daily walking routine was made in consultation with the care management team in the facility. Being capable of verbal communication and establishing relationships with staff was important for Mrs Casey, to strategically incorporate a walking routine into her care plan so that it could be integrated into staff routine delivery of care. In the making of a walking routine, Mrs Casey was anticipating and thinking through how and when staff could be involved so that staff assistance could be prescheduled. As a routine part of care, staff usually came to Mrs Casey, brought her walker in front of her and got her ready for a walk to the dining area for lunch, fifteen minutes before twelve o'clock. The efforts of Mrs Casey, the presence and assistance of staff and the involvement of her walker in her transfers, achieved a balance which enabled Mrs Casey to follow a walking routine and feel at home in the nursing home.

In the field, the resident care plan that is created on admission to a nursing home is mostly made after consultation with the resident and their significant others to reflect their own interests and preferences. As time goes on, the daily activities that are carried out become routinised into a *habit* for both residents and staff through repetitive practice. The term 'habit' is used in this thesis in the sense that Ingold (2017) has

developed from Dewey's (2015) notion of habit to refer to a forwarding and open-ended process of doing undergoing. In considering habit as process, Ingold emphasises the uncertainty, potentiality and probability involved in habitual engagements. This opens possibilities of considering routine practices, not through the notion of control but the notion of *balance* through which one's own efforts and others' engagements can be 'rightly' incorporated into residents' walking all right and feeling just right. In so doing, Mrs Casey's daily walking can be understood as demonstrating how a routine can serve as a temporal reference point organising the shared work and joint efforts of care (Mol 2008), attracting the flows of attention and movements of both residents, walking aids and staff into an assemblage (Deleuze & Guattari 1988) that supports Mrs Casey to walk and create a sense of home in the nursing home.

Conclusion

This chapter detailed how through walking Mrs Casey could recreate a sense of normality in her not-so-normal bodily condition and life situation to feel at ease in walking and living in the nursing home. She endured and attuned to her dis-eased body through relearning to walk and connecting with the right things (e.g. a suitable walking aid) and persons (supportive staff members) to discover creative ways of walking. For residents with physical disabilities and cognitive competence like Mrs Casey, feeling at home in walking is experienced as a sense of connectedness and safety through being attentive to how they walk (e.g. careful or carefree), with whom they walk (e.g. on their own or with aiding devices), towards where they walk (e.g. with or without a goal), following a walking routine (e.g. fixed aim, route and frequency), and the anticipated effects of walking (e.g. slowing down the progression of diabetes). For Mrs Casey, relearning to walk and following a daily walking routine were key to her having a sense of home in the nursing home in and through walking.

4 Beyond wandering

Mrs Sage: the wandering lady

In this chapter I critically examine the notion of wandering. Unlike residents with cognitive competence like Mrs Casey who could feel *right at home* in and through walking by being attentive, learning to watch each step and following a walking routine, residents with severe cognitive impairments, as the coming example of Mrs Sage will show, came to inhabit the nursing home in different ways. In a provocation to biomedical conceptualisations, which render the movements of these residents as pathological and problematic, I show how in wandering Mrs Sage articulated with other persons and things in an assemblage that made becoming at home in the nursing home, in and through walking, possible.

Everyone in the dementia care unit knew Mrs Sage, not always by name but rather as 'the wandering lady'. I first met Mrs Sage when I followed Mike, a registered nurse, on his last round of the 'day check' on the units that he supervises. In one of the two dementia-secured units, she walked towards us. At the first sight, I was stunned by her skeletal figure with eyes appearing disproportionally large against her hollowed face. She seemed to look towards us, yet she was expressionless. As we approached her, she held the handrail with both hands. They were bony, crawling with blue veins, her fingers were crooked and the joints red and swollen. With a solemn expression, Mike silently gave way to her and she carried on walking. He looked concerned while watching the elderly woman pass by and stagger towards the end of the hallway. This was not Mike's usual approach: ordinarily he would stop a few steps away, lower his six-foot frame to face residents, greeting them cheerfully with a grin. "Who is she?" I asked. "Mrs Sage", Mike answered in a deep and concerned tone. After spending a few days in the unit, I came to realise that Mike's response towards this resident was typical among staff. Watching her walking around, they cleared the paths before she approached. No one says anything to her, and she talks to no one.

Nursing home staff repeatedly framed the walking of Mrs Sage as 'wandering' and this was constructed as a lamentable movement that was both excessive and aimless (Hodgkinson et al. 2007). "She gets started as soon as her feet touch the floor. She is forever on her run from morning to night," Annie, a veteran care worker told me. Indeed, Mrs Sage is unstoppable once she is on the floor. Without a fixed course or goal, no definite starting and ending points, the walking path of Mrs Sage left onlookers

confused. More like a mesh of threads than a straight line from A to B, her overlapping zigzag tracks along the hallways were punctured by predicable stops at locked doors and more random stops to hold on to a handrail or a piece of furniture.

In contrast to the attentive walking exhibited by other residents, such as that of Mrs Casey, Mrs Sage appeared to roam carelessly through the halls of the nursing home. Lurking around with jerking steps, walking head-on towards laundry or food trolleys, she would push her way through people chatting in the lounge and bump into sofa chairs or dining tables. Walking haphazardly amidst fragile residents and shared furnishings in communal areas was disruptive to staff, other residents and visitors in the dementia-secured unit. Consequently, her presence often stirred up a wave of screams and scolds from other residents, such as when she held on to Mrs Hayley, a resident sitting in the lounge couch, by putting her arms around the elderly woman's neck.

"Does she know what she is doing?!" asked an angry Isabella, the daughter of Mrs Hayley. Visiting her mum and happening to witness this event, Isabella referred to the incident as "harassment", calling Sharon, the registered nurse on duty, to the spot. Remaining calm, Sharon replied in a controlled voice: "Probably not. She is not quite herself after her dementia got worse." Pointing her index finger at her own head, Sharon added: "Her mind has gone." Dismissing Isabella's idea that Mrs Sage purposely and intentionally bumped into Mrs Hayley, Sharon attributed the unusual behaviours of Mrs Sage to her "loss of mind and self", a shorthand signifier of cognitive impairments and personality changes conceived in biomedicine as the adverse outcomes of having dementia.

"What has happened to people when they get dementia? She must be crazy!" said Isabella sounding less angry but frustrated and confused. Mrs Hayley was newly admitted into the facility with a diagnosis of Alzheimer's disease. Sharon explained:

> Well, Mrs Sage can't talk. She can't tell us why and what she wants. Maybe she is bored, maybe she has no control over what she does. Whatever the causes are, it's her dementia to blame, not her.

Emphasising the fact that Mrs Sage had dementia and could not express herself, Sharon made the claim that dementia had taken control over Mrs Sage and how she would walk and act. How could anyone blame the completely mute and lost elderly

lady for being incapable of taking control over her own movements? After a pause, Sharon added:

> She can still walk. We can't stop her from walking unless she is harmful to other residents. If you insist on filing a complaint on Mrs Sage, I will contact her GP. He may agree to prescribe some medication to restrain Mrs Sage from walking.

"No, that's not what I want." Isabella looked sad and disheartened. "There is no point to blame her for what she has no control of. After all, mum seems okay with her anyway." She sighed and left.

Though staff working in the dementia-secured unit always protected Mrs Sage from the hit-backs and pushes from other residents and defended her against constant accusations from families, they thought of her walking as a nuisance—disruptive to other residents, detrimental to her own health and challenging to care delivery. Despite staff efforts, such as sitting with Mrs Sage over a cup of tea and some sandwiches, Mrs Sage showed no interest in sitting down and having food. She rapidly lost weight and was prescribed formula drink with enhanced nutrition. The care workers fed her with meals and drinks only when they could catch her on passing. One care worker expressed frustration that Mrs Sage kept marching on the same spot while being fed and would walk away with a mouthful of minced beef if not held still by others. Feeding required two staff, one to hold her and another to feed her. Since extra staff time and effort were needed to serve her meals and drinks, feeding Mrs Sage could not be integrated into the facility routine of serving meals. Extra assistance was also required to keep Mrs Sage safe from injuring herself and she was considered at high risk of falls, especially while wandering. Staff expressed concern when they saw her clenching the handrails in the hallways and panting heavily, clearly exhausted from her persistent and spontaneous walking.

As shown in her attempt to protect Mrs Sage, Sharon, the registered nurse, used the neuro-pathological model of dementia to interpret the careless walking of residents. The walking of Mrs Sage was recorded in her progress notes as 'wandering behaviour'. In medical research, constructing residents' walking as wandering, reduces their movement to a pathological behaviour. The reductionist model of behaviour focuses on individual movements that are decontextualised from the broader social, relational and material worlds in which residents are embedded. Bipedal movements are classified as 'lapping', 'pacing' or 'eloping', signifying the type of locomotion behaviour

associated with the brain damage that is characteristic of dementia and which is medically conceptualised as 'wandering' (Algase et al. 2007). It simply becomes a Behavioural and Psychological Symptom of Dementia.

The correlation between the residents' seemingly irrational ways of walking and the brain damage caused by a neuropathological condition, such as Alzheimer's Disease, is established in medical discourse and used as an interpretative framework by staff. During a Dementia Dynamics (person-centred care) Training session[10], a picture of the diseased brain, taken in autopsy, was shown side by side with a picture of a normal brain, to demonstrate the stark differences between them (see Plate 22). The message is clear and biomedically legitimated: residents with dementia could no longer sense, perceive, think and communicate as normal people usually can. These residents, like Mrs Sage, are living an altered being in their own lifeworld—unable to express themself and control how they relate to others. "There are big holes in her brain. Nothing you can do about it," said staff as they talked about Mrs Sage with a grave expression.

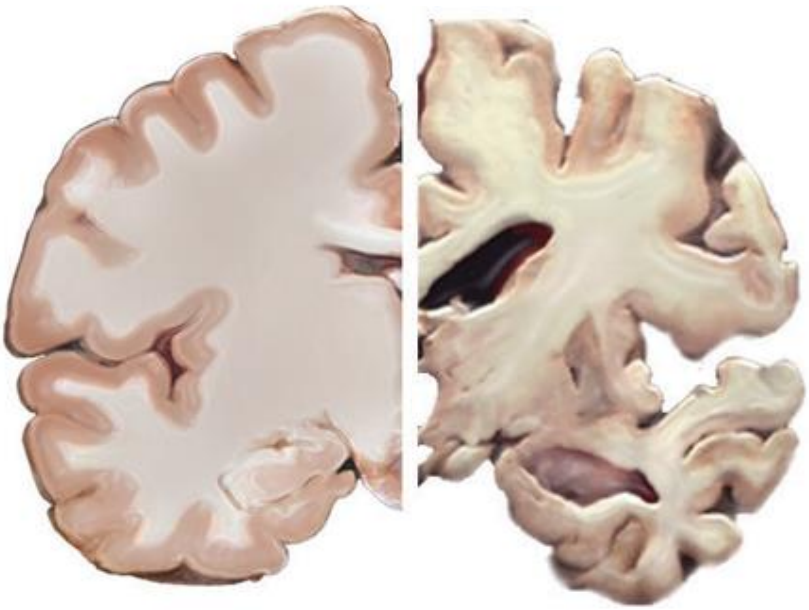

Plate 22: A 'healthy brain' (Left) compared with the Alzheimer's 'diseased brain' (Right) (as presented during a Dementia Dynamics (person-centred care) staff training session)

[10] Staff from all areas including nursing, personal care, lifestyles, hospitality and maintenance were invited to attend 6 successive group sessions (I hour per fortnight) over a 3 month time period in 2015. I attended the training sessions with permission from the management.

Suffering the “loss of mind and self”, as Sharon described her to Isabella, Mrs Sage seems to be utterly cut off from her surroundings. But, was this the case for Mrs Sage? Could residents with cognitive impairments like Mrs Sage recreate a sense of connectedness with other material things and persons? How did her seemingly excessive walking impact on her experiences with others in the nursing home? Before I turn to the experience-near (Geertz 1983, p. 57) descriptions of the walking of Mrs Sage, I will first provide some background to the cognitive impairments that Mrs Sage suffers, as well as their devastating impact on her cognition. I will start by introducing Rapport’s (2018) concept of personal preserve within his framework of social ethics of care. The links between personal preserve (of which cognitive abilities are central), individual autonomy and a sense of being-at-home-in-the-world within this framework will be summarised so that the particularities of bodily conditions and experiences of Mrs Sage, and residents with similar cognitive impairments, can then be discussed.

Personal preserve: what is left of Mrs Sage?

Rapport proposes a social ethics of care with a focus on the preservation of the individual’s ‘personal preserve’, which he defines as ‘a description of individual consciousness as a thing apart, distinct from the world around it’ (2018, p. 254). At the core of Rapport’s notion of personal preserve, is ‘the free expressions of a mature consciousness’ (2018, p. 251) in the forms of first-person point of view, personal sensorium, individual mind and agentic actions shaping their courses of life. For Rapport, the term ‘personal preserve’ signifies the character of embodied consciousness, which is the decisive centre of attention, perception and action. Focusing on the individualisation of self, Rapport promotes a notion of autonomy originated from a decisive centre—the individual consciousness.

For Rapport, personal preserve is not only what constitutes individuality and autonomy (2018, p. 254), it also contributes to the person’s sense of being-at-home-in-the-world by ‘striking a balance between anonymity and autonomy and overcoming the tension between being for oneself and being for others’ (2018, p. 256). Speaking from the assumption that any conscious individual should be autonomous, Rapport proposes a general form of ethical care that pertains to all individuals across age groups and stages of life. For the elderly, Rapport insists that the same ethics of care applies, ‘so far as possible, and for as long as possible’ (2018, p. 255). What goes without saying is that the ‘possible’ stops when the individual’s personal preserve is no more, or it becomes impossible to protect and preserve. In short, personal preserve, conceived

as the embodied consciousness making a person an autonomous individual, is in danger of gradual loss in old age, and in turn, so is the older person's individuality, autonomy and a sense of being-at-home-in-the-world (Rapport 2018).

Drawing on the phenomenological tradition, Rapport (2018) regards the embodied consciousness as a defining feature of being-in-the-world. From a phenomenological perspective, individual consciousness comes into existence in its varied modalities as a bodily aspect of one's being-in-the-world. Captured in the concept of intentionality is the notion that the person-other relatedness is characteristic of a unique directedness from self to other objects in the world. It means that 'all consciousness is about or of something' (Gallagher 2006, p. 7). The content of consciousness can be the 'self', the one who experiences; or an 'other', something or someone external to the one who experiences. These two modalities of intentionality are respectively named as the self-referential and the other-oriented intentionality, and they structure experience on the conscious level. Using these concepts, the phenomenal properties of highly subjective experience can be revealed in self-reflection and direct observation.

Yet, it is hypothesised in biomedical research that patients with Alzheimer's disease are impaired in the ability to see themselves with a third-person perspective (Salmon et al. 2005), which leads to an altered experience of being conscious of oneself—cognitive impairments of self-referential intentionality and body image. An ethnographic vignette from the field illustrates this disjuncture. One day, I had the chance to observe Mrs Sage when she had a hairdresser appointment. Staff assisted Mrs Sage sitting in a hairdresser chair. One care worker held both hands of Mrs Sage while the hairdresser quickly moved around cutting her hair. When the hairdresser finished her last touch, the care worker sat Mrs Sage into a wheelchair and brought her in front of a mirror. The care worker then made a gesture for Mrs Sage to look at her own image in the mirror. As if she was suddenly seized, Mrs Sage rose from the wheelchair in a thrust with an intense look on her face. Fixated in a motionless posture, Mrs Sage gazed at the image of herself in the mirror for a few seconds. She then brusquely collapsed into the wheelchair as if she could no longer hold herself together. Was she startled or surprised? The reaction of Mrs Sage to her own image in the mirror was clearly different from that of people with ordinary cognitive functioning.

With impaired self-referential intentionality, the boundaries between oneself and others appear blurred, which impacts on how one can interact with the world around them.

Mrs Sage could no longer experience a 'will'—perceptually and cognitively constructing a will-be self-other relationship to guide actions. She also has no insight into her own condition and situation, in wandering or clashing with others. In the example of her bumping into Mrs Hayley, Mrs Sage was not only incapable of planning deliberate attack on Mrs Hayley, it remained a question about whether Mrs Sage understood the meaning of the clash and the reactions from other people. Furthermore, she would not be able to recall the incident once she turned around and left.

Medical research suggests that almost all cognitive functions of patients with later stages of Alzheimer's disease are severely impaired (Förstl & Kurz 1999). For Mrs Sage, her abilities for logical reasoning, planning and organising had long been impaired. Incapable of relating to others through symbolic representation in any form, she became highly distractible by stimuli and could not focus on any intentional and purposive activity. Unlike Mrs Casey, Mrs Sage was incapable of being attentional, reflective and careful. Meanwhile, Mrs Sage could no longer form short-term memory and her autobiographical memory was for the most part lost. She no longer knew who she was or is and could not recognise her family members and friends.

Mrs Sage is also completely mute and does not respond to verbal language, which restricts her interpersonal communication with other people around her. Non-verbal communication also becomes difficult as Mrs Sage could no longer recognise a material object by its name or symbol. The 'meanings' of other material things and beings were not being extracted from their symbolic features. Rather, she made sense of them through immediate and spontaneous encounters with them in and through sensory incorporation and movement. In other words, Mrs Sage did not know anything by its symbolic representation or think through ideas—the representations of things or events. Rather, Mrs Sage only became aware of other material things and beings when she caught sight or heard of them or became in touch with them. Severe cognitive impairments led to devastating consequences in the everyday life of Mrs Sage—she was in danger of injuries if she was left alone. Consequently, Mrs Sage relied on staff assistance for all activities of daily living, including eating, drinking, washing and grooming.

What is shown in this section is that the cognitive impairments of Mrs Sage had hampered the agentive 'free expressions of a mature consciousness' (Rapport 2018, p. 251), in the forms of memory, attention, concentration, perception, self-reflection

and decision-making. With impaired cognitive faculties altering her conscious experience of self and others, what was left of the personal preserve of Mrs Sage? Mrs Sage seemed to have lost much of the personal preserve operating consciously that, according to Rapport (2018), makes us autonomous individuals. But, before we can draw such a conclusion, I ask, does being autonomous simply refer to what we express wilfully in speech, thought, or action? Don't we first move around making sense of whatever we are being with before we can possibly engage ourselves in conscious cognitive activities such as contemplation, communication and interaction? To extend Rapport's (2018) notion of personal preserve, I turn to Ingold's (2011) examination of walking.

Being alive in moving through the world

In his book *Being Alive*, Tim Ingold (2011) speculates that being alive is a process of moving, knowing and describing. He asserts

> … that to move, to know, and to describe are not separate operations that follow one another in series, but rather parallel facets of the same process—that of life itself. It is by moving that we know, and it is by moving, too, that we describe. It is absurd to ask, for example, whether ordinary walking is a way of moving, knowing or describing. It is all three at once. …Philosophers have meditated at length on the condition of being in the world. Moving, knowing and describing, however, call for more than being in, or immersion. They call for observation. A being that moves, knows and describes must be observant. Being observant means being alive to the world (Ingold 2011, p. xii; Italics original).

In this excerpt, Ingold makes distinctions between being *in* the world—moving without observing and describing and being *to* the world—being observant while moving. He asserts that being observant is characteristic of the ordinary way of walking. Moving, knowing and describing are three integral facets of the same process of life itself. Life is more than being *in* among others without knowing and describing them. While being immersive means being *in* the world; being observant is being *to* the world.

Before I can go further to analyse Ingold's conceptualisation on the ordinary way of walking, I will first draw on Rapport and Dawson's (1998) conception of perception and movement to discuss the two terms of 'observing' and 'describing' that Ingold has used in the excerpt to mean more than in their everyday sense. Citing Gregory Bateson, Rapport and Dawson assert that:

> To conceive relationships (and so create things) is to move or cause to move things relative to the point of perception (the brain) or relative to other things within the field of perception' (1998, pp. 19-20).

According to the authors, perceiving (observing) is to separate a 'thing' from 'others' in relation to 'self' so that meaning can be conceived and given to the 'thing' (describing) with considerations of its relationships to self and others. Considering how the person-other-world relationships are established in perception and contemplation, Rapport and Dawson state that 'Subject and object, perceiver and perceived are intrinsically connected' (1998, p. 20). According to Rapport and Dawson, movement is fundamental to the creation of thingness of self and others, and the interconnectedness between them. To follow these authors, the word 'movement' can be used to refer to the experiences of observing and describing—searching for meanings by relating the other to self while differentiating both from what are around them in a perceptual world. The experiences of observing and describing thus always involve an awareness of self and self-other relationship, which help with constructing a world of relationships for self, with references to other material things and persons. This type of movement, as Rapport and Dawson suggest, is by nature perceptual and cognitive leading to the creation of images, symbols, thoughts, ideas and speech.

Nevertheless, our experience of perception involves many bodily processes both on and below conscious level. Before subject and object can be created into 'things' and connected by 'meaning' (Rapport & Dawson 1998, pp. 19-20) through movement involved in observing and describing, they are preconsciously connected through movement involved in sensing. For example, they can be involved in sensory incorporation, on the primordial level (Dennis 2007). According to Deleuze and Guattari (1988), while movement involved in observing and describing is a 'disjunctive' process of 'stratification' in which hierarchal bodies, e.g. the sentient, the mobile and the minded, are created in perception and contemplation, movement involved in sensory incorporation is a 'connective' process of 'coding' in which no distinctions can be made between the sensing, moving and observing bodies nor between self and others.

This brief analysis leads to the understanding that for Ingold, walking is not simply about travelling over a distance, but more a matter of perceiving, knowing and understanding the person-other-world relationships while moving through the world among others. Holding a sign of a physical place in mind and walking towards it, as a

goal, is a typical example of how people move through their environments according to their understandings of their relationships with other material things and beings. In the case of Mrs Casey, the dining area where she usually went for her lunch was the destination of her daily walking. The conceived person-other relationship can be expressed as a goal-oriented activity in linguistic form: “Mrs Casey usually goes to the dining area for lunch.” In a metaphorical sense, while a goal is constructed in the mind through the movements in cognitive processes, the body that becomes moving is a *minded* body. Walking towards a goal, to use Deleuze and Guattari’s (1988) concepts, can be understood as a process of ‘territorialisations’—the ordering of the sensing, moving and thinking bodies into assemblages—an emergent unity joining together heterogeneous bodies, e.g. physiological, psychological, social, into a consistency. Walking, as a mode of moving through the world among others, thus becomes, literally, an accomplishment of the whole body in motion (Ingold & Vergunst 2008, p. 2). The sense of bodily synthesis is central to people’s ordinary everyday experience. People usually experience walking as a coherent process of concerted movements, not as parallel facets or bodily processes. Like ordinary people in similar situations, Mrs Casey just routinely walked to have lunch without wondering where or why she was going. A sense of control over her own walking came from the productive process of becoming walking, a productive process of bodily synthesis in which she felt just right.

The experience of being oneself comes from our experience of what is conceived in research as ‘psychological continuity and connectedness’ (Parfit 1984, p. 206). We assume that we are the same person across time. We are the author of our thoughts and actions, and we are distinct from the environment. This means there is a fundamental affective tone of mental, emotional and bodily unity, which gives rise to our experience of being oneself. Kontos suggests that:

> selfhood is embodied and characterised by an observable coherence and capacity for improvisation that is sustained at a pre-reflective level by the primordial as well as the socio-cultural significance of the body (2004, p. 831).

For Deleuze and Guattari (1988), what is consciously experienced as ‘psychological continuity and connectedness’ (Parfit 1984, p. 206), involves the syntheses of many preconscious and impersonal processes of desiring-production that is physiological.

Yet, for residents with cognitive impairments like Mrs Sage, the syntheses on the perceptual and reflective levels are damaged. Mrs Sage could no longer recognise a

material object by its name or symbol. Rather, she made sense of material things through her immediate and spontaneous encounters with them. The walking of Mrs Sage exhibited a lack of purpose—the symbolic expressions of self-other interrelatedness—and control over its course. Instead of being *to* the world, she was immersive, *in* the world, through her walking. For residents with cognitive impairments, the facets of deliberate or semi-automatic observing and describing are no longer integral to the process of walking. They become lost in the careless walking of Mrs Sage. Life was, in effect, a matter of being *in* the world for Mrs Sage.

The careless walking of Mrs Sage is thought by staff as *maladaptive* and *dysfunctional*, as she could no longer relate to other material things and persons around her in sensitive and sensible ways to walk safely. Yet, Mrs Sage could still walk, continuously, and on her own. Following this chain of thoughts, we then reach the understanding that, despite her cognitive impairments, Mrs Sage was still 'in touch', sensually if not cognitively, with her surroundings through excessive and persistent walking. Returning to Ingold's (2011) idea that moving, knowing and describing are parallel facets of the same process of walking, this chapter suggests that, for Mrs Sage and residents like her, instead of being alive *to* the world, they are being alive *in* the world—*in*corporated and *in*tegrated into the lifeworlds of nursing home environments—without the capabilities of reflective observation and description.

Contrary to the biomedical conceptualisation of wandering as utterly pathological and problematic, this thesis argues that the excessive, persistent and seemingly aimless walking of people with dementia has in effect an *adaptive* dimension. It involves the processes of motor-perceptual conditioning of the body, which plays a pivotal role in being-in-the-world despite the loss of a wide range of other cognitive abilities. Returning in the next section to the fuller illustrations of the unique features of the walking of Mrs Sage in terms of its rhythm and style, this chapter aims to deepen our understanding of Mrs Sage's experience of walking in relation to a sense of becoming at home in the nursing home.

At-home in wandering

How, in walking, could Mrs Sage feel at home in the nursing home? To understand Mrs Sage's experience of walking, this section turns to the detailed descriptions of how Mrs Sage walks. Mrs Sage neither walked nor ran to use the usual criteria. Instead of touching the floor from heel to toe and swinging her two legs alternatively, she touched

the floor with the front part of her soles and swung her legs forward with very short intervals between one another. It was not an easy task for care staff to assist Mrs Sage with her daily activities of living simply because once she set her feet on the floor, she started moving swiftly like gusts of wind. The care workers had to run to catch up with her. The difficulties of chasing Mrs Sage did not come solely from the speed of her movement, rather it was the unusual rhythm which made staff frustrated with running after her. For healthy able-bodied adults, the movements involved in walking are usually symmetrical; step length, cadence, torso movement, and ankle, knee, hip and pelvis motion are equal on the right and left sides, which leads to a rhythmic pattern of walking. In the case of Mrs Sage, she lurched from side to side in uneven strides: one long, one short, one shorter, one long, then short again. The loss of symmetry in motion and timing between the two sides indicated a breakdown of motor control of gait due to brain, neurologic or musculoskeletal damage.

While walking swiftly, she leant forward without visibly bending her knees, which rendered her walking jerky and unsteady. To compound the imbalanced leaning forward posture, there was also a side-to-side swing of her body when Mrs Sage was moving. She swung towards the left side when her left leg was off the floor and forward. She swung towards the right side when her right leg made the same movement. The combination of the side-to-side swing and the leaning-forward movement rendered her walking so instable that outsiders, like the visitors and I, were in constant fear that she might have a fall at any given minute.

But amazingly, Mrs Sage had relatively fewer falls than anyone had anticipated. Mrs Sage seemed to have intuitively maintained her bipedal movement in the most adaptive way despite damage to her bodily coordination and integration. Her small strides made it possible for her to change her supporting leg from left to right, and vice versa, to stop her from swinging too much to either side, which might have led to a fall. Meanwhile, Mrs Sage navigated the nursing home through the material things available to her, knowing them preconsciously through using them as they aided her walking. She stopped the accelerating lurching forward movement in a timely manner using the handrails in the hallways, or the sofa chairs in the lounge area. She did not look for the handrails. She stretched her left arm to her left to feel for the handrail when she walked on the left side of the hallway. When she walked on the right side of the hallway, she reached out to her right. Not only her arms, but her whole body was scrunched onto the handrail when it was in her grip. She did not respond to staff requests to “come, sit

down in the chair". She sat herself into the sofa or chair when she met one. She threw herself into the chair and fitted into the shape of the chair at the moment it embraced her. Repeatedly throughout each day, Mrs Sage walked through the hallways, sitting herself into the chairs and clinging to the handrails to take a breath. The hallways, the handrails and the chairs became ready to her feet, hands and body, when they were simply encountered to support her. Her engagement with entities ready-to-hand did not involve explicit awareness of their properties. With no conscious contemplation, Mrs Sage seemed to fit into a meaningful network of purposes and functions, becoming part of a world of fluid relations and perpetual movements.

Like a coordinated natural flow of movements, all the bodily movements of Mrs Sage involved in walking are in the instrumental attention, or subsidiary awareness, to use Polanyi's (1958, p. 91) term, which gives rise to a feel of what is around her and goes with the positions and movements of body parts. Merging into the matrix of sensory properties of the place with a feeling of the world as it is manifested in its totality, Mrs Sage was kept alive in this web of connectedness. In and through walking, Mrs Sage weaved herself into the lived fabric of the nursing home environment.

Living in a care facility provided her with a safe environment and organised assistance. Her excessive and careless walking was only made safe in a controlled 'wanderer-friendly' environment—created from material things (handrails and chairs) and the collective efforts of staff, other residents and visitors, which came together in an assemblage of care. Without staff taking close control over the things and persons in her path, Mrs Sage would have lost control over her own bodily movements. While severe cognitive impairments rendered her walking non-purposive, it was precisely by virtue of the excessiveness and repetitiveness that she was able to sensorially incorporate and become at-home with her surroundings—the other people and material things, like handrails and sofa chairs, that are entwined into her being without conscious attention and mental representation.

Beyond wandering

Seeking an understanding of the so-called problematic behaviours of residents with dementia, Algase and colleagues suggest that 'wandering' is in effect 'the need-driven, dementia-compromised behaviors which may express or embody the cognitively impaired person's goal or needs' (1996, p. 11). Considering wandering as an 'expression of a need' (Algase et al. 1996, p. 10), just like ordinary walking, the authors

suggest that residents who wander need either to achieve a goal or to respond to the sensory stimuli in the environments. They wander because their ways of achieving a goal or responding to a stimulus are compromised due to their cognitive impairments.

As I have discussed, using Ingold's (2011) conception of walking and Rapport and Dawson's (1998) notion of perception, a goal can be understood within the person-world relational framework as an object constructed apart from self, yet, with which one wishes to form a connection. The word 'need' is often used to describe the experience of people wanting a change of their relationships with what they wish for, e.g. from afar to proximate. French philosopher Hans Jonas suggests that both perception and desire put the living being in touch with what is spatially and temporally far away:

> … the spatial breach between subject and object, which is provisionally crossed by perception, is at the same time the temporal breach between need and satisfaction, which is provisionally crossed by emotion (desire) and is practically filled in by movement (2003: 206 as in Barbaras 2008, p. 10).

Here, Jonas uses the word 'desire' to describe what is consciously experienced as a desire for something—a psychological event when one feels motivated to move towards an object.

For residents with cognitive competence like Mrs Casey, what is wished for is conceptually known as the goal with a name and images, such as a dining area. Her walking to the dining area could be considered, recollected, anticipated, scheduled and implemented through the mental construct of a goal. As analysed earlier using Ingold's (2011) notion of ordinary walking as moving, observing and describing in relation to Mrs Casey, the spatial breach between self and her goal is practically filled in by movement in mind—searching for meanings by relating the other to self while differentiating both from what are around them in a perceptual world (Rapport & Dawson 1998, pp. 19-20)—in a metaphorical sense and in body in a concrete sense.

Similarly, Algase and colleagues (1996) suggest that residents like Mrs Sage are also driven by a goal or a need. By proposing that wandering is needs-driven, the authors suggest that residents with dementia are motivated by a goal in a rational sense or responding to sensory stimuli in their immediate environments in a physiological sense. But how residents with dementia seek to meet their needs in pursuit of a need or goal becomes problematic due to their diminished capacities.

Due to the complexity of residents' different cognitive conditions, I restrain myself from discussing whether residents with cognitive impairments could still be motivated to act towards a goal (Algase et al. 1996, p. 10). Speaking from my observations in the field, I find the conceptualisation on wandering as a need-driven behaviour simplistic and reductive in representing the walking of residents with dementia. According to the authors, wandering can be the residents' responses towards other things and beings in their immediate environments such as the approaching response towards noise or bright light, or the repelling response towards crowding (Algase et al. 1996, p. 12). By the term 'response', two aspects of this type of movement are emphasised. First, this type of movement is thought of as brief and episodic with clear indications of initiation and termination. Once the need to approach or withdraw is satisfied, the person stops moving. Second, in responding towards others, one does not take time to conceive about others, in the way that Rapport and Dawson (1998) describe, as the movement in the mind. Others come into connectedness with the person through movements of the body. Instead of constructing representational connections between one and others, the person connects with others in immediate encounters of sensory incorporation. Another material thing or being cannot emerge as a goal in such encounters. One could hardly tell what the other *is* in passing.

As this chapter demonstrates using the example of Mrs Sage, her walking was nonstop without clear indications of responsive movements towards a goal or sensory stimuli between each episode of approaching or repelling movements. Mrs Sage, and other residents with dementia who wandered, did exhibit some approaching or repelling movements in response to a group gathering of residents having high tea or a male resident who appeared to be aggressive. Yet, not as a collection of separate and isolated episodes of movements, the approaching or repelling movements are constitutive to the ongoing process of walking amongst others through environments. In her prolonged walking, Mrs Sage and other material things and beings came into the encounter with one another in a continuous manner, which can be best described using Deleuze and Guattari's (1988) concept of rhizomatic becomings, as connective syntheses. Within Deleuze and Guattari's conceptual framework of desiring-production (1977, 1988), walking is not to be understood as responding but, as suggested by Ingold (2017), corresponding. Expanding Ingold's concept of 'correspondence' (Ingold 2017, p. 9) within the theoretical framework of desiring-production (Deleuze & Guattari 1977, 1988), correspondence can be used to describe how material things—a handrail

and a pair of hands—are productive machines, coupled and drawn into a single mass of matter (Deleuze & Guattari 1988). The experience of holding a handrail may be felt by an ordinary person as a sense of relief; yet, for residents like Mrs Sage, the flow of intensities may have been attracted towards another opening before the 'thingness' of a handrail could be created in the mind. As the walking of Mrs Sage clearly indicated, her continuous walking did not involve the facets of observing, thinking and describing. It was neither constructed goals nor sensory stimuli that led to the nonstop walking of Mrs Sage. The excessive and persistent walking of Mrs Sage was not need-driven because she was unable to perceive a particular need and comprehend what was meant by meeting her need. This may explain her excessive walking—if she had a 'need' for walking, it must have been unspecific and unsatisfiable. How Mrs Sage walked is rhizomatic. It had no predefined starting or ending points, no predetermined centres, no pre-structured structures or systems, but rather new 'potentialities of becoming' (Deleuze & Guattari 1988, p. 290). How Mrs Sage walked reflected the immanent possibilities and potentialities for actualising the very nature of human mobility and more importantly, for revealing the immaterial and invisible relations between people, things and their surroundings (Miguel 2015).

For staff working in an aged care facility, how to get from A to B is a matter of task, time and efficiency. Being purposive, and precise with the aim, course, timing and frequency of walking is important for staff because walking is an essential part of their work. They come and go hastily in a straight-line, pushing a wheelchair, a lifter, or a medication trolley. Aimless walking is thought to be a sign of getting lost. For many staff members, walking is mostly a means of transportation (Ingold 2011)—travelling over distance, and nothing beyond. Holding the assumption that walking is a means of transportation from their own experience, the walking of residents with dementia is often stereotyped and simplified using the neuro-pathological interpretative model which renders walking as wandering, a symptom of dementia.

Nevertheless, as Janelle Taylor suggests in her autoethnography, people affected by Alzheimer's, like her own mother, have their 'own experience of the world that is different from' that of people around them, and 'interesting in its own way' (2008, p. 327). To illustrate, she draws on the account of Morris Friedell, who is himself affected by Alzheimer's, describing how:

> I find myself more visually sensitive ...Everything seems richer: lines, planes, contrast. It is a wonderful compensation ...We [who have Alzheimer's disease] can appreciate clouds, leaves, flowers as we never did before (Shenk 2001:193 as in Taylor 2008, p. 327).

Through her experience of walking slowly with her mother, hand in hand, around the neighbourhood of the facility where her mother lives, Taylor comes to the understanding that, while 'the loosening of memory' may leave her mother 'stranded in the present moment', it 'also allows her to inhabit it more fully' (2008, p. 372) than people who, like herself, with no cognitive impairments but caught up in the rush of their everyday lives can do. In the case of Mrs Sage, in walking she could inhabit the nursing home environment, and this was more than simply getting from one place to another. For nursing home residents with dementia, walking could never be reduced into a symptom of brain pathology. Living their highly individual and altering being, nursing home residents with cognitive impairments could discover and recreate a sense of becoming at home—in the innermost senses—through walking.

Conclusion

Chapter Four described how Mrs Sage, a resident with later stage Alzheimer's disease, becomes immersed in the nursing home through persistent walking without being cognitively observant to the world (Ingold 2011, p. xii). Nevertheless, in the same way as the diabetic feet of Mrs Casey were not just impairments but also a constitutive force to her becoming careful in walking, the absent mind of Mrs Sage cannot be simply considered as neuropathology, but also constitutive to her *in*-habiting the world—becoming sensorially *in*corporated and *in*tegrated into the nursing home environment—without the capabilities of reflective observation and description. This chapter has demonstrated that both the presence of mind for Mrs Casey and the absence of mind for Mrs Sage are the producings of the preconscious, impersonal and productive processes of walking. While being unable to mind her step, Mrs Sage remained connected with other material things and beings without relating to them in objectified terms. It is movement, not mind, that is fundamental to becoming alive *in* the world, especially for frail nursing home residents with cognitive impairments due to dementia.

This chapter has argued that the seemingly aimless, spontaneous and persistent walking of people with dementia has in effect an adaptive dimension. Through walking with staff supervision, Mrs Sage could become just right in walking among other

material things and persons. Residents with cognitive impairments could inhabit the nursing home environments through connecting, not cognitively but sensorially, with other material things and persons. Allowing residents like Mrs Sage to continue to walk, as she attempts to do so, is important because, as Rapport argues in his social ethics of care, caring that the autonomy of elderly people is not infringed is central to their having a sense of home (2018, p. 256) in the nursing home. Rapport's notion of autonomy—exercising free will through conscious choice and action—may not be able to describe how residents like Mrs Sage feel just right in walking all right. However, what Rapport conceives as 'personal preserve'—'the free expressions of a mature consciousness' (2018, p. 251) in the forms of first-person point of view, personal sensorium, individual mind and agentic actions—is the actualisation of a productive desire in and through movement. In this sense, a productive desire is the essence of autonomy in the deepest sense of embodiment. Returning to Rapport's conceptualisation of social ethics of care, I find that his argument that care needs to be a matter of preserving the personal preserve of the elderly is insightful and critical to thinking about care as an ethical practice.

5 Walking out of the freeze

The frozen gait of Mr Harris

The vignette in the Introductory Chapter describes how Mr Harris, a resident with Parkinson's disease, could feel just right in and through walking, becoming at home in the nursing home, despite the constraints of living in a secure care facility. In this chapter, I turn to examine how his walking changed over time as his mind and body declined. By exploring his 'frozen gait' I trace how walking can be switched on and off in the complex assemblages of Parkinson's disease, other persons, medications and assistive devices.

Mr Harris is one of the few residents with whom I formed a bond in the initial stage of my fieldwork. I met Mr Harris when we both were circling the 'roundabout' at the intersection of three adjourning areas of resident rooms (see Plate 23). A stranger to the facility, neither resident nor staff, I was self-conscious and felt out of place while pacing back and forth in the area. People cast their inquisitive looks at me while walking by. No one stopped to talk to me. I felt awkward and lost. Then, Mr Harris arrived. With the aid of a red 4-wheeled walker, he walked cautiously leaning forward with his neck bending over and his head drooping over his chest. Stopping in front of me, only two steps away, he gazed at my badge and asked: "What are you doing in this place?" There was a sense of authority in his low pitch tone, which was slow, flat and heavy. He wore an expression of solemnity rendering his face mask-like. "I am a student learning about aged care." I kept my answer short and simple. "Do you want to get a job here when you finish?" he asked. "I am still learning. I am not sure whether I will work here," I told him. "It is not an easy job working here," he said sombrely. I nodded with agreement. He slowly turned his walker towards the hallway and was ready to leave. Before he walked away, he patted the handlebar of his walker using his right palm and said, "You have your job to do; I have mine." As my fieldwork went on, I realised what Mr Harris meant by referring to walking as his job. Often left by staff to meander on his own, he would observe people coming and going, and he would regularly reach out and engage with them.

Plate 23: The 'roundabout'—an intersecting area in the facility

Walking extended Mr Harris' social world beyond the parameters of his room and it was how he occupied himself in the nursing home. When his bodily condition allowed, he wished to spend time on his feet. In the early days of fieldwork I seldom saw him sitting, except for a cup of tea, a meal or a break: he used to walk so much that staff no longer paid attention to his presence, especially when he could walk safely on his own. In the lifeworld of Mr Harris, walking around while checking on people was an occupation. This notion of walking as a commitment that is centrally placed in residents' lives resonates with the accounts of T. D., a North American nursing home resident. In a conversation with the ethnographer, T. D. asserted that residents 'could help themselves and be happy' in the nursing home if they could 'get walking' (Vesperi 2003, p. 88). For nursing home residents like Mr Harris and T. D., walking is productive and meaningful. It is more than simply passing time or wandering. But over time and with physical decline, walking, as nursing home residents frequently expressed in their words and their bodies, could require a great deal of effort and assistance.

As the two previous chapters demonstrated, for nursing home residents with bodily impairments, walking can never be taken for granted. Becoming mobile takes time and care. Halfway into my fieldwork, Mr Harris had increasing difficulties with walking and in walking alongside Mr Harris, I came to notice that gradually he lost his speed and stride. From time to time, he shuffled—dragging his feet along the carpet to a

standstill—before he started walking again. He could usually walk for a few meters in a string of even strides. Then, as soon as he looked down at his own feet, he started shuffling in small steps, as if the sight of his feet moving interfered with their movement.

Walking deteriorated rapidly as his Parkinson's disease further developed. He constantly struggled with initiating first steps—unable to move his feet forward even with some visible efforts from his lower limbs exerting force. It is as if his feet were glued to the floor, or too heavy to lift and move forward as he wished. Even on occasions when he could slightly tear his feet from the floor, he could barely shift his weight from one foot to the other to allow movement forward. Like a stutterer who has difficulty generating fluent utterances, pauses before speaking or repeats the first part of a word several times, he had difficulty generating coherent movements. In the nursing home, staff referred to Mr Harris' unusual form of walking as 'the frozen gait', a symptom of Parkinson's disease.

Mr Harris struggled to produce the concerted movements necessary for walking. On some occasions, an increased forward lean meant he walked with a progressive quickening of steps, which might have led to a forward fall if not assisted by staff to slow down. He usually had the frozen episodes when he attempted to walk. Sometimes he also froze on the spot in a sudden halt while walking. This happened when a certain thing in the environment became closer as he walked towards it, such as stepping through a doorway, attempting to turn around a corner or approaching a chair. Freezing was usually temporary, lasting for a few seconds or up to several minutes. Once his attention shifted from the object, his walking resumed. Although the sudden halt or acceleration was usually temporary, his walking lost a natural rhythm and flow, indicating instability and increased possibility of falling.

As his Parkinson's disease progressed it was as if Mr Harris and his ability to walk was switched off. As I will later detail, this was also how clinical staff conceptualised the cessation of movement. Observing how residents lose their capacity to move, led me to wonder what happened to the inner drive that had previously propelled them to get up and dressed and, in the words of Mr Harris, do 'his job'—to walk the halls of the nursing home. In the following section I use desire as a productive lens (Deleuze & Guattari 1977, 1988) to examine the tensions between walking and not walking. In doing so I consider how, despite being seemingly switched off from walking, Mr Harris

was entwined in an assemblage of care which propelled him to move and to continue to walk.

Parkinson's disease: living in tension between walking and not walking

Mr Harris was admitted into the aged care facility due to the progression of his Parkinson's disease. He was known to his family and friends as a "good mate"—intelligent, energetic, cheerful and easy-going. Yet, in the eyes of staff, he became a stern, sullen and stubborn resident, with whom they felt it difficult to relate. It may be that their feelings about Mr Harris arose not merely due to his personality changes, but because of the impression made from the flatness in his voice and facial masking, which are symptoms of Parkinson's disease. His face showed little expression as his facial muscles became immobilised and Mr Harris had a decreased ability to perform automatic movements, including blinking and smiling, and consequently he always appeared to be disinterested and bored. However, as described above, Mr Harris once had interests in knowing and engaging with other people.

The progression of his Parkinson's disease also transformed the appearance of Mr Harris in other ways. He once had a long career in the construction industry as an electrical engineer and was an enthusiast participating in many sports, including cricket, football and running. Posed with fellow athletes in the yellowish pictures hanging on the wall in his room, Mr Harris was once a tall man with an erect and strong build. Now, he looked much shorter with age and the forward-flexed posture, head pointing forward and arms hanging in front of his trunk. Forward-flexed posture is a bending of the lower muscles of the back. Damage to the brain can inhibit proper flexion and extension in the muscles necessary for maintaining an upright position. Upon admission, Mr Harris was assessed for mobility and prescribed a 4-wheeled walker to assist with his walking and prevent him from having falls. Like Mrs Casey, Mr Harris found out that the walker was a good fit for him. Support from the walker compensated for his forward leaning tendency and stopped him from falling forward.

After frequent occurrences of 'the freeze', Mr Harris was stopped from walking on his own without assistance from staff. He then spent most of his daytime sitting in a lounge chair snoozing. In sleeping, Mr Harris could not relax in a semi-lying position on the couch, as many other residents do. Due to the Parkinsonism of his condition, he was affected by stiffness. His arms were as stiff as dry sticks and his muscles hard like

rocks. Rigidly sitting, with his legs crossed and arms folded for hours, amplified his frozen statue-like appearance.

Mr Harris also experienced involuntary movements of fingers (rest tremor) when no movements were consciously intended. The shaking of his right-side fingers was most apparent when Mr Harris sat still watching television. Unable to wilfully exert control over voluntary movements in forms of initiation or inhibition—people with Parkinson's disease lose control over bodily volition while having involuntary and uncontrollable muscle movements—distal extremities appear to move on their own outside of residents' control, as if expressing an inner urge to reach or step out.

Ordinarily, in inhibiting unintended movements while standing, the whole body is involved in a congregation of bodily processes and activities that keep the muscles relaxed while maintaining an upright posture. It requires as much if not more active and accurate control as producing the movements themselves (Noorani & Carpenter 2017). In the case of Mr Harris, stiffness from his limbs was caused by increased muscle tone. This muscle tone is the result of the excessive and continuous contraction of muscles, which is the unnecessary preparation of the muscles for movement when no movements are intended. The experience of rigidity of Mr Harris may indicate the occurrence of neuroactivities below conscious level, which failed to actualise into walking. In Mr Harris experiencing hand tremor, it seems that, while the intensity to flow into movements was largely blocked, it found its opening at the distal extremities of hands.

The existence of a deeply embodied innermost drive to move is more obviously demonstrated in residents' persistent attempts of standing up and taking steps. When Mr Harris was awake and sitting on a sofa chair, he used to move his buttocks to the edge of the chair and push himself up, as if he was trying to rise to tear himself apart from the embracing comfort of the chair. Occasionally he could stand up and take a few steps with support from something close by, such as the small all-purpose wheelie table. Yet, his risk of falling increased on such occasions as moving away from his sofa chair, he might have ended up with a hard landing on the floor without the softening effect of the chair. The repetitive attempts of residents changing positions from sitting to standing is conceived by staff as an 'agitative behaviour', that is a behaviour described in gerontological literature as 'restless behavior, or improper physical and verbal actions that may cause trouble for family members, caregivers and other service

users' (Ijaopo 2017, p. 1251). Staff explained that agitated residents "keep trying and forget that they can no longer stand and walk on their own". The medical discourse of agitative behaviour, or agitation, together with staff remarks present these repetitive and persistent movements as symptoms—the manifestations of residents' diseased mobility and cognition.

Parkinson's disease as a clinical entity is considered as a progressive, neurodegenerative condition that results from the destruction of nerve cells in the brain area called the basal ganglia. It is hypothesised in neurological research that the basal ganglia normally exert a constant inhibitory influence on movement control systems, preventing them from becoming active at inappropriate times when moving is seen as dangerous. The role that the basal ganglia plays is to reduce inhibition for the required constellations of movements, thereby releasing them for activation. Experience of voluntary movement comes from the smooth communication—using a neurotransmitter called dopamine—between the basal ganglia and other parts of the brain. When the cells that produce dopamine die, the signal to move does not get communicated and transmitted to the muscles.

Departing from medical conceptualisations, in this thesis I approach Parkinson's disease as an interruption in the ordinarily entangled processes of movement production, or, in Deleuze and Guattari's (1988) terms, a rupture in the processes of desiring-production. For residents with Parkinson's disease, the urge to walk does not necessarily result in their becoming walking. Thinking about the body *not* in terms of systems and organs as an organised organism, the body can be seen as 'the body without organs' (Deleuze & Guattari 1988). For Deleuze and Guattari, the body without organs is in fact 'an egg, crisscrossed with axes, banded with zones, localized with areas and fields, measured off by gradients, traversed by potentials, marked by thresholds' (1988, p. 84). In this sense, Parkinson's disease can be approached through biochemistry and productive forces, where an innermost drive to move, meets with the opposing force, an energy of withdrawal, which causes blockages in the processes of connective syntheses that are constitutive to the actualisation of walking. What is conceptualised as symptoms in Parkinson's disease, e.g. limb stiffness or slow movement (bradykinesia), is a *lack* of natural flow of movements. Lack is 'a countereffect of desire' (Deleuze & Guattari 1977, p. 27), which indicates the rise of the force of withdrawal and the fall of the productive power of desire. In the situation where voluntary movements can actually be produced in the attempts of standing up,

the change of position from sitting to standing may or may not become actualised depending on the moment to moment bodily condition and situation. Approaching residents' experiences of Parkinson's from the perspective of desiring-production of movements, the so-called symptoms can be understood as the manifestations of the desiring-production processes, in changing circumstances.

The frozen gait of Mr Harris can also be understood as a particular manifestation of the desiring-production process. Being purposive with walking ordinarily involves the functioning of focal awareness—the conscious selection of an aim, path and time to walk, and the operation of subsidiary awareness—the preconscious coordination of many bodily processes leading to the actualisation of movements involved in walking. While the experience of being intentional is made present in the former, the flow of fluent movements is executed in the latter. The experience of walking as having a sense of control, certainty and easiness comes from the seamless integrated functioning of consciousness. The presence of an intention to move and the absence of executed voluntary movements indicate that the ordinarily concerted functioning of consciousness is interrupted across the conscious and preconscious levels. The frozen gait of Mr Harris indicates that there exists a disjuncture between what is intended, namely, the initiation of walking, and the execution of movements—his actual taking of steps. His wish to walk is temporarily overridden by what is experienced as being frozen—the over-inhibition of movements.

While Mrs Casey and Mr Harris were both in the situation where they struggled to continue walking, Mrs Casey was more likely to become walking in her bodily condition and Mr Harris became highly unlikely to walk on his own. He often fell back into the depth of the sofa chair. His transfers of position from sitting to standing could not be actualised as his attempts failed repeatedly—after exhausting himself in his struggle, he would fall asleep again. Sitting in one spot for prolonged hours had a significant impact on Mr Harris. Staff spoke about him as "going downhill" and deteriorating rapidly. He was mute most of the time and not responsive towards staff. Increasingly, Mr Harris was seen as having sunk into deep solitude and he was described as having become "part of the furniture", or a "statue", to use the care workers' words. Compared to his earlier self who was mobile and engaging with other people around him, the now non-walking Mr Harris was isolated, withdrawn and disinterested. According to nursing staff, Mr Harris had developed the medical condition of apathy, in which residents appear to have no motivational capacities, tendencies or dispositions. For staff, his

capacity to walk was lost due to his neurological condition of Parkinson's disease, and prolonged sitting had greatly reduced his remaining capacities to the point that he could no longer walk. In short, Mr Harris was thought to be incapable of walking and as staff remarked, he was dependent on their assistance to "get walked".

The descriptions of my observations show that residents with movement disorders, like Mr Harris, may live in tension between walking and not walking. If Mr Harris became increasingly apathetic and withdrawn, does it indicate that Mr Harris experienced more blockages in the flow of intensity and a gradual break-down of the syntheses in desiring-production (Deleuze & Guattari 1988), or, as staff often assumed, a loss of capacities due to his Parkinson's disease? The next section turns to the 'on-and-off' phenomenon to explore how other material things, such as his Parkinson's medication, could impact on his movements, including those involved in walking.

The 'on-and-off' phenomenon

Taking Parkinson's medication plays a pivotal role in reducing the impact of Parkinson's disease on patients. Mr Harris was prescribed two-hourly levodopa (a dopamine replacement) to reduce his stiffness, pain, tremor and other related symptoms. During a training session on care for residents living with dementia, the clinical nurse used the example of Mr Harris to show the importance of being strict with resident medication schedules. She explained that while Parkinson's medication might help to boost dopamine levels in the brain, it could only work for a short amount of time. For this reason, doctors usually prescribe a strict two-hourly schedule of medication for Parkinson's patients. Effective management of Parkinson's symptoms is dependent on getting medication on time, every time. If the two-hourly schedule is not closely followed, residents would experience the fluctuation of symptoms, which is called the 'on-and-off' phenomenon.

The on-and-off phenomenon in Parkinson's disease refers to this switch between being able to move and unable to move for residents like Mr Harris who were treated with levodopa. The switch may occur at the end of the dose when the medication wears off, worsening of motor function or, much less commonly, with sudden and unpredictable motor fluctuations (Bhidayasiri & Tarsy 2012). When Parkinson's medication is working well, the patient's symptoms are well-controlled. This is called 'on' time. When symptoms are not well-controlled, or patients do not respond to medication, this is called being 'off'.

Mr Harris had showed signs of such symptom fluctuation on occasions when his Parkinson's medication was skipped. He had more noticeable tremor, worse stiffness and looked more depressed. The combined effects of tremor, rigidity and joint pain could render the limb movements unbearable to Mr Harris. Forty-five minutes after taking his medication, the tremor of his hand became less obvious and his limbs were less rigid. His whole person seemed to be more relaxed and in a better mood. This was also the scheduled time of his staff-assisted walking routine. For Annie and other personal care staff, it was pivotal to ensure that Mr Harris had taken his Parkinson's medication before assisting him to walk. Forty-five minutes to one hour after taking his Parkinson's medication, Mr Harris was at his best to move—he was 'switched on'.

The effect of taking Parkinson's medication—that is this switching on of his voluntary movements—indicates that Mr Harris experienced what I call a 'fission of mind' in a metaphorical sense. There exists disruption of the connectedness between the 'decision-making' and the 'acting' parts of the neurological system. With Parkinson's medication taking effect to boost dopamine levels in the brain, coherent functioning is restored. Thinking about Parkinson's medication through the lens of desiring production (Deleuze & Guattari 1988), it can be understood in term of biochemistry enhancement leading to connective synthesis in movement production—a pivotal component of caring for patients with Parkinson's disease.

In contrast to Mrs Casey and Mrs Sage who could continue to walk mostly through their own efforts to move, Mr Harris could not walk without being switched on by the engagement with other material things and persons, including the chemical agents in his Parkinson's medication and staff assistance. If residents like Mrs Casey and Mrs Sage could feel just right in walking mostly on their own, was it possible for Mr Harris to feel right when he was assisted to move—when he was 'walked' by staff? If so, in what ways could assisted walking (e.g. by walking aid or staff) enable a sense of being right at home? For a better understanding of how Mr Harris could resume walking, I will turn to the actual process of Mr Harris' walking and describe how staff assisted him to walk out of his freeze. This next section aims to demonstrate how the *assemblages of care*—synthesised efforts of Mr Harris and other material things and persons—could contribute to Mr Harris' becoming assisted with walking through the processes of desiring-production (Deleuze & Guattari 1977, 1988).

Out of the freeze

How Mr Harris was assisted with walking, which is a lively everyday activity, was a dynamic and sensuous process not only filled with motions but also sounds, expressions and gestures. Standing on the left side of Mr Harris, Annie put her own left foot forward and said: “Left foot first, Mr Harris. One step forward.” Mr Harris copied the foot movement of Annie by moving forward his left foot. “Well done, Mr Harris,” Annie said. She then put forward her right foot for Mr Harris to copy the right foot movement. After the first three to four steps of slow and awkward imitation, Mr Harris started walking more naturally. Walking together, Annie started humming the song “Mary has a little lamb”. Stepping rhythmically with the beat of the song, Mr Harris was walking smoothly but when they approached the lounge area, Mr Harris suddenly froze in a halt. At this location, the colour of the carpet changed from darker patterns to a brighter flowery design. Putting her own foot horizontally in front of Mr Harris, Annie told him to “step on my foot”! With some hesitation, Mr Harris took his step. Annie walked backwards in front of Mr Harris saying: “Look at me, Mr Harris!” and “left, right, left, right” to draw his attention. She led Mr Harris across this threshold enabling him to walk out of his freeze and into the lounge area.

I attentively observed how Mr Harris was interrupted as soon as he looked down at his own feet—he started shuffling in small steps as if seeing his own feet moving had interfered with the moving of his feet. As demonstrated in previous discussions in Chapter 3 using Polanyi’s (1958) concepts of subsidiary and focal awareness, the coordination of the constellations of bodily movements involved in walking relies on the seamless flow of operational consciousness across preconscious and conscious levels. In ordinary walking, one’s feet and their movements are usually out of the sight of the person and merge into the operation of subsidiary awareness. By looking at one’s own feet, the feet and their movements are isolated and scrutinised in focal awareness. In the case of Mrs Casey, perceptually monitoring the continuous movements of her feet in focal awareness played a pivotal role in her careful walking. The involvement of focal awareness in the walking of Mrs Casey was essential because to walk safely, the interrupted operation of subsidiary awareness needed to be compensated with conscious attention. In having control over the initiation, continuation and termination of her walking, Mrs Casey could feel just right with walking—keeping safe and connected in the nursing home environment. In the process of her walking, both her physical impairments and cognitive competence were affected

and affecting how she walked and felt about her walking. Her diabetic feet became constitutive to Mrs Casey creating a careful way of walking.

Conversely, in the case of Mr Harris, the sight of his own feet moving formed a detachment from the connective syntheses and a rupture, which interrupted his walking. To draw his attention away from his own feet and start a new flow from the rupture of movement, Mr Harris needed assistance from Annie. By walking backwards in front of Mr Harris and counting rhythmically, Annie helped Mr Harris to move his gaze away from his own feet. He looked up at Annie and resumed walking. As shown through the examples of Mrs Casey and Mr Harris, residents respective bodily impairments can be seen as blockages leading to ruptures in a rhizomatic becomings of their movements (Deleuze & Guattari 1988). Yet, as shown in how Annie assisted Mr Harris to resume walking, a rupture is never the ending point of a rhizome—new openings often find their ways in old ruptures (Deleuze & Guattari 1988), which renders bodily impairments a force that is both constitutive and differentiating.

How Mr Harris and care workers walked together is intriguing. Though he was slow, shuffling and frozen from time to time, with the support from his wheelie walker and the company of Annie, Mr Harris could walk to rhythmical counting for a short distance in a string of even strides. Mr Harris' movements were constantly affected by the presence and movements of Annie. She led Mr Harris to walk to a rhythm through humming and counting; she shifted his attention from moving his legs forward to stepping on a given target—her foot on the floor; she drew his attention to focus on walking forward in long strides. Both her counting and foot on the floor had led Mr Harris, both in a temporal and spatial sense, to step forward following her footprints illuminated through the multisensory incorporation of sound, sight and touch.

The walking of Mr Harris and that of Annie were intertwined in the multisensory processes through their moving in relation to each other (Dennis 2007). The sight of his own feet, or that of the little gap between the carpet and wooden floor, ceased to form a disjuncture to freeze Mr Harris in his movements. Instead, the voice of Annie, the presence of her foot, the momentum and velocity of his walker flowed into the connective syntheses (Deleuze & Guattari 1977, 1988). While Mr Harris cared about continuing to walk, Annie cared for him to feel just right in and through walking. Routinely walking together entails 'relational extensions', as Latimer and Munro argue, which involves people's connections to each other (2009, pp. 322, 328). While 'feelings

of longing and belonging are affected by the relations created and sustained through 'the keeping up of routines' that matter to people (Latimer & Munro 2009, p. 318), every day mundane activity is 'not just be-ing, but [be]longing' to the world (Bell 1999, p. 2). A sense of longing and belonging is at the core of feeling at home.

Mr Harris may not have understood the meaning of a staff-assisted walking routine, which is institutionally constructed as a practice of mobility care. Yet, being connected led him to move and feel at home. Annie's able body became a supportive extension of his arms and legs as he followed her instructions— "Go on walking, this place is safe to move through". If the cause of freezing in Parkinson's patients can be linked to human defensive freezing in life-threatening situations and an embodied sense of threat and uncertainty leading to one's experience of fear and despair (Roelofs 2017), the multisensory presence and engagement of a friendly other person is like a shelter from the danger of blizzard. Mr Harris was thawed—walking out of the spell of inhibition, avoidance and isolation, imposed by his condition of Parkinson's disease.

Staff-assisted walking: routines and ruptures to care

The descriptions of how Mr Harris was assisted by staff to walk illuminate that the efforts, sensations and movements of Mr Harris and care workers were intertwined. For residents like Mr Harris, staff participation became crucial in their becoming walking. In walking with less freeze and more ease, Mr Harris could regain his whole-body syntheses and once again find his footing and a sense of home through affectively and sensorially incorporating another person into self. How the involvements of other material things and persons may have affected Mr Harris' walking is also demonstrated in his use of Parkinson's medication. Other than staff involvement in the walking of Mr Harris, the two-hourly consumption of his Parkinson's medication also played a pivotal role in the walking of Mr Harris. Both his staff-assisted walking routine and the Parkinson's medication schedule were essential elements in how Mr Harris was cared for in the nursing home.

As shown in the descriptions of Mr Harris' assisted walking, no isolated effects from an intervention, be it a walking routine or medication regime, or efforts from a single individual resident or staff member, could enable residents with movement disorders like Mr Harris to continue to walk. It took an assemblage of care—involvements of many material things and persons to walk Mr Harris out of his freeze. Among all the efforts, the efforts of Mr Harris himself, including taking his medication, following staff

instructions and actually taking each step, count as a form of self-care. Seen through the example of Mr Harris, a staff-assisted walking routine can be a productive process in which an innermost drive to move articulates with supportive other material things in an assemblage of care that enables residents to walk.

Despite the fact that a staff-assisted walking routine could work to assist Mr Harris with his walking, it had its limitations. As a key component of mobility care, a staff-assisted walking routine is a service item allocated to residents and a task assigned to staff to be carried out at fixed time, e.g. before or after lunch, for a fixed duration of 10 to 15 minutes. Through a staff-assisted walking routine, Mr Harris was only assisted to walk for ten to fifteen minutes a day. “That’s all we have time to do,” staff claimed. Instead of walking upon his urge to move, Mr Harris only became walking as scheduled. While staff commented that a staff-assisted walking routine “works” in that it assisted Mr Harris to walk safely, they also admitted that its use was limited in aiding residents as they needed more time with assistance. Instead of walking, Mr Harris was for the most of the time not walking. This deepens our understanding of a staff-assisted walking routine. While a staff-assisted walking routine can be useful in assisting residents to walk safely, it is not, as staff pointed out, designed to assist residents to walk *whenever they would like to*. While a staff-assisted walking routine works to organise a right assemblage of care and enact a productive process of movements and feelings, the term ‘routine’ shows that its use is strictly limited within the prescheduled temporal structure.

This understanding is important for residents with immobilising conditions, like Mr Harris, because a deeper understanding of their experiences of staff-assisted walking routines is crucial for service providers in terms of care allocation and prioritisation. In the following chapter I extend this discussion on the staff-assisted walking routine, to examine the multiple versions of care in nursing homes.

Conclusion

This chapter explains that it is possible for frail elderly people with movement disorders like Mr Harris to feel connected and at home in the nursing home on the occasions when they have medication on time and are routinely assisted by staff to walk. For residents with movement disorders such as Parkinson’s disease, walking becomes a matter of being ‘switched on’—becoming affected and activated. This chapter described how Mr Harris’ capacity to walk can be affected by the presence and

participation of other material things and persons, e.g. his Parkinson's medication, aiding device and staff, as an assemblage that works for residents enabling them to feel right at home in the nursing home. Compared with residents who could start walking on their own like Mrs Casey and Mrs Sage, Mr Harris was not only immobile, but also 'unaffected'—becoming apathetic, uninterested and unconcerned. In being switched on through a staff-assisted walking routine, Mr Harris regained his mobility. He was supported and propelled to move through relational and sensory extensions within an assemblage of care which enabled him to feel at ease and at home in the world. For residents like Mr Harris, mobility is not an entity to acquire or lose. Rather, mobility is a matter of relationality, affectivity and connectivity, and it is made possible when everyday scheduling opens up spaces for care through correspondence.

6 Living in tension between walking and not walking

Unable to walk

When residents approach the end of their lives, continuing to walk becomes a struggle. No longer able to walk safely on their own or stand up and balance on their feet, they spend most of the day sitting in chairs. Mr Dixon was one such resident. Every time I saw Mr Dixon, he was seated inside his room. Given its proximity to the central communal area, and with the door widely open during the day, people could catch sight of him from the corridor as they passed by. Sitting in front of the window in a 'comfort chair' specifically designated for residents who sit for long hours, Mr Dixon was often asleep. Framed by the curtains of the big window, he looked like an artwork in a gallery—with his head dropping onto his chest, his arms folded and legs crossed—he remained sitting in the same posture for hours. On his deeply wrinkled face with eyebrows locked and lips tightly pressed into each other, an expression of anguish and sorrow appeared fixed, etched onto his face giving him a statue-like appearance. His motionless carriage was in stark contrast to the world of perpetual movements right outside his door—people walking past, some at ease, others with difficulties, some moving fast, others slow, and some who could move on their own while others need assistance. When sleeping and seated in his chair, Mr Dixon appeared to be insulated in a separate world to that of people around him. Although he maintained his connections with the world through breathing in and out, and the senses of touch and pressure from the body-chair contact, in his temporary state of 'shutting-down', he was largely unresponsive towards other material things and beings around him.

Mr Dixon was not alone in his experience of falling asleep in his chair. In the field, residents who could no longer walk safely on their own tended to sit. Sitting seemed to be the primary mode of daily living for many nursing home residents, especially those who suffered from debilitating health problems that impeded their movements. Although residents were regularly assisted by staff to move around while sitting in a wheelchair, in between meals and activities, otherwise, they sat in comfort chairs in their rooms or the lounge. They spent most of the time during the day sitting in front of the television watching cartoons or musicals. Like Mr Dixon, residents often fell asleep while sitting down and staying still—sleeping on and off during the day. In sitting down and sleeping, they showed little interest in what was going on around them. My observations of what staff describe as residents' "sitting down, staying still and snoozing" are in line with research findings from other nursing home studies. In a study

with 723 resident participants from seven Netherlands nursing homes, residents are largely observed in lying or sitting positions (range: 89%-92%) and mainly seen sleeping, doing nothing and watching television (Den Ouden et al. 2015). In the first study to measure activity and sedentary patterns in residents in Australia, monitor data indicates that residents are highly sedentary, spending an average 85% (>12 hours/day) of waking hours sitting or lying, with nearly half of this sedentary time in prolonged unbroken bouts of at least 60 minutes (Reid et al. 2013).

In contrast to residents who regularly stand up and walk, residents who sit for prolonged hours are considered by health researchers as inactive (Den Ouden et al. 2015; Reid et al. 2013). But in observing by walking and sitting with residents, I came to see their seemingly stationary positions as far more complex and dynamic than the health research implies. In anthropological work, the key feature of walking—the body itself moving while moving through the world (Ingold & Vergunst 2008)—renders walking a unique mode of embodied being-in-the-world. Unlike walking, both standing and sitting are at rest in relation to the surroundings because no change of location is involved. Standing and sitting are positions, staying in one spot without moving away. Sitting is experienced as more sedentary than standing because what is crucial in standing—balance on one's own feet while maintaining an upright posture—is nonessential in sitting. Also absent from sitting is the sense of being grounded—experiencing the body as-a-whole from the feet up. Standing has more to do with movement in relation to the external world. Thus, balancing on one's feet is not just about maintaining an upright posture. It is a matter of knowing one's position in relation to the world. With or without one's feet touching the ground, in sitting, one is partially grounded or completely ungrounded.

More importantly, as this part on walking illustrates, residents' own effort was central and indispensable to a right assemblage of care in the process of becoming walking. In continuing to walk, they could feel right at home—being active, connected and in control. In sitting, residents seemed to have experienced the opposite: they made no efforts and appeared to be inactive, disconnected and withdrawn. If being alive, as Ingold (2011) suggests, is to move through the world, the path of wayfaring seems to approach its end when nursing home residents like Mr Dixon could no longer continue to walk and they eventually give way to the bodily temptation to succumb to the sedentary position of sitting. When walking becomes compromised, what happens to the lives of nursing home residents, and how might their shifting states of bodily decline

articulate with other persons and things to produce (or inhibit) new ways of walking and becoming at-ease and at-home? Is it still possible for residents who are unable to walk on their own to have a sense of home in the nursing home? This chapter explores the limits of residents' walking while sitting, and how limits to mobility should not be treated as inactivity and immobility but rather as difficulties with walking. With a shift of focus from walking to movements involved in sitting and attempted standing, this chapter explores how limits to walking can be creatively reconfigured through a right assemblage of care to produce a sense of home in the nursing home. Before so doing, I will in the next section turn to the experiences of sitting for residents with cognitive impairments due to later stages of dementia.

Sit up to move

Outside of nursing homes, 'transfer' is not an everyday word for describing movement, but in nursing homes it is, referring to changing a resident's position. Moving from one position to another is a taken-for-granted aspect of daily life among able-bodied persons. But in nursing homes, transfer, like walking, involves whole-body movements essential to changes of position such as from sitting to standing. Rising from a chair is perhaps one of the toughest tasks. It involves moving from a static, seated position through an unstable transition phase, to a 'quasi-static' (standing) position (Hughes, Myers & Schenkman 1996). Successful transition requires significant motor control, momentum and coordination (Scarborough, McGibbon & Krebs 2007).

The Netherlands nursing home study highlights that transfers, in which the resident changed position, were rarely observed (Den Ouden et al. 2015). Residents' positions, including lying, sitting, standing, walking and transferring, were observed at random times between 7 am to 11 pm. Out of the total amount of positions observed, only 1% were recorded to be in the position of transferring (Den Ouden et al. 2015, p. 967). A lack of changes of position while sitting indicates that residents may not be able to rise from their chair on their own due to impairments. The problem of the lack of transfers among sitting residents is identified in research in support of the conclusion that residents sitting for prolonged unbroken time (Reid et al. 2013), experience high level of inactivity (Den Ouden et al. 2015, p. 963). Sitting is considered as a mode of inactivity and transfer as an activity. Physical activities of sit-stand (Reid et al. 2013), standing and walking (Den Ouden et al. 2015) are recommended to be integrated into the residents' daily routine as a form of care so that their needs for activity can be met.

Yet, in nursing homes, sitting is far more complex than merely staying still and inactive. Residents experience sitting differently. They may remain seated during a period without a change of position; yet, they do not stay still during the period unless they fall asleep. And even then, they may snore, twitch or speak. While they are clearly less active in sleeping, in the waking hours, they constantly move in chairs without being able to make a complete transfer to rise up and stand. Unlike walking, during which one travels in distance, in making a transfer one remains at the same spot while the body itself moves. In either making a complete transfer from sitting to standing or an incomplete transfer that involves sitting, then attempting to stand and returning to sit, one must move their whole body. As sitting is a central yet overlooked bodily practice in the lives of nursing home residents, I will in this section describe the nuances of sitting, and its entanglement with other people and things, in the everyday life of Mr Dixon.

When Mr Dixon fell asleep while remaining seated in his chair, little staff attention and assistance were needed. Staff referred to these days as his “good days”. Mr Dixon slept during the day mostly because he was exhausted from being hyperactive the night before. At night, he acted out his violent dreams, kicking, punching and shouting at the top of his voice, as if he was fighting for his life. Staff described these as the “bad nights” and they impacted on staff and other residents living in the same area as Mr Dixon. Mr Dixon had a sleeping problem known in the field as rapid eye movement sleep behaviour disorder and which was understood as a symptom of a neurodegenerative condition of dementia with Lewy bodies. In response to action-filled dreams, such as being chased or defending himself from an attack, he threw slippers at shadows on the walls; he jumped from bed and fought staff when they tried to bring him back into bed. He could also become severely disoriented and delusional at night. He wandered into another resident’s room across the corridor searching for the toilet, and was shocked to see the female resident lying in her bed. “Who is the woman sleeping in my house?” he asked when the nightshift care worker heard the scream of the old woman and came to help.

Sometimes he hurt himself by bumping into furniture or having falls. However, worse than the bad nights, were the bad days when he was in motion, awake and alert. Constantly moving his buttocks to the edge of the chair and pushing up from the armrests, he tried to rise from the chair. Mr Dixon was usually incapable of doing transfers on his own. His attempts to stand up and walk were often unsuccessful—

most of the time he fell back into his chair. Yet, with some obvious determination, he continued to move.

In dramatically contrasting manners, Mr Dixon experienced two alternative modalities of sitting in chairs. Firstly, in sitting down, he is still and drowsy. Secondly, in continuing to move, always attempting to stand up, he is attentive and active. From minute to minute and day-to-day, staff never knew for sure how well he could stand or walk. Some days he could walk with little staff assistance, knew who everyone was and would chat with his visiting families and friends. The next day he would sit for hours, as described in the vignette in the opening section, in a somnolent state as if in a coma.

While not as drastic as Mr Dixon, many residents were found to have experienced intermittent phases of 'sitting down asleep' and 'sitting up to move' during a process of sitting in chairs for long hours. With Mr Dixon, however, the uncompleted transfers played a critical role in constituting the two modalities of sitting. The movement and activity that is lacking in sitting down is abundant when he sits up to move. Thus, Mr Dixon with his later stages of dementia is not, contrary to dominant aged care discourse, fixed in a homogeneous mode of immobility and inactivity. His shifts between sleeping and waking, and sitting down and sitting up, are in the words of aged care clinicians 'low in arousal' and 'high in activity'; they reflect an ever-changing body-world relationship, or in the Deleuzian term, a rhizomatic becoming of varied modalities of positioning and moving. Sitting can dissolve into a flow of changing positions leading to further sedating in bed, becoming asleep, or moving to stand up and becoming walking. In short, for nursing home residents with later stages of dementia, sitting is indeed a primary mode of daily living but not a mode of being stationary.

Extending this rhizomatic imagery, I turn now to explore how moving becomes entangled with other persons and things within the nursing home. In mapping the interconnected tendrils of arms and legs with persons and walkers, as they touch and connect with other sensing beings and technologies, I explore the assemblages of care that may enable residents with dementia to become and feel at-home. As the descriptions of how residents experience sitting demonstrate, the sitting of residents should not be considered as their reaching the limits of making movements. Rather, it needs to be understood as residents living the tension (or 'immanence', to use the Deleuzian term) between contesting forces that are constitutive to their becoming or unbecoming moving. In the waking hours of Mr Dixon, he was simultaneously pulled

up by a drive to move and pulled down by his impaired balance which restricted him from leaving his chair.

Mr Dixon lived this tension between moving and not moving, whilst being affected by constant fluctuations of conscious awareness, cognition and movement due to dementia. In the next section I illustrate the 'roller coaster' of ups and downs that shaped Mr Dixon's everyday life in the nursing home before then detailing how specific arrangements of care could ameliorate, or amplify, these tensions and assist him to move.

Living the 'roller coaster': shifting potentialities of moving

In the field, residents with later stages of dementia, like Mr Dixon, sit for long hours but are not always still. Their experiences of sitting are complicated due to their bodily conditions, e.g. severe cognitive impairments. Mr Dixon had a diagnosis of dementia with Lewy bodies before his entry into the care facility. Dementia with Lewy bodies is considered as the second most prevalent cause of degenerative dementia in older people; only Alzheimer's disease is more common (McKeith 2004). One of the hallmarks of dementia with Lewy bodies is the fluctuation of cognitive functioning. Often, a patient may function well one day and, on the next be totally disengaged with sudden and profound impairments of mobility, memory and speech. In the case of Mr Dixon, the switch occurred in a matter of minutes. He might be able to stand up and take a few steps at one moment and collapse at the next. As staff said, "living his everyday roller-coaster of dementia with Lewy bodies", Mr Dixon was observed to switch between different modalities of consciousness leading to a precarious existence between what is real and what is dream-like.

Once, I witnessed how the unpredictable switch between sleeping and waking, over which he had absolutely no conscious control, could catch Mr Dixon suddenly. "Is this a dream? Where am I?" Slowly turning his head and upper body towards his right, Mr Dixon asked Mrs Almond, the resident sitting to his right on the same couch. With her smile frozen, Mrs Almond stared at him with her mouth half opened. After a few seconds, Mrs Almond looked over Mr Dixon at me, sitting on the left side of the couch. Just one moment ago, Mr Dixon was sitting comfortably with Mrs Almond and me watching a gourmet food and travel program on the television. He was amiable, smiling and chatting with apparent ease and pleasure. One moment later, he looked confused, distant and frail. Caught by surprise, Mrs Almond was speechless and looked puzzled.

Sensing the sudden change in him, I responded in a low gentle voice: “Mr Dixon, you are not in a dream. You are in the lounge with Mrs Almond and me.” With no expression, he slowly sat back, dropped his head onto his chest and fell asleep. Staff usually let Mr Dixon sleep without disturbing him. “Don’t wake him up,” they said, “he hits you if you wake him up. Don't worry. He will be fine when he wakes up on his own.” There might have been more pronounced confusion between the dream and waking reality when he awakened. This might have helped to explain Mr Dixon’s extreme aggression when he woke up from his sleep.

What is indicated in his questions before he drifted away is his experience of disorientation in between the states of being awake and asleep. He was actively engaging in the conversation with Mrs Almond and I, and in a matter of minutes, he was unresponsive and not aware of other people around him. Mr Dixon’s experience illustrates that any mode of being-in-the-world is a becoming. The uncertainty, ambiguity and unpredictability of the present and the future become an embedded condition of becoming in the world. Between becoming moving, active and engaging and staying still, asleep and inactive, the everyday life of Mr Dixon was lived in rhizomatic (Deleuze & Guattari 1988) ways like ‘an amassing of middles amidst an array of multidirectional movement’ (Sellers & Honan 2007, p. 146). In his abruptly falling asleep, Mr Dixon seemed to have experienced what Deleuze and Guattari (1988) described as a catatonic empty body without organs—locked within himself in a state of serenity, stillness and solitude.

Unlike residents with impaired but relatively stable cognitive functioning, Mr Dixon lived through fluctuations of cognition, speech, memory and mobility. The most difficult part of caring for Mr Dixon came from the fact that most of the time he lived altered lifeworlds of his own, to which other people were denied access. On his bad days, Mr Dixon inhabited a hostile and threatening lifeworld due to his sensory impairments and perceptual deficits. With dementia, the message of the senses sent to the brain are not interpreted properly. Mr Dixon became upset while being unexpectedly touched or moved by staff during assisted transfer. He could be irritated by staff putting clothing on him after a shower. He was observed to feel insecure with maintaining an upright standing posture and became panicky if tipped off balance. He also suffered from visuospatial difficulties, including telling left from right, following directions, recognising objects and having awareness of his body in relation to other things and persons in the environment. He would stop in front of a rug; his impaired depth perception might lead

him to perceive a rug as a hole in the floor. In biomedical explanations dementia affects perception because the disease slowly destroys the parts of the brain that are responsible for converting sensory input into meaningful information. Mr Dixon often said things that suggested he had a different idea of 'reality'—or sense of what is really going on—from people around him. Staff frequently talked about him "seeing stuff no one else could see". One day, he was seen waving his arms over his plate of fish and chips; he was hallucinating and believed there was a young man in his room eating his lunch. On another occasion, he looked frightened and asked the care worker walking into his room: "Did you see the black pussy cat in my bed?" When she told him that no cat was there, he turned bitter and told her to have her eyes checked. He was also paranoid with his delusions. One day he was angry at the impostor who was pretending to be his daughter—stealing all his money and allowing all those strangers (staff) to live in his house. He wanted to call the police and get them to remove the unwelcome strangers from his room. Delusions were Mr Dixon's worst fears; he saw them as facts.

Cognitive impairments affect perception as well as memory and cognition. When perception is affected, it becomes very hard to make sense of the world, not to mention having a sense of home. Mr Dixon, once a head engineer of a big mining company, an amateur helicopter pilot, a vibrant sportsman, a loved father and grandfather, and a friend to many people, slowly became, to use his close friend's words, "a shadow of himself". For nursing home residents like Mr Dixon, their lives are worlds apart from that of people around them. There is little ground for togetherness with shared understanding. Scared, confused, sad and delusional—they are struggling to make connections they once made so easily and to have a sense of control amidst the chaos that they live daily.

Yet, one way that dementia with Lewy bodies differs from other dementias, is the occasional window of clarity it gives, where the residents return from their journey into the confusion of dementia and appear to be alert, verbal and mobile. Mr Dixon had days like this. He looked quite different on such occasions with his eyebrows lifted and his wrinkles flattened. People were often surprised to see him out of his own room sitting in a wheelchair or walking with staff assistance (with another care worker pushing a wheelchair and following in preparation for the emergency of his sudden collapse). "Oh, this man is not asleep. He looks a lot brighter," a visitor said about Mr Dixon. Staff referred to these days as his "better days" and he would talk to them, following their instructions for transfers, understanding the situation, being helpful and

accepting help. I could feel a sense of relief when staff could, with some apparent ease and fluency, assist Mr Dixon with his transfer from the comfort chair into a wheelchair. “We get lucky with Mr Dixon today. This is one of his better days,” they said and pushed Mr Dixon to join the group of residents in the lounge, led by the occupational therapist doing stretching exercises. Sitting with his cup of cold lemonade on the tea table, Mr Dixon looked relaxed and placid. He even started a conversation with the elderly lady sitting next to him.

On his better days, Mr Dixon was seen by people around him as “coming back with more sense”—seeing the world as it was to others and responding to it as people usually do. He perceived staff presence as coming in response to his attempt to rise from a chair; he knew what to do when staff brought his walker in front of him; he had a solid grip of what his eyes saw, the handlebars of his walker, and he leaned forward to stand up. On such occasions, Mr Dixon and other material things and persons ‘correspond’ (Ingold 2017, p. 16). In corresponding, the world becomes *real* again; it makes sense in and through sight, hearing and touch. He would respond with appropriate gestures, reaching out to grip a helping hand. In talking to someone sitting next to him and talking back, Mr Dixon seemed to have a sense of rightness of being with others and the world was again a right place to be. Being temporally free from the shadow of dementia, Mr Dixon could talk in full, clear sentences and move quickly on his feet around the nursing home. These days or hours could not last—usually without warning, and far too soon, he was again less responsive and withdrew into his solitude. Yet, as long as he could move while the drive to move flowed through him, Mr Dixon could rediscover some sense of control in and through movement, corresponding with other people and things in the nursing home.

Caring for residents with cognitive and movement fluctuations like those of Mr Dixon poses a challenge to aged care service providers and caregivers. There were limits to Mr Dixon’s ability to move, such as when he was in his somnolent state. Yet, on his better days, Mr Dixon could become alert and exhibit a desire to move. There also existed potentialities for him to continue walking. Living the tension between walking and not walking, Mr Dixon could be assisted to walk if he experienced heightened attention, cognition and mobility, and his attempt to move was responded to by a right assemblage of care—staff noticing his changes and assisting him in correspondence with his attempts to move. For residents who live in tension between walking and not walking, movement depends on their connecting and corresponding with the bodies of

other staff and assistive technologies, such as walkers. But in order for these assemblages of people and things to assist and propel residents to walk, these things and people must be attentive to the shifting states of residents' bodies. Adjustments need to be made for residents to feel just right and to walk well. Such assemblages were right for residents if they worked to produce the movements they wished to make. The right assemblage of care could not be fixed or documented easily in care plans. As good days differed from bad days, what was right for residents changed according to the vicissitudes of bodies and situations. Assemblages of care required constant 'tinkering' from one moment to the next' (Mol, Moser & Pols 2010).

What is the 'right' care for Mr Dixon?

This thesis has so far demonstrated that how each individual resident experiences his or her movements is embodied and situated and thus different. Bodily impairments are both constitutive and differentiating in how residents could continue to walk. Unlike Mrs Sage who could walk more freely on her own, or Mr Harris who could hardly walk without his Parkinson's medication and staff assistance, Mr Dixon experienced the constant fluctuations of mobility and cognition. He might have been sound asleep at one moment and then be attempting to get up and collapse in the next. As all of this can happen in the blink of eye, Mr Dixon required a multitude of supports, an assemblage of care that was responsive to his shifting states and changing needs. A male care worker, who worked previously in a hospital, once told me that, ideally, Mr Dixon should be cared for continuously with one-to-one staff supervision so that he could be promptly attended to when he attempted to move. Or, as another care worker mentioned to me, residents in similar bodily conditions as Mr Dixon can be arranged to sit together in a designated area with one staff member supervising and attending to residents while they are sitting and sleeping and calling for help from other staff while residents start attempting to stand and walk.

Nonetheless, as the male care worker pointed out to me, "We don't have the same level of funding for nursing homes as that for hospitals." Rostering extra staff to respond to residents' spontaneous movements means increased expense and decreased efficiency because staff presence and assistance has to be paid for. Furthermore, for the care management team (mostly doctors and nurses) in the facility, these initiating movements are not 'windows of opportunities' for Mr Dixon to walk. On the contrary, these were seen as risks to be managed and mitigated. The surveillance of his movements and prevention of falls became the main objective for the staff who

cared for Mr Dixon. To implement ongoing monitoring of his movements, a sensor mat was prescribed for Mr Dixon as part of his Fall Prevention Plan. When Mr Dixon stepped on the sensor mat, he activated the multisensory—audio, visual and textual—alarm system, to attract staff attention to his movements and to signal for them to take action. The sensor mat facilitated sensory extensions (Dennis 2007) that linked Mr Dixon's movements to those of staff. How staff were expected to respond to the sensor mat alarm was made explicit, documented in staff work procedures and reinforced every now and then by the registered nurse on duty.

After learning about the alarm system, an observer could tell the bad days of Mr Dixon from his good days. On the bad days, the monitor screen constantly turned red showing the room number of Mr Dixon and staff were frequently drawn from other care activities to check on Mr Dixon. But care staff must routinely deliver care to all of the residents in the unit. The bad days for Mr Dixon—seen from a staff point of view—were also bad days for care staff working in the unit. The situation with Mr Dixon was like the example provided in Chapter 5 in which the extra assistance provided to Mr Harris was additionally taxing on staff. For Mr Dixon, in addition to the heavy load of routine care work, staff had to make time (that they did not have) to react promptly to each episode of him moving from his chair. By using the adjective 'bad', staff summed up their stressful experiences coping with the constant attempts of Mr Dixon moving away from his chair. Staff told me that they felt "stretched", running from resident to resident on those bad days, while also trying to reduce the increased risk of residents' falling and the incidence of residents becoming aggressive.

In attending to Mr Dixon as per standard fall prevention procedure, staff usually told Mr Dixon to sit back into his chair while they reset the sensor mat and then rushed away to attend to other competing priorities and scheduled care tasks. When staff did attend to Mr Dixon, they seemed to not care about his inclination to stand up and his efforts of moving. Rather, they disregarded his efforts by assisting him to sit. The sensor mat effectively prevented residents from standing up and walking. As staff said, residents with later stages of dementia may forget that they could not keep balance while standing or taking steps. While Mr Dixon experienced the urge to stand up and walk, he may not have realised that, to walk safely, he needed staff assistance. As shown in the example of Mrs Sage, ongoing staff supervision and prompt assistance were crucial for residents with cognitive impairments to keep safe while walking. If staff could attend to Mr Dixon whenever the alarm was on and assist him with movements, the

use of a sensor mat, as an innovative assistive technology, could play an important role in staff delivering the 'right' care for Mr Dixon. Creating an assemblage of care that assists residents like Mr Dixon to move is critical to their becoming at ease in their shifting and unpredictable bodies. In Part III of this thesis, I foreground care, to examine the different ways it is understood and embodied, exploring how it can enable and assist residents who remain driven to move, and conversely the many ways that residents may be prevented from moving, in the name of care.

Conclusion

As the example of Mr Dixon demonstrates, there exist limits to residents' ability to move on their own; however, a concerted attempt to move through a right assemblage of care can create new possibilities for movement. How staff care about residents' urge to move and how they take care to assist them with transfer and walking become pivotal for residents like Mr Dixon, if they are to continue walking. Unlike Mrs Casey, who could strategically take care of her walking through watching each step and following a walking routine, Mr Dixon needed to be *cared for* if his urge to move was to become actualised.

As this chapter reveals using the example of Mr Dixon, how staff carry out institutionally designated care practices, such as responding to Mr Dixon's sensor mat alarm, may also become a reverse force in residents' becoming moving. Care, if it is to be right for residents to have a sense of rightness of being-in-the-world—'a sense of existential control and connectedness' (Jackson 1995, p. 154)—requires correspondence (Ingold 2017) with other people and things in assemblages of care that assist residents to do the things they want to do: to get up from their chairs, to walk and to move. Conversely, attempts to keep residents confined to their chairs or rooms restrain their capacity to move, reducing their sense of being at ease and, in turn, possibilities for becoming at home in nursing homes.

Walking in nursing homes involves the synthesised efforts of both residents and the supportive other material things and persons, an interplay of diverse forces and multiple processes. In the following part on care, I will further illustrate how these entangled elements of concrete material surroundings, daily practices and living bodies meet, connect and synthesise in assemblages of care that are ethically responsive and in correspondence with residents' bodies, hopes and needs.

III Care

Introduction

During my fieldwork, the care management team in one of the facilities started a new initiative of inviting residents to nominate a staff member to be the Star Employee of the Month. One staff member would be selected from the nominees and praised in the facility's newsletter. Once in the lounge area, a resident pointed to the picture of the care worker in the newsletter and said: "I nominated Maureen. She is a good carer. She does care!" Another care worker who was standing near the resident responded by saying: "Mrs Joyce, I also do what Maureen does for you. We all do the same care work. Do you think that I don't care?!" Mrs Joyce looked at the care worker and said: "Right, you all do the same care work, but differently. That's how I feel it." In a chat with Mrs Joyce after her conversation with the care worker, she told me that, though the carers generally do the same things with her, like showering, dressing and grooming, some carers can make things easier for her while others may leave her distressed. Mrs Joyce explained that:

> It doesn't feel right when some of the carers help me to stand up. They don't let me to do it. They just drag me up and pull me forward. I feel terrible when they rush me through the morning routines.

These conversations revealed the different, and at times contested, understandings and experiences of care in nursing homes. Care work may be a job performed by care workers, but it did not necessarily lead to residents' feeling cared for. Mrs Joyce made a distinction between staff *doing care work* and *doing care*. The former involved getting a job done, often quickly, producing feelings of being rushed and roughly handled, while the latter created the feeling of being assisted, with care. Maureen knew how to 'do care', and she made Mrs Joyce's life easier when she did it. This was particularly apparent when I saw her assisting Mrs Joyce to move and to transfer position with ease. In this section I explore this disjuncture between *how care is done* as work and *how care is felt* by residents. Care work that is itemised in work procedures, such as responding to a sensor mat alarm, as Chapter 6 described, may or may not contribute to residents' *feeling* of being cared for. There can be a discrepancy between how care is conceived in aged care plans and procedures and the need for residents to be carefully assisted to move. In other words, the kind of care that staff routinely do as

tasks may not be the kind of care that residents want to have, and it may be detrimental to feeling cared for, to achieve a feeling of being at ease and at home.

This part on care attempts to describe and understand care *not* as 'care work' but *what works* so that residents may feel cared for and at home. I seek to illustrate care as constitutive and differentiating in residents' feeling all right and at home. As shown through the ethnographic descriptions of residents' walking in Part II, residents could feel right at home when other people and things supported them to continue to walk. In walking, residents could become in touch with their social and material worlds despite their declining bodies. Similarly, staff doing care, for example by taking time to reposition residents or to help them to eat, as opposed to doing care simply as work, could produce feelings of being at ease for residents, create intimate connections and extend residents' bodies as well as their social and material worlds. The kind of care that enables residents to feel all right and at home is described in this thesis as a 'right' care.

Doing care, as residents like Mrs Joyce indicated, can never be taken for granted but always needs to be created in response to changing circumstances. What staff need to do to provide direct care for residents, e.g. showering and cleaning, is also related to other practices that have an indirect impact on residents' experiences of care, e.g. care-planning and documentation of care work. As I will show in the first section of Chapter 7, what staff do as work is shaped by multiple and often contesting discourses, perspectives and notions of care. The everyday intersection, contestation and negotiation in care practices may render nursing home care, as Perkinson claims in her ethnographic study, 'indeed, multiple realities of care' (2003, p. 258).

In her influential work, Annemarie Mol (2002, 2008) teases out the concept of 'care' with its multiple meanings and enactments. She concludes that good care is not a matter of making well-argued individual choices but is something that grows out of collaborative and continuing attempts to attune knowledges and technologies to diseased bodies and complex lives. Mol's *logic of care* (2008) is a critical framework to examine how conflicting perspectives of care coexist and intersect in care practices in institutional care contexts. Mol, Moser and Pols argue that 'Care implies a negotiation about how different goods might coexist in a given, specific, local practice' (2010, p. 13). I trace the intersections of multiple enactments of care in Chapter 7, revealing how daily care practice, care needs assessment and care-planning are intertwined.

Examining care through the lens of a sense of home, I argue in this thesis that, from an elderly person's perspective, right care needs to be understood as caring for someone to have a sense of rightness of being-in-the-world-with-others. Following Mol (2002, 2008), care is approached in this thesis as multiple and, at times, contested. A right care for residents requires tinkering (Mol, Moser & Pols 2010), for each resident requires a different assemblage of care in response to the vicissitudes and movements of a productive desire.

I attempt to illustrate a right kind of care through Mol's (2002, 2008) notion of care as multiple. Nevertheless, unlike Mol's ethnographic projects on care, this study strives to understand care in a particular ethnographic situation in which elderly people are cared for so that they could continue to move and feel at home in nursing homes. To account for a right care that is intrinsic and integral to residents' movements, through which residents could feel at home, Mol's notion of care as multiple needs to be extended so that a right care, which is itself intertwined with many other kinds of care, can be understood in its constitution as becomings. To do this, I draw on Deleuze and Guattari's (1977, 1988) concept of assemblage for an analytical framework.

Assemblage, as detailed in Chapter 1, is a key concept for Deleuze and Guattari (1988) to seek to account for multiplicity and metamorphosis in becomings. With a focus on residents' movements and a sense of home, this thesis approaches a right care as what is constitutive and differentiating in residents continuing to move and feeling at home. To distinguish this particular type of care, namely, 'doing care', from other types of care, e.g. care as a service item or designated work, this thesis calls the totality of this crucial aspect contributing to residents' movements a 'right assemblage of care'. By the word 'totality', an assemblage of care 'is a symbiosis', and its 'only unity is that of co-functioning' (Deleuze & Parnet 2002, p. 69) in residents' movements. To use the concept of assemblage to think through Mol's *Logic of Care*, I can examine how residents are assisted to move as 'the product of multiple determinations that are not reducible to a single logic' (Ong & Collier 2004, p. 12).

Shown in Part II on walking, residents' bodily impairments block the movements of desire and lead to ruptures in their walking; to continue to walk is, for residents and staff, a matter of creating a right assemblage of care. 'Caring', as Heuts and Mol propose, 'indicates efforts that are ongoing, adaptive, tinkering and open ended' (2013, p. 130), which is a productive process. Drawing on Deleuze and Guattari's (1988)

concept of assemblage and Mol and her colleagues' (2010) approach to care as a practice of tinkering, I mapped the multiplicities and interconnections between walking and care for residents with later stages of dementia. Attending to residents' movements and to the sensory extensions (Dennis 2007) made possible through the correspondence (Ingold 2017) of residents' bodies with the bodies of other people and things, I revealed the complex and shifting interplay between bodily impairments, material surroundings, aged care discourses and daily practices in the nursing home.

Understanding care as a practice that is attentive to suffering, pain and disease, Mol, Moser and Pols suggest that 'good care' becomes complicated and concerned with lightening 'what is heavy, and even if it fails it keeps on trying' (2010, p. 14). As we saw in the previous section frail residents with cognitive changes and ailing bodies suffer from compromised mobility. In the coming section I turn to sufferings of another kind—the discomfort of consuming food due to eating difficulties. If good care is to mitigate the sufferings of residents in these varied situations, I call this type of care the right care. With the use of the word 'right', this thesis emphasises the words and experiences of residents to describe the care that felt right to them—whether it be in moving, eating or refusing food. Right care is approached as a productive and attentive response to residents' needs and desires. Drawing on Deleuze and Guattari's (1988) notion of productive desire, I demonstrate how at the very last stages of lives, a right care is about always responding towards residents' shifting bodily states and desires to move and have a sense of home, with sensitivity and responsibility.

This part consists of Chapters 7 and 8. Using ethnographic examples of Mrs Joyce, Mr Harris, Mrs Wilson and Mr Dixon in Chapter 7, I aim to expose how care is variously understood, articulated and practised from person to person, be they management, clinicians, care staff, residents or family. I draw on the example of Mrs Joyce to deconstruct nursing home care into the different compositional elements of its multiple assemblages: attending to assessments of residents' care needs; care-planning: and staff assistance in routinised activities. In so doing, I attempt to map these components in the different assemblages of care to expose the entangled processes of connecting, overlapping, contesting and competing in these compositional elements, leading to residents like Mr Harris' walking and not walking. I will use the examples of Mrs Wilson and Mr Dixon to demonstrate how the different interpretations of resident movement, namely, capacity to move in the case of Mrs Wilson and risk of falls in the case of Mr Dixon, could lead to residents having different assemblages of care; some were

‘right’—productive and supportive to residents’ efforts to move and to have a sense a home, while some were not so ‘right’—less productive, even restrictive of residents’ efforts to move.

I will demonstrate in this part that there are limits to residents’ continuing to move, to eat and to create a sense of home through movements. Yet, a right care can traverse limitations and generate new ways of walking and eating. Thinking about this kind of care *not* as ‘good’ but ‘right’, I intend to move away from an emphasis on the moral meanings about the ‘different goods’ (Mol, Moser & Pols 2010, p. 13) to focus on the practicality of “what makes things work” (staff remarks)—the use of innovative practices, technologies and people’s creative endeavours. In doing so, care is not to be thought as being dictated by any dogmatic value principles. Rather, the value of care is inexorably tied to residents’ sense of becoming-at-home-in-the-world.

As I will demonstrate in Chapter 8, a right care is what works and this is most obvious in the situation where residents close their mouths to food. In responding to residents’ shifting and waning desire to eat and in relieving residents’ thirst when death is imminent, a right care is always tied to residents feeling relief, comfort and being at ease. In this sense, I argue that for residents to feel at home in nursing homes before they die, there should exist no limits as to how elderly people can be cared for across their life course. In doing so, a sense of home can be created for dying residents in nursing homes if they could feel all right while being relieved from the struggle and suffering of their dying body.

The division between Part II and Part III mainly reflects a shift of focus from residents’ own efforts to move to the pivotal role that a right care can play in assisting the most vulnerable residents with their walking, moving and eating. Despite the change of emphasis, it is demonstrated in both parts that a right care is crucial in responding to residents’ movements of desire so that they could feel just right and at home in and through their relations with other people and things in a nursing home.

7 Care as multiplicities

Deconstructing nursing home care

In nursing homes care is centrally placed. But how it is understood and enacted varies from person to person, be they management, clinicians, care staff, residents or family. In this chapter I attend to care in nursing homes as multiplicities (Deleuze & Guattari 1988), examining how tensions between care practice and policy, in their respective diverse forms, become embodied in the movements of residents. I explore contradictions and contestations of care by extending assemblages of care beyond the bodies and physical things that are involved in daily care activities to the care policies, plans and assessments that construct and itemise care delivery. As I will show, care as it is currently constituted in residential aged care can reduce possibilities for residents to become at home. To create right assemblages of care for residents with impaired mobility and cognition, innovative ideas and technologies are crucial.

It is important to note that the contesting forces, embedded in the government funding scheme and the cultural imperatives of medicine, economy and domesticity, interplay in rhizomatic ways, intersecting and parting, over and under-lapping, rather than just being seen to operate alongside each other. With Deleuze, as Dyke argues, we have 'the possibility of holding in tension multiple interplays and paradoxes' (2013, p. 161) and examining them as multiplicities—different assemblages of things, persons, processes, discourses and practices—emergent from the actualisation of a productive desire into movements in ever changing circumstances.

The concept of multiplicity (Deleuze & Guattari 1988) is useful for opening a new analysis on the interplay of diverse forces and the entanglement of multiple processes that constitute the medicalised treatment and support with daily living for nursing home residents. In this section, I will draw on the example of Mrs Joyce to deconstruct nursing home care into its multiple assemblages, attending to assessments, care-planning and staff assistance in routinised activities as compositional elements of different assemblages of care. In so doing, I aim to reveal how care is variously understood, articulated and practised in the nursing homes.

Assessments: constructing care needs

In Australia, an overwhelming proportion of elderly people are admitted into residential aged care due to acute medical conditions which lead to their hospitalisation. Mrs Joyce was transferred by ambulance to a hospital emergency department with a

cracked femur after having a fall onto the floor while she took herself to the toilet at night. After spending five weeks in hospital, her bone crack was stable, and she was allowed to walk and weight bear as pain permitted. However, she could no longer take care of herself on her own. She needed someone to standby her and to assist her with all daily activities. Older Australians are supported to live independently in their own homes through the Home Care Packages Program (also see Footnote 2). This program is funded by the federal government and provided through a Home Care Package—a coordinated mix of services that can include: help with household tasks; equipment (such as walking frames); minor home modifications; personal care; clinical care such as nursing, and allied health and physiotherapy services (Department of Health 2020b). To be discharged from hospital and eligible to receive government-funded care services an older person needs approval from an Aged Care Assessment Team (ACAT). Staff in the hospital referred Mrs Joyce for an assessment conducted by ACAT to find out whether she was eligible, and if eligible, the level of Home Care Package she could be approved for. The ACAT is a Government unit responsible for carrying out assessments of older people's needs, using the Aged Care Funding Instrument (ACFI), to determine what services are needed. The result is referred to as an Aged Care Client Record.

In the case of Mrs Joyce, she was assessed as not suitable for a Home Care Package; even with the highest level (Level 4) of home care, Mrs Joyce could not live alone at home because of her complex care needs. Her husband had died from bowel cancer five years before. Her daughter had moved overseas with her family and her son was interstate working in a mining company. They both made regular phone calls and sent her birthday and Christmas cards but neither of them could do anything to help with her daily living. Before her hospital admission, Mrs Joyce often sought help with maintenance or financial issues from Helen, her niece who also lives in Adelaide. As Mrs Joyce could no longer manage at home without help, she was approved for high level residential aged care. Residential aged care can be offered as either permanent or short-term care. Short-term care in an aged care home is called residential respite care, which is designed to give family carers a break for a limited period of time. In the case of Mrs Joyce, she entered the nursing home as a permanent resident. Previous discussions on the medicalisation of elderly people's needs in Chapter 2 demonstrated that only those elderly people who are assessed as in need of high-level care and eligible of taking a nursing home place are admitted into residential aged care facilities.

As more people choose to age in their own homes, permanent residential aged care is increasingly focused on catering for people when they are nearing their end-of-life. In fact, the average age of admission to residential aged care is now 84.6 years (Department of Health 2019). As a needs-based funding tool, ACFI assessments are conducted to allocate the government subsidies to cover senior Australians' most up-to-date care needs. The ACFI affects how elderly Australians are supported with daily living by differentiating (through eligibility assessment) and categorising (into different levels) elderly people into the aged care system per the type and level of care, as shown in the example of Mrs Joyce.

On her admission day, I joined Mrs Joyce and her niece Helen in their meeting with Julie, the admission nurse. Sitting at the side of her hospital bed, Mrs Joyce looked lost, sad and exhausted. Julie seemed to understand how Mrs Joyce felt on her first day in a nursing home and tried to comfort her. "Don't worry, Mrs Joyce," Julie said and added:

> In four weeks, we will work out a care plan for you. Every detail of your daily living will be discussed and covered. For now, we only need to work out some basics so that staff are prepared when they come to help you.

Julie then started asking questions about the ways Mrs Joyce undertook everyday activities including: bathing, dressing, grooming, toilet use, feeding, transfers, walking and climbing stairs. Mrs Joyce told Julie that she had gone through the same list of questions with another nurse in the hospital. "What you had in the hospital is an eligibility assessment", Julie replied. "What we are doing now is part of the admission assessments". Julie continued to explain to Mrs Joyce and Helen that the results of the admission assessments would show her level of functional ability and degree of independence, which would indicate her immediate care needs. As previously discussed, government funding was the essential component for Mrs Joyce to be cared for in a residential facility. Upon admission into a care home, more comprehensive assessments are conducted to further allocate human (staff shift-time, attention and assistance) and material (aiding devices, assistive equipment, and technology) resources to each individual resident within the co-funding scheme of government subsidy and residents' own payment.

Julie then used the Barthel ADL Index (Wade & Collin 1988) to measure the performance of Mrs Joyce on the Activities of Daily Living (ADLs) (see Appendix).

When Julie went through the scale with her, Mrs Joyce simply told Julie that she could “manage” on her own when she was not in pain. Julie then asked Mrs Joyce to show her how she got herself out of bed. Mrs Joyce found that she could not: when she tried to move her buttocks away from the edge of the bed, she fell back onto the bed. Julie scored 5 points for both the activity of ‘transfer’ and ‘walking’ for Mrs Joyce, which meant that she needed some help to do both activities. She scored 0 points for the activity of climbing stairs as Mrs Joyce was unable to use stairs even with the aid of her walking stick. Based on the results of this initial assessment, ‘one staff physical assistance with transfer and locomotion’ was temporarily assigned to Mrs Joyce.

In aged care service provision, residents’ walking, making transfers from one position to another, eating, drinking, showering, dressing, grooming and toileting are named the Activities of Daily Living (ADLs). As shown in the Barthel ADL Index that Julie used to measure Mrs Joyce’s performance, ‘care needs’ of a resident are identified if the resident needs staff supervision or assistance with making necessary movements involved in doing the ADLs, such as the transfers of changing positions from lying to sitting and sitting to standing. In this sense, the term ‘care needs’ refers to staff attention or assistance that is necessary for supporting residents to move. Take Julie’s prescription for Mrs Joyce as an example. ‘One staff physical assistance with transfer and locomotion’ is the ACFI term for a specified caregiving activity. In the ACFI User Guide, activities are defined as ‘the action steps to meet a care need’. The care need of a resident is ‘informed by an assessment’ (Department of Health and Ageing 2013, p. 3).

Care needs assessment relates to another two components of nursing home care—government funding and care-planning. The government funding scheme regulates financial support to care service providers while daily service delivery is organised through care-planning. The logic of the ACFI as a medicalised funding instrument is to match the resident’s needs with the provided care so that what is conceived as lacking in the resident’s bodily conditions can be provided through the caregivers’ action steps designed to assist residents with meeting their needs. The key to matching care with ‘needs’ is, as Mrs Joyce’s example shows, to focus on residents’ experiences of making movements. Then, how they can or cannot move can be described quantitatively so that care—in the form of a walking aid or staff attention and assistance—can be matched and prescribed. This leads to the understanding that assessments may affect how staff assistance is to be provided in its varied forms and

styles, and how residents could continue to move and engage in doing daily activities. Table 4 (below) is an example of how residents in different areas of a facility have had their care levels, in terms of mobility and transfer, assessed by the facility using the ACFI.

Table 4: Staff and equipment support to meet residents' care needs in terms of mobility and transfer

Site	Area	Care Level	Residents	self-care	1-Assist*	2-Assist*	Lifters*
Auxilia	A1	Mixed	29	14	10	1	4
	A2	Low	22	10	8	1	3
	A3	Low	14	5	8	1	0
	A4	High	21	2	9	5	6
	A5	High	22	0	6	5	11
	A6	Dementia secure	19	5	5	5	4
	A7	Dementia secure	23	3	10	5	5
Total	150		150	39	56	23	33
Dulce Domum	B1	Mixed	8		5	2	1
	B2	Mixed	8		6	1	1
	B3	Mixed	8		5	3	0
	B4	Dementia secure	13		5	3	5
	B5	Mixed	10		8	2	0
	B6	Mixed	13		6	4	3
	B7	Mixed	13		9	3	1
Total	73		73	0	44	18	11

* In this table the industrial terms such as the one-person assist (1-Assist), two-person assist (2-Assist) and lifters are used. The numbers in these terms refers to the number of staff members needed in the assistance with residents' mobility and transfer. The term 'lifters' refers to the lifting equipment, on most occasions either a standing lifter or a full-body lifter, used in activities of transferring residents from bed to shower chair, wheelchair or comfort chair, or vice versa.

Within four weeks of her admission into the care facility, Mrs Joyce went through all the comprehensive assessments on her care needs. The assessments covered her medical history, diagnosis, ongoing medication and treatment, as well as her life history, family and cultural background, habits and preferences. The process of medicalisation of the aged care service is one in which an increasing number of the older persons' bodily processes are subject to what Foucault described as the medical

gaze (Foucault 2012). As this subsection shows, bodily movements, senses and feelings of elderly people are considered through medical observation, diagnosis and treatment, which renders the aged as the diseased (O'Neil 1985 as in Csordas 1994, p. 6). Upon nursing home admission, the older persons' movements become the nurse's 'transfer', the older persons' walking becomes the physiotherapist's 'ambulation', the older persons' food becomes the nutritionist's 'diet', the older persons' eccentricities become the staff's 'behaviours', and the older persons' life becomes the institutional 'record' (Stafford 2003a). As an organised meaning system, medicine provides the regulating norms (Butler 1993) for thinking and doing in the nursing home settings.

'Care-planning': entanglement of meanings and processes

Providing support and assistance to each individual resident poses a challenge to aged care service providers. The challenge comes from the complexity of allocating limited human and material resources to each resident in need of assistance. As shown in the previous subsection, care-planning is a key component for organising material and human resources into daily care practices, within the constraints of the government funding scheme. In the field of residential aged care, it is mandated that a service provider conduct a clinical process of care-planning and produce a written care plan. Care-planning interlinks resources, such as aiding devices, equipment and staff assistance, with residents who need support. Connections between residents and supportive other material things and persons are first notionally created in the written form of a care plan and then implemented in routinised activities of daily living.

In nursing homes, routine 'quality care practice' involves 'a written and up-to-date care plan for each person, one that reflects the current health status of the person and respects their individual personhood' (Yun-Hee et al. 2013). In the case of Mrs Joyce, mobility was a key aspect of her care-planning. After the physiotherapist reviewed her medical history and conducted a mobility care assessment using the Physical Mobility Scale, he recorded that Mrs Joyce needed a 4-wheeled walker while walking, and staff physical assistance with transfers. According to her medical history, Mrs Joyce was also identified as at risk of falling at night. Her hospitalisation before nursing home placement was to treat injury from a fall at night at home. A Fall Prevention Plan was created for Mrs Joyce to have a sensor mat alarm placed at her bedside at night.

The discourse of person-centred care has had increasing impact on daily care practices, and especially on care-planning. With an emphasis on providing individualised care, information about family, education and work life histories, interests, hobbies, habits and preferences are collected in admission assessments, considered in care-planning, and used in daily care delivery. An individualised care plan is thought to help the resident to adapt and adjust to her nursing home life through establishing and following a daily routine that reflects the resident's needs, likes and preferences. After familiarising themselves with her care plan, morning-shift staff knew to come in to unplug Mrs Joyce's sensor mat straight after their handover, and in turn Mrs Joyce learnt to not attempt to get up on her own and activate the alarm. She would wait in bed for staff assistance with transferring position and walking. After a long night of lying in bed, she felt stiff and pain from her neck, back and shoulders. While she had an evening shower at home, she found the routine of the morning shower soothing and refreshing. Knowing what to expect—warm water on her aches and pains—enabled Mrs Joyce to feel at ease and to look forward to the new day. Care services are divided into Mobility Care and Fall Prevention because the two categories are funded differently. These care services, which are jointly delivered and include the use of a 4-wheeled walker, staff assistance with transfers and a sensor mat to alert staff of her movements at night, create a right assemblage of care for Mrs Joyce to mobilise as she wishes and feel at ease and at home in the nursing home.

Nevertheless, itemising residents' conditions and needs into separate categories in residents care plan and using ACFI criteria to allocate and deliver services do not always lead to a right assemblage of care. For example, Mrs Joyce could have missed out on treatment for her pain. A massage from a registered nurse or physiotherapist was rightly prescribed in her Pain Management Plan, but was not always delivered, as explained later. The daily massage she regularly received arose in another way.

Treatment for pain is categorised in the ACFI as addressing residents' Complex Care Needs. Residents were widely assessed for pain after this category of Complex Care Needs was added to the ACFI. Staff chose to use the Pain Assessment IN Advanced Dementia (PAINAD) scale to assess pain for Mrs Joyce though Mrs Joyce did not have a medical diagnosis of dementia. The PAINAD assessment shows higher sensibility and validity as the instrument is observational and does not depend on resident's recounts of their experience of pain. Staff explained to me that they used PAINAD assessment for Mrs Joyce because pain is experienced by many residents and yet,

some residents tended to downplay their experience of pain, discomfort and difficulty, as shown in how Mrs Joyce said that she could manage her changing of position from sitting to standing when she could not.

Mrs Joyce did experience pain and usually received a daily massage on her neck, shoulders and lower back after her morning shower. Massage is part of the Activities of Daily Living (ADLs), done daily by personal care staff. After her pain assessment, Mrs Joyce was prescribed 20-minute massage sessions administered weekly by either a registered nurse or a physiotherapist. Daily and weekly massages belong to different categories. The weekly sessions are part of the Pain Management Plan to address the resident's Complex Care Needs (a category in the ACFI). Extra funding is provided by the federal government to service providers for meeting residents' Complex Care Needs. However, a daily after-shower massage is not a government funded service item. While showering is funded under the category of Personal Care Needs, an after-shower massage is provided per residents' request and preference, with the agreement of staff.

The ACFI is *not* designed to guide day-to-day service provision but to assess 'core care needs' of residents for allocating funding to residential aged care facilities. What residents need in terms of support and assistance with their day-to-day living may exceed what can be categorised and covered using the ACFI. Mrs Joyce knew nothing about the categories and funding. She just preferred a thorough and relaxing massage right after a morning shower. A right assemblage of care to treat Mrs Joyce's pain would have included a daily massage session after her shower. However, as part of the sequence of activities between showering and dressing, the time allowed for massage was often cut short by care staff as time was almost always tight. As for the weekly prescribed pain management massage, Mrs Joyce asked, what is the point in getting undressed for a massage in the middle of the day? While she was expected to benefit from her 20-minute weekly massage, she often missed out on this afternoon massage session because she was taking part in social activities like a Cafe & Chat session.

Among aged care researchers, the written care plan is widely believed to orient staff to deliver individualised care, maintain the continuity of care and promote team communication (Dellefield 2006). Yet, what is often unstudied is the financial considerations embedded in the process of care-planning and the written care plan.

To maximise financial support from government funding, residents' care needs are constructed within the ACFI conceptual framework so that services provided can be accounted for and funded by the government. It is important for staff to do the paperwork—to document what they do for residents by completing the relevant boxes—such as on a Bowels Chart or by filling in numbers on a Food and Fluid Intake Form. "It is essential to get the work documented if the work is done", the care manager emphasised. If the work is not documented, it is regarded as not done even if it is actually done. Documentation of care work makes staff accountable for their work on occasions such as accreditation and for funding approval. A tick of the box on Mrs Joyce's Pain Management Weekly Massage Record Sheet was directly linked to the facility's claim for extra subsidies to meet Mrs Joyce's Complex Care Need of managing pain. ACFI thus possesses in text form a defining power in how care is inscribed, funded and practised in nursing homes. Extra staff-time is made available by the extra funding: A registered nurse massage shift was created in care facilities to deliver weekly massage sessions to residents after the Complex Care Needs category was created in ACFI.

The invisible but overarching and decisive impact of the funding scheme on residents' care-planning may lead to unexpected consequences. It is reported that staff did not refer to care plans in care delivery, as they often thought care plans were not meaningful for delivering individualised care (Yun-Hee et al. 2013). It is also reported in a Norwegian study that when the residents were provided with person-centred care even their care needs were not reflected in their care plans (Sandvoll, Kristoffersen & Hauge 2012). My fieldwork reveals that staff are more likely to be oriented, not by the resident's care plan but the local work/task sheets (a schedule of tasks to be carried out within the time frame of a shift (see Plate 24) to respond to residents' emerging and changing needs. Residents' habits and preferences are often updated day-to-day, service by service, on the worksheets not the care plan. In comparison with what is planned (what should be done) and documented (what is done), the actual play-out of events in real time, situations and relationships is far more nuanced than care plans imply. Life 'on the ground' in nursing homes comprises care as multiplicities—the coming-together, playing-out and intertwining of many components including government funding schemes, care needs assessments, care-planning and daily care delivery—different assemblages of care, some productive in meeting residents' needs while others fail to do so. It is in daily routinised activities that different assemblages of

care are enacted and connections between residents and supportive other material things and persons are actualised. As I now turn to demonstrate, it is in this space that tensions between contesting forces become evident in and through residents' becoming and unbecoming moving.

TOTAL CARE LIST
FIRST FLOOR
0700 – 1500

TIME	M	T	W	T	F	S	S	M	T	W	T	F	S	S
0700 – Rm 127	*	*	*	*	*	*	*	*	*	*	*	*	*	*
0720 - Rm 130	*	*	*	*	*	*	*	*	*	*	*	*	*	*
0740 – Rm 107	*	*	*	*	*	*	*	*	*	*	*	*	*	*

*= Sponge and dress assist - * Shower and dress assist ?

AFTER BREAKFAST SHOWERS

0840 –Rm 109	*	*	*	*	*	*	*	*	*	*	*	*	*	*
0905 – Rm 101	*	*	*	*	*	*	*	*	*	*	*	*	*	*
0935 - Rm 106	*	*	*	*	*	*	*	*	*	*	*	*	*	*

Daily bed strips:
Monday -101-102,103
Wednesday- 104-104-105
Friday - 108 – 109 -
Sunday -112-113
Tuesday - Rm:114 - 115
Thursday -106-107
Saturday - 110-111

- Assist with all V/C bells
- Make beds from room 101 – 115
- **10:00 – Morning tea round for residents in room 101 – 115**
- To assist with lunch trays **ONLY** in the north servery.
- Meal orders to be taken on **Saturday ONLY**, in the north servery.
- **30min lunch break from 12:30 to 13:00.**
- Complete any toileting as per scheduling times - 104,113,115,117,119,120 & 126. * = LIFTER x2 staff. ?
- Complete all activities, bowel diary and ACFI documentation. This is to be filled in daily from room 101 **TO** 115.
- from room 101 – 115.
- End of shift at 1500- THANK YOU!

If you find you have any spare time please:
1 - Wash and cut finger nails
2 - Tidy up residents room and bathrooms
3 - Tidy wardrobe's and take out excess coat hangers
4 - Clean over ways
5 - Clean sluice room

R/V date 11/01/2015

Plate 24: Sample care staff worksheet

Routines: the actual play-out of events 'on the floor'

As the brief description of Mrs Joyce's morning routine demonstrates, how elderly people could adjust to the institutional way of life in a nursing home is affected by how staff assistance is provided. This includes establishing and following everyday personal routines, such as sleeping/waking, eating and washing, which involves both residents' own efforts and staff assistance within scheduled and allocated time. Residents' initial care plan is mostly made after consultation with residents and their significant others to reflect their own interests and preferences at the beginning of their residency. As time goes on, daily activities become routinised through everyday practice. As Chapter 3 demonstrated using the example of Mrs Casey, her personal routines were closely associated with a sense of being at ease and a feeling of being synchronised with nursing home operations.

Instead of attending to one resident, personal care staff were usually allocated to a unit attending to all the residents living there. In the care facility where Mrs Joyce lives, four morning-shift care staff attended to 28 residents in the unit with varied physical and cognitive impairments.[11] Staff either worked in pairs or on their own, depending on the level of care needed by residents, e.g. a 1 or 2 staff physical assist with transfer. The allocated time of personal care for each resident in the morning was around 20 minutes, including but not limited to, toileting, showering, dressing, grooming, making the bed and cleaning the room. Aside from general tasks like showering and dressing, personal care staff also needed to perform some specific tasks (in the category of 'technical needs', see Table 5) for each resident, such as 'saline eye lid scrub to both eyes', 'alcohol wipes between toes' and 'tubigrip to both legs, toe to knee'.[12] According to agency staff, in comparison with other care facilities, this resident-staff ratio (7:1) was quite reasonable as a few residents were 'self-care' with transfers and walking.[13]

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[11] Day shifts for care worker included: from 7 am to 3 pm, 7 am to 2 pm, 7 am to 12 pm and 7 am to 11 am. The 7 am to 11 am shift was a 'floating shift' that can be relocated to other areas when the workload in this area is reduced due to changes in residents' numbers or overall conditions.

[12] Tubigrip is a specially designed elasticated tubular bandage that provides firm but comfortable support for sprains, strains and weak joints. It can also be used to reduce swelling and to keep dressings in place.

[13] According to research the Australian Nursing and Midwifery Federation (ANMF) commissioned, the current aged care resident in Australia receives roughly 2.5 hours of care per day and the staffing mix is usually comprised of 70% personal care workers (PCWs) and 15% of both registered nurses (RN) and enrolled nurses (EN). On Wednesday 13 February 2019, the Federal Secretary of ANMF, Annie

In a Canadian residential aged care facility, a caregiver is reported to undertake ADLs for nine residents with physical disability and cognitive impairment on day shift while two staff members care for 27 residents at night. The caregivers describe the workload as “overwhelming” and “insane” (DeForge et al. 2011, p. 419).

Table 5: List of care activities in the Technical Needs Category* (for one resident during the 7 am–3 pm shift)

	Care Activities (Technical Needs)	Time on	Time off
1	Prantal powder under both breasts	BD**	
2	Saline eye lid scrub to both eyes	BD	
3	Elmore oil to both hips, back & ankles	BD	
4	Alcohol wipes between toes	daily	
5	Tubi-grip to both legs, toe to knee	08:00:00	20:00:00
6	Restraint review	08:00:00	
7	Restraint review	10:00:00	
8	Restraint review	12:00:00	
9	Restraint review	14:00:00	

* Adapted from residents’ technical needs list dated 10/02/2015 for 7 am–3pm shift in Area B6
** Twice daily

The 20-minute per resident time frame in the morning was an integral part of the overarching institutional routine—a structuring of temporal patterns regulating the collective ways and styles of work organisation. Characteristic of institutional routines are the temporal markers placed on the commencing and completing of certain tasks, for example, serving lunch from 12–1 pm, administering medication at mealtimes, assisting residents in the morning from 7–11 am, etc. Serving as ‘temporal reference frameworks’ (Zerubavel 1979, p. 84), institutional routines affect staff work performance through how staff are expected to complete a list of certain tasks at a certain rhythm, speed and tempo and within a particular duration in order to

Butler, appeared before the Royal Commission into Aged Care Quality and Safety, and explained why mandated minimum staffing levels and skills mix are an essential part of any solution to ensure safe care for every elderly resident (ANMF 2019). The ANMF’s research has shown that an average of 4.3 nursing and care hours are needed each day and also identifying the ideal skills mix required to deliver this care. In order to achieve the recommended care time, the ANMF proposes that by 1 January 2022, average care time should increase to 3.75 hours per day per resident with a minimum of one RN per 30 residents during day shifts and one RN on other shifts, and by 1 January 2025, average care time provided to residents should increase to a minimum of 4.3 hours, with a minimum of one RN per 15 residents during day shifts and one RN per 30 residents during evening and night shifts (Cheu 2018).

synchronise with co-workers and staff working in other departments, such as kitchen or housekeeping.

How staff are organised by the institutional routines affects how they can assist residents with their doing daily activities. While the duration of time to assist each resident, e.g. 20 minutes, is set and there are always some residents waiting to be assisted, staff must keep the pace moving quickly from one resident to the next. Unlike staff who can adjust by speeding up or slowing down, residents move at their own individual pace, due to their bodily conditions, and cannot be rushed to move faster, as described by Mrs Joyce in the Introduction to Part III on care. When staff face time pressures to finish work with one resident, rather than assisting residents to walk using a walker, they are more likely to use other aiding equipment, such as a wheelchair, to speed up the transportation. In replacing a walker with a wheelchair, residents may not feel 'right'—they are restrained from making their own movements and feeling a sense of control and connectedness in and through walking. In this sense, the institutional power of nursing home is exerted directly upon the bodies by allowing them to connect and move or restraining them from extending and moving.

Part and parcel of the institutionalisation of people living and working in nursing homes is that they come to regard institutional routines as the habitual and accustomed structure of daily functioning. Bland cites Savishinsky to suggest that a 'clockwork schedule of meals, medications, therapies, bathing and changeovers in work shifts (1991: 119 as in Bland 2007, p. 942) constitutes the framework of routine care practice. The institutional routine care practice is often criticised for its emphasis on efficiency. In her nursing home study of residents' experience of comfort, Bland concludes that:

> 'Cultural practices, such as care delivery routines, were so entrenched they had become the taken-for-granted way of functioning', and 'are driven more by a desire for organizational efficiency than the comfort of residents' (2003, p. 187).

Nevertheless, in recent years in Australia, with new government initiatives emphasising the person-centred care approach, staff received training on how to provide flexible support and assistance to residents depending on personal necessity and preference. As I observed in my fieldwork, mealtimes were extended to suit an individual resident's condition and situation while shower routines were negotiable within the availability of time, resources and staff.

How each staff member organises daily work is often contested and negotiated with not only residents' habits and preferences but also these 'background expectations' that require staff to perform 'the act of time management' (Adam 1995, p. 42). In this sense, *staff routines* can be understood as to some extent a justified stable structure for the ADLs to be carried out in a timely, labour-saving, 'straightforward and simple manner' (Sandvoll, Kristoffersen & Hauge 2013, pp. 368-369) with reference to both the institutional and residents' personal routines. Some veteran caregivers had the reputation of being able to, as the managers and nurses said, "know their work" to "get the work done" and "know their residents" to provide individualised care.

In the entangled processes of daily care delivery, unexpected events may disturb the routinised work plan and expose the complex interplay of contesting and competing forces and discourses, including the overarching institutional routines, the staff roster and allocation system, and the discourses of person-centred care and efficiency. In the following two graphs, I use the numbers of resident call-bells to illustrate how, on two consecutive mornings, staff shortage may have impacted on residents' experience of care delivery. In the first morning (colour blue) at 7 am, one care worker did not arrive for his 7 am to 3 pm shift. As no contracted care staff were available that morning, an agency care worker was booked. Being called in for an emergency, the agency worker arrived at 9 am. Between 7–9 am on that morning, instead of having three care workers on the floor, there were only two. In the following morning (colour red), all three regular care staff (rostered to work for the same shift in the same area) were for work.

Kitchen staff routinely started serving breakfast at 8 am. A certain number of residents (as specified on the "shower list"; see Plate 24) need to be showered and dressed and set up for breakfast before 8 am. While kitchen staff were serving breakfast in the dining area and sending out breakfast trays into the residents' rooms, care workers were expected to assist residents with their breakfast and feed those residents who could not feed themselves. One care worker short on the floor would lead to some residents being unattended before and during breakfast. Residents usually ring their nursing call-bell to alert staff that they need help. A ring of the call-bell indicates a resident's effort to seek staff assistance. Repeated rings of the call-bell from the same resident would indicate that staff had failed to respond promptly to the resident's call. With this understanding, I took the opportunity to collect the numbers of resident call-bells on the two consecutive mornings to explore how staff shortage, the *absence* of staff

assistance which is a key component of daily care delivery, may impact on residents experience.

As shown on the graphs (see Figure 4 and Figure 5), the dramatic increase in the total number of resident call-bells and the pattern of repetitive calls demonstrates a gap between residents' need for staff assistance and its provision. There was a dramatic increase of resident call-bells (see Figure 4) when there were only two care staff on the floor (19 calls compared to 7 for the next morning). More importantly, as shown in the repeated call-bells graph, resident in room 1 (colour blue; see Figure 5) made four calls in the span of one and half hours, on that morning. What is conveyed by the repetitiveness of call-bells is the experiences of frustration and anxiety of the resident who urgently needed help but was kept waiting and waiting for 90 minutes. To note, on the following morning when there were three regular care staff on the floor, there was not a single repetitive call-bell from these residents.

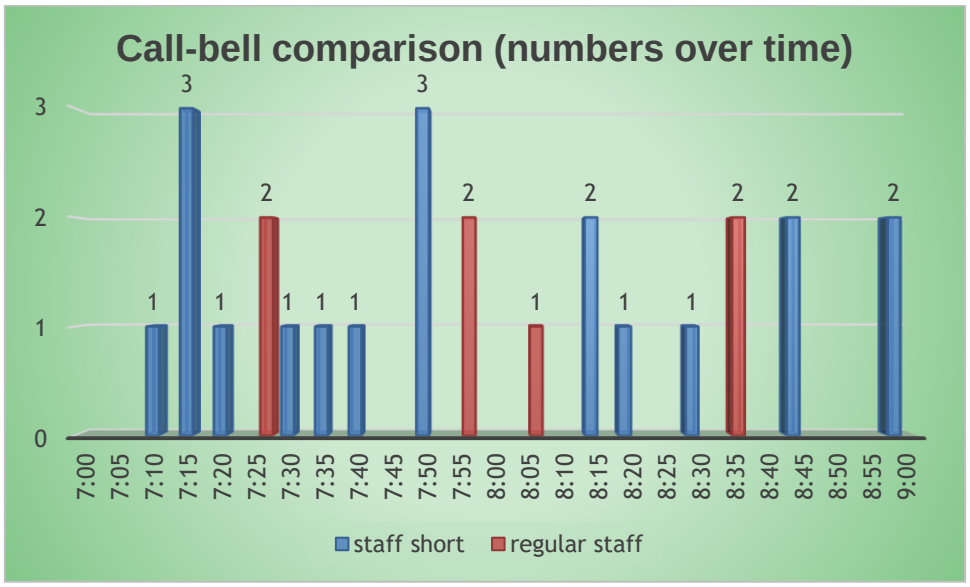

Figure 4: Comparison of resident call-bell numbers

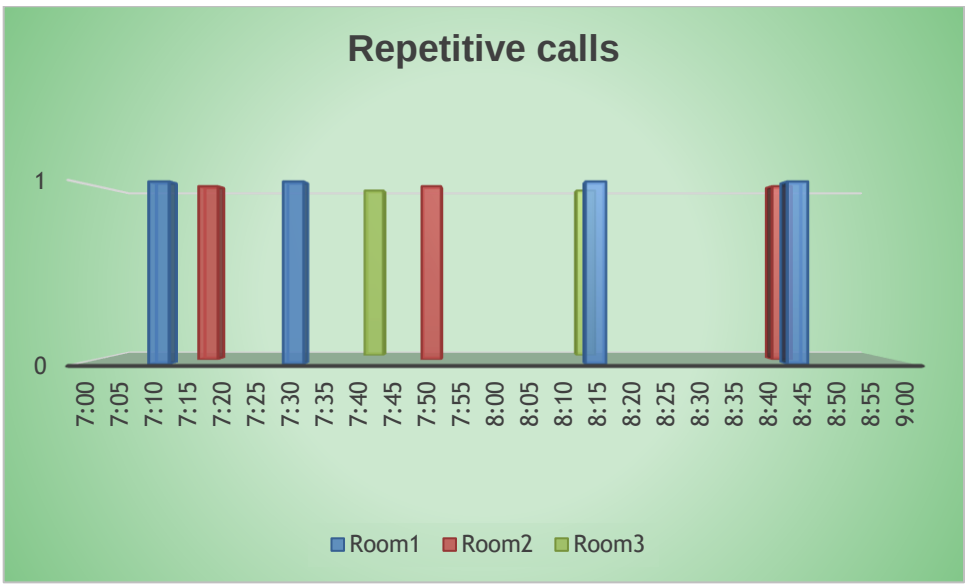

Figure 5: Pattern of repetition of resident call-bells

Institutional routine care practice is characteristic of orchestrated and repeatable patterns of activity enabled by the systematic organisation of resources into processes. Staff assistance provided to residents in unexpected situations, such as with one care worker short on the floor, is *contingent* on the availability of *extra* resources, such as assistance from nursing and kitchen staff. In an ethnographic study conducted in five American nursing homes, Eileen Jackson (1997) finds two kinds of care: routine care prescribed by the institution and care provided in response to residents' need of care, either as requested by a resident (e.g. verbally or using a call-bell as found in my fieldwork) or observed by caregiver. As the former is basic, visible and formal in the institutional setting, the latter remains invisible, informal but pivotal to the residents' wellbeing (Jackson 1997, p. 198).

This subsection highlights the dynamic and processual features of routinised activities in institutional settings. In the daily actualisations of routinised activities, different forces interplay, compete and negotiate. As will be shown, walking in a nursing home is a productive process where: concrete material surroundings and living bodies; assessments, daily practices and auditing processes; walking aids and equipment; notional care plans; and unexpected happenings on the ground, meet, connect and synthesise, often in states of tension.

Mapping care in and through walking

In the previous section, I drew on the example of Mrs Joyce to expose the various components of nursing home care, including medicalised assessments, care-planning,

government funding schemes and daily care practices that are prescribed, pre-scheduled, routinised but rarely actualised as planned. In this section, I will use the example of Mr Harris and return to residents' experience of walking and not walking. I attempt to map these components to expose the entangled processes of connecting, overlapping, contesting and competing of these elements in different assemblages of care, which may enable or constrain residents from walking. The central question that I ask in this section is: How do these components articulate and come together to produce a right, or not so right, assemblage of care?

Mr Harris used to walk as much as he wanted when his bodily condition allowed him more time on his feet. With the aid of a 4-wheeled walker, he walked cautiously. Hours and hours of Mr Harris pushing his walker through the corridors, lounge and dining areas, indenting carpeted floors, created pathways constituting lines of movement. At this stage of his walking, Mr Harris mostly relied on his walking aid for support and stability with little staff supervision. The ongoing support from his walker, among other material things and persons, was the key component in an assemblage of care that assisted Mr Harris with excessive, yet safe walking. While both Mrs Sage and Mr Harris wandered, in contrast to the high visibility of Mrs Sage, Mr Harris seemed to have been invisible. Though having constant encounters with staff, Mr Harris appeared to be transparent to them. Many staff members overtook or walked past him face-to-face saying nothing. In paying no attention to Mr Harris on passing, staff appeared to be *unaffected* by the presence and movements of Mr Harris. Why did Mr Harris draw no staff attention to his walking? When asked, staff explained that, though Mr Harris had been walking excessively, he was *safe* to walk. He appeared to be all right—he was neither disruptive to other residents nor harmful to himself. Unlike the wandering of Mrs Sage that was challenging to care management and delivery, the walking of Mr Harris was *safe* to both himself and people around him. Staff said they would therefore "leave him to wander". While Mr Harris walked safely with his walking aid, he was allowed to walk as he liked. A right assemblage of care for Mr Harris to walk *at that time* did not require staff attention and assistance.

However, staff awareness of the walking of Mr Harris gradually changed after his frozen gait increasingly affected his walking. Although the sudden halt or acceleration was usually temporary, his walking became unstable with an increased possibility of falling. Staff attention was increasingly drawn to his walking in the situation where it looked unsafe. From staff paying no attention to Mr Harris' safe walking to their

increasingly attending to his unsafe walking, staff attention, or to use the ACFI term, ‘supervision’, became an indispensable element in a right assemblage of care for Mr Harris to walk. It was not needed in a right assemblage of care while Mr Harris could walk safely with his walker. It became pivotal in a new assemblage of care after Mr Harris developed the frozen gait. With this new element of staff attention drawn into the unsafe walking of Mr Harris, the composition of a right assemblage of care for Mr Harris to walk had changed. By drawing constant attention from staff, the walking of Mr Harris became staff-supervised walking. It is important to note that, there is a difference between a ‘staff stand-by’ style of supervision, which is an actual funding item and task, and a staff ‘keeping an eye on Mr Harris’ style of supervision. The latter kind, as Jackson (1997) observed in her study, is an informal practice of carers, which is not funded, and was mostly what Mr Harris received at this time.

Though staff felt being, as they said, “stretched” by the extra attention paid to the walking of Mr Harris and occasional hands-on help with his walking, they managed within their load of work to assist Mr Harris to walk safely. There existed, in effect, a tension between what Mr Harris needed, namely, intermittent staff attention and assistance to continue to walk, and what was made available—the unprescribed and unscheduled extra care through staff informal practice (Jackson 1997). The informal nature of staff assistance that was involved in Mr Harris’ walking made it an unstable and precarious component to the assemblage of care.

The confluence of the combined support from Mr Harris’ walker, staff engagement and Mr Harris’ own efforts to walk was disrupted when his walking further deteriorated. More and more often, Mr Harris was seen by staff as struggling with keeping balance and having near-miss fall incidents. Concerned that he might fall, staff would rush to him with a chair or wheelchair when he became wobbly. Staff began to feel that their assistance to Mr Harris was disruptive to their work routines. Staff assistance was the key component *not only* in a right assemblage of care for Mr Harris to walk, but also in *any* assemblage of care if it is to be actualised in assisting residents with daily living. As discussed in the previous section, all personal care workers were assigned with a work/task list—a list of care duties to be carried out in a sequence within a timeframe. They ‘ran’ from resident to resident to keep themselves on time. Staff tended to foreground routine work rather than residents’ movement when getting work done and efficiency are prioritised at the organisational level. They also said that it would be “unfair” to other residents if they could not get other staff to help with a shower or

serving breakfast as scheduled, when staff were assisting Mr Harris. In effect, residents and their families *did* complain about staff being late for scheduled care activities, e.g. showering.

On the other hand, staff felt an overwhelming sense of being stretched due to stress and exhaustion. They had a duty of care for Mr Harris not to have falls and fall-related injuries while also having a duty of care for all the other residents in the same area. The considerations for residents safety (legally significant), mobility, hygiene, nutrition and hydration (biomedically vital), and the expectations for staff to be simultaneously caring (morally essential) and efficient (economically important) do not just co-exist, they contest and compete for priority in staff time, attention and energy. Navigating these entanglements of contesting forces and discourses inexorably affects how staff respond towards residents' attempted unsafe movements. While staff liked to have a smooth performance of care work, which gave them a sense of ease, they were frequently pulled out of the scheduled flow of work. In assisting Mr Harris, they felt overwhelmed. The balance between staff engagement and Mr Harris' efforts to walk was broken when the difficulties for Mr Harris to walk safely increased. An increasing amount of staff assistance needed to be formally allocated'—by means of care-planning—to overcome a tension between what is required (care needs) and what is available (care provision) for Mr Harris to walk safely.

Yet, as previously discussed using the example of Mrs Joyce, while its function is to organise and allocate human and material resources into daily care delivery, care-planning works within the constraints of the government co-funding scheme. The component of staff assistance relates not only to residents care needs (which are often medically constructed) but also to the availability and distribution of funds (which are affected by government policy, investment and a financial management of service provider). In the current Australian aged care system, the component of staff assistance is an itemised service provision through hourly paid human labour. As staff are rostered and paid for shift work that is counted by hours, the availability of staff assistance is always timed and limited by funding level. "More money more care," a care worker said. As I previously discussed, the staffing level in a care facility is directly affected by the funding level of its residents. So, while staff assistance is understood to be the key component in a right assemblage of care for residents like Mr Harris to walk safely whenever they attempt to do so, *how* this component could *function* in an

assemblage of care, may it be formally and consistently or informally and occasionally, leads to care as *multiplicity*—emergent becomings.

To map the movement and morphosis of staff assistance in assemblages of care as multiplicities, I now return to Mr Harris' walking and not walking. In the situation where staff could barely handle the extra work (staff assistance that is *not* care-planned, funded and paid for) and were stressed due to the unsafe walking of Mr Harris, they began to *resist* assisting Mr Harris with his walking as informal and extra practice of care. They orally reported to the registered nurses (RNs) on duty about Mr Harris' unsafe walking. Working as supervisor and team leader on the floor, RNs further reported Mr Harris' unsafe walking to the care management team by writing 'progress notes'. They drew on the institutional discourse of risk, an important component in care-planning, in their reporting practice to seek changes to the status quo. Mr Harris had a formal assessment for risk of fall (for funding purposes) after he was reported by staff as having 'high risk of falling due to impaired balance' (from Mr Harris' progress notes) and had a few near-miss incidents of falls while unattended. After a high risk of falls was reported, recorded, measured and recognised through assessments, Mr Harris' care plan was updated addressing his emergent care needs, which were described as walking with staff assistance (mobility care needs) and preventing walking while unattended (fall prevention needs). Both a Mobility Care Plan and a Fall Prevention Plan were set up to address these seemingly separate needs for care.

Mr Harris' Fall Prevention Plan was created with the understanding that he was no longer fit to walk whenever he liked with his wheelie walker and it would be better for him to sit than to walk while unattended. Staff attending to Mr Harris, took away his walker, replaced it with a sensor mat and sat him in a chair. To prevent him from walking while unattended, his walker was kept out of his reach. His walker was clearly *not* a component in this assemblage of care, namely, fall prevention. Meanwhile, as a key component of his Mobility Care Plan, Mr Harris was prescribed a '2-staff assisted daily walking routine' after he was restrained from walking on his own. His use of the walker, and other elements including the timed consumption of Parkinson's medication and allocated staff-time, could be organised into fixed temporal, spatial and relational structures of a staff-assisted walking routine so that he could walk safely.

As shown in the example of Mr Harris, like a 'line of flight' in Deleuze and Guattari's (1988) sense, the discourse of risk works to break open a closed structure—an

assemblage of care that could assist Mr Harris with walking more often but not safely—by taking away the walking aide and stopping unscheduled staff assistance, which limited his walking. It also works to arrange new assemblages of knowing and doing risk-oriented approaches towards residents' walking, e.g. the use of a sensor mat and a staff-assisted walking routine.

But, as shown in my previous discussions, in effect, it was the accumulated tension between what was required (care needs) and what was available (care provision) for Mr Harris to walk safely that broke the balance which supported Mr Harris to walk as he attempted. In other words, he was stopped from attempting to walk when his difficulty with walking safely *outgrew* the limited provision of staff assistance. However, instead of providing *more* care in the form of staff assistance to enable Mr Harris to continue to walk, more *forms* (in separate funding categories of Mobility Care and Fall Prevention) of care were planned with timed and limited staff assistance in routinised activities. In this interplay of multiple forces (government funding scheme, financial management of a service provider, and care-planning based on medicalised assessments with embedded economic considerations) and discourses such as residents safety, staff duty of care for residents and work efficiency, the discourse of risk plays a pivotal role in the reconfiguration of care assemblages while the rest became hidden in the making of care plans and the daily doing of care activities. Nonetheless, as discussed earlier using the example of Mr Harris, residents' risk of falling and having fall-related injuries is a lived problem which is socially constructed in nursing home settings as an indicator of a biomedical condition.

From the perspective of care management, a staff-assisted walking routine is an example of providing, as a senior staff member said, the "best possible care". Having routines were seen by staff as a way to manage the unexpected and unpredictable events by organising residents' movements to maintain their safety as well as the smooth operation of care work. Despite its limitations, according to care workers, the staff-assisted walking routine had been "working all right" in assisting Mr Harris with his needs to mobilise safely within the constraints of funding and staffing levels.

Nonetheless, critical to the notion of a right assemblage of care is the understanding that an assemblage of care only becomes right when it is productive, responsive and supportive, when it enables residents to move, to extend and connect, and to have a sense of home in the nursing homes. Approaching staff-assisted walking routines

through the lens of a right assemblage of care, the assemblage did not “work all right”, as staff claimed, because it was less productive and even restrictive for residents to move whenever they attempt to do so and to feel a sense of rightness of being with others. After hours and hours of walking with his wheelie walker, Mr Harris had become inseparable from it. While through walking his feet were grounded and his legs became flexible, they became so with the aid of his walker. Mr Harris’ walker was an indispensable material thing in his right assemblage of care to sensorially extend his body to connect with others and to counter the restrictive forces that stopped him from walking. His walking was badly ruptured when his walker was taken and the extensions were severed; Mr Harris was left sitting in a chair like a statue or a piece of furniture. A staff-assisted walking routine, while aiding, *per* a fixed procedure or plan, could thus further rupture residents’ walking beyond their impairments. The once smooth flow of movements became blocked and broken. The assemblage of care described in Chapter 5 may not be all right if Mr Harris was left sitting in a chair for prolonged hours before and after a routine walk, without engaging in other activities.

Fall prevention for Mr Harris, on the other hand, with a sensor mat alarm and a comfortable chair as its key components, is an assemblage of care which foregrounds safety rather than movement, and supervision rather than assistance. It is *not* an assemblage to care for Mr Harris to walk but to stop him from walking. In examining residents’ walking and not walking through the lens of a right assemblage of care, care can be revealed as multiplicities; various components of care practices and discourses are assembled and enacted differently in changing circumstances. Some are productive and responsive to residents’ efforts to move while others were less productive or even restrictive, preventing movement and limiting residents’ sense of rightness of being-in-the-world-with-others. In the next section, I will further explore the restrictive practices of restraint and their impact on residents’ moving or not moving and having a sense of home in the nursing home.

Restraint: a duty of care?

This section aims to demonstrate that staff responses towards residents’ attempts to move are heavily mediated by: dominant medical discourses of risk and agitation; practices of fall prevention and behavioural management that aim to keep residents safe; and overarching organising structures that prioritise economic efficiency. Fall prevention frameworks and some measures, such as thick carpet in corridors, non-slip floor coverings and the footwear of residents, are practical initiatives which are least

restrictive to resident movement. However, more restrictive practices do exist in nursing homes. Restraint to nursing home residents is defined in Australian aged care policy as 'any aversive practice, device or action that interferes with any person's ability to make a decision or which restricts their free movement' (Department of Health and Ageing 2012a, p. 1). The intentional restriction of a resident's voluntary movement or behaviour by the use of a device, or removal of mobility aids, or physical force for behavioural purposes is considered as physical restraint (Department of Health and Ageing 2012a, p. 24). Aside from physical restraints, chemical restraints are also used in nursing homes. Chemical restraint refers to the intentional use of medicines, which sedate or tranquillise, to control a resident's behaviour when the behaviour to be affected by the active ingredient does not appear to have a medical cause (Department of Health and Ageing 2012a, p. 25). Here, while residents' problematic behaviours are interpreted as symptoms of dementia, these behaviours are not considered medically 'treatable' conditions. A chemical restraint is thus the use of any drug for discipline or staff convenience, and which is not required to treat the symptom. Pharmacological agents used as chemical restraint, such as antipsychotic or neuroleptic medication, can further impair residents' efforts to move. At the time of my fieldwork the over-medicalisation of residents and use of restraint practices, gained widespread media attention after an investigation into the death of Bob Spriggs, a former nursing home resident at the Older Persons Mental Health Facility at Oakden, in Adelaide, South Australia, who had Parkinson's disease and Lewy body dementia and experienced significant inappropriate chemical and physical restraint.[14]

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[14] In early 2017, Oakden was in the headlines in media across Australia. The investigation on the death of Mr Spriggs revealed some extreme practices in the facility. It was revealed in media after his death in February 2016 that during his stay, he was overdosed with 10 times his prescribed amount of antipsychotic medication on at least three occasions. The use of antipsychotic medication for Mr Spriggs is an example of chemical restraint. He also had bruises thought to be caused by being restrained in a chair. The family lodged a complaint to South Australia Health. A review of the entire facility was commissioned after the media coverage of the story. The review of the Oakden Auxiliary by chief psychiatrist Aaron Groves identified workplace practices that inappropriately used seclusion and restraint of residents. This helped lead to the current Royal Commission into Aged Care Quality and Safety.

According to the findings from the review on the use of restraints in the elderly in hospital and nursing homes from 1990 until 2004: residents with poor mobility, impaired cognitive status and high dependency on care are more likely to be physically restrained (Hamers & Huizing 2005, p. 19). In other words, residents who often 'forget', due to cognitive impairments, that they cannot balance while walking and changing positions, and attempt to do so without staff assistance have a higher chance of being restrained. In most cases, physical restraints, such as chairs with a table and belts, are used as safety

The use of restraint in nursing homes and hospitals often reflects the limited capacity for institutions to care for residents with complex needs due to dementia. This was the case with Mrs Wilson, a resident with later stage Alzheimer's disease, and utterly mute. Described by staff as "a big wanderer" when she could walk, her balance became affected as her dementia progressed. After she had multiple successive falls and badly bruised herself, she was assigned a princess chair to sit in the lounge area. In the case of Mrs Wilson, a princess chair was not meant to be a method of restraint, but it limited her movements even though she was not tied to the chair. In this chair she became restless and shuffling. Staff documented these movements as a 'behavioural problem' and described how she often became "agitated, fought back staff and lashed out from fatigue, pain and confusion". During a hospital stay when she was treated for a urinary infection, Mrs Wilson was diagnosed as having 'agitation' and after returning to the nursing home, antipsychotic treatment was added to her medications. As a side effect of her neuroleptic medication Mrs Wilson became sedated and her eating and drinking rapidly decreased as she was often overly drowsy. She returned to hospital with acute kidney injury from severe dehydration and aspiration pneumonia.

Aside from the practice of restraint, prolonged sitting could also bring an end to residents' walking. Mr Harris stopped trying to move after getting exhausted from his attempt to stand up and walk. Staff said that Mr Harris developed a condition of 'apathy' due to the progression of his Parkinson's disease and he appeared to be unaffected, uninterested and unconcerned with his surroundings. In staff readings, his apathetic state was understood as the sole outcome of disease progression. In this thesis, by contrast, I approach this lack of engagement as intimately entwined with residents being restrained and receiving limited assistance to move and to walk. I draw on Deleuze and Guattari's (1988) notion of empty bodies without organs to problematise the condition of 'apathy', suggesting that the body becomes unproductive when one's desire to move is no longer assisted and supported, and in turn begins to wane. The problem is not simply the agitated movements of the body, but the eradication of the movements of others, a lack of sensory articulation with other people and things. When

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measures— 'the main reason is the prevention of falls' (Hamers & Huizing 2005, p. 19). As staff of Oakden routinely reported, mechanical [physical] restraint was used to prevent residents risk of falling (Groves et al. 2017, p. 110). Many staff of Oakden held the view that the only effective tool to prevent falls was the use of restraints, in particular pelvic restraint (Groves et al. 2017, p. 83) by which the residents' buttocks were kept from lifting up from the chair.

these assemblages of care fall apart, one's very desire to move and to be in touch with the world eventually vacates the body.

As I observed in the field, residents' movements, if appearing to be unsafe, would attract staff attention and spontaneous responses to assist, especially from newly-recruited care staff and students on work placement. In talking about their care work with Mr Dixon, care staff acknowledged that Mr Dixon was trying to move away from his chair in order to walk, a practice that was considered unsafe. "You can feel it. All he (Mr Dixon) wants is to stand up and go. But he can fall at any minute", they said. Yet, instead of joining his effort and assisting him with walking, staff mostly assisted Mr Dixon to sit back in his chair. "It's better for Mr Dixon to be seated", one worker said. In what ways could staff consider that, while feeling his urge to walk, stopping Mr Dixon from walking is better for Mr Dixon than assisting him to walk? "Mr Dixon has high risk of falls. It's safer for him to remain seated", another explained. Here, it is clearly demonstrated that staff response towards residents' attempts to move is heavily mediated by staff interpretations of resident movement, which is largely affected by the discourse of risk. As previously discussed, risk is a key component of care needs assessment, care-planning and care management. Yet, risk, I contend, is mis-conceptualised. Risk did not arise from lack of staff attention and assistance, but from residents' efforts to move, and risk was managed not by providing staff assistance to residents who intended to move, but by physically forcing residents to remain seated.

In the situation where residents' attempts to move are persistent, it can be further labelled as 'agitative behaviour'—a Psychological and Behavioural Symptom of Dementia—which 'may cause trouble for family members, caregivers and other service users' (Ijaopo 2017, p. 1251) because while unattended, patients with agitative behaviours may make unsafe movements and injure themselves. As we have seen, the medical discourse of agitation is dominant in nursing home settings such as in the case of the movements of Mrs Wilson who when confined to her chair was described as "restless" and "senseless". The Oaken Review report also reveals that residents' movements in chairs were most likely to be perceived by staff as 'pathetic, irrational and harmful' to themselves and others, and thus labelled in the setting as 'agitated behaviour' associated with 'restless sleep patterns and episodes of hyperactivity' (Groves et al. 2017, p. 106). The medical discourse of agitation as a symptom of dementia measures people and their movements against 'the statistically normal, relegating everything that falls beyond this range to the register of the ''pathological'

(Smith 2018, p. 107). ‘Agitation’ emphasises the repetitiveness and persistence of residents attempts to move. However, these persistent yet failed attempts display some embodied tensions and reflect both an innermost drive to move and the difficulty of doing so without proper assistance. I contend that what is conceived as ‘trouble’ is in effect a disjuncture between the assistance residents need and the support that is made available to them. Both the discourse of risk and the discourse of agitation can reconfigure existing assemblages of care and arrange new assemblages of knowing and doing. If an attempt to move is considered a sign of agitation, residents with dementia are more likely to be rough-handled by staff, prescribed with seductive medication, or physically restrained in a chair. In this sense, the discourse of agitation is a key component in assemblages of care that use restraint to reduce resident capacities and prevent residents from creating movements.

From mobility (capacity to move) to a risk of falls (potentially harmful attempt to move), to the ‘agitative behaviour’ (harmful movements to self and other people), a resident’s attempt to move is codified, which can have direct impact on staff interpretations of resident movement and indirect effects on the organisation of staff attention and assistance. The discourses of risk and agitation translate resident effort of moving into what is harmful and needs to be prevented. Chemical and physical restraints to residents are therefore used to eliminate their risk of falling by stopping them from moving and preventing them from harming self and others. Contrary to staff belief that restraint is a practice of care, restricting residents’ movements may in effect be a form of violence—creating and reinforcing the reverse forces that inhibit residents from sensory engagements with others and reducing possibilities for becoming at ease and at home in the nursing home.

Preventing residents from harm and having falls is important for resident safety and thus a critical aspect of care. While residents with later stages of dementia like Mrs Wilson and Mr Dixon usually can no longer care for their own safety while moving, their safety is the central concern for staff, management of the facility and the service provider. During the Royal Commission into Aged Care Quality and Safety Sydney Hearing from 6–17 May 2019, the Royal Commission heard evidence from Professor Henry Brodaty, who gave an example of how a patient with severe Parkinson’s disease and moderate dementia lived the tension between staying safe and taking the risk to walk. On one hand, his wife said, “I’m very happy for him to walk and to take that risk because his quality of life is more important than his safety”; on the other hand, the

nursing home has what is called a duty of care and responsibility for residents' safety. Professor Brodaty referred to this tension as "between cotton wool, safety and autonomy and independence", which is "one of these wicked problems that we have in looking after people in nursing homes" ('Royal commission into Aged Care Quality and Safety Sydney Hearing 17 May 2019 Transcript' 2019, p. 1903). In contrast to Mobility Care, Fall Prevention is given greater emphasis in the daily operation and management of care delivery. Resident safety from harm, falls and fall-related injuries are important: they directly implicate the duty of care of the organisation as well as each individual employee, in both a legal and moral sense.

It becomes evident in the analyses that it is the perspective of the service providers and caregivers, and their medico-legal duty of care, not the people who are cared for, that is embedded in discourses like risk and agitation. The discourses of agitation and risk work together to construct a particular kind of care for residents—producing medicalised responses in the form of interventions to prevent harm and falls by restricting movement, as opposed to the sensory extensions made possible through staff and things that can assist bodies to move. As shown in this section, care as it is currently constituted in residential aged care can reduce possibilities for residents to continue to move and become at home.

In his conceptualisation on a general form for the social ethics of care, Rapport (2018) suggests that the elderly may be constrained from exercising their free will while being cared for. If resident movement, such as the persistent walking of Mrs Sage and attempted standing and walking of Mr Dixon, is to be understood as an essence of autonomy—an exercise of free will in Rapport's sense—the type of fall prevention that this section has discussed can be regarded as an infringement of resident autonomy.

Creating the 'right' care

How can a right assemblage of care be created for residents with impaired mobility and cognition? How can they be assisted to move all right and feel at home in the nursing home? Learning from my work with residents, I start to see that the creation of a right assemblage of care for residents with impaired mobility and cognition to continue to move, relies on the right interpretation of resident movement. To do so, the established discourses of risk and agitation need to be destabilised. In this section, I draw on the examples of Mrs Wilson and Mr Dixon to demonstrate how the different interpretations of resident movement, namely, capacity to move in the case of Mrs

Wilson and risk of falls in the care of Mr Dixon, could lead to residents having different assemblages of care; some were ‘right’—productive and supportive to residents’ efforts to move and to have a sense a home; some were not so ‘right’—less productive or even restrictive to residents’ efforts of moving. With the right understanding of resident movement, new possibilities of doing care with increased responsiveness and flexibility emerge.

I will start from the example of Mrs Wilson to demonstrate how a change of interpretation about her movement in her chair could lead to the creation of a right assemblage of care to overcome the tension between moving up and staying still, in ways that recreated a sense of home. As I described in the previous section, Mrs Wilson was assigned a princess chair to sit for long hours after having successive falls. Her movement in the chair was interpreted as agitative behaviour and was subjected to medical diagnosis and pharmaceutical treatment—chemical restraint that severely restrained her movements, even those involved in eating and drinking. The implementation of a ‘no restraints’ policy in the daily care practices became an opportunity for innovative ideas and technologies to be considered. This was demonstrated in the everyday life of Mrs Wilson which was transformed when her attempt to move in her chair and to stand was recognised and she was supported to move. During a week-long period of hospitalisation, her medications were reviewed and the antipsychotic medication was stopped; she was rehydrated and treated for aspiration pneumonia. When she returned to the care facility, her oral intake significantly improved without the antipsychotic medication. Her Mobility Care Plan was also updated after careful assessments on her remaining capacities to move.

One day, I was surprised to see Mrs Wilson not in her princess chair when I walked past the lounge area. Instead, she was sitting in a high-back day chair, which looked different from normal lounge chairs. I later realised that compared to her princess chair, the new chair had two special features. First, the seat width of the chair was shorter than that of the princess chair, which left a one-inch gap between the outermost part of her hip and the arm of the chair. Instead of leaning heavily on one side of the arm in her princess chair, which could lead to her feeling unstable and uneasy, Mrs Wilson could sit more in the middle with her lower arms resting evenly on the arms of the chair. Secondly, the seat height was adjusted so that her feet could firmly touch the floor with a larger than 90-degree angle formed between her upper and lower thighs. Seeing Mrs Wilson in a more normal-looking chair with her feet on the floor, I felt puzzled—could

Mrs Wilson stand up again with her feet on the floor? Sitting down in a corner to observe, I was surprised when Mrs Wilson put her hands-on the arm rests and leant forward to lift her buttocks. She froze in the posture for two seconds and stood up. She maintained the upright posture for a few seconds, with her hands holding onto the arms of the chair. Once she let go of the armrests and stretched her arms forward, she sat back into the chair. Taking a deep breath, she made another move. After she repeated these movements half a dozen times, she seemed tired from exerting herself. She sat for a few minutes with her back leaning against the chair and her arms loosely hanging by her side. Then, she started moving again.

With her feet on the floor and her lower arms supported by the arms of the chair, Mrs Wilson could easily push on the armrests of the chair to stand up and bend down to sit back safely into her chair. Other than the apparent ease with the change of position, while she is grounded—having something underneath her feet—she looked more stable, secure and calmer. When a resident does not have a sense of 'grounding' or stability they might seek sensory feedback by trying to find the floor, leading to an increased risk of falls. For Mrs Wilson, much of her body weight went through her feet so that pressure was distributed throughout the body. She would not feel the same pressure, pain and discomfort on her buttocks as she did while sitting with her body tipped back in the princess chair. This change in position evidently changed Mrs Wilson. Unlike the Mrs Wilson who sat in the princess chair looking anxious and distressed, the Mrs Wilson in her new chair appeared to be relaxed. Her body, chair and the ground beneath her came together in a concerted and successful effort to move—standing up and sitting down—just as she was inclined to do.

When free to sit and stand, Mrs Wilson's everyday life transformed—she became more grounded and connected with others while being in control of her own body (in its entirety) and its movements. Moving made her more visible to others. People coming and going said "Hello!" and although she remained silent, she was at least seen and attended to. Moving is fundamentally a way to connect and interact. Her simple repetitive movements of sit-stand made Mrs Wilson a distinctive figure in the dementia care unit. People recognised her presence and existence. Members of families, visitors, volunteers and students doing work placement often turned to staff asking: "Who is the old lady doing sit–stand in the lounge?" "It's Mrs Wilson. She is now doing pretty well, isn't she?" staff reply with a hint of pride. In moving, her expressions of frustration and confusion were replaced by that of concentration (while moving) and

relaxation (while sitting). It was shown in the daily documentation that Mrs Wilson ate more and slept better after the new arrangement with her chair. This is in line with the research findings that physical exercise significantly benefits individuals living with a dementia in nursing homes (Brett, Traynor & Stapley 2016).

A purposefully designed chair and staff attention could benefit Mrs Wilson by enabling her to become at ease with making movements. Like walking, changing position is a kinaesthetic form of activity involving whole-body movements, balance on one's feet, perception and action coupling. Feeling the texture of the carpeted floor is to absorb the haptic sense of pressure from under one's feet. Standing up is to attend and respond to the sensory inputs so that one can balance on one's feet. In the closed loop of sensory incorporation and response initiation (perception and action coupling), one can feel just right in standing up. While moving inside, away from and back into the chair, the body is itself moving. Neurons in muscles, joints and tendons respond to sensory inputs from touch and pressure and work with the brain to let a person unconsciously know where the body parts are to produce bodily synthesis (Merleau-Ponty 1962) and coordinate movements. The entire nervous system is responsible for the kinaesthetic sense to monitor the body's own movements. In the concerted moving of the head, trunk, limbs, feet and hands, in relation to the chair and floor, one experiences effort, 'the particular feeling of that energy being exerted', which 'is accompanied by a sensation of strain and labour' (Preston & Wegner 2009) from the contracting of muscles. A sense of effort is the conscious awareness of one's own voluntary movements which is crucial for the judgement of personal actions (Preston & Wegner 2009) and is at the core of a sense of self expansion in the manifestation of the world. Though residents like Mrs Wilson may not have had a conscious awareness of their own efforts, she still underwent the many preconscious processes of desiring production and synthesis (Deleuze & Guattari 1988).

The example of Mrs Wilson demonstrates that, for the elderly people with severe physical and cognitive impairments, the sense of becoming at home in the nursing home is deeply rooted in their innermost drive to move, to flow in and out of positions. Residents with later stages of dementia could temporarily break away from their bodily restraints and make efforts to move. Assistance from others can be attracted into the residents' efforts so that what are constitutive to their becoming moving could be assembled and arranged into shared work and joint efforts. The synthesis of efforts of

residents, staff, assistive devices and technologies could thus overcome the tension between moving and staying still.

The descriptions of how Mrs Wilson could continue to move while being cared for through staff attention and a purposefully designed chair challenge the biomedical conceptualisation of residents' movements in sitting as agitation, a Psychological and Behavioural Symptom of Dementia (PBSD). Contrary to the conception that these movements are pathological markers which ought to be controlled or ameliorated through the application of biomedical, psychological and social interventions, residents' efforts of moving in correspondence (Ingold 2017) with innovative assistive technologies could potentially transform daily care practices and residents' everyday experiences. Supporting residents like Mrs Wilson to continue to move as they can and attempt to do is important because, as Rapport (2018) argues in his social ethics of care, caring that their autonomy is not violated is central to residents' having a sense of home in the nursing home, and resident movement is a way of exercising free will *outside of* conscious choice and action.

I now want to return to the question that I asked at the beginning of this section, namely, how to create a right assemblage of care for residents with impaired mobility and cognition to move all right and feel at home in the nursing home. As shown in the example of Mrs Wilson, the creation of a right assemblage of care only becomes possible if resident movement is *not* misinterpreted as risk or agitation, but as their effort to move, to extend and connect, to feel 'right' and to have a sense of home in the nursing home. To further illustrate this point, I will now turn to the example of Mr Dixon to demonstrate how the misinterpretation of his attempt to stand and walk as risk of falls could lead to an assemblage of care that is not so right for Mr Dixon to be supported to walk and feel at home in the nursing home. By changing the misinterpretation, innovative ideas and technologies could be integrated into care organisation and management to make possible a right assemblage of care for residents like Mr Dixon.

I will start my analysis from Mr Dixon's particular bodily condition in relation to that of Mrs Wilson and Mr Harris. The ways that each resident experienced their movements was embodied and situated differently. Bodily impairments are constitutive and differentiating in how residents could continue to walk. Mr Dixon experienced the constant fluctuations of attention, mobility and cognition. Mr Dixon needed staff

assistance to walk, yet, *only* at the moments when he became aware of the world and started attempting to move. This was unlike residents who could walk or stand safely with little staff assistance (e.g. Mrs Wilson did not need staff assistance to stand), or residents who could hardly walk without staff assistance (e.g. Mr Harris could not initiate movements without staff assistance after his condition deteriorated). Mr Dixon's moments of being able to walk were unpredictable. Staff assistance in correspondence with Mr Dixon's movements thus could not be pre-scheduled in care-planning within a fixed temporal structure, e.g. daily at 11am for 15 minutes. While staff assistance could not be organised for Mr Dixon with temporal markers, he may have become alert and attempted to move at any moment and urgently need staff assistance to move and to prevent him from falling. Two aspects became pivotal in assisting Mr Dixon to move safely. First, Mr Dixon needed to be monitored for movements while sitting still and asleep. At these times, staff assistance was not essential. Second, once Mr Dixon started attempting to walk, he needed to be attended to promptly by staff and assistance became essential.

Being prescribed a Fall Prevention Plan with a sensor mat alarm as its key component, Mr Dixon was *monitored* for potential movements, which covered the first aspect of assisting him to move safely. The ongoing monitoring of residents' movements does not require staff ongoing supervision. As an innovative technology, a sensor mat can aid in catching the signs of residents' attempt of moving. Staff only respond when the resident starts moving, the alarm sounds, and their assistance is needed. A sensor mat works to ensure that residents can have prompt staff assistance whenever they are inclined to stand and walk. In this sense, residents are freer to walk (to improve their mobility) and walk safely (to prevent falls and fall-related injuries), with the aid of the sensor mat. This leads to the understanding that the use of a sensor mat alarm may potentially aid in both ways—preventing residents falls while improving their mobility, if, prompt staff assistance is made available to residents whenever they attempt to move and set off the alarm.

Nevertheless, as I discussed in the previous section and in Chapter 6, Mr Dixon's Fall Prevention Plan, as an assemblage of care, was created to reduce his risk of falls, *not* for the purpose of assisting Mr Dixon to walk, and thus did not include the element of staff assistance prescribed to help him with walking. According to his Fall Prevention Plan, staff were required to 'check on him', not to assist him to walk; they would usually assist him to sit back into his chair. In assisting Mr Dixon to sit not to stand up and

walk, this element of staff assistance could not be considered as the kind of staff assistance that was needed for Mr Dixon to walk. Following this chain of analysis, Mr Dixon's Fall Prevention Plan was *not* a right assemblage of care for Mr Dixon to walk because resident movement was interpreted by its key component—the discourse of risk—as unsafe and unnecessary, which needed to be stopped by sitting the resident in a chair.

To create a right assemblage of care for Mr Dixon to walk, his movement in the chair needed to be interpreted as his mobility—capacity and effort of moving. His seemingly unsafe walking was neither *sense*less nor *meaning*less. It should have been interpreted as his longing for sensory extensions and connections (Dennis 2007), an endeavour and an invitation to a moving alongside one another, which made an opening for supportive other material things and beings to assist and enable walking. Staff are often taught, through training sessions, to mitigate the risk of unsafe walking, but they might be better equipped to understand walking deemed to be unsafe if they were prompted to question their own knowledges and practices. Re-education about the impact of the discourses of risk may cultivate their 'empathic imagination' (Kleinman 2009, p. 293) and unsettle taken for granted notions of the right ways of caring for residents.

From a staff perspective, prompt staff assistance reacting to the spontaneous movements of residents like Mr Dixon, is only made possible within a care management structure with less emphasis on time management and the keeping up with routines. As previously discussed in the subsection of 'routines', organising prompt staff assistance within the constraints of staffing and funding levels is difficult. Institutional routine care practice promotes regularity and encourages efficiency. Within the routinised daily operation of care activities, little flexibility is allowed for the provision of prompt staff assistance in a consistent manner. To overcome the tension between resident urgent need for staff assistance and the availability of prompt staff assistance, increasing flexibility in care organisation and management is crucial.

Meanwhile, assistive technologies and equipment, are right when they fit residents' bodies and conditions and can effectively reduce the usage of human labour and improve the overall efficiency. As shown in this section, a right assemblage of care for Mrs Wilson to stand and sit safely did not require the element of scheduled staff assistance. The combined support from the adjustable chair and the attention of all

staff members on the floor was sufficient for Mrs Wilson to do stand-and-sit on her own. Her stand-and-sit exercise was safe to do as she was unable to take steps and walk. After standing for a few seconds, she sat back into her chair. The adjustable chair may not have fitted her after she became no longer weight bearing. Yet, with the understanding that a right assemblage of care requires tinkering in order to be productive and supportive to residents' efforts to move, more innovative ideas and technologies could have been integrated into her care. This section has demonstrated that, while assisting residents to move to provide them with right care is complex and difficult, there exists no limits to how nursing home residents could feel at home through a right care.

Conclusion

As this chapter demonstrated using ethnographic descriptions, residents' movements are situated in complex assemblages of care—in which material things, discourses, bodies, practices and technologies are entangled. Resident walking is characterised by uncertainty and potentiality. The chance of having a fall is intrinsic and integral to movement. Residents may continue to walk with assistance or stop walking while unattended. Nevertheless, the discourse of risk, while it is not linked to mobility care and staff assistance but to fall prevention and restraints, significantly impacts on residents' everyday experience.

This chapter argues that the right care for residents with impaired mobility and cognition is to assist them to walk safely and freely. In doing so, residents could feel more at ease and at home through walking all right and feeling just right. In the next chapter, I turn to the experience of eating and not eating for residents with later stages of dementia. Using the example of Mrs Brie, I will describe the phenomenon of residents closing their mouths to food as a tipping point that arises when bodies and circumstances change and eating becomes undesirable. Exploring the complexity of residents eating and not eating, I aim to extend my consideration of a right care to residents living the very last stages of their lives.

8 Caring at the threshold of life and death

Eating and not eating at the end of life

In his Afterword to the articles collected in *The Australian Journal of Anthropology* special issue 'Moralities of care in later life', Rapport (2018) cites Patricia Gillespie's account of her mother's refusal of medications and food for several weeks prior to her death. Rapport uses this example to suggest that caring should not infringe upon the autonomy of the elderly at the end of their lives (2018, p. 255). 'Over and against an impersonal, social-structural or institutional power is an existential power', the human capacity to 'have scant respect for the rules' as reflected in Patricia Gillespie's mother's decision 'to set and pursue an individual path for oneself' (2018, p. 251). Rapport (2018) understands the elders' starving to death as a deliberate choice and an agentic action—the expression of one's free will to shape one's own course of life and death.

In examining the relations between food, agency and care for older people who are at the end of their lives, Rapport (2018) shows how eating and not eating are centrally placed at this critical life course juncture. If one stops eating it leads to malnutrition and eventually, death. The regular incorporating of food into self is essential to physical survival. To eat or not to eat is thus not simply an individual choice over food; it can be an individual choice between life and death (Harbers, Mol & Stollmeyer 2002). For Rapport, it is *possible* for frail elderly people to take control over their own life and death through taking control of their consumption of food, if their choice is respected and supported by other people around them. As starving to death is demonstrative of a wish to die, Rapport (2018) suggests that Patricia Gillespie's mother executed full control over her own life and death through her deliberate action of rejecting food. To eat to live or not to eat to die is a matter of acting upon one's own will free of the influence of external forces. Finally, for Rapport, in allowing frail elderly people, like Patricia Gillespie's mother, to starve to death, a general form of ethical care is imagined as 'a particular kind of social framework or environment that endeavours to give an appropriate proportionality to autonomy and inclusion' (2018, p. 250). For Rapport, individual autonomy is experienced as maintaining one's 'abiding authorship of his or her life-project(s) but also authority, determining the course of that life and the trajectory of its becoming' (2018, p. 255). By the word 'proportionality', Rapport proposes an ethical care which is in balance: 'between engagement and inclusion on the one hand, and a preservation of autonomy and personal sovereignty on the other; between action and inaction' (2018, p. 250). Here, Rapport is referring to those

impersonal powers that inhibit or prevent the exercise of free will of the elderly. His emphasis on the overarching importance of autonomy in an ethical care is well considered as, shown in Chapter 7, the restrictive practices that were prescribed to nursing home residents preventing walking and standing, blocked the flow of a productive desire, and put an end to the becomings that emerge in and through movement. Although for residents with cognitive changes, a productive desire could no longer manifest itself in a conscious exercise of free will, the detrimental effects of inhibitive forces upon nursing home residents are profound.

In this chapter, I turn to the lives of nursing home residents with dementia to explore the experience of eating and not eating among frail elderly people at the very last stages of their lives. For these residents, not eating was marked by ambiguity and ambivalence. Staff and family did not unanimously agree that the residents self-determined or decided to not eat, or to die. Unlike Patricia Gillespie's mother who had the insight into how the regular consumption of food is essential to physical survival, many elderly people living in nursing homes do not have this insight due to severe cognitive impairments related to later stages of dementia. In other words, they would not be able to control their own life and death by taking control of their eating. Furthermore, they cannot *take control* over their consumption of food through a wish or will. It is not a considerate choice and deliberate action if they stop eating. In short, for nursing home residents with severe cognitive impairments living their very last stages of lives, eating and not eating are not about taking control, be it over food, or the timing of life and death. Rather, as this chapter aims to show, not eating is for these residents a matter of moving through the threshold between living and dying where bodies are relieved of the tension, pain and suffering of ageing and the end of life.

In questioning Rapport's position that not eating is a resident's choice, this chapter examines eating and not eating through the lens of productive desire (Deleuze & Guattari 1977). I attempt to map the movements of a productive desire through the varied modes and modalities of moving food in and through the body. An appetite for food marks a heightened desire to attract and incorporate foodstuff, to fill and to nourish the body. A lack of appetite indicates a weakening of the productive forces that propel one to eat. In the field I observed how appetites appeared to be triggered by a home-cooked dish, a companion or a gentle stroke on the throat, and diminished by texture-modified food and fluid and a lack of staff assistance, thus propelling residents closer to or further away from life or death.

At the very last stages of their lives, residents' relationship with food is often complicated by severe cognitive impairments and eating difficulties. Sensory and perceptual changes and chewing and swallowing problems due to muscle paralysis may lead to reduced appetite. The use of sedative medication may accelerate residents' decline to a tipping point where they close their mouths to food and stop eating. Using the example of Mrs Brie in this chapter, I tap into the vicissitudes of a productive desire, exploring how residents become moved or propelled to eat. Mapping the flows of productive movements, the tipping points and thresholds of forces that are productive and counterproductive, I attempt to reveal the complex entanglement of food, assistive technologies (the aids and utensils used to modify and transfer food and fluid), daily practices of feeding residents and deteriorating and dying bodies. In nursing homes, the act of a resident closing their mouth when offered food is understood in multiple ways, and these various interpretations impact on how staff attempt to feed residents who are unable to feed themselves. Some methods of feeding, as this chapter will show, work better than others. I thus extend my consideration of right care to practices of eating and not eating in nursing homes. Using the example of Maureen assisting Mrs Brie to eat, this chapter demonstrates that caring for non-eating residents involves experimentation and tinkering, such as through a gentle touch on the lips using a carefully placed spoon or cup (Mol, Moser & Pols 2010).

When eating solid food is no longer permitted or pleasurable for fear of choking, and not eating is easier for the body but life-threatening, finding a right way to care often calls for experimentation. Right care at the end of life is not prescriptive; it is multiple, situational and dependent on context, and it is inexorably tied to feeling relief from sufferings and a sense of peace as residents face imminent death. If feeling at ease is at the core of residents' feeling at home in nursing homes, a sense of home is closely tied to their feelings of comfort, company, relief and peace in dying. For residents to feel at home in nursing homes before they die, I argue in this chapter that a right care is always responsive to their desires, even as appetites wax and wane. To start, I will describe in the next section how Mrs Brie could enjoy eating while having a taste of home.

Taste of home

Being close to the last stage of Alzheimer's disease, almost all cognitive functions of Mrs Brie were severely impaired (Förstl & Kurz 1999). Mrs Brie could no longer walk

or talk. Sitting in her princess chair parked in the lounge, she was often seen snoozing on and off, or staring into the distance with no expression. Yet, lunchtime was the highlight of the day for Mrs Brie, as Heather, her elder daughter, often came at lunch for a visit. Upon hearing the voice of Heather greeting staff, Mrs Brie started moving in her chair and looking around. Her face lit up with a soft glow when she saw Heather. While, on any day, she may or may not have recognised Heather, she nonetheless looked invigorated to have her company. Shared between the mother and daughter was a love for food and cooking. On each of her visits Heather brought a home cooked meal—one day it might be a tomato-cheese quiche, on another a roast beef and rocket leaf sandwich. Over a slice of her mother's favourite—home style apple pie, Heather chatted about her siblings, relatives, friends, children and grandchildren. Although Mrs Brie showed little expression as Heather talked, she was usually interested in the food on her plate. Having lunch with Heather became a regular and pleasurable social event for Mrs Brie; the company of Heather and the home cooked meal was something to wait for and to enjoy. The senses and sensibilities imbued in food and eating cannot be reduced to nutrition or physical survival. Eating is intimately entangled with relationships—in this case, the intimacy between mother and daughter and their connection through food. Similarly, the significance of family visitors bringing a favourite food to their institutionalised relatives is widespread as described in other nursing home research conducted in other countries and times (High & Rowles 1995; Rowles & High 2003).

In eating, Mrs Brie often directly used her fingers to pick up a small portion from the plate and put into her mouth. She could not handle regular cutlery due to her arthritic finger deformation. Yet, by eating with her fingers, Mrs Brie engaged with her food. While food is often thought as taken through one's mouth, for Mrs Brie, it was also through her hands. Getting into contact with edibles, by touching, watching, holding and feeling, she exhibited more facial expressions showing content and pleasure from eating. Eating with her hands allowed Mrs Brie to cultivate nourishing connections with her food beyond its nutritional value.

Bodily movements involved in eating and drinking are an essential part of the lived reality of human lives. '…from the very beginning, we all have mouths that open and close, and that edibles and other things are and can be put inside them' (Sheets-Johnstone 2011, p. 122). Nevertheless, consuming food is never as simple as the opening and closing of the mouth, especially at the later stages of life. In his nursing

home study on food, Savishinsky (2003a) cites the classic study of physician Walter Cannon which found that human food intake can be motivated both by nutritional need and a desire for certain sensations of delight. In the latter case, Cannon said, the person ‘seeks satisfaction, not relief’ (1939: 75 as in Savishinsky 2003, p. 116). Food is both nutrition and pleasure. Eating is often thought of as involving a pang (a sense of needing and wanting) and an appetite (a sense of craving and liking), both leading to the actual consuming of food. Leon Kass, a physician and biochemist also suggests, ‘the germ of appetite governs, guides, and integrates awareness and action: Appetite or desire, not DNA, is the deepest principle of life’ (1994, p. 48). According to Fox, ‘our appetites and our desires play a part in structuring our waking lives’ and that ‘these desires not only affect our thoughts and feelings, but also how we are motivated to act on a daily basis’ (2012, p. 106).

Here, the food that one consumes also plays a role in one’s eating. Good taste is stimulating and motivating. Sensory properties of food, including its taste, aroma, temperature and texture, are found useful in triggering swallowing (Loret 2015). The actual or imagined presence of food may also trigger the sensation of appetite and craving—a desire to eat. According to staff, triggers, as simple as seeing someone eat, can bring residents to a point where they are likely to engage in eating. Handling food with one’s fingers, as Mrs Brie seemed to enjoy doing, can also work as a triggering through sensory stimulation, which is helpful in releasing digestive juices and enzymes. The nerve endings on fingertips can relay the message that one is about to eat, thereby preparing the stomach for digestion, staff said.

Alongside the body and the edibles, there are also other material things and persons that are involved in Mrs Brie’s eating. Modified eating and drinking utensils, such as a lipped (high-sided) plate, adapted cutlery and a non-spill cup, are used in the facilities to enable residents like Mrs Brie to continue feeding themselves. Sitting with her mother, Heather closely watches how Mrs Brie took food from the plate to her mouth, or drank from the feeding cup (see Plate 25) with its vented lid and drinking spout and, from time to time, she carefully guided her mother’s hand to her mouth. Mrs Brie would have been unable to drink without the assistance from Heather and the purposefully designed feeder cup.

Plate 25: Feeding cup

The hands (of Mrs Brie and Heather), the feeder cup, the mouth and the edibles were drawn together, assembled into a productive process in which the body desired and is moved to eat. Food is not some passive object that is consumed. Rather, it may trigger movements so that the hands, mouth, teeth and cheeks entwine in the event of eating. A mouth opens to the feeder cup because a desire to incorporate what is contained within makes the move through the mouth. In this sense, food and fluid can be thought of as food-machine and fluid-machine producing affects and motions (Deleuze & Guattari 1977). A set of dentures and a piece of buttered bread, a spoon with a rubber handle and a shaking hand due to Parkinson's disease, are all paired up to produce events of eating. In holding a small portion of apple pie, the arthritic fingers of Mrs Brie entered into combination with the food in a way which allowed them to do what they otherwise could not do. In the event of eating a favourite dish the use of fingers could open up new potentialities, connections and opportunities to recreate a familiar sense of home.

This leads to the understanding that residents' eating may be approached as an event or process of desiring-production (Deleuze & Guattari 1977, 1988). In moving food into and through the body, the hands (of Mrs Brie and Heather), the cup and spoon, the mouth, saliva, the tongue and dentures, all worked, in coordination and synchronisation through coupling, to produce movements of desire. For Mrs Brie, eating was productive—the potentiality of Mrs Brie feeding herself with some ease and joy was

actualised through a right assemblage of care, despite her situation where arthritis finger deformation and confusion from Alzheimer's disease rendered eating a difficult task.

In nursing homes, attempts are made to cater to residents' likes, dislikes and preferences, which is in line with the research finding that staff could combine 'a medical attitude towards food (appreciating it for its nutritional value) with a caring attitude (which tries to accommodate and please a person)' (Harbers, Mol & Stollmeyer 2002, p. 216). When care facilities lay emphasis on both the quantity and the quality of food, eating and drinking not only play a pivotal role in terms of residents' nutrition and hydration (Milte et al. 2017) but also increasingly become events of pleasure and enjoyment (see Plate 26). Residents' eating is considered not only as need- but also desire-driven. Cooking, and eating afterwards, is regularly organised in the facilities as a type of lifestyle activity for residents who do not have eating difficulties. How the sight of fresh baked goods and the smell of a BBQ could cheer residents up and put a smile on their faces helped me to 'appreciate the many pleasures the senses stimulate in the elderly and how many meanings food may carry for them' (Savishinsky 2003, p. 117).

Plate 26: Residents having tea and a snack in the onsite cafe

The example of Mrs Brie feeding herself demonstrates that the assemblage of a favourite home-cooked dish, the company of Heather and eating with fingers and modified utensils could jointly contribute to Mrs Brie's feeling at home in the nursing home. Yet, the severe deteriorations of the last stages of life often lead to residents'

living in tension between eating and not eating. In approaching residents' eating not as a simple binary of eating and not eating, but as a rhizomatic becoming, I trace the multiple and at times contested threads as they meet, entangle and break open. If residents' eating and not-eating are to be considered as becomings, as found in this study, there exist some points where residents' eating turns into ruptures—they seem to lose interests and stop eating. These ruptures are related to their difficulties with taking food due to medication or the impact from later stages of dementia. In the next section, I will describe how a period of hospitalisation and use of sedative medication may lead to a 'tipping point' where residents like Mrs Brie are no longer able to consume the food they once enjoyed and which made eating and living pleasurable.

Fed with 'mash and jelly'

Mrs Brie experienced a tipping point in eating when she had a urinary infection and was sent to hospital. A dramatic change in staff and environment, and a sudden interruption from her lunch routine with Heather, left her severely disoriented. She fought with hospital staff during care activities and was diagnosed with agitation. She was prescribed with antipsychotic medication during her hospital stay. Due to a lack of improvement, antipsychotic medication was also added to her medications after her return to the nursing home. In a similar situation as that for residents like Mrs Wilson described in Chapter 7, Mrs Brie's food consumption rapidly decreased due to the impact of the antipsychotic medication. She ate little as she was often overly drowsy under the influence of the sedative drug. After several near misses of choking, Mrs Brie was reassessed by the speech pathologist as needing a vitamised diet and thickened fluid. Like many residents with severe chewing and swallowing problems, Mrs Brie started having 'mash and jelly'—texture-modified food and fluid.

In nursing homes, texture modification of food and fluid is essential in supporting residents to continue with eating and drinking. Texture modification changes solid food, making it minced, shredded or liquidised to ease residents' difficulty of moving food into and through the body. When solid food is not completely broken down through chewing, it poses a choking risk to residents. As a solution to residents' chewing difficulty and choking risk, texture modified food is thought by staff as making the process of eating easier for residents like Mrs Brie. As staff informed me, "All she needs to do is to open her mouth to eat and close her mouth to swallow."

When food is texture modified, it does care work—assisting with residents' chewing and swallowing. In the context of care, food and drink are not merely 'means for physical survival' but also 'media for care—they do care' (Harbers, Mol & Stollmeyer 2002, p. 217). However, in all its complexity, how modified food may assist residents with eating often remains uncertain. For residents eating a normal diet, food texture is an important indicator of what is being consumed. They could feel the texture and recognise the food through chewing in between the teeth. Texture modification could take away the sensory properties of the edibles and render them less tasty and harder to recognise. Mrs Brie was observed to move food around in her mouth with an expression of bafflement. I could hardly recognise what was served to Mrs Brie both by visual examining and oral tasting: a big plate with three scoops of white, green and brown 'mash' (see Plate 27). Also, the sensations of eating, such as the senses of taste and texture, are felt through making subtle oral movements involved in chewing and swallowing. Making efforts to chew—breaking down solid food through oral movements—is important not only in processing solid food but also producing swallowing movements. While Mrs Brie was stopped from making her own effort of chewing so as to swallow, little sense was made of eating.

Plate 27: Pureed food

Unlike home-cooked and often favoured dishes, texture-modified food is often bland and smooth, which produces little sensations, yet, is easier to swallow. If eating is to be thought through the concept of multiplicity (Deleuze & Guattari 1988), with decreased intensities (e.g. of flavour) and reduced dimensions (e.g. the absence of chewing), the nature of eating, as desiring production, connection, activity and enjoyment, is changed. Being fed with mash, Mrs Brie lost something profoundly

productive and connective that previously had allowed her to play out what her mouth and arthritic fingers could do in each meal. With little movements of desire produced by the modified food, there is hardly any productive desire to propel a mouth to open and to eat. Contrary to staff expectations, the eating of Mrs Brie further deteriorated after having pureed meals. She turned her head away from the spoon delivered by staff and firmly closed her mouth. Instead of assisting her with eating, vitamised food became an object of aversion.

Another example of this kind is thickened fluid. While ordinary drinking water—a daily necessity to health and physical survival—is texture-modified to reduce choking risk, it becomes an object of distaste. On one occasion, I was stopped by a resident in the dining area asking for “a glass of real water”. He pointed to a plastic cup half-filled with jelly-like orange coloured fluid and said, “This is not real water. It’s yuck. I want real water.” With nods of his head, he stressed on the word ‘real’ a few times. Not to disappoint him, I went to a staff member with his request. Yet, the old gentleman was not permitted to have unthickened clear water due to his high-level choking risk. Deeply intrigued by how the old man longed for a sip of clear water, I went to staff and asked for a taste of what he is usually permitted to have. He was absolutely right. Thickened fluid is NOT real water. I had this funny sensation in my mouth when I had a half mouthful of the ‘jelly’, which was so different from the experience of having clear water.

Health researchers have noted that, for residents with later stages of dementia who have difficulties with eating and cannot express their needs and choices, the consideration of residents’ choice and individual preference of food arrives at a ‘tipping point’ and stops (Milte et al. 2017). Using the example of Mrs Brie, I now turn to demonstrate how residents eat, highlighting the tipping point in nutrition care, and also a tipping point in residents’ eating—when they close their mouths to food and stop eating. Eating is no longer pleasurable and it does not enable residents to feel at ease, comforted and at home in the world. Lacking a sense of enjoyment through food, residents close their mouths leading to ambiguity and ambivalence in care practices. In the next section, I will turn to this phenomenon and explore its multiple meanings and implications.

Closing one’s mouth to food: caring with ambiguity and ambivalence

In nursing homes, the phenomenon of residents’ closing their mouths to food is understood in a multitude of different ways. Residents’ refusal of food may be

considered, as in the case of Patricia Gillespie's mother, as purposeful, as a self-determined wish to die. Reporting from his North American nursing home study, Savishinksy (2003) describes how staff attitudes towards residents' decisions to starve to death were divided and contested. Some staff were sympathetic with residents' wish to die and stopped pushing for them to eat while others disapproved of their colleagues' support for residents' suicidal attempts. In today's Australian nursing homes where I did my fieldwork, such a wish is respected on the facility level and supported with organised due care. For example, a female resident was not pressed to eat, and her care plan was carefully adjusted to maintain hydration and comfort after she, with support from her family, clearly expressed her wish to stop eating and to die. For residents with full cognitive capacities, their decision to stop eating is considered as their chosen way to end their life.

Residents' closing their mouth to food could also be a protest against how they are fed. Losing capacity to handle cutlery, residents are assisted by staff with taking food from the plate to their mouth. For these residents, as staff said, eating is no longer feeding oneself but being fed by others. The involvement of staff in the residents' taking each mouthful of food changes how eating could be experienced by residents. Once, a care worker blended vitamised meat and vegetable together with added milk and put the liquidised mixture into a feeder cup for the resident. "She only takes a tiny bit each time if I feed her using a teaspoon. Instead, a drink will be a lot easier and faster", she said. Sadly, the old woman had a bewildered expression on her face when she was assisted to have a sip of the 'drink'. She firmly pressed her lips together when the care worker tried to feed her with the feeder cup again.

Staff involvement in residents' eating can also change how residents' experiences of eating could be understood and communicated between residents and staff. It is especially so in the situation where residents with advanced dementia were assisted to eat. Taking full responsibility for residents' safety from choking and burns, staff often rely on their own experience and judgement while feeding residents with dementia. Once, when Maureen was feeding Mrs Anderson, a resident with later stage of Alzheimer's, Mrs Anderson made a clear utterance, loud enough for Maureen and me to hear. "It's hot," she said. Maureen was alarmed and stopped feeding with an expression of disbelief. She put her left index finger on the pureed beef in the spoon. "I'm sure it is not hot. I left the lid open for quite a while before I started", Maureen said. Maureen double-checked to ensure that Mrs Anderson's food was not overheated. She

changed to another spoon and continued to feed Mrs Anderson. “It’s hot.” Mrs Anderson spoke again. She looked into the distance in front of her and swallowed without much expression. This time, I was fully convinced that Mrs Anderson was not complaining about her food being too hot. “It’s great that Mrs Anderson talks again. Is that because you are here watching her eating?” Maureen said jokingly. This scenario showed that while what residents said was listened to, staff mostly relied on their clinical judgement when feeding residents.

Residents are not only *how* they eat but also *what* they eat. Mrs Brie was a ‘soft diet’ when she could feed herself. She becomes a ‘vitamised diet’ when she is fed by staff. Similarly, as described by Laird forty years ago in American nursing homes, eating could come to define residents: those who could walk to the dining room for meals and those whom staff had to hand-feed in their own rooms, were classified as ‘feeders’ (Laird 1979, p. 63). Being ‘fed’, residents’ experiences of eating and drinking are inevitably shaped by the sort of assistance that is made available in an institutional setting. Residents have less control over what and how to eat while being fed. Yet, they have control over the key movements in eating—the opening and closing of the mouth. While the opening of the mouth would initiate the eating process, closing would stop it. Oral feeding becomes impossible when residents close their mouths to food. In his ethnography, Savishinsky reports that residents’ closing their mouths when being fed was considered as their ‘rejection of food’, which ‘may constitute a resident’s reappropriation of his or her body from those who clean, dress, fill and empty it’ (2003, p. 119).[15] Vesperi describes how some residents went on suicidal hunger strikes while others rejected the impersonal and isolating meals as a way to contest ‘the institution’s ability to adequately perceive and fulfil’ their needs’ (1983, p. 234). In nursing homes, residents’ rejection of food can bring to the fore multiple and complex (mis)understandings about physical survival and social relations (Harbers, Mol & Stollmeyer 2002, p. 207).

[15] In using the word ‘fill’, Savishinsky (2003) describes how residents are passive and submissive while feeding by staff is carried out in the manner of filling a mere container. For Savishinsky, food is a powerful entrance into practices while he explores the meanings of food in the institution and the ways in which it is entwined with issues of conflict and control. Yet, as this chapter will demonstrate, even for the most severely impaired residents, eating cannot be reduced to being fed as a mechanical process of stuffing. A body that eats is attentive, responsive, and productive. Eating is always an event and a process in which a body connects and extends.

When residents stop eating, have later stages of dementia and are unable to verbally express their needs, likes and dislikes, closing the mouth to food could be a contested site of meaning. In the field of nursing homes, families were inclined to interpret this as a non-verbal expression of their dislike for the food, and they would often advocate for their loved ones and negotiate with staff for alternatives. While some staff shared this view, others reasoned that residents had a reduced appetite and had a decreased desire for food. Accordingly, they described residents closing their mouth to food as indicating the absence of need for nutrition: “Do they need so much food while sitting all day doing nothing?” nursing and health professionals often said, as they upheld a medical opinion and thus considered residents closing their mouth to food, among other behaviours such as holding food in their mouth, as a swallowing problem, and therefore neither an expression of dislike nor desire. Residents turning their head away from food was interpreted by nursing staff as a sign that they had lost interest in eating, an indicator of ‘withdrawal behaviour’ characteristic of the condition of ‘apathy’. Norberg and colleagues (1988) suggest that the term 'food refusal’ does not seem appropriate in cases involving dementia. In their describing residents fastening of their lips together during feeding as indicative of a loss of capacity to move food through the throat, closing the mouth is medicalised in their research as the ‘inability to swallow’.

Not eating reveals multiple and ambiguous meanings; however, what matters in nursing homes is the ambivalence around how to care for these not eating residents. One day at lunchtime in the dining area, I observed how, despite his persistent attempts, Mike, a registered nurse working in the dementia units, could not feed Mrs Brie with her lunch while she closed her mouth to the food in the spoon. Looking worried, Mike said: “Mrs Brie didn’t eat in the morning and the entire day yesterday. She only had some milkshake. She can’t last living on milkshakes.” Not eating can have dire consequences. Unable to access food themselves, residents with advanced dementia starve if they do not consume the food delivered by staff in a spoon. Residents who stop eating over a longer period will eventually become malnourished and die. Some staff in the nursing homes held the belief that difficulties with swallowing and eating were the outcomes of the progression of their condition. As dementia is irreversible, residents with later stages of dementia, like Mrs Brie, will unavoidably stop eating due to the progression of their condition, which marks the imminence of death. During the dying process, the need for fluid and food reduces and eventually, is totally eliminated. As not eating is part of dying, there is no need for intervention if residents

close their mouth to food at the very last stages of their lives. Forcing a dying person to eat can cause choking. Or it can cause aspiration, which is when the person ‘inhales’ food or fluid into the lungs, which can be painful.

Nonetheless, the starving to death of residents with advanced dementia may also be the consequence of neglect and abuse—premature death due to malnutrition, which needs to be addressed. Some aged care homes are reported to spend as little as just over A$6 a day on food per person as experts warn malnourished residents are ‘starving to death’ (Neil 2019). Like Mrs Wilson, Mrs Brie was affected by the antipsychotic medication and was tipped over the edge of functioning on her remaining capacities. Closing her mouth to food was related to a change of diet from soft to vitamised as an intervention to her swallowing difficulty and choking risk. She might have closed her mouth to food because she disliked a mash or jelly that tasted terribly. She might have lost interest in eating as it produced more discomfort than pleasure. She might have hardly experienced any innermost drive to move or eat due to the sedative medication.

In contrast to Patricia Gillespie’s mother, who had clearly articulated her wish to starve to death, Mrs Brie might have closed her mouth to food without deliberately choosing to die. As Chapter 4 demonstrated using the example of Mrs Sage, making a wish or will in the mind becomes unlikely, if not utterly impossible for residents with later stages of dementia. Unlike residents who make their own decisions when they stop eating in the wish to die or refuse eating as a protest against how food is served, residents with later stages of dementia could hardly take deliberate action or make choices when they close their mouths to food. They would barely have been able to comprehend the correlations between opening the mouth, letting in food and their physical survival. In other words, they did not eat to live or reject food to die. Thinking about these residents closing mouth to food within Rapport’s conceptual framework of the social ethics of care, ‘caring that the autonomy of the elderly is not infringed till the end of their lives’ (2018, p. 255) becomes impossible. Foregrounding agentic wish or will, Rapport’s (2018) general form of social ethics of care reaches its limits in the situation where residents with later stages of dementia are cared for. To create a right care for residents with advanced dementia, Rapport’s (2018) conceptual framework of the general form of social ethics of care needs to be extended through the lens of a productive desire.

Thinking about care within the framework of desiring-production (Deleuze & Guattari 1977, 1988) and care as multiple (Mol 2002, 2008), I explored right care through residents' movements involved in walking and eating. As I demonstrated in Part II on walking, for residents with impairments, making movement becomes difficult and limited, despite their best efforts. But through the right care in which residents' bodies correspond and move together with other persons and things, a productive desire to move becomes possible. In this assemblage, residents could feel just right and at home in walking. Thinking about care through the lens of a productive desire does not foreground residents' wish or will, but rather it attends to residents' efforts to move and to how their needs are attended and responded to. To not care for, or to prevent, residents' attempts and efforts to walk or eat has detrimental effects. As shown in the example of Mrs Wilson, the practice of restraint may block the flow of a productive desire, inhibiting movement and reducing possibilities to become at home. Mrs Brie was also affected by the antipsychotic medication and was tipped over the edge of functioning on her remaining capacities. Closing her mouth to food was related to a change of diet from soft to vitamised as an intervention to her swallowing difficulty and choking risk.

Acknowledging that life is approaching its end for these very frail nursing home residents who close their mouths to food, some staff members and families do not simply work following prescriptive rules. Instead, they work with ambiguity and ambivalence, which is at the core of caring for these most vulnerable elderly people at the very last stages of their lives. According to Musolino and her colleagues, this pairing of ambiguity and ambivalence is at the heart of desire (Musolino, Warin & Gilchrist 2018, p. 546). In their study on young women's eating disorders, the authors use Bauman (1991) to argue that 'ambiguity constructs knowledge that designates opposing states, and ambivalence directs action that pulls and propels people in multiple directions' (Musolino, Warin & Gilchrist 2018, p. 546). In nursing homes, staff could often expand on the fixed and singular notion of not eating and consider the ambiguities, multiple meanings and possibilities of residents' closing their mouths to food. In the next section, I aim to map the movements of a productive desire through the eating and not eating of Mrs Brie. This helps to understand how, through the many ambiguities and ambivalences that residents' closing mouth to food entails, creating a right care for residents who close their mouths to food is to be achieved through

‘practical tinkering’ (Mol, Moser & Pols 2010, p. 13) at any given time, condition and situation.

Caring at the threshold of life and death

Most of the personal care workers who attempted to feed Mrs Brie failed—she often closed her mouth to food. They drew the conclusion that, due to the progression of her dementia, she was no longer aware of her need to eat and had no interest in food. Maureen, a veteran personal care worker disagreed with them. For Maureen, it was important not to assume that Mrs Brie did not want to eat. She may, as Maureen suggested, not be prepared for eating. “You can’t go straight to the task [of feeding]”, Maureen said. “She needs to prepare herself for it [eating].” When asked, Maureen explained to me what she meant by the word ‘prepare’.

For residents who feed themselves, eating is not a straightforward process. The sense of eating is made in and through the movements involved in each phase from preparing to eat to those of transferring food, chewing and swallowing. The idea of consuming food, the sight of food and the trip leading to the dining area prepare them for eating. Before food is transferred from plate to mouth, bodies adjust to support an ‘openness’ to the edibles. It starts from the multisensory processes of incorporation (Dennis 2007)—inspecting the dish (appealing or disgusting), smelling the aroma (familiar or unknown), feeling the plate (warm or cold) and handling the cutlery to get an appropriate mouthful of food. The movements of hands and fingers, the touch and temperature of utensils and the sight and smell of food all lead to a sense of craving, an understanding of the situation and a response: opening the mouth while food is transferred from plate to mouth. Residents with later stages of dementia may have difficulties responding to the situation of taking food from a spoon delivered to their mouths. In the case of Mrs Brie, she needed to be attuned. She could not open her mouth at will. Someone needed to get her started. To prepare for eating, Mrs Brie needed staff assistance.

To illustrate, Maureen once showed me how she usually assisted Mrs Brie with her lunch in the open dining area of the facility. Maureen first checked that Mrs Brie was wearing her glasses and hearing aids. “She may not be able to understand what I say to her,” Maureen said, “but at least she could see me talking and what is coming in the spoon. Not being able to see and hear can be scary for residents, which adds to their confusion.” Lowering herself to face Mrs Brie at eye level, Maureen drew the attention

of Mrs Brie by gently holding her hands in her own. “It’s time for lunch, Mrs Brie,” Maureen said calmly while giving a brief hand massage to Mrs Brie. Seeing Mrs Brie lifting her head and fixing her gaze at her, Maureen adjusted the princess chair so that Mrs Brie could sit upright with her head inclined forwards. “If the resident is drowsy, she may struggle to swallow safely,” Maureen explained. “Before offering food and drink, I make sure they are alert, comfortable and sitting upright.” The drowsiness of Mrs Brie was indicative of the impact of the antipsychotic medication and her diminished conscious connections with others. In preparing Mrs Brie through touch and the adjustment of her posture, Maureen counteracted the medication-induced drowsiness so that the connectedness of Mrs Brie with other physical things in her material surroundings could be enhanced.

What Maureen did to get Mrs Brie ‘started’ demonstrates that attentional and postural adjustments could help with incorporating food into and through her body while eating. Posture is important while eating. Sitting up and tilting the head forwards while swallowing will help protect the airway. Meanwhile, Mrs Brie seemed to become more attentive and responsive towards Maureen—as shown through how she slightly tilted and turned her head to follow the movements of Maureen—through the sensory cues of touching and talking. As Mrs Brie became increasingly aware of the presence and movements of Maureen, a friendly and comforting other person, Mrs Brie could prepare herself for further connection with food and sensory incorporation though eating.

How Maureen assisted Mrs Brie with her preparation for eating reveals a process, as Maureen said, of ‘wakening up’—affecting a body so that connections and extensions can be created. Though this process is ordinarily experienced as sensual by nature without conscious attention, for residents like Mrs Brie, sensual stimuli from other persons seemed to be important to enhance the intensity of sensual arousal. Moving food into and through the body is primarily a sensuous experience. Yet, for residents who were fed by staff, what may have prepared them for eating and triggered their movement of opening the mouth was often absent. In the field residents were sometimes expected to start eating as soon as staff started feeding them, before they were ready.

Sitting in the line of sight of Mrs Brie, Maureen started helping Mrs Brie with her lunch while explaining to me:

> Residents with dementia like Mrs Brie do not open the mouth if staff feed them straight away. They need to be reminded to open the mouth to take in food and close the mouth to swallow.

Mrs Brie may not have been able to understand the situation cognitively as people ordinarily do due to her advanced dementia. Yet, she could become sensually attuned to the situation. Using a small teaspoon, Maureen touched Mrs Brie's lower lip with the tip of the spoon and waited for Mrs Brie to open her mouth. It was only a gap between her lips when Mrs Brie opened her mouth. Maureen then fed Mrs Brie with two small mouthfuls of ice-cream through the gap. For some residents, reduced or thicker saliva might make the mouth dry, increasing swallowing difficulty. Ice-cream could both ease the sensation of dryness in the mouth and further activate the nerves. Mrs Brie further tilted her head while holding the ice-cream in her mouth. A clear motion of swallowing was observed after a few seconds.

As I described earlier in this chapter, Mrs Brie could eat and enjoy her home-cooked apple pie using her fingers. In doing so a productive desire could be ignited by the sensory properties of food. Bodily parts and material things, e.g. the hands, mouth, lipped plate and feeder cup, are not only pulled into productive desire, they themselves are desiring-machines triggering the movements of a productive desire. As shown in how Maureen prepared Mrs Brie for eating, a motion of the mouth was triggered by a gentle touch on the lip and a spoon of ice-cream. The coolness, sweetness and smoothness of the ice-cream increased the intensities of sensation so that a mouth that could open and a body that could eat were produced. Mrs Brie was ready to have her meal.

Filling the teaspoon with a small mouthful of pureed beef, Maureen lifted the spoon to the direct front of the left eye of Mrs Brie and in two seconds, moved the spoon right in front of her mouth. Mrs Brie did not open her mouth. Maureen then repeated her previous movements—positioned the spoon in front of the left eye of Mrs Brie for two seconds and moved the spoon right in front of the mouth of Mrs Brie. This time Mrs Brie opened her mouth. Maureen inserted the teaspoon flat into the gap between her lips and lifted the handle of the spoon to form a sharp angle so that a lump of pureed beef could be left inside her mouth. Intrigued by her movements, I asked Maureen why she first put the spoon not directly in front of the mouth of Mrs Brie but her left eye. Maureen explained:

> Mrs Brie has zero vision on her right eye and the vision on her left eye is limited. I need to show her the food on the spoon so that she understands that I am feeding her and opens her mouth to eat.

To prompt Mrs Brie to make a swallowing motion, Maureen used the fingertips of her left hand gently tapping on Mrs Brie's throat. "Swallow," Maureen said. She then pressed her lips together and made a swallowing motion of her throat. "Swallow," she repeated. She looked attentively at Mrs Brie's face and throat for signs of swallowing movements. The fine muscles around Mrs Brie's mouth were fastened while she half closed her eyes and slightly tilted her head. Her throat was visibly shaken when the lump of meat travelled through her epiglottis. Spoon by spoon, both Maureen and Mrs Brie repeated, in turn, their respective share in the sequence of bodily movements of assisted eating. "How do you know whether Mrs Brie is full or not?" I asked Maureen. "She pushes out the spoon using her tongue and seals her lips." Maureen finished the sentence with a mouth movement of pressing her lips tightly together.

In Deleuze and Guattari's (1977, 1988) theories of desiring-production, a 'line of flight' (1988) works to break open existing structures and create new connections in a productive process of change and morphosis. For residents living the tension between eating and not eating, there exists a threshold of intensities leading up to a change from not eating to eating. A trigger, the sight of other people eating, or the sensation of sweetness and coolness of ice-cream, may work like a line of flight inducing changes in sensory intensities leading to a threshold between the bodily states of eating and not eating, after which a mouth, a throat and a stomach are constituted. In this sense, while a relational process (seeing people eating or swallowing ice-cream) is triggered, it instantly creates a type of connection between person and food, changing and transporting a person's mode of being and ways of relating in the world (Warin 2002; Warin 2010).

This demonstrates that, from eating to not eating, there exists a certain turning point, or a threshold, over which a craving is induced. Once residents have been attuned by staff to become ready to open their mouths and become interested in eating, the unproductive state of not eating can be converted into a productive process of eating. Meanwhile, it is also important to note that the discomfort induced by swallowing difficulty can be another dimension involved in residents' eating. A trigger, such as a lump of undercooked potato or a soup that is spicy, may induce choking and coughing,

movements that are counterproductive to an event of eating. A productive process of eating can be reversed in this situation where the feeling of discomfort becomes intense and leads residents to stop eating to avoid the turbulence. Triggering is concerned with the movements of a productive desire as multiplicities; it is an intensity that goes in many different directions and produces openings and closures and possibilities of becomings.

This leads to the understanding that a right care for residents with eating difficulties involves experimenting and adapting (Mol, Moser & Pols 2010) to ambiguities and ambivalences of residents' eating and not eating. In experimenting, staff used the tool of triggers: seeing someone eating, a gentle stroke on the throat, ice-cream and so on, tinkering with eating aids and the movements of their own bodies in ways that may have enabled residents to open their mouth and to eat. A right assemblage of care can thus help to overcome the limits posed by residents' eating difficulties. In so doing, a right care for elderly people with advanced dementia at the end of their lives goes beyond 'an appropriate proportionality to autonomy and inclusion' (Rapport 2018, p. 250) to respond to the shifting conditions of residents.

Dying residents may experience neither a need to eat, nor an appetite for food. For these residents, there exists no sense in taking food—the body is losing connections and its final dispersal is imminent. Dying brings about the end of the breathing, sensing and feeling body. Mrs Brie died during my fieldwork. As death approached, her breathing became laboured. With increased weakness and fatigue, she eventually stopped eating and drinking, and slept most of the time. Heather consented for her mother to receive palliative care. Mrs Brie's care plan was then adjusted. As part of her palliative care plan, a routine was set up to reposition Mrs Brie in bed to prevent pressure sores and to do oral hygiene to relieve her dry mouth. Staff used oral swabs and lubricants to clean her mouth. A syringe driver was also used for her pain management because it was the easiest way to give Mrs Brie the pain medication that she needed to feel comfortable at that time of dying.

Saddened that the life of her mother was approaching its end, Heather came to see Mrs Brie every day and spent time sitting at her bedside. "Dying must be hard," Heather said, seeing Mrs Brie's laboured breathing with her chest visibly rising and falling under the white bedsheet. Studies on elderly people's experience of dying in nursing homes highlight the discomfort of dying with residents often experiencing pain, pressure sores

and thirst, as well as loneliness and depression (Greenwood et al. 2018; McNamara 2001). Between stopping to eat and taking the last breath, life lingers at its own pace. For nursing home residents with later stages of dementia, both living with profound impairments and dying with pain and discomfort are difficult life situations. The right care for these residents is thus to care for them as living a good life during the last years or months of their lives and dying a good death (Green 2008). In both living and dying, caring for these residents is a matter of attending to them, responding towards their innermost drives and assisting to meet their needs. Once death arrives, movement stops. No longer propelled to walk or eat, senses of pleasure, power and freedom are irrevocably lost. Yet, with the right assemblage of care residents may be comforted and assisted to feel at ease and at home right up until the final moment.

Conclusion

This chapter has addressed attending to residents' experience of eating and non-eating at the very last stages of their lives. Exploring the practices, meanings and limits of a right care through residents' experience of closing their mouths to food, I argued in this chapter that there should exist no limits to a right and ethically responsive care, if a right care for dying residents is to be understood as assisting in their process of dying so that they could die with a feeling of being at ease in the nursing home.

With an emphasis on cognitive capacities, Rapport (2018) reduces his 'social ethics of care' to conscious choice and autonomous action. As this chapter demonstrated, his conceptual framework needs to be extended to facilitate exploration of the experience of residents with cognitive impairments due to later stages of dementia. Drawing on the Deleuzian concept of assemblage (Deleuze & Guattari 1988) and Mol's (2002, 2008) critical framework of care as multiple, I showed that a right care is what works and what works will be different for different residents across different stages of their life course. Right care can enable residents to move by attending to their urge, their propulsion towards, or away from, other people and things. It is an attentive and immediate response to residents' seemingly small efforts to move, to stop, to withdraw and to die, contributing to their sense of being at ease and at home as they transition from life to death.

IV Conclusion

Introduction

This ethnographic project explored how a group of frail elderly Australians with severe physical and cognitive impairments could feel at home in nursing homes. Drawing on Deleuze and Guattari's (1977, 1988) theories of becoming to expand Jackson's notion of home (1995, 2002), I proposed in this thesis that home is a matter of becoming-at-home-in-the-world. By the phrase, becoming-at-home-in-the-world, I suggest that a sense of home is experienced as feeling 'just right' and 'at ease' in and through the processes of continuous movements, which are driven by a productive desire to move. With a shift of focus from conscious experience, will and agency to preconscious process, productive desire and bodily movements, this thesis has attempted to understand residents' everyday experience of becoming at home through the most mundane activities of walking, transferring position and eating.

9 Becoming ethical through care

Becoming-at-home-in-the-world

Spending the last years or months of their lives in a nursing home, can elderly Australians experience a sense of home in the nursing homes? If yes, in what ways? This thesis critically examined how frail nursing home residents came to feel at home and found that they experienced home as a sense of rightness of being-in-the-world. Drawing on Deleuze and Guattari's (1977, 1988) theories of becoming and desiring production to extend Jackson's (1995, 2002) notion of home and existential imperative, this thesis explored how bodily impairments affect the ways that people could create a sense of home through the central analytic of becoming-at-home-in-the-world.

Examining movement through the lens of home, this thesis demonstrated how other things and persons could be assembled to open up potentialities for residents to feel at ease despite bodily dis-ease, and to become at home in the nursing home. Using the concept of assemblage (Deleuze & Guattari 1988), this thesis attended to the walking, standing and eating of residents to analyse how resident movement can articulate with multiple persons and things in ways that could sensorially extend (Dennis 2007) residents' bodies in correspondence (Ingold 2017) with movement of other things and persons to create a sense of home.

Part II on walking consists of Chapters 3 to 6. Tracing residents' movements and their entanglements with other persons and things, this part examined how residents were assisted to walk, for an understanding of how bodies are constituted through their striving to become mobile and, key to the theme of this thesis, to become and to feel right at home. In following the steps of Mrs Casey, Mrs Sage, Mr Harris and Mr Dixon, I came to realise that continuing to move became a way of creating a sense of home in their nursing home.

Chapter 3 illustrated how frail elderly people with physical impairments like Mrs Casey came to feel at home in the nursing home through careful and routine walking. It was demonstrated how the diabetic feet of Mrs Casey could become constitutive to her careful walking, and how, in watching each step, Mrs Casey experienced her body as simultaneously 'mobile' and 'minded'. Able to plan and to think ahead, her course of walking was aided by cognitive processes and physical efforts—her minded body worked together with staff and walking aids enabling her to become at home.

Chapter 4 demonstrated the process of becoming at home for people with cognitive impairments like Mrs Sage, revealing how she came to feel at home in the nursing home through wandering. I detailed the sensibilities of persistent walking to show that walking is a connective process of growth and expansion, a sensory extension (Dennis 2007) that can enable residents to be in touch with the world. While unable to control the aim, course and frequency of Mrs Sage's wandering, the facility gave her room to move, and in accommodating this unrestrained walking she engaged and responded to other people and things in the nursing home. In the process of wandering, as this chapter showed, Mrs Sage *in*-habited the world (Ingold 2011)—becoming sensorially *in*corporated and extended (Dennis 2007) in ways that are far more in correspondence (Ingold 2017) with other people and things than DSM criteria of dementia imply.

Chapter 5 turned to how those with movement disorders, like Mr Harris with Parkinson's disease, felt at home in the nursing home through a medication schedule and a staff-assisted walking routine. Due to his condition Mr Harris was dependent on medication delivered by staff, and assistive technologies such as his 4-wheeled walker to 'switch on'—becoming affected and activated to move around in the facility. Chapter 5 extended the analysis on the synthesised efforts of staff and material things in enabling residents to move to reveal the productive potential of an assemblage of care that, as staff said, worked "all right" in unblocking residents' urge to stand up and move to feel just right in and through walking.

For residents with fluctuating attention, cognition and mobility, their persistent attempts to move may be constrained. Chapter 6 used the example of Mr Dixon, a resident with dementia with Lewy bodies, to explore residents' experiences of sitting and living in tension between walking and not walking. It further demonstrated how residents' wish to move can be responded to by other people and things in an assemblage of care that supports them to feel right at home. Yet, providing a right care for these residents may also pose a challenge to service providers and staff.

Part II demonstrated that walking was not an action performed by an isolated individual body; it was entwined with the care provided to the resident by others. A right assemblage of care could create new possibilities for residents to walk all right; however, it also took time and resources. Part III extended the analysis on walking to other movements and it foregrounded the multiple and contested understandings and practices of care, particularly for residents with late stage dementia and those who are

approaching the end of their life. Attending to resident walking and not walking, sitting, standing, eating and not eating, this part revealed the complex and shifting interplay between bodily impairments, material surroundings, aged care discourses and daily practices in the nursing homes.

Using the notion of home to extend anthropological analyses on care (Mol 2002, 2008; Mol, Moser & Pols 2010; Rapport 2018) to the productive potentials of movement, this thesis approached care as multiplicities—different assemblages of varied components. These included: government funding schemes, aiding devices and equipment, staff attention and assistance, and medical discourses, all actualised in the entangled processes of care needs assessment, care-planning and routinised daily care activities. I drew on Mol and colleagues' (2010) work of care as a practice of tinkering and Rapport's (2018) notion of care as a balance between inclusion and autonomy to show how care, if it is to rightly assist residents to have a sense of home, must be enacted differently as multiplicities, depending on the situation and on the residents' changing conditions and circumstances across different points of their life course.

Chapter 7 demonstrated that care can be conceptualised, positioned, practised and experienced differently by different people in aged care facilities (staff, family and residents themselves) and across different stages of the life course. In following these intersections, I showed how residents' experiences of care can conflict with and contradict institutional approaches to care. I drew on the example of Mrs Joyce to deconstruct nursing home care into its compositional elements of different assemblages of care: attending to assessments, care-planning and staff assistance in routinised activities. I turned to residents' walking and not walking using the example of Mr Harris to map these components and expose the entangled processes of connecting, overlapping, contesting and competing of these elements in different assemblages of care that enabled or restricted residents' walking. Drawing comparatively on the examples of Mrs Wilson and Mr Dixon, this chapter demonstrated how, the different interpretations of resident movement, namely, capacity to move in the case of Mrs Wilson and risk of falls in the care of Mr Dixon, could lead to residents having different assemblages of care. Some were 'right'—productive and supportive to residents' efforts to move and to have a sense a home, while some were not so 'right'—less productive or even restrictive to residents' efforts of moving.

Chapter 8 explored the experience of eating and not eating among frail elderly people at the very last stages of their lives, and I turned to the lives of nursing home residents with dementia to do so. This chapter used the example of Mrs Brie closing her mouth to food to demonstrate that, at the end of life, a desire to move and to become alive came to an end. Dying residents lived in tension between the struggle to live and move, and seeking relief from their painful and declining bodies. A right care for dying residents is a matter of taking time to care and to respond to their shifting situations and circumstances, assisting with their departure by reducing suffering.

Extending the ethics of care beyond 'personal preserve'

The conception of home as a matter of becoming-at-home-in-the-world has its ethical implications. At the last stages of their lives, residents' feeling at ease in bodies that are dis-eased involves a relational practice of care. In becoming at home in the nursing home residents become intimately entwined and engaged with other people and things that assist them to do what they want but are unable to do on their own. As shown in Chapter 8, in a spirit of ethical care, some nursing and care staff interpreted residents closing their mouth to food as signs of difficulty incorporating food into their bodies, or of them being close to the end of their life. Before residents were assessed as dying and in need of palliative care, efforts were continuously made to assist with their eating and drinking. It was through 'practical tinkering' (Mol, Moser & Pols 2010, p. 13) with different flavours, textures, shapes and colours of food, and methods of feeding that a right care was assembled. This thesis proposes that a general form to ethical care needs to focus on the promotion of relationality—correspondence (Ingold 2017) and sensory extensions (Dennis 2007)—to protect the productive potentials of resident movement.

Conceptualising on a general form of the social ethics of care, Rapport also draws on Jackson's notion of home to emphasise the importance of caring for the elderly to achieve a sense of being-at-home-in-the-world (2018, p. 256). He asserts that autonomy of the elderly may be violated while being cared for (Rapport 2018), such as in the care for Mr Harris and Mr Dixon when they were restrained from standing and walking as they wished.

Rapport's notion of autonomy—exercising free will through conscious choice and action—may not be able to describe how residents like Mrs Sage and Mrs Wilson feel just right in walking, and standing all right. However, what Rapport conceives as

‘personal preserve’—‘the free expressions of a mature consciousness’ (2018, p. 251) in the forms of first-person point of view, personal sensorium, individual mind and agentic actions—is the actualisation of a productive desire in and through movement. In this sense, the productive potentials are the essence of autonomy that are constitutive to not only movement, sensation and perception, but also memory and mind, choice and action. Extending Rapport’s notion of personal preserve through the lens of productive desire leads to the understanding that both protecting productive potentials, as this thesis proposes, and ‘preserving the “personal preserve” of the elderly’ aim for ‘caring that their autonomy is not infringed’ (2018, pp. 255-256). Drawing on ethnographic materials, this thesis finds that Rapport’s argument that care needs to be a matter of preserving the personal preserve of the elderly and protecting their autonomy is insightful and critical to thinking about care for people with dementia as an ethical practice.

As I discussed in the section ‘Reframing biomedical approaches to ageing and dementia’ in the Introduction, the biomedical discourse of dementia poses a threat to the traditional cognitive-centred concept of personhood. With a conceived loss of mind and self, residents with later stages of dementia were often thought by staff as being unable to make autonomous choices and take deliberate action. As shown in the example of Mrs Sage in Chapter 4, staff made the claim that since Mrs Sage had dementia, this disease had taken control over how Mrs Sage could walk and act. Staff said things like: “Whatever the cause [of her wandering] is, it’s her dementia to blame, not her.”

If, as Rapport asserts, caring that the elderly’s autonomy is protected is to strike a balance ‘between engagement and inclusion on the one hand, and a preservation of autonomy and personal sovereignty on the other’ (2018, p. 250), how can this balance, conceived as ‘an appropriate proportionality to autonomy and inclusion’ (Rapport 2018, p. 250) be achieved when residents with later stages of dementia are involved? As I demonstrated in Chapters 5 and 8 using examples of staff assisting residents to walk and eat, right care, as assemblages of engagements and relations that enable residents to walk and eat as they attempted to do—a sensorial and mobile form of autonomy—but could not do on their own, did achieve a balance between autonomy and inclusion.

Thinking about ethical care through the lens of home, this thesis demonstrated that an ethical care needs to respond to residents' efforts to move, and support them to create a sense of home through a right assemblage of care. Right care, as an analytical lens, highlights caring for people in ways that enable them to continue to move and to become at home in the world with others. Nevertheless, as shown in this thesis, biomedical discourses of resident movement, such as wandering and agitation, worked to produce assemblages of care that were restrictive to resident movement. In a similar way to 'senility' being 'reduced' to a medical problem within the logic of dementia diagnosis and care (Cohen 2006, p. 3), the movements of residents with dementia have been reduced to medical problems requiring pharmaceutical treatment and psychological intervention. In the next section, I will draw on the ethnographic descriptions presented in this thesis to draw the conclusion that, to create right care for people who suffer from dementia, biomedical constructs of resident movement need to be contested to foreground the productive potentials of movement in creating sensory connections and affective relations between people with dementia and those who move alongside and care for them.

Becoming ethical through care

As I previously discussed in the Introductory chapter, the logic of dementia diagnosis highlights loss—brain damage and cognitive decline—and the associated disabilities of being unable to remember, reflect, recognise objects and persons and communicate using language. The logic of dementia diagnosis leads to disease-centred dementia care where lived experiences of people with dementia are approached, perceived and understood as symptoms. As this thesis described in Chapters 4 to 8, movements of residents with later stages of the common types of dementia were medically constructed into wandering and agitation, the Behavioural and Psychological Symptoms of Dementia. Examples considered were the walking of Mrs Sage with Alzheimer's disease, the attempted standing and walking of Mr Dixon with dementia with Lewy bodies and Mr Harris with dementia of Parkinson's disease. This thesis demonstrated that discourses that label bodies as mindless or moving meaninglessly, foreground restrictive practices of falls prevention, which use bodily restraint on nursing home residents and lead to detrimental effects on residents' daily living.

Demonstrating that residents' movements of walking, of standing and of eating were their efforts to extend, connect and feel at home in the nursing home, this thesis presents a challenge to biomedical assumptions and clinical constructions of resident

movement and is at odds with the cognitive-centred concept of personhood. Strongly criticising the cognitive-centred conception of personhood, Tom Kitwood presents the person living with dementia as 'still' a human being—'the situated embodied agent' (Hughes 2001, p. 87; Hughes 2011, p. 227)—who 'is still an agent, one who can make things happen in the world, a sentient, relational and historical being' (Kitwood 1993, p. 541). He redefines personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' stressing 'recognition, respect and trust' (Kitwood 1997, p. 8). The notion that a patient with dementia will *still* be a person if they are *related to* by other people and *recognised as* a person is central to Kitwood's (1993, 1997) theorisation of person-centred care.

In nursing homes, the discourse of person-centred dementia care, opposing the disease-centred and task-oriented dementia care approaches, plays its role in staff training to bring changes to staff attitudes and care practices. A key component in Dementia Dynamics (person-centred care) Training is to recognise that a patient with dementia is still a person who is 'no different to you and me' in terms of human value and human right. It was emphasised in the training sessions and I quote:

> Every person has the right to enjoy the freedom to fully participate in life, regardless of their disabilities. No disability can take away your dignity or value as a human being. The person lying in a fallout chair who cannot speak, or eat without help, who can't take themselves to the toilet or let you know what they need, or can't walk about anymore—that person has the same human value as you and me.

The assertion that people with dementia are 'no different to you and me' is powerful in advocating for their rights while being cared for. However, staff talked insightfully, during training sessions and in chats at the intervals, about how residents were *different* in their ways of relating to people around them. One female care worker said:

> It's not always about treating residents like objects. My Nanny is of the same age as the old people living here and I treat residents like they are my own old people. Sometimes it's hard to relate to residents who are completely mute and have 'behaviours'. I want to help but don't understand what they want.

The changes occurring in how residents with advanced dementia could relate to other people impact on daily care delivery. As Jackson's study on the two kinds of care, namely, routinised and extra, finds, in response to residents' emergent needs, staff more often reserve their assistance for those residents 'to whom a staff member felt

connected' (1997, p. 198). The extra, informal care is provided 'less frequently to patients that a staff member related to only with difficulty' (Jackson 1997, p. 198).

The discourse of person-centred dementia care also plays its role in daily care practices. An example of using a person-centred approach in dementia care was how staff sought meaning in Mrs Sage's wandering. With the assumption that the excessive walking of Mrs Sage must be purposeful and only compromised due to her dementia (Algase et al. 1996), the nursing team agreed with the suggestion that Mrs Sage must have been in search of something or someone in her past. They worked diligently through the medical records, life histories and chats with the loved ones of Mrs Sage in the hope of rediscovering the real Mrs Sage—the person hidden in the construct of 'person with dementia', and what, concealed within the speechless elderly lady, drove her tireless searching efforts. With the underlying assumption that people with dementia always have an aim and purpose in what they do, just like staff have, staff were imposing meaning on residents' movements.

As described in Chapter 4, residents like Mrs Sage made sense of material things and persons through sensory extensions (Dennis 2007) and correspondence (Ingold 2017) in their immediate and spontaneous encounters with others. For these residents, it was not the meaning but the sensory extensions and correspondence with other material things and persons that gave them a sense of rightness of being-in-the-world-with-others. While suffering an 'absent mind' due to cognitive changes, their movements were *still* sensible and productive enabling residents to extend and feel at home in the nursing homes. Equally important to the recognition of residents with dementia as being no different to other people in terms of human value and right, the *differences* in their ways of relating to other things and beings in the world needed to be addressed and understood.

For Janelle Taylor, an anthropologist whose mother has Alzheimer's and lives in a nursing home, her recognition of her mother as still 'in many ways the cheerful, affectionate person' who she still enjoys being with, is achieved through the many 'stills' and 'firsts', such as 'The first time she tried to sign her own name and could not; The first time she needed my help in the shower' (2008, p. 316). Despite all the changes her mother has been through, she maintains the relationship with her mother through the walks that they share and the chats that they exchange. Living through all the painful firsts with her mother, Taylor strives to relate to her mother by finding the stills—

the continuity of becoming in the world with others in face of the debilitating effects of disease. Although the progress of her dementia makes it difficult for her mother to comprehend the sources of other people's suffering, 'but she still does notice and respond to others and is still moved to try to alleviate their distress' (2008, p. 329). At the core of how Taylor relates to her mother is moving alongside her and finding the stills—what people with dementia are still capable of and enjoy doing—and to always join together with her mother in doing these activities such as having a conversation or walking.

Drawing on the ethnographic descriptions presented in this thesis I conclude that cognitive changes, like bodily impairments, could be the productive potentials for residents to move, extend and feel at home in the nursing homes. This thesis provided new knowledges about how people with dementia can *still* relate to other things and persons *not* cognitively but sensorially. To create right care for people who suffer from dementia, biomedical constructs of resident movement need to be contested to foreground the 'stills' (Taylor 2008, p. 316)—productive potentials of movement in creating multi-sensory connections and affective relations between people with dementia and those who move alongside and care for them.

Epilogue

In walking, caring and doing research, we are all connected in one way or another in our endeavour to create a sense of home. On those days of fieldwork while walking up and down the corridors of the nursing homes, immersed in and touched by their sights, smells and sounds, my heart sank and my legs grew heavy. Images of home and my father and mother came flashing back. My father was diagnosed with Alzheimer's in 2000. He was cared for at home by my mum, with love and dedication. He died at dawn, on 26 January 2010 in Beijing, China. My brother sat up for his last night, holding his hands till the last minute of his life. I was not there for his departure, but in walking with nursing home residents and writing up this thesis, I felt him with me. I came to realise that this nursing home ethnography is how I have created a sense of home away from home while attempting, in the words of Janelle Taylor, to 'hold on' (2008, p. 332) to my Mum and Dad and the time that we shared. My effort to hold on is doomed to fail as, like everyone else, I am ageing and will eventually, decline and die. However, despite being aware that 'eternity is infinite and human life finite' (Jackson 2002, p. 14), I cannot help but strive to make a sense of home, which can be created, as this thesis

shows, by holding on to each other to produce a right care. Only in so doing, does life becomes bearable and meaningful.

Appendix

Barthel Index of Activities of Daily Living

Instructions: Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation. Refer to the Guidelines section on the following page for detailed information on scoring and interpretation.

The Barthel Index

Bowels
0 = incontinent (or needs to be given enemata)
1 = occasional accident (once/week)
2 = continent
Patient's Score: _____

Bladder
0 = incontinent, or catheterized and unable to manage
1 = occasional accident (max. once per 24 hours)
2 = continent (for over 7 days)
Patient's Score: _____

Grooming
0 = needs help with personal care
1 = independent face/hair/teeth/shaving (implements provided)
Patient's Score: _____

Toilet use
0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)
Patient's Score: _____

Feeding
0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent (food provided within reach)
Patient's Score: _____

Transfer
0 = unable – no sitting balance
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical)
3 = independent
Patient's Score: _____

Mobility
0 = immobile
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., stick)
Patient's Score: _____

Dressing
0 = dependent
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)
Patient's Score: _____

Stairs
0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down
Patient's Score: _____

Bathing
0 = dependent
1 = independent (or in shower)
Patient's Score: _____

Total Score: _____

(Collin et al., 1988)

Scoring:
Sum the patient's scores for each item. Total possible scores range from 0 – 20, with lower scores indicating increased disability. If used to measure improvement after rehabilitation, changes of more than two points in the total score reflect a probable genuine change, and change on one item from fully dependent to independent is also likely to be reliable.

Sources:

- Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud*. 1988;10(2):61-63.
- Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J*. 1965;14:61-65.
- Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud*. 1988;10(2):64-67.

1

Guidelines for the Barthel Index of Activities of Daily Living

General

- The Index should be used as a record of what a patient ***does***, NOT as a record of what a patient ***could do***.
- The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
- The need for supervision renders the patient not independent.
- A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives, and nurses will be the usual source, but direct observation and common sense are also important. However, direct testing is not needed.
- Usually the performance over the preceding 24 – 48 hours is important, but occasionally longer periods will be relevant.
- Unconscious patients should score '0' throughout, even if not yet incontinent.
- Middle categories imply that the patient supplies over 50% of the effort.
- Use of aids to be independent is allowed.

Bowels (preceding week)

- If needs enema from nurse, then 'incontinent.'
- 'Occasional' = once a week.

Bladder (preceding week)

- 'Occasional' = less than once a day.
- A catheterized patient who can completely manage the catheter alone is registered as 'continent.'

Grooming (preceding 24 – 48 hours)

- Refers to personal hygiene: doing teeth, fitting false teeth, doing hair, shaving, washing face. Implements can be provided by helper.

Toilet use

- Should be able to reach toilet/commode, undress sufficiently, clean self, dress, and leave.
- 'With help' = can wipe self and do some other of above.

Feeding

- Able to eat any normal food (not only soft food). Food cooked and served by others, but not cut up.
- 'Help' = food cut up, patient feeds self.

Transfer

- From bed to chair and back.
- 'Dependent' = NO sitting balance (unable to sit); two people to lift.
- 'Major help' = one strong/skilled, or two normal people. Can sit up.
- 'Minor help' = one person easily, OR needs any supervision for safety.

Mobility

- Refers to mobility about house or ward, indoors. May use aid. If in wheelchair, must negotiate corners/doors unaided.
- 'Help' = by one untrained person, including supervision/moral support.

Dressing

- Should be able to select and put on all clothes, which may be adapted.
- 'Half' = help with buttons, zips, etc. (*check!*), but can put on some garments alone.

Stairs

- Must carry any walking aid used to be independent.

Bathing

- Usually the most difficult activity.
- Must get in and out unsupervised, and wash self.
- Independent in shower = 'independent' if unsupervised/unaided.

(Collin et al., 1988)

References

Abram, D 1996, *The spell of the sensuous: perception and language in a more-than-human world*, Pantheon, New York.

ABS 1988, *History of Pensions and Other Benefits in Australia*, Australian Bureau of Statistics, Canberra, viewed 14 August 2020, <https://www.abs.gov.au/ausstats/abs@.nsf/94713ad445ff1425ca25682000192af2/8e72c4526a94aaedca2569de00296978!opendocument>.

ABS 2015, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, Australian Bureau of Statistics, Canberra, viewed 30 November 2019, <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Previousproducts/4430.0Main%20Features302015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>.

Adam, B 1995, *Timewatch: The Social Analysis of Time*, Wiley, New Jersey.

Adamek, ME & Balaswamy, S 2016, 'Long Term Care For Elders In Developing Countries In Asia and Africa: A Systematic Review', *The Gerontologist*, vol. 56, no. Suppl_3, pp. 413-413.

Adelman, RD, Greene, MG, Charon, R & Friedman, E 1990, 'Issues in the Physician-Geriatric Patient Relationship', in NC H. Giles, & J. M. Wiemann, (eds), *Communication, Health and the Elderly*, Manchester University Press, Manchester, pp. 126-134.

Adolph, KE, Cole, WG, Komati, M, Garciaguirre, JS, Badaly, D, Lingeman, JM, Chan, G & Sotsky, RB 2012, 'How Do You Learn to Walk? Thousands of Steps and Dozens of Falls Per Day', *Psychological Science*, vol. 23, no. 11, 10/19, pp. 1387-1394.

Ahmed, S 1999, 'Home and away: Narratives of migration and estrangement', *International Journal of Cultural Studies*, vol. 2, no. 3, pp. 329-347.

AIHW 2007, *Dementia in Australia: national data analysis and development*, Australian Institute of Health and Welfare, Australian Institute of Health and Welfare, Canberra.

AIHW 2012, *Residential aged care in Australia 2010–11: a statistical overview*, Aged care statistics series no. 36. Cat. No. AGE 68, Australian Institute of Health and Welfare, Canberra.

Algase, DL, Beck, C, Kolanowski, A, Whall, A, Berent, S, Richards, K & Beattie, E 1996, 'Need-driven dementia-compromised behavior: An alternative view of disruptive behavior', *American Journal of Alzheimer's disease*, vol. 11, no. 6, pp. 10-19.

Algase, DL, Moore, DH, Vandeweerd, C & Gavin-Dreschnack, DJ 2007, 'Mapping the maze of terms and definitions in dementia-related wandering', *Aging & Mental Health*, vol. 11, no. 6, pp. 686-698.

Allan, G & Crow, G (eds) 1989, *Home and family: Creating the domestic sphere*, Palgrave Macmillan, Basingstoke, UK.

ANMF 2019, *ANMF National Aged Care Survey 2019 – Final Report*, ANMF (Federal Office), Melbourne, Victoria.

Augé, M 1995, *Non-places: Introduction to an Anthropology of Supermodernity*, Verso, London & New York.

Bachelard, G 2014, *The poetics of space*, Penguin Classics, London, England.

Ballenger, JF 2006, 'The biomedical deconstruction of senility and the persistent stigmatization of old age in the United States', in A Leibing & L Cohen (eds), *Thinking about dementia. Culture, loss, and the anthropology of senility*, Rutgers University Press, New Brunswick, New Jersey, pp. 106-120.

Barbaras, R 2008, 'Life, movement, and desire', *Research in Phenomenology*, vol. 38, no. 1, pp. 3-17.

Barnes, S 2003, 'Space, choice and control, and quality of life in care settings for older people ', PhD thesis, University of Sheffield.

Bauman, Z 1991, *Modernity and Ambivalence*, Polity Press, Cambridge.

Bell, V 1999, *Performativity and belonging*, Sage Publications, London; Thousand Oaks, Cal.

Bergland, A & Kirkevold, M 2005, 'Resident-caregiver Relationships and Thriving among Nursing Home Residents', *Research in Nursing & Health*, vol. 28, pp. 365-375.

Bergman, H, Ferrucci, L, Guralnik, J, Hogan, DB, Hummel, S, Karunananthan, S & Wolfson, C 2007, 'Frailty: An Emerging Research and Clinical Paradigm—Issues and Controversies', *The Journals of Gerontology: Series A*, vol. 62, no. 7, pp. 731-737.

Bhidayasiri, R & Tarsy, D 2012, *Movement Disorders: A Video Atlas*, Current Clinical Neurology, Humana Press, Totowa, NJ.

Bland, M 2003, 'All the Comforts of Home? A Critical Ethnography of Residential Aged Care in New Zealand', PhD thesis, University of Newcastle.

Bland, M 2007, 'Betwixt and between: a critical ethnography of comfort in New Zealand residential aged care', *Journal of Clinical Nursing*, vol. 16, no. 5, pp. 937-944.

Borkan, GA, Hults, DE & Mayer, PJ 1982, 'Physical anthropological approaches to aging', *American Journal of Physical Anthropology*, vol. 25, no. S3, pp. 181-202.

Bowlby, S, Gregory, S & McKie, L 1997, '"Doing home": Patriarchy, caring, and space', in *Women's Studies International Forum,* vol. 20, pp. 343-350.

Bradshaw, SA, Playford, ED & Riazi, A 2012, 'Living well in care homes: a systematic review of qualitative studies', *Age and Ageing*, vol. 41, no. 4, pp. 429-440.

Brett, L, Traynor, V & Stapley, P 2016, 'Effects of physical exercise on health and well-being of individuals living with a dementia in nursing homes: a systematic review', *Journal of the American Medical Directors Association*, vol. 17, no. 2, pp. 104-116.

Brooke, V 1989, 'Nursing home life: How elders adjust', *Geriatric Nursing*, vol. 10, no. 2, pp. 66-68.

Brown, J 2016, 'Self and Identity Over Time: Dementia', *Journal of Evaluation in Clinical Practice*, pp. 1-7.

Butler, J 1993, *Bodies that matter: On the discursive limits of "sex"* Routledge, New York, London.

Canguilhem, G 1998, *On the Normal and the Pathological*, trans. CR Fawcett & RS Cohen, Zone Books, New York.

Cheu, S 2018, 'New analysis indicates staffing ratios in aged care also provide economic benefits', Australian Ageing Agenda, online, viewed 18 August 2020, <https://www.australianageingagenda.com.au/executive/new-analysis-indicates-staffing-ratios-in-aged-care-also-provide-economic-benefits/>.

Cohen, L 1998, *No aging in India: Alzheimer's, the bad family, and other modern things*, Univ of California Press, Berkeley.

Cohen, L 2006, 'Introduction', in A Leibing & L Cohen (eds), *Thinking about dementia: Culture, loss, the anthropology of senility*, Rutgers University Press, New Brunswick, New Jersey, pp. 1-19.

Cohler, B 1993, 'Aging, Morale, and Meaning: The Nexus of Narrative', in WAA T. R. Cole, P. L. Jackobi & R. Kastenbaum (eds), *Voices and Visions of Aging*, Springer, New York, pp. 107-133.

Cooper, C 1974, 'The house as symbol of the self', in J Land (ed.), *Designing for Human Behavior*, Dowden, Hutchinson and Ross, Stroudsburg, pp. 130-146.

Cram, F & Paton, H 1993, 'Personal possessions and self-identity: The experiences of elderly women in three residential settings', *Australian Journal on Ageing*, vol. 12, no. 1, pp. 19-24.

Crombie, A, Boyd, J & Snell, T 2008, 'The ABC of managing behavioural and psychological symptoms of dementia', *Geriaction*, vol. 26, no. 2, p. 14.

Csordas, T 1990, 'Embodiment as a Paradigm for Anthropology', *Ethos*, vol. 18, no. 1, pp. 5-47.

Csordas, T 1994, 'Introduction: the body as representation and being-in-the-world', in T Csordas (ed.), *Embodiment and experience: The existential ground of culture and self*, Cambridge University Press, Cambridge, UK, pp. 1-24.

Darke, J 1994, 'Women and the Meaning of Home', in R Gilroy & R Woods (eds), *Housing women*, Routledge, London, pp. 19-35.

Debru, C 2011, 'The Concept of Normativity from Philosophy to Medicine: An Overview', *Medicine Studies*, vol. 3, no. 1, 2011/11/01, pp. 1-7.

DeForge, R, Wyk, P, Hall, J & Salmoni, A 2011, 'Afraid to care; unable to care: A critical ethnography within a long-term care home', *Journal of Ageing Studies*, vol. 25, pp. 415-426.

Dekker, NL 2018, 'Moral frames for lives worth living: Managing the end of life with dementia', *Death Studies*, vol. 42, no. 5, pp. 322-328.

Deleuze, G & Guattari, F 1977, *Anti-Oedipus: Capitalism and Schizophrenia*, trans. R Hurley, M Seem & HR Lane, The Viking Press, New York.

Deleuze, G & Guattari, F 1988, *A Thousand Plateaus: Capitalism and Schizophrenia*, trans. B Massumi, The Athlone Press, London.

Deleuze, G & Parnet, C 2002, *Dialogues II* trans. H Tomlinson & B Habberjam, Continuum, London.

Dellefield, ME 2006, 'Interdisciplinary Care Planning and the Written Care Plan in Nursing Homes: A Critical Review', *The Gerontologist*, vol. 46, no. 1, February 1, 2006, pp. 128-133.

Den Ouden, M, Bleijlevens, MHC, Meijers, JMM, Zwakhalen, SMG, Braun, SM, Tan, FES & Hamers, JPH 2015, 'Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study', *Journal of the American Medical Directors Association*, vol. 16, no. 11, pp. 963–968.

Dennis, SJ 2007, *Police beat: the emotional power of music in police work*, Cambria Press, Amherst, NY.

Department of Health 2019, *6th report on Funding and Financing of the Aged Care Sector, July 2018*, Department of Health, Canberra.

Department of Health 2020a, 'Extra services agreements for residential aged care', viewed 19 July 2020, <https://www.health.gov.au/initiatives-and-programs/residential-aged-care/managing-residential-aged-care-services/extra-services-agreements-for-residential-aged-care>.

Department of Health 2020b, 'Home Care Packages Program', viewed 21 June 2020, <https://www.health.gov.au/initiatives-and-programs/home-care-packages-program/about-the-home-care-packages-program>.

Department of Health and Ageing 2012a, 'Decision-making Tool: Supporting a Restraint Free Environment in Residential aged care', Department of Health and Ageing, Canberra.

Department of Health and Ageing 2012b, *Living longer, Living better: aged care reform package*, Department of Health and Aging, Canberra.

Department of Health and Ageing 2013, *Aged Care Funding Instrument User Guide*, Department of Health and Aging, Canberra.

Dewey, J 2015, *Experience and education*, Free Press, New York

Diamond, T 1992, *Making Gray Gold: Narratives of Nursing Home Care*, University of Chicago Press, Chicago, IL.

Dovey, K 1985, 'Home and Homelessness', in I Altman & C Werner (eds), *Home environments*, Plenum Press, New York pp. 33-64.

Downey, G 2011, 'Learning the "banana-tree": Self-modification through movement', in T Ingold (ed.), *Redrawing Anthropology: Material, Movements, Lines*, Abingdon UK: Ashgate, pp. 77-90.

Dutt, D 1998, 'Care for the growing number of elderly people in developing countries needs to be addressed.', *BMJ (Clinical research ed.)*, vol. 316, no. 7141, pp. 1387–1388.

Dyke, S 2013, 'Disrupting ‘anorexia nervosa’: an ethnography of the Deleuzian event', in R Coleman & J Ringrose (eds), *Deleuze and Research Methodologies*, Edinburgh University Press, Edinburgh, pp. 145-164.

Estes, CL 1979, *The Aging Enterprise*, Jossey-Bass, San Francisco.

Finighan, WR 1980, 'Some empirical observations on the role of privacy in the residential environment', *Man-Environment Systems*, vol. 10 pp. 3–4.

Fiveash, B 1998, 'The experience of nursing home life', *Int J Nurs Pract*, vol. 4, pp. 166-174.

Förstl, H & Kurz, A 1999, 'Clinical features of Alzheimer’s disease', *Eur Arch Psychiatry Clin Neurosci*, vol. 249, pp. 288-290.

Foucault, M 1980, *The History of Sexuality. Volume 1: An Introduction*, Penguin Harmondsworth, UK.

Foucault, M 2012, *Discipline and punish: The birth of the prison*, Vintage, New York.

Fox, N 2012, *The Body*, Polity Press, Cambridge.

Gallagher, S 2006, *How the body shapes the mind*, Oxford University Press, New York.

Gault, ML & Willems, MET 2013, 'Aging, functional capacity and eccentric exercise training', *Aging and Disease*, vol. 4, no. 6, p. 351.

Geertz, C 1983, *Local Knowledge: Further Essays in Interpretive Anthropology*, Basic Books, New York.

Geertz, C 1988, *Works and lives: The anthropologist as author*, Stanford University Press, Redwood City, California.

George, K & George, G 2011, 'Destitute Asylum (1851 - c. 1917)', viewed on 19 July 2020, <https://www.findandconnect.gov.au/ref/sa/biogs/SE00062b.htm>.

Giannouli, E, Bock, O, Mellone, S & Zijlstra, W 2016, 'Mobility in old age: capacity is not performance', *BioMed Research International*, vol. 2016.

Giddens, A 1984, *The constitution of society: Outline of the theory of structuration*, Univ of California Press, Berkeley.

Goffman, E 1961, *Asylums: Essays on the Social Situation of Mental Patients and Other Innates*, Anchor Books/Doubleday, New York.

Green, J 2008, *Beyond the Good Death: The Anthropology of Modern Dying*, University of Pennsylvania Press, Philadelphia.

Greenwood, N, Menzies-Gow, E, Nilsson, D, Aubrey, D, Emery, CL & Richardson, A 2018, 'Experiences of older people dying in nursing homes: a narrative systematic review of qualitative studies', *BMJ Open*, vol. 8, no. 6.

Groves, A, Thomson, D, McKellar, D & Procter, N 2017, *The Oakden Report*, SA Health, Department for Health and Ageing, Adelaide, South Australia.

Gubrium, JF 1975, *Living and Dying at Murray Manor*, St. Martin's Press, New York.

Gubrium, JF 1993, *Speaking of life: Horizons of meaning for nursing home residents*, Transaction Publishers, New Jersey.

Guen, RL 1993, *Residential care for the aged: An overview of Government policy from 1962 to 1993*, Parliament of the Commonwealth of Australia, Canberra.

Gurney, CM 1997, '"… Half of me was satisfied": Making sense of home through episodic ethnographies', in *Women's Studies International Forum,* Elsevier, vol. 20, pp. 373-386.

Hallowell, AI 1955, *Culture and experience*, University of Pennsylvania Press, Philadelphia, Pennsylvania.

Hamers, JPH & Huizing, AR 2005, 'Why do we use physical restraints in the elderly?', *Z Gerontol Geriatr.*, vol. 38, no. 1, pp. 19-25.

Harbers, H, Mol, A & Stollmeyer, A 2002, 'Food Matters', *Theory, Culture & Society*, vol. 19, no. 5-6, pp. 207-226.

Harnett, T 2010, 'Seeking exemptions from nursing home routines: Residents' everyday influence attempts and institutional order', *Journal of Aging Studies*, vol. 24, pp. 292-301.

Hastrup, K 1990, 'The Ethnographic Present: A Reinvention', *Cultural Anthropology*, vol. 5, no. 1, pp. 45-61.

Hastrup, K & Hervik, P 2003, *Social Experience and Anthropological Knowledge*, Taylor & Francis, London & New York.

Hazan, H 2002, 'The home over the hill: Towards a modern cosmology of institutionalization', *Journal of Aging Studies*, vol. 16, pp. 323-344.

Heidegger, M 2010, *Being and Time*, trans. J Stambaugh & DJ Schmidt, State University of New York Press, New York.

Helliwell, C 1996, 'Space and sociality in a Dayak longhouse', in M Jackson (ed.), *Things as they are: New directions in phenomenological anthropology*, Indiana University Press, Bloomington & Indianapolis, pp. 128-147.

Henderson, JN 2003, 'Alzheimer's Units and Special Care: A Soteriological Fantasy', in P. B. Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 153-172.

Heuts, F & Mol, A 2013, 'What Is a Good Tomato? A Case of Valuing in Practice', *Valuation Studies*, vol. 1, pp. 125-146.

Higgins, J 1989, 'Homes and institutions', in G Allan & G Crow (eds), *Home and Family: Creating the Domestic Sphere*, Palgrave Macmillan, UK, pp. 159-173.

High, DM & Rowles, GD 1995, 'Nursing home residents, families, and decision making: Toward an understanding of progressive surrogacy', *Journal of Aging Studies*, vol. 9, no. 2, pp. 101-117.

Hodgkinson, B, Koch, S, Nay, R & Lewis, M 2007, 'Managing the wandering behaviour of people living in a residential aged care facility', *International Journal of Evidence-Based Healthcare*, vol. 5, pp. 406-436.

Hollander, J 1991, 'The idea of home: A kind of space', *Social Research*, vol. 58, no. 1, pp. 31-49.

Hughes, JC 2001, 'Views of the Person with Dementia', *Journal of Medical Ethics*, vol. 27, no. 2, pp. 86-91.

Hughes, JC 2011, *Thinking Through Dementia*, Oxford University Press, Oxford.

Hughes, MA, Myers, BS & Schenkman, ML 1996, 'The role of strength in rising from a chair in the functionally impaired elderly', *Journal of Biomechanics*, vol. 29, no. 12, pp. 1509-1513.

Hull, W, Sturt, EPS, Smith, WC, Agg, AJ & HOWITT, G 1863, *Report of the Commissioners appointed to enquire into the Municipalities and Charitable Institutions of Victoria*, Report No.52, Parliament of Victoria, GP John Ferres, Melbourne.

Ijaopo, EO 2017, 'Dementia-related agitation: a review of non-pharmacological interventions and analysis of risks and benefits of pharmacotherapy', *Translational Psychiatry*, vol. 7, no. 10, p. 1250.

Ingold, T 2008, 'Bindings against Boundaries: Entanglements of Life in an Open World', *Environment and Planning A*, vol. 40, no. 8, pp. 1796-1810.

Ingold, T 2010, 'Ways of Mind-Walking: Reading, Writing, Painting', *Visual Studies*, vol. 25, no. 1, pp. 15-23.

Ingold, T 2011, *Being alive: Essays on movement, knowledge and description*, Routledge, Milton Park, Abingdon, Oxfordshire.

Ingold, T 2017, 'On human correspondence', *Journal of the Royal Anthropological Institute*, vol. 23, no. 1, pp. 9-27.

Ingold, T & Hallam, E 2007, 'Creativity and Cultural Improvisation. An Introduction', in Elizabeth Hallam & Tim Ingold (eds), *Creativity and Cultural Improvisation*, Berg Publishers, Oxford, pp. 1-24.

Ingold, T & Vergunst, J 2008, *Ways of walking: Ethnography and practice on foot*, Routledge, London.

Iwasiw, C, Goldenberg, D, MacMaster, E, McCutcheon, S & Bol, N 1996, 'Residents' perspectives of their first 2 weeks in a long-term care facility', *Journal of Clinical Nursing*, vol. 5, no. 6, pp. 381-388.

Jackson, EM 1997, 'Dimensions of care in five United States nursing homes: identifying invisible work in care-giving', *Int. J. Nurs. Stud.*, vol. 34, no. 3, pp. 192-200.

Jackson, M 1995, *At home in the world*, Duke University Press, Durham, North Carolina.

Jackson, M 1996, *Things as they are: New directions in phenomenological anthropology*, Indiana University Press, Bloomington.

Jackson, M 1998, *Minima Ethnographica: Intersubjectivity and the Anthropological*, University of Chicago Press, Chicago, IL and London.

Jackson, M 2002, *The politics of storytelling: Violence, transgression, and intersubjectivity*, Museum Tusculanum Press, Copenhagen.

Jackson, M 2016, *As Wide as the World Is Wise: Reinventing Philosophical Anthropology*, Columbia University Press, New York.

Kass, L 1994, *The Hungry Soul: Eating and the Perfecting of Our Nature*, University of Chicago Press, Chicago.

Kaufman, SR 1994a, 'Old Age, Disease, and the Discourse on Risk: Geriatric Assessment in U. S. Health Care', *Medical Anthropology Quarterly*, vol. 8, no. 4, pp. 430-447.

Kaufman, SR 1994b, 'The social construction of frailty: an anthropological perspective', *Journal of Aging Studies*, vol. 8, no. 1, pp. 45-58.

Kayser-Jones, JS 1981, *Old, Alone, and Neglected: Care of the Aged in the United States and Scotland*, University of California Press, Berkeley, California.

Kayser-Jones, JS 2003, 'The Treatment of Acute Illness in Nursing Homes: The Environmental Context of Decision Making', in P. B. Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 23-68.

Kearl, M 1996, 'Dying well the unspoken dimension of aging well', *American Behavioral Scientist*, vol. 39, pp. 336-360.

Kehoe, M 1998, 'The Benevolent Asylum', Hotham History Project, viewed 14 August 2020, <https://www.hothamhistory.org.au/the-benevolent-asylum/>.

Kinley, J, Froggatt, K & Bennett, MI 2013, 'The effect of policy on end-of-life care practice within nursing care homes: a systematic review', *Palliative Medicine*, vol. 27, no. 3, pp. 209-220.

Kitwood, T 1993, 'Person and Process in Dementia', *International Journal of Geriatric Psychiatry*, vol. 8, no. 7, pp. 541-545.

Kitwood, T 1997, *Dementia Reconsidered: The Person Comes First*, Open University Press, Buckingham & Philadelphia.

Kleinman, A 2009, 'Caregiving: the odyssey of becoming more human', *The Lancet*, vol. 373, no. 9660, pp. 292-293.

Knappett, C 2011, *An Archaeology of Interaction: Network Perspectives on Material Culture and Society*, Oxford University Press, Oxford.

Kofod, J 2008, 'Becoming a nursing home resident: An anthropological analysis of Danish elderly people in transition', PhD thesis, University of Copenhagen.

Kontos, PC 2004, 'Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease', *Ageing and Society*, vol. 24, no. 6, pp. 829-849.

Korosec-Serfaty, P 1984, 'The home from attic to cellar', *Journal of Environmental Psychology*, vol. 4, no. 4, pp. 303-321.

Laird, C 1979, *Limbo*, Chandler & Sharp, Novato, California.

Lamb, SE 2009, *Aging and the Indian diaspora: Cosmopolitan families in India and abroad*, Indiana University Press, Bloomington, Indiana.

Latimer, J & Munro, R 2009, 'Keeping & dwelling: Relational extension, the idea of home, and otherness', *Space and Culture*, vol. 12, no. 3, pp. 317-331.

Lee, DTF, Woo, J & Mackenzie, AE 2002, 'The Cultural Context of Adjusting to Nursing Home Life: Chinese Elders' Perspectives', *The Gerontologist*, vol. 42, no. 5, pp. 667-675.

Lee, DTF, Yu, DSF & Kwong, ANL 2009, 'Quality of life of older people in residential care home: a literature review', *Journal of Nursing and Healthcare of Chronic Illness*, vol. 1, no. 2, pp. 116-125.

Leibing, A & Cohen, L (eds) 2006, *Thinking About Dementia : Culture, Loss, and the Anthropology of Senility*, Rutgers University Press, New Brunswick, New Jersey.

Lock, M 2013, *The Alzheimer conundrum: Entanglements of dementia and aging*, Princeton University Press, New Jersey.

Loret, C 2015, 'Using sensory properties of food to trigger swallowing: a review', *Critical reviews in food science and nutrition*, vol. 55, no. 1, pp. 140-145.

Lovatt, M 2018, 'Becoming at home in residential care for older people: a material culture perspective', *Sociology of Health & Illness*, vol. 40, no. 2, pp. 366-378.

Luborsky, MR, Lysack, CL & Van Nuil, J 2011, 'Refashioning One's Place in Time: Stories of Household Downsizing in Later Life', *Journal of Aging Studies*, vol. 25, no. 3, 2011/08/, pp. 243-252.

Mallett, S 2004, 'Understanding home: a critical review of the literature', *The Sociological Review*, vol. 52, no. 1, pp. 62-89.

McKeith, I 2004, 'Dementia with Lewy bodies', *Dialogues in Clinical Neuroscience*, vol. 6, no. 3, pp. 333-341.

McNamara, B 2001, *Fragile lives: death, dying and care*, Allen & Unwin, Sydney.

Merleau-Ponty, M 1962, *Phenomenology of perception*, trans. C Smith, Routledge, London & New York.

Miguel, M 2015, 'Towards a New Thinking on Humanism in Fernand Deligny's Network', in D Sharma & F Tygstrup (eds), *Structures of Feeling: Affectivity and the Study of Culture*, De Gruyter, Berlin, Munich & Boston, pp. 187-198.

Milanović, Z, Pantelić, S, Trajković, N, Sporiš, G, Kostić, R & James, N 2013, 'Age-related decrease in physical activity and functional fitness among elderly men and women', *Clinical Interventions in Aging*, vol. 8, pp. 549–556.

Milligan, C 2000, ''Bearing the burden': towards a restructured geography of caring', *Area*, vol. 32, no. 1, pp. 49-58.

Milligan, C 2003, 'Location or dis-location? Towards a conceptualization of people and place in the care-giving experience', *Social & Cultural Geography*, vol. 4, no. 4, pp. 455-470.

Milligan, C 2016, *There's No Place Like Home: Place and Care in an Ageing Society*, Taylor & Francis, London & New York.

Milligan, C & Wiles, J 2010, 'Landscapes of care', *Progress in Human Geography*, vol. 34, no. 6, pp. 736-754.

Milte, R, Shulver, W, Killington, M, Bradley, C, Miller, M & Crotty, M 2017, 'Struggling to maintain individuality – Describing the experience of food in nursing homes for people with dementia', *Archives of Gerontology and Geriatrics*, vol. 72, 2017/09/01/, pp. 52-58.

Minney, MJ & Ranzijn, R 2015, '"We Had a Beautiful Home... But I Think I'm Happier Here": A Good or Better Life in Residential Aged Care', *The Gerontologist*, vol. 56, no. 5, pp. 919-927.

Mol, A 2002, *The Body Multiple: Ontology in Medical Practice*, Duke University Press, London.

Mol, A 2008, *The logic of care: Health and the problem of patient choice*, Routledge, Milton Park, Abingdon, Oxfordshire.

Mol, A, Moser, I & Pols, J 2010, *Care in Practice: On Tinkering in Clinics, Homes and Farms*, Columbia University Press, New York.

Musolino, C, Warin, M & Gilchrist, P 2018, 'Positioning relapse and recovery through a cultural lens of desire: A South Australian case study of disordered eating', *Transcultural Psychiatry*, vol. 55, no. 4, pp. 534-550.

Nay, R 1995, 'Nursing home residents' perceptions of relocation', *Journal of Clinical Nursing*, vol. 4, no. 5, pp. 319-325.

Neil, M 2019, 'Malnourished aged care residents "starving to death" warn experts',

thesenior.com.au, viewed 14/05/2020, <https://www.thesenior.com.au/story/6278038/malnutrition-a-silent-abuser-in-aged-care/?cs=13891>.

Nolan, M, Walker, G, Nolan, J, Williams, S, Poland, F, Curran, M & Kent, BC 1996, 'Entry to care: positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers', *Journal of Advanced Nursing*, vol. 24, no. 2, pp. 265-274.

Noorani, I & Carpenter, RHS 2017, 'Not moving: the fundamental but neglected motor function', *Philosophical Transactions of the Royal Society B: Biological Sciences*, vol. 372, no. 1718.

Norberg, A, Bäckström, Å, Athlin, E & Norberg, B 1988, 'Food refusal amongst nursing home patients as conceptualized by nurses' aids and enrolled nurses: an interview study', *Journal of Advanced Nursing*, vol. 13, no. 4, pp. 478-483.

Nord, C 2013, 'A day to be lived. Elderly peoples' possessions for everyday life in assisted living', *Journal of Aging Studies*, vol. 27, no. 2, pp. 135-142.

Olsen, C, Pedersen, I, Bergland, A, Enders-Slegers, M, Jøranson, N, Calogiuri, G & Ihlebæk, C 2016, 'Differences in quality of life in home-dwelling persons and nursing home residents with dementia – a cross-sectional study', *BMC Geriatrics*, vol. 16, no. 1, 2016/07/11, p. 137.

Ong, A & Collier, SJ 2004, *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, Blackwell, London.

Ouellet, LL & Rush, KL 1996, 'A study of nurses' perceptions of client mobility', *Western Journal of Nursing Research*, vol. 18, no. 5, pp. 565-579.

Palm, R, Jünger, S, Reuther, S, Schwab, CG, Dichter, MN, Holle, B & Halek, M 2016, 'People with dementia in nursing home research: a methodological review of the definition and identification of the study population', *BMC Geriatrics*, vol. 16, no. 1, p. 78.

Parfit, D 1984, *Reasons and persons*, Oxford University Press, Oxford.

Parker, RA 1987, *The Elderly and Residential Care, Australian Lessons for Britain*, Gower, Aldershot, Hampshire, UK.

Paton, H & Cram, F 1992, 'Personal possessions and environmental control: The experiences of elderly women in three residential settings', *Journal of Women & Aging*, vol. 4, no. 2, pp. 61-78.

Perkinson, MA 2003, 'Defining Family Relationships in a Nursing Home Setting', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 235-262.

Pink, S 2015, *Doing Sensory Ethnography*, SAGE, London.

Polanyi, M 1958, *Personal Knowledge: towards a post-critical philosophy*, University of Chicago Press, Chicago.

Polanyi, M 2009 [1966], *The Tacit Dimension*, The University of Chicago Press, Chicago and London.

Preston, J & Wegner, DM 2009, 'Elbow grease: The experience of effort in action', in E Morsella, JA Bargh & PM Gollwitzer (eds), *Oxford handbook of human action*, Oxford University Press, New York, pp. 469-486.

Productivity Commission 2011, *Caring for Older Australians: Overview*, Report No. 53, Productivity Commission, Canberra

Rapport, N 2018, 'The action and inaction of care: Care and the personal preserve', *The Australian Journal of Anthropology*, vol. 29, no. 2, pp. 250-257.

Rapport, N & Dawson, A 1998, *Migrants of identity: Perceptions of home in a world of movement*, Berg Publishers, Oxford.

Reid, N, Eakin, EG, Henwood, T, Keogh, J, Senior, H, Gardiner, RA, Winkler, E & Healy, G 2013, 'Objectively measured activity patterns among adults in residential aged care', *International Journal of Environmental Research and Public Health*, vol. 10, no. 12, pp. 6783-6798.

Riebe, D, Blissmer, BJ, Greaney, ML, Garber, CE, Lees, FD & Clark, DJ 2009, 'The Relationship Between Obesity, Physical Activity, and Physical Function in Older Adults', *Journal of Aging and Health*, vol. 21, p. 1159.

Robbins, J 2013, 'Beyond the suffering subject: toward an anthropology of the good', *Journal of the Royal Anthropological Institute*, vol. 19, no. 3, pp. 447-462.

Roelofs, K 2017, 'Freeze for action: neurobiological mechanisms in animal and human freezing', *Philosophical Transactions of the Royal Society B: Biological Sciences*, vol. 372, no. 1718.

Rowles, GD 1993, 'Evolving images of place in aging and "aging in place"', *Generations*, vol. 17, no. 2, pp. 65-70.

Rowles, GD & High, DM 2003, 'Family involvement in nursing home facilities: A decision-making perspective', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 173-201.

Royal commission into Aged Care Quality and Safety 2019, 'Royal commission into Aged Care Quality and Safety Sydney Hearing 17 May 2019 Transcript', *Royal commission into Aged Care Quality and Safety*.

Rykwert, J 1991, 'The idea of a home: a kind of space', *Social Research*, vol. 58, no. 1, pp. 51-62.

Ryvicker, M 2009, 'Preservation of self in the nursing home: Contradictory practices within two models of care', *Journal of Aging Studies*, vol. 23, no. 1, pp. 12–23.

SA Health 2013, *A Framework for Recognition and Management of Challenging Behaviour*, Department for Health and Ageing, Government of South Australia, Adelaide.

Salmon, E, Ruby, P, Perani, D, Kalbe, E, Laureys, S, Adam, S & Collette, F 2005, 'Two aspects of impaired consciousness in Alzheimer's disease', *Progress in Brain Research*, vol. 150, pp. 287-298.

Samanani, F & Lenhard, J 2019, *Home: ethnographic encounters*, Bloomsbury Academic, London.

Sandvoll, A, Kristoffersen, K & Hauge, S 2012, 'New quality regulations versus established nursing home practice: a qualitative study', *BMC Nursing*, vol. 11, no. 1, 2012/06/07, pp. 1-7.

Sandvoll, A, Kristoffersen, K & Hauge, S 2013, 'The double embarrassment: Understanding the actions of nursing staff in an unexpected situation', *International Journal of Nursing Practice*, vol. 19, no. 4, pp. 368-373.

Sankar, A 1984, '"It's Just Old Age." ', in DKaJK Ithaca (ed.), *Age and Anthropological Theory*, Cornell University Press, NY, pp. 250-280.

Savishinsky, JS 2003, '"Bread and Butter" Issues: Food, Conflict, and Control in a Nursing Home', in P. B. Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 103-120.

Scarborough, DM, McGibbon, CA & Krebs, DE 2007, 'Chair rise strategies in older adults with functional limitations', *Journal of Rehabilitation Research Development*, vol. 44, no. 1, pp. 33-42.

Schutz, A 1967, *The Phenomenology of the Social World*, Northwestern University Press, Evanston, IL.

Sellers, M & Honan, E 2007, 'Putting Rhizomes to Work: (E)merging Methodologies ', *NZ Research in Early Childhood Education Journal*, vol. 10, pp. 145-154.

Serres, M 2014, *Les cinq sens*, Grasset, Paris.

Sheets-Johnstone, M 2011, 'The Imaginative Consciousness of Movement: Linear Quality, Kinaesthesia, Language and Life', in T Ingold (ed.), *Redrawing Anthropology: Materials, Movements, Lines*, University of Aberdeen, Ashgate, Farnham, UK, pp. 115-128.

Shield, RR 2003, 'Wary partners: Family-staff relationships in nursing homes', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 203-233.

Smith, D 2018, 'What is the body without organs? Machine and organism in Deleuze and Guattari', *Continental Philosophy Review*, vol. 51, no. 1, 2018/03/01, pp. 95-110.

Somerville, P 1992, 'Homelessness and the meaning of home: Rooflessness or rootlessness?', *International Journal of Urban and Regional Research*, vol. 16, no. 4, pp. 529-539.

Spry, T 2001, 'Performing autoethnography: An embodied methodological praxis', *Qualitative Inquiry*, vol. 7, no. 6, pp. 706-732.

Spurling, L 1977, *Phenomenology and the Social World: The Philosophy of Merleau-Ponty and Its Relation to the Social Sciences*, Routledge and Kegan Paul, Abingdon-on-Thames, UK.

Stafford, PB 2003a, 'Introduction: the nursing home as cultural code', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 3-22.

Stafford, PB 2003b, 'Homebodies: Voices of place in a North American community', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 121-151.

State Library of SA 2015, *SA Memory*, viewed 23/04/2020, <https://www.samemory.sa.gov.au/site/page.cfm?u=678>.

Stoller, P 1997, *Sensuous scholarship*, University of Pennsylvania Press, Philadelphia, Pennsylvania.

Stones, D & Gullifer, J 2016, '"At home it's just so much easier to be yourself": older adults' perceptions of ageing in place', *Ageing & Society*, vol. 36, no. 3, pp. 449-481.

Taylor, J 2008, 'On recognition, caring, and dementia', *Medical Anthropology Quarterly*, vol. 22, no. 4, pp. 313-335.

The Sydney Morning Herald 1860, 'The Benevolent asylum at New South Wales', *The Sydney Morning Herald (NSW : 1842 - 1954)*, 3 January 1860 edn, Sydney, <https://trove.nla.gov.au/newspaper/article/13035228?searchTerm=%22%22The%20Benevolent%20asylum%20at%22%22&searchLimits=sortby=dateAsc%7C%7C%7Cl-state=New+South+Wales%7C%7C%7Cl-decade=186>.

Thomasma, DC 1991, 'From Ageism toward Autonomy', in SGP R. Binstock (ed.), *Too Old for Health Care?*, Johns Hopkins University, Baltimore, pp. 138-163.

Twigg, J 2000, *Bathing - the Body and Community Care*, Taylor & Francis, London.

Vesperi, MD 1983, 'The reluctant consumer: Nursing home residents in the post-Bergman Rea', in J Sokolosovsky (ed.), *Growing old in different societies: Cross cultural perspectives*, Wadsworth Press, Belmont, CA, pp. 225-237.

Vesperi, MD 2003, 'A Use of Irony in Contemporary Ethnographic Narrative', in PB Stafford (ed.), *Gray areas: Ethnographic encounters with nursing home culture*, School of American Research Press, Santa Fe, New Mexico, pp. 69-102.

Wade, DT & Collin, C 1988, 'The Barthel ADL Index: a standard measure of physical disability?', *International Disability Studies*, vol. 10, no. 2, pp. 64-67.

Warin, M 2002, 'Becoming and unbecoming: Abject relations', PhD thesis, University of Adelaide.

Warin, M 2010, *Abject Relations: Everyday Worlds of Anorexia*, Rutgers University Press, New Jersey

Warnock, C 2013, 'Barefoot Running: Feeling the World Through Your Feet', Master's thesis, University of Ottawa.

Whitehead, GJ 2018, 'The Melbourne Benevolent Asylum Comes to Cheltenham', viewed 15 December 2017, <http://localhistory.kingston.vic.gov.au/htm/article/302.htm >.

Whitmore, H 2001, 'Value that marketing cannot manufacture: Cherished possessions as links to identity and wisdom', *Generations*, vol. 25, no. 3, pp. 57-63.

Willcocks, D, Peace, S & Kellaher, L 1987, *Private lives in public places: a research-based critique of residential life in local authority old people's homes*, Tavistock Publications, London.

Wilson, SA 1997, 'The transition to nursing home life: a comparison of planned and unplanned admissions ', *Journal of Advanced Nursing*, vol. 26, pp. 864-871.

Yun-Hee, J, Govett, J, Lee-Fay, L, Chenoweth, L, McNeill, G, Hoolahan, A, Brodaty, H & O'Connor, D 2013, 'Care planning practices for behavioural and psychological symptoms of dementia in residential aged care: A pilot of an education toolkit informed by the Aged Care Funding Instrument', *Contemporary Nurse: A Journal for the Australian Nursing Profession*, vol. 44, no. 2, pp. 156-169.

Zerubavel, E 1979, *Patterns of Time in Hospital Life. A Sociological Perspective*, University of Chicago Press, Chicago.