INTRODUCTION

Becoming at Home through Right Care

'At Home' in Old Age

'I want to go home', Mr Harris sighed as he held on to his walker, hauled himself upright, and walked away. Mr Harris lived in the aged care facility where I undertook fieldwork, and we spent many an hour and day walking together. Sitting opposite the main entrance of the facility, Mr Harris would routinely fix his gaze at the glass doors, through which people constantly came and went. Every resident leaving the facility had to be accompanied by someone, a staff member, a relative or friend, a volunteer or visitor, who would unlock the door by entering a security code – a string of characters printed in tiny font on a notice affixed to the wall next to the security lock. Added 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 added that he intended to ask his daughter to get him out of this place the next time she came to visit.

A few days after my chat with Mr Harris, I discovered that he was 'out' as he had wished – his daughter had taken him on 'social leave' to spend the weekend with her family. I felt happy for him – he could have a break from routinized nursing home life and spend time with his family. However, in the late afternoon, and to everyone's surprise, Mr Harris was back inside the facility in time for afternoon tea. Distraught and exhausted, his daughter explained the situation to me. After a car trip to the beach and a fun picnic, the family had returned home. Mr Harris then became restless, walking all over the house looking for his own room. When she told her father that he would be spending the night in her spare bedroom, he grew more distressed and insisted that he should return before it got too late. So, feeling confused and heartbroken, his daughter took 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 red 4-wheeled walker, he was back on his feet, walking again.

How can we understand the perplexing experience of Mr Harris, who longed to leave the nursing home but chose to go back to it during his social leave? Mr Harris was able to clearly voice his resentment over the constraints of living in a secure care facility, and yet he also evidently found reassurance and comfort in its purposefully designed and structured environment and the assistance it offered him. I was confronted with questions: where was *home* for people like Mr Harris? Did Mr Harris feel more at home in the nursing home than in his daughter's house? What is the best way to care for Mr Harris and other residents like him who live out the final phase of their lives in nursing homes? This is a book about the complexity of living and ageing in a nursing home.[1] It is an enquiry that is of critical relevance to those who care for the aged, in professional or informal capacities as healthcare or aged care staff, or as relatives or friends of residents. The fieldwork I carried out considered the diverse ailments and different care structures I encountered with a particular group of people in a particular location; however, it speaks to a vast and growing audience. In ageing societies across the world, where a growing percentage of the population is experiencing physical and cognitive decline, the question of how best to care for the aged is one that increasingly affects us all.

I intend to show that it is possible for older people to live a good life in a nursing home if they can be assisted to do the things that they want to do with their bodies but are unable to do on their own. In conducting twelve months of fieldwork in two residential aged care facilities in metropolitan Adelaide, South Australia and then writing my understandings into this book, I came to realise how older people like Mr Harris could feel at home by being assisted to move. As this book will show, the location where older people receive care matters, but it does not determine whether they feel at home. Disease and decline affect people's experience of life as they age, and what may be characterized as 'the good life' in one's youth continually shifts and is always contingent on social and material circumstance. So what may largely be considered good for healthy and able-bodied people, such as spending a weekend away with family, may not be experienced as good for people with Parkinson's disease. Mr Harris could not manoeuvre his walker easily in his daughter's house, in rooms cluttered with furniture. Constricted in this way, he could not walk with this essential aid. Nor could he walk without it. With no handrails lining walls and corridors, he had nothing to hold on to. Off balance and unable to firmly put one foot in front of the other, he could not walk freely or feel safe in his daughter's house. He felt safer in the nursing home environment, where aid devices were available and staff readily came to his assistance. Rather than asking where home is located for older people like Mr Harris, this book follows the daily movements of some nursing home residents to understand how, with the right sort of assistance, they might come to experience a good quality of life. It traces the forms of care that can support them to feel 'all right' in a nursing home.

Movement capability is strongly related to admission into residential aged care. Mr Harris was admitted into the aged care facility due to the progression of his Parkinson's disease. After his wife died, he lived alone but after having frequent falls, tripping over rugs and his own feet, Mr Harris and his family felt that living independently at home was no longer an option for him. He was having difficulty with walking safely, needing someone to stand by his side to assist when he was struggling to balance. Because Mr Harris needed continual supervision and assistance to walk, a 'home care package'– tailored services designed to support elderly people to keep living in their own homes – was inadequate. Many nursing home residents will have been previously hospitalized due to injuries from falls before their admission into an aged care facility. This is a common pathway for the 1 in 20 elderly Australians who live in residential aged care facilities, according to the Australian Bureau of Statistics 2016 report on disability, ageing and carers (ABS 2016). In the current aged care system, home care packages and different levels of residential care provide senior Australians with options for nursing care and daily life assistance. Residential aged care is often seen as the last resort for care and support with daily living, yet it is usually turned to if assistance from family carers is not available.[2]

In aged care policy and research, a good life for older people is often conceptualized around the ideal of self-determination, which is all about autonomy – having control and choice over one's own life. However, moving into a nursing home is rarely perceived by the elderly as a decision that they willingly make on their own. Mr Harris entered the nursing home not out of choice but as a solution to his increasing inability to move around safely on his own. He hated the idea of living in a 'Home', but given his bodily condition, there was, he told me, no way to fight it. Although he entered residential care with his own consent, Mr Harris was forever resentful about being institutionalized. 'I want to go home,' he repeatedly complained. Residents often expressed their wish to go home, especially in the transition process of adjusting to life in the nursing home. Time and again they criticized 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 felt anything but 'at home'. In expressing his desire to go home, Mr Harris repeated his idea that the nursing home was a place in which he felt constrained – he did not feel 'right' there, and he wished he were free to leave. For Mr Harris and residents like him, home is less about bricks and mortar and more about a sense of being 'all right' in the living environment: being supported to move safely, to reach out to people and things in his surroundings, and to feel comfortable.

But despite wishing to leave the institution and to go home, Mr Harris could not feel at home in his daughter's house, where he felt even less comfortable – he later explained to me that he did not feel right there as he had 'no way to walk around'. At the core of Mr Harris feeling right and at home was his need and desire to walk freely as he wished. 'Going home', then, could be seen as a metaphor expressing his wish to find a way to feel all right – a sense of rightness of being. Though Mr Harris clearly voiced his resentment about having to live in a secure care facility, he also felt right there, especially on occasions when he was assisted to walk safely in that familiar environment.

As time passed during my research in the field, I noticed that all residents experienced an innermost drive to move, to connect and to stay in touch with the world. Yet, in studying the day-to-day lives of these residents, I also observed the loss of sensory capacities, motor coordination, balance and strength. Bodies increasingly became numb, weak, slow and unstable, and this limited their possibilities to act in the world in ways that they wished. I realized that the realities of physical and cognitive decline appear at odds with narratives of 'self-determination' that circulate in aged care policy and research. Movement for residents was not really about choice and control over one's own life. Rather, it was a matter of working interdependently with other people and things, simply to enable bodies to move. I saw that it was often through the most mundane everyday activities, like changing position from sitting to standing, walking or eating, that residents could, despite their bodily limitations, feel cared for and at home in the nursing home. These were occasions when Mrs Wilson could stand up on her own from an adjustable chair, Mrs Brie could eat from a lipped plate, and Mr Harris had his Parkinson's medication on time and, with the aid of care workers and his walker, could move freely around the facility.

For nursing home residents to feel a sense of being-at-home, they need the kind of care that responds to their innermost drive to move, by generating for them new ways of walking with relative ease. I call this kind of care 'right care'. The purpose of this book is thus to help those who care for older people to practise right care by understanding what right care is and how to deliver it in the context of residential aged care. I will do so by pointing to some important differences – different understandings of people' needs, and different experiences of care that older people receive in the nursing homes.

Right Care

Care that is responsive to residents' bodies and needs is at the core of residents' experiences of feeling right in the nursing home. It happened when residents' need to move was attended to, such as when an arm reached out to support them to stand upright, or a walker was conveniently placed within reach, or a carer took time and used a gentle hand to get them dressed: all instances where vis-à-vis attentiveness and care from others allowed residents to continue doing the things that 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 any difficulties to do with their bodies, communal living or 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 a constant theme of conversations at the nursing home; it is key to how residents feel, think and talk about being 'at home' in residential care.

Nevertheless, older people may not feel right while receiving care in the existing system. In September 2018, the Australian Broadcasting Corporation's (ABC) current events programme *Four Corners* aired a two-part documentary called 'Who Cares?' It presented a disturbing insight into the lives of those living in residential aged care facilities, highlighting examples of isolation and neglect. Following a number of reviews of aged care, and media exposure of poor care in the aged care system, the Royal Commission into Aged Care Quality and Safety was established to examine the quality of aged care services in Australia and whether those services are meeting the needs of the community.

Mr Anthony O'Donnell, who lives in residential aged care, gave evidence to the Royal Commission into Aged Care Quality and Safety. He said:

> The definition of care on both daytime shifts seems to be centred on making sure that there is something formally set down to do as a series of tasks. … In one sense while immediate needs may well be met in this way, if considered objectively and without any intrusive thoughts about costs and the like, then such a definition of care is little more than is given to our sheep or cattle in the export business. (Pagone and Briggs 2021: 222)

Ms Johnson, another nursing home resident, also gave evidence to the Royal Commission, describing how staff members would enter her room as if she were not there, continuing their conversations with each other: 'Often not a word is said to me. I feel as though I am just an object that has to be moved from A to B' (Pagone and Briggs 2021: 222).

These narratives, drawn from the commission's Final Report, illustrate how care provided in the existing system can leave nursing home residents feeling dehumanized, isolated and ignored when they are handled and processed like a passive object, as staff tick off their tasks. During my fieldwork, residents talked about this task-based approach to care provision as staff ‘doing care work’. Itemized as tasks to be completed, this form of ‘care work’ could actually contradict the essential meaning of care. In a task-orientated approach to care, staff strictly follow work schedules without being able to respond to residents in the moment – to their spontaneous efforts to move, to participate in the activities of daily living, to feel all right and at home. There can be a disjuncture between how care is conceived in aged care plans and procedures and fulfilling the actual needs of residents to be assisted to move with care. In other words, the kind of care that staff routinely carry out as tasks may not be the kind of care that residents need or want.

Introducing Assemblages

This is a book about human and non-human actors and how they come together in different ways to enable different sorts of care, tailored to different bodies and levels of disability. Home, as this book will show, was made possible when the right elements came together at the right time to produce specific movements, senses and feelings. Home, as I will demonstrate, was a matter of moving and of being moved, with the right sorts of care, of shaping and of being shaped by one’s body and one’s world, and it is intimately connected to other people and things in what has been called an ‘assemblage’ (Deleuze and Guattari 1988).

It is important to describe the variety of things that can comprise these assemblages, many of which are centrally placed in the day-to-day lives of nursing home residents. Some tangible things, such as mobility aids and handrails installed in corridors, obviously play a pivotal role in supporting residents’ efforts to move. A 4-wheeled walker is designed to provide balance to users when walking; it makes it easier for residents who have issues with stability to get around. Similarly, a modified armchair can provide optimum hip support and assist in standing and transfers when it is designed with adjustable seat height and angle and comfortable padded armrests. A special plate with built-up rims and ridges allows residents to more easily manage their food by fork or spoon. It works well for residents with low vision or for those who have difficulty grasping and manipulating eating utensils.

Technologies such as a call bell and sensor mat alarm systems are widely used in nursing homes to facilitate the connection between residents and staff. Such systems allow residents to alert staff when they need assistance. A call bell can be wired and installed in residents’ rooms or be wireless and worn on the person. The call bell system displays the room number on staff deck phones, monitors in the nurses’ station and LCD screens in corridors when a resident presses their 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 monitor vulnerable residents' movements. Staff are required to give a quick response to sensor mat alarms by attending immediately to the resident.

Alongside this diverse range of technologies, nursing home residents spend most of their last years or months being attended to by personal care workers. Their job is physically demanding, and it calls for their own bodies to move in response to residents' movements. Whether walking or eating, putting feet on the carpet or food in the mouth, the interlaced hands of care staff and residents come together as one, co-functioning in an assemblage. In examining how these people and things come together, this book shows how a sense of home comes from residents' everyday movements, which are intimately entwined in the relational social world of the nursing home.

The assistive devices, medications and staff assistance that support residents to move are all part of the provision of care services in nursing homes and are routinely delivered within the limits of care plans and aged care funding policy. However, while staff, medications and aid equipment can be assembled to support residents to move, they can also restrain residents from moving. For example, residents are often seated in 'princess chairs', pressure-cushioned chairs that are designed with a curved backrest to provide extra postural support and comfort for residents sitting for long hours. On the other hand, being left sitting in this chair for long periods can restrain voluntary movement or prevent the person from engaging with other residents.

The term 'care' is understood in this study as being made up of not one but multiple assemblages of care. Using the Deleuzian concept of assemblage, I analyse how elderly residents' movements meshed with multiple entities, including staff, medications, walking aids, assistive utensils, adjustable beds and chairs, as well as aged care policies, assessments, care plans and fall prevention programmes. I will show how some components are assembled productively, to facilitate the movements residents wish to make, and conversely, how other assemblages could be counterproductive, such as certain discourses of risk or agitation, which could be used to restrain people and inhibit movement. I outline what I believe are productive and right 'assemblages of care' (Musolino 2016) and explore the tension between how care is presently conceived – in the contexts of policies and care plans – and how, conversely, it could be practised; for example, by assisting residents to make movements they feel they cannot make on their own, in ways that would feel right to them.

Care That 'Works All Right'

This book attempts to describe and understand care not as 'care work' but as what works so that residents may actually feel cared for, at ease and at home. Bodily impairments create blockages that lead to ruptures in movement: incomplete attempts to stand or to walk by smoothly putting one foot in front of the other. Enabling movement was, for residents and staff, a matter of assembling the right people and things so that 'bad knees', 'weak legs' or 'diabetic feet' can, as staff said, 'work all right'. The word 'right' was frequently used by staff to refer to situations when residents were observed to be able to move with just the right type and amount of assistance. These were occasions when a walker became 'just right', or the assemblage of a staff-assisted walking routine and medication schedule were delivered on time. As I will detail in Chapter 1 of this book, using the example of Mrs Casey, care that 'works all right' depends on synthesized efforts. In this case, extra funding was invested by the service provider to hire a physiotherapist and assistant. Mrs Casey's wish to relearn to walk was supported by the integrated care management team in the form of allocated staff time; and her efforts to walk joined with those of allied health professionals and personal care staff.

In the nursing homes, I could see how care that enabled residents to feel right was not delivered *because of* the system but *in spite of* the system. It was delivered if and when situations were favourable and staff were free to respond to individual residents' needs. Right care is what works, and what works for residents requires shifting arrangements of people and things coming together to 'step in' or 'lend a hand', often outside of their time-poor work schedules. Right assemblages of care cannot be fixed or documented easily in care plans. Adjustments need to be made constantly, depending on the vicissitudes of bodies and situations. Right assemblages of care require constant 'tinkering' from one moment to the next' (Mol, Moser and Pols 2010).

While Mol et al. (2010) have examined tinkering practices and technologies as a way into theorizing the nature of care, the theme of power, developed by Martin and colleagues (2015: 628), is also useful for analysing how caregiving involves a complex entanglement of multiple things and people, amid asymmetrical power relations. Thinking about power as entailed in affective dis/engagements through multisensory modes and means enables sensory analysis (Dennis 2018) of how power relates to care, and is thus always entailed in the question of how residents become at home in nursing homes.

Caring beyond the Limits

Within biomedical framings of ageing, the aged are regarded by health professionals as people struggling with physical limitations: declining bodies, damaged bodies, bodies that are painful, insensible, slowed down or in stasis. As the process of deterioration is irreversible, ageing bodies will inevitably fail to function at some stage. The widespread equation of old age with disease has led to the medicalization of old age and death, from which perspective the aged are viewed as frail, often mentally impaired and otherwise limited in human capabilities. 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: 432). Defined as 'older adults or aged individuals who are lacking in general strength and who are unusually susceptible to disease or to other infirmity' (Bergman et al. 2007: 731–32), the term 'frail elderly' has become a medical concept associated with disease and disability. Culturally conceived as regression, old age is made equivalent to decline. Nonetheless, as revealed in Kaufman's discussion of frailty beyond instrumental definitions, frailty is a lived problem that is socially constructed as a parameter of risk for institutionalization (1994b: 54–56).

Difficulties with daily life activities and normal functioning are understood in physiological research as the result of the ageing process, characterized by reduced functional capacities. This is most obvious in how residents' difficulties with walking are biomedically constructed into a loss of bodily sensitivity, flexibility, strength and coordination. In this singular attention to biological aspects of ageing, decreased function is foregrounded and is presented as natural and inevitable. Yet, this direct association of bodily decline with loss of capacity in old age is at odds with the complexities of movements that I observed in the day-to-day lives of nursing home residents. What is missing in this approach is how elderly people can actively adapt and adjust to bodily changes in their real-world environments, and how the right care can enable people to develop new ways of moving with relative ease.

The mental deficit associated with age has been among the most deeply stigmatized conditions in human history (Cohen 2006). It is also viewed as a medical issue first and foremost (Ballenger 2006: 106). Since German physician Alois Alzheimer first discovered the dramatic shrinkage and abnormal structures in the brain of his patient Auguste D. in 1906, a condition that was coined as Alzheimer's disease by psychiatrist Emil Kraepelin in 1910, dementia has largely been studied and defined through biomedical discourse. In biomedicine, dementia is conceptualized 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 ageing. She highlights just how much we do not know, from problems with Alzheimer's pathology, testing and diagnosis, to the search for drug treatment. Nonetheless, with its genetic, diagnostic and predictive uncertainties, the usual biomedical discourse about Alzheimer's disease shapes how people perceive and understand the experiences of those who are affected. In relation to dementia diagnosis, people use such references as the 'gothic and zombie stories' or the 'horror of Alzheimer's' (Taylor 2008: 317, 324). People with dementia are regarded as suffering a loss of both mind and self – as people incapable of rational communication or maintaining relationships. What Cohen (1998) terms as 'senility' has been 'reduced' to a medical problem, a progressive and terminal cognitive disease, within the rigid logic of dementia diagnosis and care (Cohen 2006: 3).

The biomedical construction of dementia diagnosis is to focus on brain pathology and symptoms of cognitive decline, which focus on impairments. These include: lack of capability in logical reasoning, planning, and ability to focus on intentional and purposive activity; decreased ability to be attentional, reflective, to form short-term memories or access long-term memories, such as autobiographical memory, as well as to communicate effectively using language. If we construct dementia as a cognitive disease, its biomedical framing poses a threat to the traditional concept of personhood, which is centred around cognition. 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 functioning mind is considered central to a meaningful existence of being able to sustain relationships with others in the world. Thinking about dementia in terms of brain pathology and symptoms of cognitive decline, dementia is seen in terms of loss: of mind, of self and of a meaningful existence in relation to other people and things.

In nursing homes, residents in the later stages of dementia are often described by some staff as 'dementia full stop', a phrase that suggests futility and finality. In this version of dementia, personhood is disintegrated and eventually dissolves into disease itself. Drawing on Erving Goffman's (1961) conception of mortification, Neil Henderson argues 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' marks the social death of the person (2003: 154). This represents the first burial (Kayser-Jones 2003: 66; Stafford 2003a: 17) before the person's second, biological death.

The power of biomedical framing 'reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives' (Foucault 1980: 39). When care is disease-centred, the lived experiences of people with dementia are perceived and understood as symptoms. Focusing on mental loss, their speech and movements are classed as 'behaviours' that are void of meaning. When their behaviours are thought to be excessive, persistent or harmful to other people and themselves, those behaviours are further constructed as 'behavioural problems', the behavioural and psychological symptoms of dementia, which require drug treatment or psychosocial intervention. As long as the lived experiences of people with dementia are biomedically constructed into symptoms that are pathological and abnormal, these constructs will affect how these people are cared for. This book will show how discourses of 'mindless' bodies or 'meaningless' movement promote the restrictive practices of fall prevention that often translate into restraint on aged care residents.

Biomedical framings and contemporary social imaginings of ageing and age-related decline limit our understanding of what can be made possible for elderly people to live a good life despite their various conditions and situations. While the notion of care is represented in aged care policy as a way of enhancing people's physical and cognitive capacities by extending the limits of what is possible for people who are severely impaired or dying, in practice care is often reduced to strict biomedical constructs. In contrast, this book advocates a rethink on what is 'reasonably possible' for the elderly by looking beyond biomedical understandings. My fieldwork with residents with a range of physical and mental disabilities (due to various forms and stages of dementia) enabled me to record and analyse the variety of their experiences, as well as to critically reflect on the surrounding ethics, politics and operationalization of care in the nursing homes.

In his conceptualization of a social ethics of care, Rapport (2018) draws on Jackson's (1995) notion of 'home' to emphasize how caring for the elderly is imperative to their achieving a sense of being-at-home-in-the-world. He points to the tension between 'being for oneself and being for others' and suggests that even as they are being cared for the elderly may simultaneously be constrained from exercising their free will. He thus argues that care needs to be a matter of upholding 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: 255–56). 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, within

Rapport's conceptual framework of social ethics of care, it is difficult to situate an ethical form of care for residents with cognitive impairments due to late-stage dementia. With its emphasis on cognitive capacity, his conception of 'personal preserve' is really only applicable to people who have mental competence.

In this ethnography on the minutiae of nursing home residents' movements, I argue that autonomy needs to be understood as something more than conscious choice and action. I examine the potential benefits of resident-staff-assistive technology assemblages to provide new knowledge about how people with dementia can still relate to others, not cognitively but sensorially and affectively, through movement.

Theoretical Directions: Becoming-at-Home in Movement

Writing from different theoretical perspectives, ageing and care-related studies frequently draw on the concept of home to think about older people's lives. The etymology of the word 'home' in both German and English shows a close association between house, or a dwelling place, and home in the material sense. Contemporary Eurocentric conceptions of home suggest a physical structure or dwelling. Founded on the distinction between public and private, and the inside and outside world, home is also conceived as a haven, a confined space that offers freedom and control, security, an intimate context for close, caring relationships and scope for creativity and regeneration. Related to this concept of home is the idea that it is an enclosed, private and domestic space, clearly differentiated from public space and shielded from public scrutiny and surveillance (Mallett 2004).

Unlike the notion of home as a domestic space, the nursing home is conceived as a contested cultural space 'composed of elements drawn from oppositional spheres of meaning: home and hospital' (Stafford 2003b: 121). It conflates 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 relationships, the concept of 'nursing' is associated with the fragility, disability and decline of aged bodies, and the 'bed-and-body work' involved in an institutional care setting (Diamond 1992; Gubrium 1975: 123). This contradictory meaning is seen by Stafford as 'the chief problematic of the nursing home – its *inherent cultural ambiguity*' (2003a: 8; italics original). Extending Stafford's illustration of the 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: 941) claims that nursing homes have two additional characteristics: that of hotel (in that older persons are customers) and as hospice, a place for those who are dying. Seen in this way, the institution is a hybrid of all four characterizations.

Researchers often frame their nursing home studies, explicitly or implicitly, within the relationship between home and nursing home and tend to focus on the movement of people from the home to the nursing home; that is, about making a transition from one place to another. Some researchers consider moving into residential care as a rupture, 'a transition from "doing for" to "being done for", as well as a transition from independence to dependence' (Higgins 1989: 141). In the analysis of the transition as a rupture and displacement from home, home and nursing home are conceived as two opposing concepts, domains or sociocultural spaces. The focus is often around the structures and practices at the institutional level (such as the care culture, routine practice and built design), which are seen as having significant influence on residents' lives. The transition from home to the nursing home is widely seen to involve multiple forms of loss – displacement from the family home, dispossession of pre-loved objects and dissociation from loved ones – leading to an overwhelming sense of withdrawal and disconnection. The loss incurred in the transition to nursing home life is often thought of as irreversible because residents can neither re-create their home in a nursing home or return to their own homes. The majority will eventually die in nursing homes, and with escalating dependence on assistance, tools and facilities, residents are portrayed as being a burden, increasingly helpless and lacking in autonomy.

The notion of home and nursing home as fixed and finished structural entities is increasingly questioned in contemporary research. 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. With a shift of focus from rupture to continuity, researchers gradually come to understand home as a *sense of home* and describe how home is felt and thought.

For theorists on home, a sense of home is made not only through social and discursive constructs as meanings but also through lived experience as senses and feelings (Ahmed 1999; Gurney 1997; M. Jackson 1995; Somerville 1992). As life goes on, a different sense of home may evolve over time. It can be oriented to production, a sense of security, stability and belonging; it can also be experienced as a sense of defence, protection and autonomy, as conveyed in the nineteenth-century saying, 'The Englishman's house is his castle'. The domestic environment is thought to imbue elderly people with a sense of control; it is where they can interact with their own long-held possessions and thus retain important memories.

Nursing homes today have evolved into a more home-like environments through their architectural and interior design. Residential aged care facilities encourage residents to bring personal possessions with them as an initiative intended to create a sense of continuity of life before and after nursing home placement. In both facilities where I did my fieldwork, I noted that on admission residents were encouraged to personalize their rooms using their own furniture, souvenirs and photos of families and pets (see Illustration 0.1). It is assumed that these objects from their former homes can help to transfer a sense of personal identity, home and belonging to their new lives in an unfamiliar institutional setting (Cram and Paton 1993; Rowles 1993). In discussions about what it means to retain a sense of home, researchers often refer to the objects, beings or relationships (such as with their beloved pets; see Illustration 0.2) that came from home and moved with people into the nursing homes.

Arguing that objects are not just passive symbols representing a sense of home, Lovatt wrote that it is not the objects themselves but the interactions between residents and these objects that enable residents to feel at home while 'doing home' (2018: 366). By the term 'doing home', Lovatt refers to a particular set of regular practices and routines, including acquiring new things, displaying existing possessions, and everyday domestic practices such as cleaning and hosting guests.

ILLUSTRATION 0.1. A resident interviewed in her room in the aged care facility in 2015. © Angela Zhang.

ILLUSTRATION 0.2. A resident and her cat in the aged care facility. Image provided courtesy of Elder Chinese Home.

With a shift of focus away from the physical surroundings where elderly people live and the objects that they possess, researchers are increasingly placing their study focus on individual residents and their own efforts to adapt to nursing home environments. Nursing home residents are often portrayed as being able to settle into their lives in nursing homes with a sense of peace, stabilization and satisfaction. As Minney and Ranzijn reported in their study on a South Australian nursing home, one resident grieved the loss of her beautiful home, but said, ‘I think I’m happier here’ (2015: 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: 271).

In describing practices of ‘doing home’ as residents transition to their new lives in residential care, researchers look for threads of continuity in what residents themselves do in order to adjust. This approach views the transition from home to nursing home as the process of becoming-at-home. 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: 11), Lovatt suggests that a feeling of belonging and a sense of control comes from the effort that residents make to incorporate objects from a previous life into their new nursing home environment. It is further argued 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: 375). For this to be true, the way that people feel and experience home would have to remain largely the same across different stages and settings of life.

However, residents' ability to manage everyday activities is affected over the course of their lives by their bodily conditions. Bodily deterioration accelerates in the latter stages of life. In failing to consider how ageing affects us physically as we go through life's stages, an important dimension of change is ignored. Although some research suggests that physical disabilities do not necessarily prevent residents from living active lives, the impact of bodily deterioration is captured in other studies and has been conveyed using residents' own narratives. Lily Robinson, a nursing home resident interviewed by Gubrium, contrasted her experience as a 'whole being' at home with her sense of 'being partial' living in a nursing home, regretting her inability to 'take care of everything' after the amputation of her legs (1993: 128–29).

The effort required to carry out daily activities is also affected by residents' material surroundings. Whether or not material things (e.g. an electric kettle or a toaster) can be made available to a resident (with or without signs of cognitive impairments) and how these material things should be provided (temporarily or permanently) and used (supervised or unsupervised) vary in different settings and permutations. Similar to the multidimensional home, as a site of caregiving, a nursing home is also a multidimensional institution, a site of contestation and complexity, made up of residents' regular practices, routines and interactions with their material surroundings. While in Lovatt's study residents could exercise a level of choice over which material things were provided in their individual rooms, acquisition of these material things was only made possible with the support of facility management and staff. Similarly, how various forms of assistance are provided (or not) impacts on residents' re-creation of a sense of home in the nursing home. Individual efforts to re-create home are always made according to the availability of supportive material things and persons, such as aid devices and carers.

This book has at its heart the lived experience of residents' declining bodies, specifically the care they need to enable them to move. As we know, and this book will show, ageing affects bodies; thus living out the final stages of one's life in a nursing home is not the same as living at earlier stages of one's life course. And yet residents in this study could often re-create a sense of home through the most mundane everyday activity – that of venturing to walk beyond the physical confines of their rooms. Instead of interacting just with objects within their rooms, residents moved beyond their personal quarters. With the help of assistive hands and mobility aids, they could be physically in touch with objects in communal areas: handrails in the corridors, or tables and chairs in the lounge and dining areas. Conceptualizing home in terms of household objects, which must, by definition, relate to domestic objects in residents' rooms, can be simplistic and reductive, as that definition cannot accommodate the complex and productive interrelationships between residents and other people and fittings in the wider nursing home environment, such as carpeted floors, grab-rails and corridors. As will be shown, the feeling of being-at-home emerges through the lived experience of being in contact with other people and other objects in the nursing home. When other bodies and material things support and respond to residents' attempts to move, this can lead to an overall feeling of satisfaction and wellbeing. It is precisely at this point that this study takes a departure from the existing literature on *what* home means to individual residents, to foreground instead the relational and embodied experience of *how* home is experienced in residential care. Although residents with severe physical or cognitive impairments could no longer carry out the routine activities that may conform to the usual idea of 'doing home', they could still experience a sense of home in the nursing home. This book explores what this means by investigating to what extent residents with different bodily conditions, including those with and without cognitive impairments, and with different medical conditions and disease trajectories, are able to move.

A sense of home will not be examined here through the lens of transition, which treats the idea of moving from home to residential care as an inevitable rupture, nor will it be explained in terms of objects or practices that inspire memories of a previous home. Instead, I shift my focus towards the *everyday movements* that residents in care are able to make. I hold the view that life continues across home and the nursing home not because of particular possessions, persons or practices but because, even in care, people continue to live their everyday lives through walking, standing and eating – the ordinary daily movements that are fundamental to our being-in-the-world (Barbaras 2008; Ingold 2011).

For Merleau-Ponty, 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: 311). Physical things and spaces can be incorporated into self on the motile, sensual, perceptual level by means of sensory extension through multisensory processes (Dennis 2007). For Dennis (2004), sensory extension or contraction gives rise to feelings of joy or pain. Approaching movement through the notion of sensory extension leads to the understanding of movement as both sensorial and affective. Dennis's notion of sensory extension is a form of relational extension (Latimer and Munro 2009): establishing person–world connectedness through routine practices in order to create a sense of belonging.

For Barbaras, life as such 'must be understood as movement in a radicalized sense, in which the living being is no more the subject than the product' (Barbaras 2008: 3). 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 in which being is movement (2008: 8). He suggests that movement is the manifestation of the life of a living being, 'a moment of accomplishment [which] passes into exteriority because it is only realized through concrete movements' (Barbaras 2008: 14).

Ingold (2011, 2017) considers that being alive is a mode of moving through the world with others. He coins the term 'correspondence' (Ingold 2017: 9) to describe the dynamic processes of engaging with other material things and beings as attending to and responding to in and through movements. In the context of this book, correspondence can be seen as the process in and through which residents' efforts to move are 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 in walking together. Thinking about home in residential care through the theoretical concepts of perception (Merleau-Ponty 1962), sensory extension (Dennis 2004, 2007), movement (Barbaras 2008) and correspondence (Ingold 2017) confirms the importance of supporting a variety of experiences for residents in different states of bodily and/or cognitive decline.

Returning to the notion of home, the sense of rightness experienced by nursing home residents resonates with what Michael Jackson, an anthropologist who studied among Warlpiri people in central Australia, describes as 'a sense of existential control and connectedness' (1995: 154). For Jackson, home is not associated with any particular property, place, possession, person or practice. 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 retains some control over and connectedness with the world. Feeling 'at home in the world' emerges 'when what we do has some effect and what we say carries some weight' (1995: 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 that can represent how 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: 14).

My fieldwork results suggest that some residents experienced a sense of being-at-home in the nursing home. However, unlike Jackson's informants, participants in this study were hampered by ageing and dying bodies. They experienced the existential imperative, not as a need for some degree of choice or control over their own lives but primarily as an innermost drive to move. This study follows their footsteps and traces their attempts to move and to act in the world despite their various states of bodily and cognitive decline. Accordingly, I extend Jackson's (1995, 2002) notions of home and the existential imperative to the everyday experiences of nursing home residents with physical and/or 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. Rather than understanding the world to be composed of relatively stable entities of things and beings, let us assume everything is in a state of motion, a process of becoming, a multiplicity (Deleuze and Guattari 1988). Becoming is thus not about what is already constituted and settled – subject or object, body or mind, wish or will – but about the shifting generative potentials made possible through desiring-production. In this sense, for aged and frail nursing home residents, walking is always a becoming-walking in which tensions between walking and not walking must be continuously negotiated. Drawing on Mol, Moser and Pols's (2010) work of care as a practice of tinkering, Puig de la Bellacasa (2011) and Martin, Myers and Viseu's (2015) work examining care through themes of power, and Rapport's (2018) notion of care as a balance between inclusion and autonomy, I want to show how right care, if it is to properly assist residents to have a sense of home, must be enacted differently, as multiplicities.

In this book, I set out to destabilize deficit models of ageing. The theory of desiring-production offers a useful analytic lens with which to examine how residents' stiff and sore bodies were set in motion in the actions of walking, standing and eating. The term 'desiring machine' (Deleuze and Guattari 1977) is used to describe how bodies and things come together in the process of desiring-production. A mouth is coupled with an edible thing, a pair of feet is paired with a surface to walk on; these become 'desiring machines', simultaneously affecting and affected, in connective and associative syntheses that induce movements and feelings. In walking or eating, the feet and the carpet, and the mouth, edibles and cutlery, respectively, come together as one, co-functioning in an assemblage

(Deleuze and Guattari 1988). The concept of assemblage is intimately related to ‘becomings’, processes in which disparate objects, beings, events and discourses co-exist as multiplicities through metamorphosis. Deleuze and Guattari’s terms of productive desire, assemblage and multiplicity are useful linguistic hangers for thinking about and articulating how residents may be supported to become mobile and feel more at home. In sum, I propose here that home is a process of becoming-at-home-in-the-world, and I explore how becoming-at-home occurs through shifting and entangled movements made possible through assemblages of things and persons.

The Nursing Homes

Fieldwork for this project occurred in two residential aged care facilities, Auxilia and Dulce Domum, situated in the suburbs of Adelaide, South Australia. Situated in an affluent area of Adelaide, Auxilia is a not-for-profit facility with over 150 government-subsidized aged care beds, while Dulce Domum, with around 80 beds, is affiliated to a large multistate aged care service provider in the private sector. The 230 residents living in these two care facilities had access to a wide range of amenities, including a community centre, café (see Illustration 0.3) and outdoor café (see Illustration 0.4), library, hairdressing salon (see Illustration 0.5), chapel (see Illustration 0.6), internet café and garden area (see Illustration 0.7).

Features such as the grand lobby, elevated interior decor, ‘deluxe’ rooms and polite well-trained staff were similar to those found in hotels. In that way, the commoditization of care is evident today in the aged care industry in Australia. Nevertheless, elderly Australians admitted into aged care facilities situated in less affluent suburbs may (and often do) live in environments that are quite different from those that form the background of this study. 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 have to share a toilet and bathroom. Residents living in other facilities may not have access to the many on-site amenities that are referred to this study. I try to describe the nursing homes in this book accurately, but it is important to remember they are by no means representative of all aged care homes in Australia.

Consistent with the aged demographic in the two 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. Most of the residents spoke English, even though some of them had difficulty with finding words or composing meaningful sentences due to cognitive impairments. Some overseas-born residents had

ILLUSTRATION 0.3. Residents receiving visiting family and friends in the on-site café. Image provided courtesy of Helpinghand.

lost their English proficiency and switched back to their mother tongue (e.g. German).

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 employed in Auxilia.

Moving, Observing and Describing in the Nursing Home

In this fieldwork-based study, I aimed to acquire a deep understanding of whether and how elderly Australians could feel at home in a nursing home during the last stages of life. I did so by attempting to feel in my own

ILLUSTRATION 0.4. Outdoor café seating. Image provided courtesy of Helpinghand.

ILLUSTRATION 0.5. A hairdresser serving a resident in the on-site hair salon. Image provided courtesy of Helpinghand.

ILLUSTRATION 0.6. On-site chapel. Image provided courtesy of Helpinghand.

ILLUSTRATION 0.7. A resident gardening. Image provided courtesy of Helpinghand.

body the movements that residents and staff made so that I could share in them. The word 'understanding' here thus refers to the ethnographic insights I gained through experiencing other ways of moving and feeling and then reflecting on my experience. It would not, of course, enable me to intimately know the experience as if I were an aged care resident actually living that life. Rather, instead of exploring what it is like to be a nursing home resident, I set out to acquire a deep understanding of residents' ways of inhabiting nursing home environments.

Undergoing an immersive process of gradual familiarization and differentiation was key to my decision to use movement as the prime methodological vehicle. 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 was a scenario for me to have different experiences (being assisted by different staff members in different contexts), see things from different perspectives (of residents, physiotherapists, nurses and personal care workers) and assimilate different care practices (assessment, care planning and staff-assisted walking and transfers) into my developing understanding of how residents are assisted to move in the nursing homes.

This multifaceted, open-ended process involved multisensory engagement with various objects and persons, such as aiding devices, other equipment and staff, and the complex interplay of discourses (e.g. funding schemes, work efficiency, staff workload and resident risk and safety). As shown in the photograph taken during my fieldwork (see Illustration 0.8), at one stage I relearned how to walk with assistance from a physiotherapist and a walking frame. I videorecorded myself walking with assistance, and also walking to assist residents, so that I could later visualize the movements and processes.

In watching movements in context, I could relate how I felt while moving with what I observed while watching, to later reflect on the process and make it explicit through description and analysis. In playing multiple roles – walking like residents, walking with residents, observing residents and staff walking, and then writing a care plan for staff-assisted walking and transfer – I became attuned to a mix of sensory, affective and cognitive experience and could then draw ethnographic insights. In moving, touching, watching, and being moved, touched and watched, as Latour argues, the body may be thought of as 'an interface that becomes more and more describable as it learns to be affected by more and more elements' (2004: 206).

My bodily engagement in daily care delivery revealed to me the asymmetrical power relations entailed in the social institution of the nursing home. This was made apparent when I was assisted by two personal care

ILLUSTRATION 0.8. The ethnographer learning to walk with a walking frame and assistance from a physiotherapist in 2015. © Angela Zhang.

workers with transferring from bed to chair (See Illustration 0.8), an activity that requires both the resident and staff to exert some force in order to push, pull, lift and turn in coordinated movements. With two care workers standing on opposite sides of the bed and looking down at me from above, I instantly felt the dead weight of my body, given my supine position, and I experienced for the first time the vulnerability of being a care recipient. 'You are in our hands now', the carer (with whom I had made an acquaintance) said jokingly, as she held up her hands. This feeling of being weak and vulnerable was deepened later when I watched the videorecording, which showed the specific deployment of my body in relation to the bodies of the carers in vivid detail.

By being involved in the particular bodily relations applied by a particular social institution, as Lyon and Barbalet (1994) argue, one's own body can be extended into a certain social order through sensory modes and means. What characterizes bodily relations in the nursing home are the authorized and authoritative touches and gazes of staff upon a resident's body and the effects on the recipient of such intimate contact. In this situation, power infiltrates care. This was revealed to me when I was myself 'manually handled' at different times, and staff made various comments about my performance. When I was more responsive to staff movements – namely, turning my torso to assist as one carer pushed and the other pulled – we could move together smoothly. They placed their palms gently on my shoulders and buttocks and described me as 'helpful'. But, when I appeared to be reluctant in responding, and staff had to lift my legs to turn

ILLUSTRATION 0.9. The ethnographer being assisted by two personal care workers with transferring from bed to chair in 2015. © Angela Zhang.

me, they described the situation as 'difficult', and I could feel discomfort when their fingers gripped me.

I also found that different staff used different manual handling techniques with me, according to their understanding of the resident's bodily condition, as described in the written care plan but also through their long-term experience caring for residents with or without cognitive impairments. One carer might ask me to turn to one side or to lift my leg, whereas her partner, who said that she had most of her shifts in the dementia unit, just silently applied the manual handling procedure, rolling me from side to side. Instead of giving me instructions, she moved me forcibly by pushing, pulling, patting or gripping. 'Residents with dementia don't follow instructions', she explained to me.

Methods used in this study fluctuated as I conducted the fieldwork, and I often expanded beyond research conventions that depend on language and reason. My study of movement needed to include residents with cognitive impairments, who are often excluded from research. This approach departed from conventional methodologies that depend heavily on language, in which participants are expected to produce oral narratives in interviews. The underlying assumption in much qualitative research (even that conducted in nursing homes) is that knowledge about people's experiences, the subjective meanings of what has been lived, can only be gained through verbal communication. But this cannot work for most nursing home residents. Cognitive impairment was very evident at my field study sites, and it meant most residents could not reflect on and articulate their thoughts and feelings. I realized that examining movement was one way that I could study the issues of participants whose concerns could not be articulated, or who articulated their concerns in a fashion that is 'imperceptible' within dominant ways of understanding (Papadopoulos, Stephenson and Tsianos 2008). This study thus offered a different window into how the elderly live their lives in residential care, and at the same time it challenged contemporary perspectives on ageing and dementia.

Structure of the Ethnographic Study

The book is divided into two sections. The first part focuses on walking by describing how various individual residents experience this important way of moving: it demonstrates that walking is more than an action performed by an isolated individual body; it is an activity entwined with the care provided to the resident by other people and things. Right assemblages of care could create new possibilities for residents to move. Part II extends the analysis on walking to other significant movements. Moving beyond walking as such, to consider sitting, attempted standing and eating, shows the complex and shifting interplay between bodily impairments, material surroundings, aged care discourses and daily practices in the nursing homes. Dying residents live in a kind of tension between the struggle to live and move and the urge to seek relief from their painful and declining bodies.

Notes

1. The COVID-19 pandemic has led to increased complexity of living and working in an aged care home due to outbreaks and restrictive measures to reduce the spread of COVID-19. My fieldwork was undertaken prior to the pandemic.
2. Final Report of the Royal Commission into Aged Care Quality and Safety (issued on 26 February 2021) revealed that older people in need of care prefer to receive care in their homes (Pagone and Briggs 2021).