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Voices of In-home Care

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Preface

This book is dedicated to people like Mr Perry whose anguish over his disabilities was such that he contemplated suicide; and Mrs Martin who laughed and cried as she recounted the experiences of receiving and recovering from a double amputation; of Mrs Jackson whose intelligence and vigour had led her to prominence in the community and who was desolate in her later years to find her experiences and knowledge dismissed by agencies and their care workers.

Family carers too have their own tales: of the tensions between caring for a parent while wanting to be with grandchildren; of Mrs Lee's problem of caring for a sick and demanding husband while others helped care for her own terminal cancer; of Mrs Barton's anguish of watching others care for her husband and getting it wrong. She sobbed in the Carers Circle that 'they won't listen to me, and he can't see to eat, and they don't feed him, and I have to go in to the ward and feed him.' Her husband's carers were unable to understand too that Mr Barton couldn't unwrap the sandwiches on his plate let alone see to eat them—and they reported him as 'not being hungry.'[1]

In this book we contest how society thinks about older people, especially those with frailties and vulnerabilities. Instead of the homogeneity, expressed as 'the elderly', which normally describes those of 65 and over, we offer a perspective of transition, of changes and differences in status and identity, as we focus on older people as they become more frail and vulnerable and move into increasing dependence.

The Age of Supported Independence offers a detailed view of significant changes experienced by older people and their families, as they face the frailties and disabilities which require formal care to remain at home. 'Challenging' is the best description of these later years, for older people, for the services they require to remain at home safely, and for their families to continue caring.

Remaining at home with care confronts the ideals of stability and continuity of both home and care, by challenging the identities of older people who face disruptions to their agency and autonomy in these later years. These senior citizens also

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[1] These instances are from Hale's work and writing (2000, 2006).

experience challenges to their feelings about their homes, their bodies, their relationships with family and friends, and their relationships with formal providers of health and care. To examine the changes which, to repeat, ‘challenge’ older people and their families, we use a secularised version of the classical rites of passage model. Ours is the first book to apply this concept fully, despite its being considered of use by many social gerontologists. The concept’s value lies, in the first place, in its holistic focus on transition and its grouping of spatial, temporal and relational changes which accompany the passage from independence to increasing dependence. Subsequently, the value lies in emphasizing a third stage, of ‘reconnection’, leading us to consider the situation of frail older people in terms of the wider society.

This concept of rites of passage has a further value in that it helps us identify a specific population who share a culture of ageing with disabilities at home and with care. We suggest these experiences lead to a distinct late-life stage, different from independence and from greater dependence. We describe this stage as one of ‘supported independence’ where remaining at home is intended to provide continuity and stability, but where living and coping with disabilities and receiving care presents a major disruption of this apparent stability.

Our conclusions recognise the critical necessity for considering how best to support, enable, or empower older people to maintain agency and autonomy. This, then, is the third stage suggested by the rites of passage model, of reconnection to the wider society, or perhaps, in our terms, maintaining interests and valued roles, and assuming a status of a valued identity in our society. We emphasise the role of in-home care work here, and offer other ideas to assist in fulfilling the wish of New Zealand and other governments to age-in-place successfully.

This perspective has emerged through the work and research of the authors in the field of ageing and health, and care at home. Beatrice Hale worked in the field of community development, with older people as a social worker, and as a volunteer coordinator, before completing her doctorate on ageing and home care. Patrick Barrett writes in his capacity as lecturer and researcher in health and policy issues, and has recently spent time at Aristotle University of Thessaloniki in Greece where he lectured on New Zealand social policy. Health policy specialist, Robin Gauld, who currently holds a Harkness Fellowship in America, studying American health and care systems, writes from his wide knowledge of New Zealand and American health issues.

The authors would like to acknowledge the help and support they received from their families, friends and colleagues. We owe special thanks to Andrew Parsloe for his meticulous work on the index.

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Introduction: Stake in the Ground

We invite you to explore with us the conception of a new social category within the once considered homogeneous group, 'older people'. We invite you to reflect on the situation of those older people who experience disability and who receive care and support at home. Such individuals sit between the full independence of the Third Age, those also described as the young old, and the dependence which necessitates institutional care.

With an increasingly ageing population there are growing numbers of older people with later onset disabilities who choose, or are encouraged, to remain at home, with care. These are revealed in new demographic categories in a number of countries, prompting the reflection that here we have a new social group, identified as a specific category by social statisticians.

There is, however, a danger in reducing vulnerable people to mere statistics in the demographic classification process, and in ignoring their lived experiences. There is also a serious risk in assuming that the reality of these lived experiences is derived from and maintained by the twin ideals of home and care.

The ideals of home and care evoke notions of warmth, familiarity, continuity and stability. Such an ideal permeates the ageing in place philosophy but as Twigg (2000) and Dalley (2002), among others, observe, the privacy of the home obscures many different situations. What takes place behind closed doors can be lonely, isolating, abusive, violent, and far from the ideal notions permeating ageing in place. The unspoken belief in remaining at home is that it is *the* place where the provision of support and care will best ensure wellbeing, comfort and safety. Thus, the assumption is that the cared-for individuals will continue to remain safely and comfortably in the familiar home environment to continue with their lives as they wish.

Our exploration of this time of life shows a somewhat different picture, one which reveals considerable challenges associated with the experience of advancing into receiving in-home care. Such a progression produces a series of not only physical, but also social and emotional disruptions, and not only for the older individual. Family members who become carers also experience their own significant disruptions as they move deeper into a caring role.

Given the number of people moving into in-home care, and the unique but shared experience of doing so, we suggest that this period of time be known as The Age of Supported Independence, a title which groups together those individuals with experiences in common, but also highlights the apparent contradiction in requiring help to be independent. Older people who experience the slow or sudden onset of disabilities find themselves moving from independence, caring for themselves and others, to a situation where they are dependent on help at home, but supposedly sufficiently independent to maintain other activities and interests.

For family members, this passage of a spouse or parent into increasing dependence is often accompanied by a now well-recognized transition to a new role of carer (Hirst, 2004). For the older person, many late-life transitions, such as retirement, bereavement, or a move into residential care, have long been recognized, often through formalised social events. However, this transition at home is only now beginning to be understood as another significant late-life stage (Bury, 1995 Efraimsson, Hoglund, & Sandman, 2001; Hallman, 1999; Kingston, 2000; Barrett, Kletchko, Twitchin, Ryan, & Fowler, 2005; Hale, 2006). Nevertheless, it lacks wide recognition as an important development.

Analysing the move to increasing dependence reveals the real nature of the disruptions involved: the need to adjust to living with an age-related disability, change in the daily patterns of living, the disruption of family and social relationships, and challenges to self-identity. Becoming a recipient of services in the home often encourages passivity, even when the goal is independence. With our practitioner gaze, we see such disruptions as amenable to informed interventions. For example, passivity and acceptance, or struggle and resistance, may mean an intervention to assist in regaining or maintaining autonomy is appropriate. This, of course, leads to questions about the relationship between autonomy and independence, something which will be discussed in more detail in the chapters. Such questions include: what is the independence in the phrase ‘supporting independence’? What does independence mean in this context? Is it synonymous with autonomy, and if not, what is the distinction between independence and autonomy, and how important is this in older age?

As Laslett (1996) observed, our world has never before experienced this increasingly ageing population with increasing numbers of older people. Members of the current generation of older people receiving formal in-home care have no models on which to base their actions. Their experiences are themselves the models for future generations. In the past, where there were needs, these were usually met by informal family care (although Laslett’s (1996) research shows that this was less so than we have always believed), with minimal formal home care and institutional responses including residential care and hospital care. Now family care is supplemented with in-home care, and often day care and respite care, and for the family carers, time out in the form of carer support breaks.

Families themselves are changing. Families today are more mobile and geographically dispersed, more likely to experience spousal separation and family reconstitution, and women are more likely to be in paid employment, usually outside of the home. For many, this means that they are unable to care for older members. Such changes contribute to the need for more formal home support for older people.

In our minds, these changes suggest that this cohort of older people is a 'threshold' generation, who, given broader changes in the economy, society and family, are experiencing for the first time the provision of formal home care provided on such a large scale. Members of this generation stand between the arrangements that involved predominantly informal care and those involving institutional care, due in part to their level of need, often greater than the families can manage, and their wishes to remain at home, now able to be fulfilled due to the current arrangements of formal paid care.

Our Approach

To clarify this process, and to emphasize that there is such a group, we have drawn a line round this particular set of experiences, and concentrate on the changes and experiences specific to this situation. Our goal is to examine these changes and experiences in greater depth. Our initial observations of the experiences of older people undergoing these changes suggested patterns of events similar to those of a secular rite of passage. We therefore draw on the rites of passage notion and use it in this secular situation, as Turner (1974) suggested, as a means of providing 'flashes of insight' to illuminate the personal and social dimensions of these experiences.

Van Gennep's (1909) tripartite rites of passage concept depicts key life stage transitions as constituting three distinct processes. The first of these is a separation from the current stage through some type of disjunctive experience. The second is a stage of liminality, an 'in-between' stage characterised by an unsettled social status and identity. The third involves reincorporation and reconnection with the wider society, with 'a new set of rules, roles and obligations' (Hockey & James, 2003, p. 25). Focusing on these broad processes has potential, we suggest, to highlight this little-explored period of ageing and provide a fresh understanding of the experience of transition. By following this period of ageing from the onset of frailty, through assessment to acceptance of care and thence to a question of 'reconnections', we have a closer view of some of the key dynamics of the transitions within the home from independence to increasing dependence.

We position this work alongside examinations of ageing, structured dependency, and agency. Our concern is with not only locating the experience of the individual within structural contexts that disempower and isolate, but also with challenging those contexts with the specific aim of empowerment and promoting greater inclusion of older people in decisions that affect them (Achenbaum, 1978; Moody, 1988; Minkler, 1996; Phillipson & Walker, 1986). Like Polivka and Longino (2004), we aim to achieve a synthesis that gives

> equal weight to ensuring the economic security of the elderly and creating more flexible self-empowerment-oriented policies that reflect the freedom and individual autonomy (p. 5).

The transition into frailty, disability and the need for care, which is our primary concern has typically been examined from an individual, biomedically focused perspective as Markle-Reid and Brown (2003) have suggested. Such analyses of these processes tend to focus on the interaction between the ageing body and the environment, and the loss of equilibrium that occurs when an older person crosses a certain threshold in ability to continue to live independently. Early studies in this tradition have emphasized that the individual's relationship with their environment in old age was characterized by a process of disengagement (Cummings & Henry, 1961). Bond and Cabrero (2007), among many others, observe that this contributed to '[a]n enduring stereotype of human ageing [as] one of inevitable ill-health and mental and physical incapacity leading to disability and dependency' (p. 113). Such a negative stereotype underpins ageist ideas and attitudes, and these pervasive stereotypes in turn shape personal constructions of ageing as Bytheway (1997) has observed. Decline and disengagement approaches ultimately explain many of the experiences in later life in ways that emphasise passivity, acceptance, and less active individual and physical processes. As a consequence, the policy and practice interventions that emerge tend to focus primarily on the individual and on efforts to hold back and perhaps even reverse individual decline (Heywood, Oldman, & Means, 2002, p. 23).

Critical approaches to the study of ageing have challenged this type of analytical framework for the underlying principle behind it, of individualizing old age, and presenting it as some type of pathology. The significant contribution of the political economy approach was to conceptualise old age as a 'social construction', with shared experiences in later life being understood as the outcome of broad economic and social structures. So, for example, a nation's compulsory retirement policies, its pension system, or its arrangements for the provision of social and health care services began to be seen as structuring the lives and framing the opportunities, or lack of them, of older people. Biological ageing was not denied, but with this social constructionist approach the focus shifted to how policies were rooted in ageism and in conflicting power relations. Dependency in old age began to be recognized as a social creation (Walker, 1980) and the role of the medical and care industry, developing around the social category of the elderly, was recognised as contributing to such dependency (Estes, 1979). Townsend's (1963, 1981) work is a major example of observing the categorizing of the elderly but also of assigning the feature of dependency, when he suggested that elderly residential care models were a very clear illustration of the way in which ageism had become institutionalized. His criticism has extended to community care also, with a concern that community care models could create dependency. Institutional ageism, from this perspective, then, was seen as a consequence of discrimination purely on the grounds of chronological age, resulting in the marginalization of older people and their exclusion from full participation in society.

More recent iterations of the critical approach have insisted that older people are not passive subjects within these structural contexts and that the study of ageing should include a concern with questions of identity and meaning in old age. To gain an understanding of issues of identity and meaning attached to the life events and circumstances of old age, according to this approach, requires understanding what Tulle (2004, p. 185) describes as the 'normalizing discourses which people have to manage and negotiate as they get old.' This requires interpretive and/or qualitative methodologies to capture the subjective experiences of older people and privilege their voices and their descriptions of the experience of ageing. It also brings a humanistic (Phillipson, 1998; Heywood et al., 2002) concern into the study of ageing, shifting the focus to include consideration of the way older individuals respond to and, in turn, influence their environments, and to how they adjust their behaviour in response to their changing abilities and surroundings. The capacity to act on one's environment, or human agency, is thus also recognized. Gilleard and Higgs (2002, p. 3) comment that 'only in the late twentieth century has the idea emerged that human agency can be exercised over how aging will be expressed and experienced.' This is not, as Phillipson (1998) says, to argue for:

> a narrow 'postmodern' view of aging which focuses simply on choice and reflexivity, ignoring the profound inequalities of class, gender and ethnicity which continue to shape the lives of older people. Rather, it is a middle position between these two (p. 127).

We aim to make a contribution by illuminating the experiences of frail or disabled older people, who move into dependence in their own homes and who are at risk of being denied agency. As Polivka and Longino (2004) observe:

> It is precisely when the individual begins to experience the erosion of freedom and agency that often comes with impairment and frailty that public policies should be designed to provide the resources needed to resist the loss of agency and allow the individual to exercise as much autonomy as possible under conditions of impairment (p. 5, supported by Tulle, 2004, p. 185).

Finally, we recognize the importance of understanding ageing within the context of the life course. This implies a need to understand, as Conway (2004) says, 'the life course paths that people follow which shape their sense of social identity' (p. 87). Doing so enables us to capture both individual and the common aspects of ageing, and the way in which the life course overlaps with broader social and institutional structures within the context of distinctive historical periods. These social and institutional settings frame the channels for action and establish the boundaries of what is and what is not possible for older people.

Our concern is to hear the voices of older people facing the transition into frailty, observe how they respond to this situation, and understand the means by which social and institutional processes marginalize and exclude them as they experience that process. We are also concerned with how their families respond to and cope with these situations. That is, we are concerned with examining how families cope when an older member moves into the stage of needing additional care to remain in the home, how this affects family and social relationships, and how individuals and families re-make or re-establish social meaning after the onset of frailty. The rites of passage concept provides insights into the detail of such transitions, allowing each set of changes to be examined more closely. By highlighting the difficulties many older people face in making 'reconnections' following the onset of frailty and disability, the approach provides a new basis for the critique of the philosophies and policies of ageing in place. Finally, we aim to recognize and reaffirm through our own work, and the work of others, the self-worth of older people by enabling them to tell their stories of becoming dependent on informal and formal home care in later life. Contemporary research from a number of countries has indicated an increasing consciousness of the growth and situation of such a group of older people, though the initial ideas underpinning this book have come from field research conducted in New Zealand by Barrett et al. (2005) and Hale (2006). We have drawn on this work and considered it alongside comparable research from Australia, the United Kingdom, the United States of America, and, in particular, the Scandinavian countries. We believe the strength of the book lies in such a broad-based, comparative approach which has sought to integrate the insights of researchers from various countries with our own.

Outline of Chapters

The first chapter of this book explains and justifies our idea of a proposed new life stage of supported independence through an examination of the demographic and policy contexts. The chapter also introduces the process of the passage, or transition, from physical wellbeing into physical frailty and greater dependence.

Chapter 2 combines quantitative analyses of broad demographic trends with qualitative analyses of the individual dynamics involved in the transition, including the role played by concerned family members and the formalised needs assessment processes.

In Chapter 3 our focus shifts to the experience of becoming dependent and remaining at home. This chapter continues the theme of transition in terms of housing moves, internal spatial changes in the home, and the introduction of aids to independence. We build on Rowles' (1993) analyses of the changing subjective meanings of space in the home, as the mobility range of the older person reduces in size and we consider the compensatory role of prosthetic devices and technology. Our analysis of issues around space includes consideration of the tensions that arise from these spatial and prosthetic adjustments—how they are welcomed to compensate for lost abilities and at the same time disliked for their restrictiveness and invasiveness. These relate to the body, currently a sociological preoccupation, but significantly here a major preoccupation for older people with disabilities, which we examine in terms of 'site of care', self-presentation of bodily limitations, and presentation to others. On reflection, our argument is that these individual, specific, and microscopic data generate a sense of the liminal and that individuals are experiencing the second stage of the rite of passage, liminality, with its anxieties, uncertainties, contested autonomy and changing roles and norms.

Further individual reflections and experiences, this time on temporality, are explored in Chapter 4, where we consider the issue of 'time' and the temporal experiences of older people receiving in-home care. We provide an account of how the older person becomes part of a system, which assesses needs and funds home help in terms of ‘hours’. We hear the voices of older people discussing a mixture of time frames and consider how such plurality can leave the care recipient in a liminal situation, lacking authority and with compromised autonomy. We discuss, using examples, the tensions arising from different perceptions of time, such as the clock time of the agency workers and the disability time of the older person.

The next chapter explores the new relationships formed at this time of life, usually with formal care providers. We extend this examination to consider the changing relationships with family members who become informal care providers. Subsequently in this chapter, we consider the transition of family members themselves as they too experience an ambiguity of role, of being both family and caregiver. We consider the stories of family members from the onset of decline that triggers the needs assessment process, and the subsequent provision of in-home care to the older person. From these original data, which trace the experiences of family members who ‘take it on’ and ‘see it through’ (Wilson, 1989a, b), we again have a sense of the liminal, this time in terms of negotiating autonomy and agency in new and changing relationships for the older person, and in terms of the changes to the roles and norms of family members.

Chapter 6 considers the liminal situation as it has been developed throughout previous chapters. Transition into greater dependency has significant implications for the autonomy of the older person. The policies of ageing in place assume the ideal of home, and that independence is maintained by being supported to remain at home. We question the use of the words independence and autonomy, and suggest that while a certain independence is maintained, autonomy in terms of choices and authority is compromised. In Chapter 6 we explore, first of all, the implications of frailty and in-home care on autonomy. We offer an interpretation of these experiences of older people which emphasises their position somewhere between independence and dependence, a status that can be understood in terms of the second stage in the rites of passage sequence as one of liminality. We challenge current policies to assist in creating reconnections, a theme that we pick up in the next chapter.

The dual position of the care workers is the focus of Chapter 7, and we examine their place in home care, as individual workers and as representatives of the agency and industry. Our exploration of different models of care leads us to ask: can the role of care workers be extended to that of active catalysts for positive ageing, and in reconnecting older people? The care worker position is significant, and we consider it in terms of the relationship with the older person, and the family carer, within the home and within the industry.

In the final chapter, as a direct result of applying the rites of passage to this period of the life course, we emphasize the need for policy and practice to give consideration to the liminal situation in which many care recipients and carers find themselves. By drawing attention to a stage beyond liminality, Van Gennep’s (1909) third stage of ‘re-incorporation’, we highlight what can lie beyond experiences of separation, disruption and ambiguity in social role. We perceive new patterns of behaviour, new ‘rules, roles and obligations’, new features and activities in the lives of older people and their families. We suggest, therefore, that policy makers be aware of this potential and give attention to models of in-home care that assist the passage beyond experiences of liminality. We make recommendations for care worker practice and emphasize the need for social workers, in particular, to be more involved in this time of ageing, to guide older people and their families through the liminal stages. We consider care policies, housing needs and policies, and transport needs and policies under the umbrella of 'reconnections'.

We end by summarising our concept: this is a new age for older people at home which involves important changes in personal identity, relationships, and engagement with the wider social involvement. There are as yet no role models for this age. We are all pioneers in considering how to ensure the best possible ageing-in-place. In writing this book we have, we hope, created an awareness of the difficulties, of the lack of agency which so many people experience. By identifying the key features of this age and stage in the life course, we have provided more information for policy makers and certainly practitioners, to improve this time for older people.

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Chapter 1
The Demographic and Policy Context of Supported Independence in Later Life

1.1 Introduction

In the late twentieth century, in response to the changing age structure of the population and an awareness of the preferences of older people, there developed a broad agreement around the idea of supporting ageing in place. As a result of this broad agreement and consequent policies, countries have seen a considerable growth in the number of people who want, and are now able, to remain at home with care. We argue that a new social category has emerged—of older people living at home in a state of supported independence. But because the home is in the private sphere, individuals experiencing disability and care at home often feel their experiences are unique, or that they are amongst only a small group of like people. Rarely, in our experience, do those receiving home care services realise the larger-scale nature of the needs and policies behind these services. Nor is there the ability and opportunity to create or experience communitas, either spontaneous or normative (Turner, 1969, p. 132). Because of the isolating factors of disability and the privacy of home, there is little scope for common feelings of solidarity and togetherness among care recipients. Needless to say, however, policies, services and individuals are inextricably linked, and we provide here a selective review of the demographic and policy features that have a bearing on the increasing number of older people who are now enabled to remain at home with formal assistance.

We emphasise that this is not an unproblematic life stage and that, for the policy of ageing in place to deliver its promise, we need to understand better the particular challenges and experiences of people facing the transition into receiving care in the home, as well as those challenges and experiences of remaining at home with care.

1.2 Key Concepts

The study of ageing is described in different ways. In this section we outline key concepts which we draw upon in discussions throughout this book. We use impairment and disability in the same way as the WHO (1980) International classification of impairments, disabilities and handicaps (ICIDH) which says, ‘Impairment concerns the physical aspects of health; disability has to do with the loss of functional

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capacity resulting from an impaired organ.' Further, disability is defined as a restriction or inability to perform an activity in the manner or within the range considered normal for a human being, mostly resulting from impairment.

The term home care seems self-evident, and the definition we use is shared internationally: assistance with domestic and/or personal care tasks which support the individual in his/her activities of daily living. There is often some confusion over the terms of carer, care worker and caregiver. We have adopted the term 'carer' to be that of the family member while 'care worker' or 'caregiver' is that of the paid formal worker who assists the older person in the home.

Our term 'supported independence' is used to mean the specific care work or services that enable the older person to continue to live at home and in the community. These include both informal and formal care. Informal care is unpaid and provided by spouses or partners, children and other family and household members, neighbours, friends or others within the older person's social networks. By formal care we mean services provided by employees of public, private or community and volunteer organisations, where the actual care work is carried out by either professionally trained caregivers or untrained care workers (OECD, 2005, p. 17). This care work or these care services include personal care with showering, toileting and dressing, supervision of medication and any other medically related work, domestic cleaning, cooking assistance, and assistance with shopping. The formal services may be paid for by any combination of private, social insurance or public sources (Burau, Theobald, & Blank, 2007; Doyle & Timonen, 2007). Here, however, we are more concerned with those services funded by governments, and resulting from policies from various governments.

Clearly, the older people with whom we are concerned depend on these domestic, personal or health services provided to them in order to remain safely at home. While the amount and type of care may fluctuate over time, this type of dependency is ongoing. Reducing dependency and promoting independence has been a touchstone in international debates around ageing and aged care policy (Gibson, 1998, p. 199). We recognise the generally negative connotations of dependence and the positive connotations of independence, with dependence being something to be avoided, and independence something to be aimed for. That this is not entirely the case can be seen in Baltes and Silverberg's (1994) work on ageing and dependency. They state that increases in dependency which are a consequence of decline or loss of physical or mental functioning can be thought of as a:

> positive adaptation strategy, if dependence in some areas is used to protect reduced resources in order to maintain independence in 'key' areas for that individual. Certain levels of dependency can thus be seen as positive (and 'normal') at latter stages of the life cycle (Gibson, 1998, p. 198).

The issue which many older people face is not so much the care that is provided and dependence on that care, but the degree of autonomy and control over their lives. The acceptance of the need for care, then, can be seen as a type of positive dependency and the challenge for service providers is to deliver that care in a way that sustains, or supports, the autonomy of the older person.

The notion of ‘supported independence’ can be found in the New Zealand Government’s document ‘Support for Independence’ (Ministry of Health, 1992), where it was defined as being enabled by assistance with personal and domestic care to continue to live independently at home. In that report, though, the implication was that the ideal for the older person was to have as little reliance as possible on the formal services funded by the state and to maintain independence, free from state assistance. Our use of the phrase ‘supported independence’ implies something a little different. Supported independence accepts positive dependence and promotes support to enable the pursuit of individually defined goals and activities. When we refer to ‘supported independence’, we are endeavouring to capture this notion of positive dependence—whereby frail or disabled older people are supported to maintain decisional autonomy and control over their lives. We explore this theme throughout the following chapters and return to it explicitly in the final chapter.

1.3 The Demographic Context

We approach the study of this life stage transition against the backdrop of significant change in the age structure of populations, resulting in growth in both the proportion and number of older people in many countries. This age-structural transition (Pool, 2005), the causes of which are underpinned by deep-rooted socioeconomic and health related factors (Dunstan & Thomson, 2006, p. 12), has to date been primarily evident among those in the under 65 years of age group, but it has begun to work its way through the remainder of the life course and will be most strongly evident among those over 65 years of age in the coming decades. If we assume that gains in life expectancy will continue, that the fall in fertility will not be rapidly reversed, and that international migration will play only a minor role in population age structures, then we can project an impending rapid increase in both the proportion and the actual number of older people across OECD nations (OECD, 2005, pp. 99–100; Harper, 2006, p. 3).

This historically unprecedented change will result in older people making up a greater proportion of the population as a whole. In New Zealand, for example, those over age 65 in terms of the proportion of the total population have increased from 8% in the 1960s to 12% in 2005, and are expected to increase to over 25% in the 2030s. Here, the over 65s is the fastest growing sector of the population, with growth occurring at more than twice the rate of growth for the population as a whole, and between 2005 and 2051 growth in this age group is expected to make up 87% of the growth in the total population (see Dunstan & Thomson, 2006, p. 15). Table 1.1 lists the shares of older people in the population for selected OECD countries (Germany, Japan, New Zealand, Sweden, the United Kingdom, the United States—these countries being selected as they represent exemplars of different home care regimes) and shows projections that the proportion of older people will increase rapidly over the coming decades up to 2040. The share of those 65 and over in the population is projected to nearly double in these countries between 2000 and 2040.

Table 1.1 Share of older persons in the population, 1960–2040

	65 and over					80 and over				
				Change in % points					Change in % points	
	1960	2000	2040	1960–2000	2000–2040	1960	2000	2040	1960–2000	2000–2040
Germany	–	16.4	29.7	–	13.3	–	3.7	8.7	–	5.0
Japan	5.7	17.4	35.3	11.7	17.9	0.7	3.8	14.1	3.1	10.3
New Zealand	8.6	11.7	22.8	3.1	11.1	1.5	2.8	7.0	1.3	4.2
Sweden	11.7	17.3	25.2	5.6	7.9	1.9	5.0	7.9	3.1	2.9
United Kingdom	11.7	15.9	25.4	4.2	9.5	1.9	4.0	7.3	2.1	3.1
United States	9.2	12.4	20.4	3.2	8.0	1.4	3.3	6.9	1.9	3.6

Source: OECD (2005, Annex A, Table A.1).

There will be significant growth in the share of the population aged 80 and over, with Japan having by far the largest projected change in share of older people.

Another indicator of the changing demographic context is the age of those who make up the older old proportion of the population. The OECD (2005) projections show this trend in terms of growth in the share of older persons (65 and over) who belong in the oldest age group (80 and over). In 1960, one in seven belonged in the oldest age group; today it is more than one in five; and by 2040 this is expected to rise to one in three (Table 1.2). As this group has the highest care needs, we might conclude that there will be growing demand for long-term care in all OECD countries in the coming decades, although there will be differences across countries given different ageing patterns and trajectories. Table 1.2 indicates that Sweden, for example, already has the proportion of oldest old persons in its elderly population that is close to the estimation for all countries in the year 2040.

Increases in life expectancy at both age 65 and age 80 has increased over the latter half of the twentieth century (Table 1.3). Increases in life expectancy at age

Table 1.2 Share of older persons (80+) among the elderly, 1960–2040

				Change in % points	
	1960	2000	2040	1960–2000	2000–2040
Germany	–	22.3	29.9	–	7.6
Japan	12.6	22.0	41.1	9.5	19.1
New Zealand	17.1	23.8	30.5	6.8	6.7
Sweden	15.9	29.0	31.5	13.1	2.5
United Kingdom	16.4	25.4	29.1	9.0	3.7
United States	15.2	26.4	33.3	11.2	6.9

Source: OECD (2005, Annex A, Table A.2).

Table 1.3 Life expectancy at age 65 and 80, 1960–2000

	Life expectancy at age 65				Life expectancy at age 80			
	Male		Female		Male		Female	
	1960	2000	1960	2000	1960	2000	1960	2000
Germany	12.5	15.7	14.6	19.4	5.2	7.0	5.9	8.5
Japan	11.6	17.5	14.1	22.4	4.9	8.0	5.9	10.6
New Zealand	13.0	16.5	15.6	19.8	5.5	7.4	6.4	9.2
Sweden	n.a.	16.7	n.a.	20.0	5.7	7.1	6.2	8.8
United Kingdom	11.9	15.7	15.1	18.9	5.2	6.9	6.3	8.6
United States	12.8	16.3	15.8	19.2	6.0	7.6	6.8	9.1

Source: OECD (2005, Annex A, Table A.3).

80, especially, imply growth in that age group among whom functional limitations are more prevalent.

Table 1.4 shows disability-free life expectancy, this being ‘the number of years without major functional limitations with activities of daily living’ (OECD, 2005, p. 106). The direction of evidence on this topic does support the hypothesis that increasing longevity is being matched by increases in the years of disability-free living, but the OECD data suggests this trend is not clear for many countries. These data also suggest that some countries—New Zealand, the United Kingdom and the United States—have lower rates of disability-free life expectancy than other countries, suggesting proportionally greater demand for services in the future, as well as a need to pursue the development of preventive services.

This brief demographic review suggests that the overall trend towards an older population is shared across countries, although there are differences in patterns and rates of ageing (Pool, 2005). To these broad trends in OECD countries can be added the observation of the important trend in the living arrangements of older people, the tendency for a greater number to be living alone, especially women. A part of this is that women outlive their husbands. Further, fewer are likely to be living with relatives, especially adult children (Grundy, Jolley, & Heath, 1999). Remaining in their own home instead of living with children or in residential care has been shown to be

Table 1.4 Disability-free life expectancy at age 65

	Male				Female		
	Year	DFLE	LE	DFLE/LE in %	DFLE	LE	DFLE/LE in %
Germany	1995	12.2	14.7	83	14.9	18.5	81
Japan	1990	14.9	16.2	92	17.3	20	87
New Zealand	1996	7.5	15.5	48	9.2	19	48
United Kingdom	1995	8.3	14.6	57	9.5	18.2	52
United States	1990	7.4	15.1	49	9.8	18.9	52

Source: OECD (2005, Annex A, Table A.5).

the preference of most older people (Peace & Holland, 2001, p. 8). Increasing financial independence, with the extension of pensions through the twentieth century has led to more older people being able to avoid co-residency and maintain their privacy (Glaser, Tomassini, Racioppi, & Stutchbury, 2006, p. 81; Grundy, 2006, p. 118). In addition, broader demographic trends such as lower fertility mean there are fewer relatives to reside with and receive support from if it is needed. The capacity of families to provide care is also changing. Increasing participation by women in the labour market is linked with a reduced ability and willingness to perform the caring role, especially for the greater length of time implied by trends in longevity. Furthermore, trends in separation and divorce are said to be weakening family ties and therefore the feelings of obligation that lead to family caring activities. This all does increase the need for formal care services.

How have countries responded to these changes? Timonen (2005, p. 47), in her review of policy paradigms and long term care, notes the common shift towards greater emphasis on home care. The growing importance of home care can be seen through time series data within specific countries. Comparisons of trends are complicated by the different definitions that are used, but the OECD review of patterns of care within countries shows a steady increase in the number of people receiving care in the home, with Sweden having provided a higher level of care in the home, for a longer period than other countries (Table 1.5).

The OECD (2005) observes that, increasingly, member countries are exploring the provision of more intensive care in the home as an alternative to institutional care, and note Sweden and the United Kingdom as being in this category. Providing care to the more severely frail and disabled is resulting in an increase in the overall amount of care being provided in the home, but the OECD (2005) also note that in the United Kingdom and Sweden, this is going to a smaller number of severely disabled people. In the United States, the Medicare programme, which for older people needing care is primarily aimed at meeting nursing home costs, is allowing an increasing number of states to waive these requirements and support people in their homes. In Germany and Japan, new schemes have been introduced to direct a

Table 1.5 Recipients of institutional and home care services aged 65 and over

	Year	65+ receiving long-term care in an institution (%)	Year	65+ receiving home care benefits (%)
Germany	1997	3.3	1997	7.3
	2003	3.9	2003	7.1
Sweden	1991	6.4	1990	13.4
	1995	8.8	1995	8.9
	2000	7.9	2000	9.1
United States	1985	4.6	1992	3.0
	1995	4.2	1996	5.3
	1999	4.3	2000	2.8

Source: OECD (2005, p. 41, Table 2.3).

greater amount of resources to supporting disabled older people in their own homes, in Japan through the direct provision of services, in Germany through either cash or in-kind services.

New Zealand is also developing models for more intensive care for older people in the community, although the capacity of the care sector to meet these growing demands within the context of an ageing population has been questioned. The New Zealand Department of Labour's (2009) review of the future demand for paid care in an ageing society asserts that the projected growth in the aged population, assuming a similar prevalence of age-related disability, will see demand for paid care workers more than double. Similar observations are made regarding the aged-care sector in Australia (Hugo, 2007). In this context, unless there is an increase in the proportion of paid aged-care workers in relation to the population as a whole, there will be a significant shortfall. The New Zealand Department of Labour concludes that the current trajectory of growth in the aged-care sector is not sustainable and recommends long-term planning around the future of the aged-care workforce.

1.4 Policy Contexts

Recent reviews of care policies for older people suggest that consistently divergent patterns of social service provision evident in the notion of distinctive welfare state regimes can be found also in the area of care policy, although Timonen (2005, p. 47) notes that there is a shared tendency among countries from all regimes increasingly to use markets and private providers in the delivery of home care. In part, the reason for this includes a continuing wish to support independence and strengthen individual choice among service users. Variations in home care policy across countries determine the relative responsibilities of the family, voluntary and community sector, the public sector, and private organizations and markets. As it is, care systems typically are complex, with different combinations of policy instruments and different emphases on the roles of state, market, community organisations and family. These policy settings also determine the funding and regulation of services, and the degree of choice and control an older person has in using services. They determine those with whom individuals interact throughout the assessment process and the level and type of care they receive. The transition into supported independence, then, occurs within different structural contexts, with profound implications for the individual's experience.

Timonen (2005) has proposed three broad paradigms of home care which capture different policy orientations for the organisation of home care services. While all paradigms have common policy instruments for the provision of care, her classification distinguishes models of care by identifying the overwhelming characteristics of a country's policy settings. She distinguishes three ideal types, broadly consistent with Esping-Andersen's (1990) social democratic, liberal and corporatist welfare regimes: the statist model, where assistance is universal and the state takes extensive responsibility for delivering services, and where the focus is on providing services in kind; the familial/individualist model where assistance is means-tested and families and individuals take responsibility for delivering the majority of the care; and the mandated social insurance model where the state mandates universal insurance and where families and not-for-profit agencies overwhelmingly provide the social care. Denmark is a country example of the statist model, the United States an example of the familial/individualist model, and Germany an example of the mandated social insurance model. These different policy arrangements do affect the experience of care to the extent that they influence the eligibility criteria, the assessment process, the financing and regulation of care systems, and the opportunities for choice and control by the care recipient.

1.4.1 Determining Eligibility

The assessment of the older person's needs is central to the process of determining eligibility for home care. Typically, the process is concerned with determining whether older people who are frail or have a disability are having such difficulty in performing everyday tasks, such as dressing or preparing meals, that they are likely to need to go into a nursing home or residential care facility. Decisions about whether an individual is eligible occur within the context of a country's broader approach to welfare assistance and countries differ markedly in the procedures to determine eligibility (Doyle & Timonen, 2007, p. 106). For example, Denmark has an egalitarian eligibility system which provides universal eligibility to all Danish citizens who need care and who can remain at home. Care is provided through general taxation, and a person's income or assets are not taken into account in the assessment. Nurses employed by the local municipality carry out the assessment, the criteria for which are not based narrowly on functional capacity or minimum standards, but on a holistic view of the older person's situation. Broader psychosocial needs and circumstances of the potential care recipient are taken into consideration. Denmark begins offering such assessments to all older people every 6 months after reaching age 75. There is therefore an important preventive component to the system, with a good chance of identifying problems at an early stage, before the point where the individual requires residential care, and providing assistance to delay or avoid such an admission. The Danish system, therefore, exemplifies a model that provides for early intervention with lower level problems and, thus, the provision of protective services that reduce the rate of deterioration. It also means more older people receive services, creating an environment where in-home care is normalized and without a negative stigma.

In Germany, the long-term care insurance system covers all older people and does not take into account financial history and income. Assistance, however, is provided only on the basis of meeting strictly applied functional status criteria. Assessments define individuals as having one of three levels of need: substantial, severe or very severe, based on assessments of difficulties with activities of daily living. The assessment is conducted by either a nurse or physician employed by the insurance fund using a nationally standardized assessment tool, which aims at ensuring equality in assessment. The emphasis is on the individual concerned and their physical capacity, with no account taken of either financial means or of the presence of a family member able to care. In these circumstances, by comparison with the Danish experience, there is potential for the assessment to be limited primarily to medically related needs. If eligible, care is provided either in payments for services or in in-kind services.

Moving to the USA, public funded home care in California, as an example of the familial/individualist model of care, is strictly means-tested by comparison with Denmark and Germany. Its availability is limited to only a small segment of the older United States population and it is not typically described as a system of care (Doyle & Timonen, 2007, p. 107). It is funded by a combination of federal and state taxes and eligibility does vary across states. The capacity and commitment of the individual state to provide funded care services determines to a large extent the level of service. In California the criteria for means-testing are contained within Medicaid rules, and include an income test, an asset test, provision for estate recovery, and prohibitions on asset transfer (Tilly et al., 2000). Functional eligibility is based on state-wide assessment formats which measure the ability to perform activities of daily living. Assessments are conducted by social workers who take into account the family situation and the help provided by a spouse.

New Zealand's home care services can be located within a broadly egalitarian cultural framework, with some formal care services provided on a means-tested basis and others provided on a universal basis. The result is a combination of services that are either partially or fully subsidised. There is also significant dependence on family care, private services and charitable services (Burau, Theobald, & Blank, 2007, p. 60). Public funding is from general taxation and allocated to district health boards. While this implies some local autonomy, the care sector is centrally regulated, with central government determining the overall framework, in terms of eligibility criteria and quality standards. Since the policy of ageing in place was adopted in the early 1990s, there has been rising public spending on home care and related support services. Eligibility for care and the amount of service provided are determined through the needs assessment process, this being typically initiated following discharge from hospital, by the family doctor or a community group. An older person who is assessed for home care, therefore, is more likely to be at a more advanced stage of frailty or a higher level of need. Eligibility is determined by recognised needs assessors, with a health or allied professional background, according to a nationally standardized format.

Different countries, then, have different funding mechanisms and different formalized procedures for determining eligibility to home care services. We suggest the experience of being assessed for in-home care, explored further in Chapter 2, is a part of the first step in the rite of passage into supported independence. As we show, the policy settings frame that assessment process by determining the assessment criteria used, how the assessment takes place, the options that are available following the assessment, and the potential for the older person to exercise directional control in the selection of those options.

1.4.2 Regulation, Choice and Control

Arrangements for the financing and regulation of home care influence the opportunities for choice and control by the older person over their care. Enhancing choice and control is recognised as desirable, since without control and with no say in the type of assistance in terms of tasks performed and amount of help provided, the older person's abilities to make assessments and marshal resources are suppressed and their coping capacities diminished. There are typically greater levels of 'client satisfaction' when the recipients can direct their own care programmes. As we will discuss in Chapter 7, managerial and bureaucratic demands for accountability, impartiality, predictability and efficiency in the administration of public and privately funded care programmes often sit uncomfortably alongside consumer or user direction of services (Twigg, 2000, p. 162). Managing home care and demonstrating accountability for the use of resources often means the care work itself has to be transformed into something that can be measured or counted; it can result in those tasks being very precisely defined in unambiguous terms with specific limitations placed around the tasks to be performed to avoid the risk of incurring 'unnecessary' costs. This tends to result in packages of care to meet an individual's specific needs being carefully determined and delivered according to carefully prescribed contracts, and thus a loss of flexibility and the potential for responsiveness to the needs of the cared-for person.

The idea of consumer power is most established in the United States system, and there care recipients have greater opportunity to hire and fire, and therefore directly supervise their care work. Consumer directed care programmes which fund care recipients give them greater control and autonomy in the process of hiring, supervising and firing caregivers (Tilly et al., 2000). While formal care plans exist, they can be changed by the care recipient. Germany also provides the choice of a cash benefit, to be used to cover the cost of care services, or there is an option of the direct provision of services. In the statist system of Denmark, care recipients do have choice over the provider organisation, whether it is public or private.

1.5 Summary: Demographic and Policy Indicators of a New Social Category

Such policies, then, frame the experience of a growing group of people in our communities—those who live at home with care. The ageing in place policy, bolstered by in-home care, presents new options for frail or disabled older people. This new form of living demands that we write new scripts and make decisions about a wide range of issues that were once largely determined by adherence to strong traditional values and ways of life. Our challenge in this book is to propose policy settings and practice arrangements that support the maintenance of autonomy and control among the members of this group. As Polivka and Longino (2004) have eloquently stated, it is precisely when such control is threatened by frailty and disability that we should endeavour to support it:

> Most discussions . . . about greater agency and creativity among the future elderly of the baby boom generation, treat physical and mental decline as definitive limits on agency. In our view, it is within these limits and those imposed by the lack of economic resources that public policies should operate to support those who require assistance in order to maintain their freedom and agency. We do not, in short, see frailty and impairment as the antithesis of agency. It is precisely when the individual begins to experience the erosion of freedom and agency that often comes with impairment and frailty that public policies should be designed to provide the resources needed to resist the loss of agency and allow the individual to exercise as much autonomy as possible under conditions of impairment (p. 5).

Our purpose in this work is to focus on the environment of home and community at this time of life, and explore the character of the changes that occur as a result of increasing dependency within the home. By focusing on this stage in life we aim to enhance the understanding of the experience of the transition into becoming a recipient of care services in the home, with a view to discovering insights with the potential to improve models of care and service delivery. Following Harper's (2000, p. 116) recommendation that research should 'restore the individual, their family and support network to the centre of the research question,' we aim to describe, analyse and interpret the intimate social and emotional processes which accompany this new life stage. The home is an important element in an older person's identity, as well as being an important point of connection with sources of support. This examination of the experiences of care recipients, their families and care workers will provide a basis for evaluating the success or otherwise of policies by exploring, with the participants, the experiences of the provision and receipt of care within the home environment.

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Chapter 2
The Move from Independence

2.1 Introduction

The focus in this chapter is the conceptualisation and general application of the rites of passage approach. The work is grounded first of all in the statistical indications of growth in the number and proportion of older people reaching either the age of frailty or the older old age, and receiving home care. Our brief review in Chapter 1 of OECD data demonstrated that while many are staying in good health for longer, the numerical growth of those among the older old is leading to increases in the need for and use of long-term care programmes (Cornwall & Davey, 2004; OECD, 2005). Our goal is to achieve an understanding of the experience of this group of receivers of in-home care, of their situations and the subtlety of the changes in their lives. The greater number of people remaining at home receiving formal care points to the new life stage of supported independence.

Within the context of the policy of ageing in place, this macro trend has resulted in growth across many countries in home care services, and a corresponding interest by researchers to study the experience of the transition from independent living to greater dependence on informal care, and into receiving formally funded in-home care. Recognizing the components of this transition is a beginning to understanding the experiences of the older people as they encounter the changes which create their greater dependence. Focusing on this transition allows us to recognize, also, the combined influences of national policy settings, family and social arrangements as well as the individual adaptations that are made by older people (Fennell, 2004, p. 309).

Clearly, we need to identify the role of late-life frailty and disability experienced by individuals, and the disruption this creates, but we also seek to account for how the experiences of living with disability are framed by the policies and practices which have grown up because of these experiences. This policy context creates the different channels by which in-home services are made available, determining, as we saw in Chapter 1, the criteria for eligibility, the financing and accountability mechanisms for care, and the degree of control the cared-for person has. Specifically, in this chapter we consider the experiences of people undergoing the transition from

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independence to increasing dependence, and introduce the rites of passage concept to help clarify these experiences. This analysis has led us to postulate a new stage in life.

2.2 New Life Stage

We began in the previous chapter to establish the case for a new life stage by considering the contexts of demography and care policies. An important subdivision of the category ‘older people’ is Peter Laslett’s (1996) proposal to distinguish between ‘independent’ Third Agers and members of the Fourth Age of ‘decrepitude’. This model we believe can be extended (Higgs, 1995, 1997) to account for frail older people who are supported to remain independent at home: those whose degree of frailty is enough to demand formal care, with or without support from family members, but not such as to require full residential care.

So what will constitute such a new life stage? We draw on anthropologist Dorothy Jerrome (1992) and the earlier work of Tamara Hareven (1982) who say in general terms that recognition of a new stage of life will involve an increasingly overt acknowledgement of the complex process of experience for a group of individuals. It will involve not only the demographic count, based on the shared characteristics, but importantly, also, the creation of institutions designed to meet the special needs of this group; the emergence of a new group of professionals who articulate the unique conditions of the group; and growth in academic research which identifies and labels the experiences of the group. Such features contribute to the policy focus on such a group, emphasizing its uniqueness. According to both Jerrome (1992) and Hareven (1982) such awareness will end in public acknowledgement through wider recognition in the media.

If we apply these observations to the age care scene in various countries, we can see that there is considerable growth in specialist areas and institutions focusing on care and support of older people at home. For example, in the United Kingdom and Denmark, the local municipalities take responsibility for age care, while in New Zealand the national Ministry of Health mixes national directives and devolved responsibilities to local hospitals, and in Germany, there are social insurance agencies. Actual service delivery is devolved to agencies such as the local municipalities, not-for profit agencies and private care agencies which are playing a greater role in home care in European countries.

In these terms, there is support for Jerrome’s and Hareven’s criteria for a new stage in life; further criteria were the development of new policies, growth in the number of personnel, and growth in the level of academic research and media attention, all of which have occurred in the area of in-home care for older people. Implementing the philosophy and policies of ageing in place has required health and social service authorities to develop new policies and delivery systems. There has been considerable growth in the number of agencies hosting needs assessors. Work in this area by medical agencies, not-for-profit organisations, municipalities and private agencies has increased, with coordinators, care-workers, and administrators increasingly specialising in the assessment and oversight of care of older people at home. At the same time, this growth in home care services has necessitated the recruitment, training, monitoring and supervision of a new workforce of caregivers, caregiver training programmes and new employment legislation to address the specific needs of this group.

There has also been growth in research that identifies the particular needs and characteristics of this group, and the issues in delivering formal care in the home, exemplified in the work of Scandinavian researchers, among others, Szebehely (1995), Efraimsson, Hoglund, and Sandman (2001), Janlov, Hallberg, and Petersson (2006), Olaison and Cedersund (2006), and in the seminal work of Julia Twigg (2000) in the United Kingdom, which has paved the way for others. The media, too, pays considerable attention to the situation of care at home, whether it be concern over waiting lists, concern over care worker recruitment and pay, the inadequate number of care workers or over the quality of care work that is provided.

This new stage contains the current generation of older people in their 70s, 80s and older, who are the first to experience such a degree of formal care at home, under the policies and institutional criteria outlined. There are no role models for this group and no historical experience to draw on to inform policy and models of care. Our aim here is to contribute to understanding the experiences of those in this group, by exploring the way in which they perceive the changes they face and the meanings they give to that experience. Applying Russell's (1981) comments on ageing in general to our group of older people with frailty, we consider that:

> Without such understanding, anthropologists (and others) maintain, we have only a hollow and imperfect understanding of social processes and problems (pp. 7–8).

What, then, is the experience of older individuals, their family members, and those who provide care? And what is the experience of older people moving into this new stage of life?

2.2.1 Transitions

Life transitions continue in old age, for example, from employment to retirement; from partnership/marriage to bereavement and widow(er)hood; or from home to sheltered care and to residential care (Shield, 1988, 1997; Percival, 1997; Frank, 2002; Hyde & Higgs, 2004). Such transitions can be defined as critical phases during which significant developmental, social or economic change takes place. Hyde and Higgs (2004) explain late life itself as a period of multiple transitions and not one of stability. Based on their analysis of change in labour market status, health status, household composition and residential location, they conclude that old age today is a dynamic period of life. Their concern was with considering the changing pattern of late-life in terms of the shift from modernity and the de-institutionalisation, and therefore de-stabilisation, of the once relatively fixed progressions through old age. They assert that traditional concepts of stability in old age following retirement do not capture the experience of ageing in contemporary society. They classify the micro-transitions in old age into those typical of the young old age and those typical of the older old (Fennell, 2004, p. 310).

Earlier social gerontological analyses of old age emphasised transitions associated with the young-old, these primarily being non-pathological aspects of ageing—for example, the transition from paid work to pensions and changes in residential location associated with retirement. Increasingly attention is being given to understanding the transitions experienced by the older old. In 2003, Baltes and Smith asserted that the new frontier in research on ageing is with the older old, understanding the particular biological, physiological and psychological changes in late life and the impact on the experience of the older person. This reflected a new appreciation of the need to 'bring the body back in' to the study of ageing and understand better the experiences of morbidity and co-morbidity that leave many older people beyond the age of 80 requiring assistance to carry out the normal activities of daily living (Janlov et al., 2006, p. 326). We note here, though, that the proposed new stage is not confined to a chronological age of 80 and over but rather, it is based on the degree of frailty and need for in-home care.

While the progression towards frailty or disability, be it rapid or gradual, represents the trajectory of experience which concerns us, Gill, Gahbauer, Allore, and Han (2006, p. 421) remind us that transitions are not unidirectional towards reduced capacity. Kirkwood (1999) quoted by Kingston (2000, p. 218) shows that while there are links between ageing and decline, there is a very wide degree of variability among older people. Frailty, then, is often characterised as a dynamic process, with people moving in either direction along a continuum between frailty and fitness, determined in large part by the degree of the preceding state of frailty or fitness, and also the nature and availability of support that is available. We agree with Hyde and Higgs (2004) that:

> more attention is needed to fully understand the patterns and meanings of these multiple, potentially complementary, potentially conflicting, transitions in later life (p. 328).

Late life, then, clearly involves many transitions and these are not always towards frailty as a consequence of the accumulation of deficits. We focus on an important and overlooked transition, one which will become normal for an increasing number of people, that of moving into a state of supported independence in the home. It is a transition which can be seen as a function of ageing and might therefore be described as a developmental transition. However, it can also be seen as an institutional transition to the extent that it involves the movement into a new and different institutional context—involving engagement with home care agencies (cf. Mallory, 1995, p. 214). Our concern with the social aspects of change leads us to consider these altered ways of living and new patterns of social interaction.

2.3 Rites of Passage

How best can we understand this transition? We approach this task bearing in mind Stacey's (1994) recommendation to value 'lay information' and 'people knowledge'. Kingston's (2000) terms 'status passage' and 'preferred identities' and Bury's (1982) notion of a 'biographical disruption' represent useful concepts with potential to provide insights into this experience beyond those that focus on purely biomedical aspects. Each of these concepts can be accommodated within the broader notion of 'rite of passage'. The choice to use the rites of passage framework as an overarching analytical tool developed from our reading and categorising the data in the New Zealand studies (Barrett, Kletchko, Twitchin, Ryan, & Fowler, 2005; Hale, 2006) and also from the social gerontological work of Moore and Myerhoff (1977), Hazan (1984), Shield (1988, 1997) in terms of residential care, Teather (1999), Hugman (1999), Hallmann (1999) in family caregiving, Hockey and James (1993, 2003) in considering passages through the life course, Twigg (2000) applying a rite of separation to bathing and baths, Frank (2002) observing an incomplete rite of passage in her study of assisted living, and Parks (2003) with her focus on care at home.

Van Gennep's (1909) original concept of three stages, separation, liminality and reconnection, was developed to understand the different religious rituals in the cultures he studied, in particular the rituals which marked transitions between different life stages and movement from one role to another. A criticism of the concept is that, in practice, it is too rigid to be applied meaningfully in secular and individualized societies (Hockey & James, 2003, p. 37). However, Turner (1974, p. 3) observes in his first paragraph that 'it is not a theorist's whole system which so illuminates but his scattered ideas, his flashes of insights taken out of systemic context.' Moore and Myerhoff (1977) suggest this concept can be used in secular social contexts, while Hockey and James (2003) assert that the analytic model has wide applicability:

> According to the analytic model, passage through each of the three phases of the ritual meant that individuals had been detached from their previous social position, processed through an intermediary state which shared the features of neither the previous nor the successive social position, and then had been incorporated into a new set of rules, roles and obligations (p. 25).

We use the concept in the same way as Turner (1974, p. 1), as a framework for understanding situations of change, in our case beginning to live at home with care. By drawing on this framework, we can highlight those changes which many take for granted, with suggestions that 'it's all to do with getting old,' a general anecdotal statement, but which has a strong impact on individuals, their environment, their networks and relationships, and on the wider society. At the same time it is possible to incorporate individual turning points so that 'biography and history thus join in the interpretive process' (Denzin, 1989, p. 18). These insights are particularly useful in the discussion of reconnections, whether these are individual, or whether there are forms of social reconnection to be considered, through, for example, different models of service delivery. Such an application of the rites of passage concept focuses our thinking by providing a structure to examine change, according to Moore and Myerhoff (1977). It stimulates, too, the detailed examination of the ideas that create the shape of the particular passage, in this case the transition to dependence and receiving care.

The passage into in-home care is, we argue, a major life transition, filled with complex change. As such, it is similar in many respects to other transitions throughout the life course. However, as Hallman (1999, p. 221) notes, 'the transition into eldercare (or receiving care) is routinely not marked with any sort of ceremony or rite.' Ceremony and ritual lend 'authority and legitimacy to the positions of particular persons, organizations, occasions, moral values, views of the world, and the like', through the ability to 'structure and present particular interpretations of social reality in a way that endows them with legitimacy' (Moore & Myerhoff, 1977, p. 4).

Despite the lack of ceremony and ritual in the 'uncelebrated passage' (Hallman, 1999, p. 208), we consider it worthwhile exploring the application of the concept of a ritualised passage into in-home care, not only because of the formal processes involved in accessing care, but because it offers potential to understand the way this passage is structured and how we might contribute to an alternative structuring of the process. As (Moore & Myerhoff, 1977) continue,

> Ritual not only belongs to the more structured side of social behaviour, it also can be construed as an attempt to structure the way people think about social life (p. 4).

A brief summary of Van Gennep's (1909) original concept should be sufficient to demonstrate its relevance. He identified three stages to ceremonial rituals: the removal of the individual from his or her former status; a suspension from normal social contact; and a readmission, reconnection or reintegration into society in a newly acquired status. He also observed, as a further value of such rituals, that others in society would recognise and respond to the new social status. The rites, therefore, signify recognition of the transition and of the new identity.

2.3.1 Transition as a Rite of Passage

On the face of it, the rites of passage concept has ready applicability to understanding change in old age. Janlov et al. (2006) observed a number of distinct phases in late life transitions, these being

> marked by a starting point of change, through a period of instability, discontinuity, confusion and distress to a new beginning or period of stability that is likely to be at a lower level than before (p. 334).

The main focus in the study of transitions among older people in care has been on the movement from one site of care to another, from home to hospital (Hirst, 2002, 2004), to residential care (Shield, 1997), between facilities (Diamond, 1992), within residential care (Diamond, 1992) and into assisted living (Frank, 2002). Each of these moves involves changing social relationships and a challenge to one's social identity (Murphy, 1987). We know far less about change for those who remain at home and receive care. In fact, the notion assumes continuity rather than change. The transition involves, though, change from home as a place of independent living to home as a place of care, with altered social statuses and relationships, and in Hockey and James' (2003) words, 'new rules, roles and obligations' (p. 25). Nor do we know much of how the transition is made from home as a place of independent living to home as a place of care (Taam, 1999; Janlov et al., 2006). We do know, however, that there are changes for both the person needing care and other household members, as implied in the following passage by Efraimsson et al. (2001):

> natural caring was changed into patient-care-giver relations and the home became a public room. The patients had to deal with decreased abilities and the family members with adjusting to caring need (p. 813).

Understanding such transitions at home, according to the relevant literature, would require giving attention to spatial issues (cf. Lawton, 1977), temporality (Twigg, 2000), social relationships and networks (Gubrium & Sankar, 1990; Twigg, 2000; Efraimsson et al., 2001; Barrett et al., 2005; Janlov et al., 2006; Hale, 2006), and identity. Hugman (1999) captures the interlinked nature of these themes in the observation that:

> Home is the location in which, through the use of time and space, self-hood is enacted in the routines and decisions of daily living (p. 201).

The potential of the rites of passage concept lies in how it provides a view of the structure of social change, with the changing rules, roles and obligations. Further, it implies recognition of the risk of failing to complete the passage and reach a state of reconnection or reintegration. With the concept's focus on outsiders, too, it highlights issues for those who become carers, be they formal or informal, who are concealed within the privacy of the home.

Applying the concept reveals the unseen separation experiences associated with formalised assessment processes themselves, a period of an hour or two, but in their effect creating a potentially prolonged stage of uncertainty and anxiety caused by the personal disruption of the onset of frailty and disability. All of this is often experienced in an uncertain care environment in terms of the care services provided. The post-assessment stage corresponds to a liminal phase, with conflicting emotions, improvisatory practices, and the dis-ablement which can sustain a strong sense of dis-connectedness, rather than en-ablement and re-connectedness.

2.3.2 Rites of Passage: Separation

Kaufman's (1994) description of the 'frailty process' outlined the social interactions that define the experience of being assessed for home help. She asserted that:

> when any combination of . . . symptoms and behaviours . . . [are] construed to tip the balance towards a problem of more dependence than independence with regard to functional ability

> and social role performance, … [individuals and families are forced] to reconsider and renegotiate the meanings of autonomy and freedom, risk and responsibility, choice and surveillance, and interdependence (p. 49).

The process is initiated by symptoms and behaviours that bring the older person to the attention of family members and health professionals. The experience of loss of either physical abilities, energy or social relationships is the common trigger initiating the transition (Janlov et al., 2006).

> *I know there was no other choice but it's so hard to say, "well that's another step back, that's another thing I cannot do anymore"* (p. 329).

Triggers include the development of multiple medical conditions, such as combinations of cardiovascular problems, arthritis, respiratory problems, complications arising during or after surgery, and stroke, cancer and diabetes that lead to problems of pain, limited mobility, low levels of energy and problems with stability and balance. The result is decline in functioning and greater difficulty in carrying out key daily tasks—washing, cooking, housework, shopping and visiting. This combination of symptoms is typical of those variously identified in biomedical frailty studies as diminished reserve capacity, unstable disability, co-morbidity, dependence in activities of daily living, and failure to thrive.

Whether conceived as the consequence of a sudden trigger or the reaching of a tipping point in a slower process of cumulative loss, is conveyed in the following comments by Barrett et al.'s (2005) respondents:

> *I've had this last fall and have, sort of, passed from 'before fall' to 'after fall'* (p. 29).

> *All of these things just sort of dwindled away progressively. Not all of a sudden … it is a process of saying to yourself, there it goes, another bit. It just slowly, slowly gets less* (p. 32).

These symptoms or behaviours prompt the involvement of family members and/or health and allied care professionals. Assessments are systematically implemented following discharge from hospital, or on the referral by the family doctor, or community based groups (e.g., arthritis, asthma, cardiovascular health problem support groups). The changing interactions with family members, and new interactions with health professionals and home care assessors constitute the social exchanges that signal the rite of separation. Being assessed to determine functional capacity, level of need and eligibility for assistance is the critical social interaction that initiates the rite of passage.

When an older person enters this social exchange, they do so from a lesser position, one of little power. Encounters with medical and allied professionals are framed by their institutional roles, professional identities and broader social structures that embody implicit power relationships. Janlov et al. (2006, p. 27) point to the relative lack of power of older people in these interactions. They emphasise the low hierarchical position of older people in society generally, leaving them less able to exercise power over their own care arrangements. They conclude that as 'professional power dominates the health and social care system, and [as] it has been argued that it forms a barrier to genuine patient/client participation' (Janlov et al., 2006, p. 27) the experience of the transition into dependence needs to be understood in terms of the potential for the will of the older person to be overridden—their voices silenced, and their preferences ignored.

Descriptions by Barrett et al.'s (2005) participants of this process indicate the extent to which decisions about the nature of care and need for prosthetic support can be determined by the assessors alone, without input from the cared-for person:

> *The hospital sends out assessors and they assessed me and said, 'yes,' I need this, I need that, I need this, that, the other thing.*
>
> *They came from, well, I'm not sure where they came from but, they're government departments . . . they came and looked round the house and supplied me with a list of things that they thought I needed to have done* (p. 93).

In the Swedish context, Janlov et al. (2006) observed:

> older persons have difficulties coping and adapting to their new life situation and have no actual influence over the decisions about their home help. The officer told them what was available (p. 26).

It is this lack of power in the assessment process and in the development of subsequent care plans that challenges the sense of identity and autonomy and which constructs the experience of separation.

> *Somebody came whilst I was in hospital and asked me what I had at home and so they bundled me up into an ambulance and took me home to see what I could do and what I couldn't do. . . . They put rails up for me and rails in the bathroom and in my bedroom beside my bed so that I could pull myself up. And they supplied me with boxes to put my chair up a bit higher. . . . I got terribly depressed, I'm sorry I just – I can't cry, I have no tears. And sometimes I wanted – I felt if only I could have a damn good howl I'd feel better, but I can't* (Barrett et al., 2005).

Richards (2000) and Olaison and Cedersund (2006) consider the implications of this process of assessment to be under-acknowledged and regard it as a significant time in the lives of older individuals. Their work and that of Janlov et al. (2006) supports our observation that the assessment process signifies an official point of separation from a former independent identity. The assessment is performed by needs assessors, case managers, nurses, social workers, and care coordinators, professionals who are new in the life of the older person and who are the gatekeepers of help. The procedure is carried out by means of face-to-face interviews, usually in the individual's home, which cover physical and cognitive abilities as well as the family and social situation. It seems simple enough, but in accepting a needs assessment, the older person is acknowledging that he or she belongs to a particular category of older people, a sub-group that is in need of care at home. Janlov et al. (2006, p. 334) observe that, 'asking . . . for help seems to be a turning point, the start of a new phase in life marked by an awareness that life is nearing its end,' this point of change being captured by one of their research participants in the comment, 'The countdown has begun.'

The acknowledgement of change requires the older person to begin to reframe or become conscious of a changing identity. Olaison and Cedersund (2006) have described how the interactions between the older person and the assessor contribute to this. They suggest these interactions are a type of institutional conversation, a discursive practice, with the effect that the person being assessed learns the philosophy and rationale of home care and the terms of accepting care. The person being assessed becomes aware of the particular needs categories and begins to see his or her situation as falling within these. This can lead them to construct a 'category-based identity'. One of Hale's (2006) respondents indicated this when she said:

> *Who are you really? You become a set of ticks in boxes* (p. 96).

Hale's (2006) research participants described seeing their assessment as a type of test, one that they were worried they would not pass:

> *It felt like an exam.*
>
> *[I was] worried in case I didn't qualify* (p. 96).

Passing the assessment 'test' involves fitting within the provisions of that identity. Such anxiety influences how the older person positions his or her situation and presents it within the context of the needs categories, and doing so reinforces an identity in terms of that need. Kingston (2000) observes that in this exchange:

> Individuals may overemphasise the degree of damage ... [this being perhaps] more psychological than physical. This leads to the individual placing themselves in a lower status preferred identity, which is in effect, a reduced status identity not based on reality, but rather imposed by subtle negative societal portrayal (p. 229).

This positioning is part of a subtle process of negotiation. Olaison and Cedersund (2006) in analysing the assessment dialogue identify certain negotiating identities that tend to be adopted by the older person in order to access the care considered necessary by the potential recipient. Nevertheless, the power to determine eligibility in these exchanges lies with the assessors. This is evident through the way the dialogue about the older person's situation between the parties is controlled by the assessor. For example, it is the assessor who introduces and closes off the topics which are examined. The experiences recounted by Olaison and Cedersund (2006) and Janlov et al. (2006) show that having a voice in these exchanges is difficult, especially when the focus is on 'embarrassing' questions such as incontinence, showering ability and personal hygiene. Such exchanges are accompanied by feelings of confusion, anxiety and anguish, 'I wasn't sure what was going on', as well as appreciation and relief. Janlov et al. (2006, p. 26) described it as 'excruciating', and 'marked by mental difficulties and strong resistance to accepting being in need of public home help.'

The overt exercise of power by assessors is evident in practices such as that described in Hale's (2006) study. In one instance, a young occupational therapist asked an older woman to undress and dress again, to prove whether and how she could dress herself. The older woman commented:

> *Why couldn't she take my word for it? Why did I have to go through all that as well? I needed help—couldn't they just see that?* (p. 96).

As well as indicating that professionals do not believe people are the best judges of their own capabilities (Jerrome, 1992) it shows that individuals in need of assistance have to accept that the assessor has a right to ask these questions.

> *They've got to do it, that's what happens if you want help* (Hale, 2006, p. 96).

The spectre of either residential care or of 'failing the test' and being judged as ineligible to receive assistance in the home reinforces compliance. In short, 'old age' here is considered as a category, rather than a process where for many people, discontinuity from the expected life course begins with the onset of disability. We argue that a simple focus on the onset of symptoms or behaviours leading to a needs assessment and the subsequent development of care plans does not represent fully the nature of the loss or trauma that is experienced. The development of symptoms and behaviours and the assessment process needs to be seen in a wider context.

Conceptualising this onset as discontinuity and therefore as the first stage shows that individuals move through a distinct separation process, to be labelled frail by a health-care assessment procedure, and thus eligible to receive a variety of government funded services. It also facilitates our examination of the minutiae of challenges to the sense of self.

> *I know there was no other choice but it's so hard to say, "Well that's another step back, that's another thing I cannot do anymore."* (Barrett et al., 2005).

The assessment contains many elements found in ritual practice: a clear sense of purpose; repeated activities in a set pattern; and the subordination of personal experience to pre-established practices. This occurs through the use of standardised criteria which structures experience into a set of needs to be met. The individual must pass through the routinised or ritualised procedure to establish eligibility to public support for care. Doing so reinforces a particular social script of ageing: that older people with frailties are a separate group with their own special services and personnel, and that society through government must provide care and protection for older people.

In the analysis of rituals, the 'separation' implied in the first step of the rite of passage is understood as involving the stripping of social status. We suggest a similar experience occurs for older people facing the assessment process. Turner (1969) claims that in a rite of transition, the material possessions which mark a social identity are often removed and that people become 'invisible' as the people they used to be (p. 93). In this situation as well, new material possessions in the form of assistive devices and care support, still suggest that people are 'invisible' as the people they used to be. Such additions which occur through the process of assessment also challenge the social identity of the assessed person.

The assessment is comprehensive and the assessed person's life is laid bare before the assessor. It has important existential implications within which, as noted above, the older person is relatively powerless. Standardised assessment schedules aim to account for: a person's background and living situation, the nature of current formal and informal support networks, income sources, medical history and diagnoses and current treatments, communication ability, vision and hearing, mobility, personal care ability, capacity for safe household management, and cognitive functioning. Unlike Kane's (2004) proposed assessment schedule based on personal preferences (e.g., 'what would you prefer, what makes you comfortable?'), the typical form emphasises losses, be they in functional capacity and areas of domestic and personal hygiene, and it is used to structure assistance to compensate for those losses. It corresponds with Aronson's (2002a, 2002b) observation that '[o]lder people are treated as bundles of expertly defined needs to be accorded priority in some standard process of resource rationing' (p. 60). The result is that the elderly person *becomes* a client and a care recipient, and a care plan is developed by the needs assessor based on their perception of the level of need. Care plans are then often sent to the agency of choice to 'put in' the hours and types of care required. Gilleard and Higgs' (1998) comment, in this context, is relevant:

> ironically at the point when the body becomes the defining element in a person's life, the health care professionals reorientate themselves . . .[and] construct disembodied packages of care in which the fourth ager becomes a series of categories of response: a new cultural text of met and unmet need (p. 19).

The physical onset of frailty and/or disability does constitute a biographical disruption as Williams (2000) avers, one that leads to a break with historic roles and identities and a narrowing of social networks, especially for the more severely frail, as unstable health and related problems of reduced mobility weaken the capacity to maintain roles, identities and networks. The extent of the biographical disruption is, it would seem, determined in part by the social environment and expectations around the normal process of ageing. The disruption is, according to Williams (2000, p. 50) interpreted differently by diverse groups and sub-groups, pointing to the potential for multiple socially derived meanings. Williams (2000, p. 50) referred to the way in which London's predominantly working-class East-Enders were less likely to be 'shattered' by the development of chronic illness in late life by comparison with the middle classes. Godfrey and Townsend (2008) cite others who write in support of this argument: Pound, Gompertz, and Ebrahim (1998) discuss the perception of stroke as a 'normal' crisis, reflecting the predominantly working-class lifetime of struggle and adaptation to adverse events and anticipated health problems, and Faircloth, Boylstein, Rittman, and Young (2004) and Faircloth, Boylstein, Rittman, and Gubrium (2005) have taken the same approach.

As these authors have all indicated, notions of health problems were understood as 'normal illness', something inevitable, to be expected at the end of a hard working life, accepted and approached stoically with the 'right attitude', in contrast with middle class views that illnesses like strokes 'shatter lives'. Williams (2000) suggests that widely held assumptions about the inevitability of the onset of frailty and disability lead individuals to see this experience simply as a confirmation of an inevitable development. An important qualification to this argument, though, is that the stoicism of these working class respondents may well be masking the individual emotions and inner responses, and the ability to cope at this stage depends on the home and community arrangements of the older individuals themselves.

Despite this qualification, however, Williams and others raise questions about the extent to which such assumptions about the inevitability of disability and illness in late-life are manufactured by dominant narratives and images of ageing. An interesting question is the provenance of the dominant narratives: for Williams' participants, this appears to be local community narratives. Other older people may subscribe to a different narrative. However, common to all narratives, is the concept of status passage. These passages are the transitions that all individuals make as they 'move from one situation or period of their life to a series of different locations or phases' (Kingston, 2000, p. 18), and Kingston's elaboration of the concepts of status passage and preferred identities goes some way to illuminating the social meanings of the transition.

2.4 Summary: Separation and the Move from Independence

In this chapter we have developed our conceptualisation and application of the rites of passage approach for the study of a new life stage of supported independence, through a consideration of the assessment process as the first stage of separation. We have shown that the emergence of health specialisations, a body of academic research, and policies and practices around the care of older people who become frail and/or disabled and who receive formal care in the home, supports the case for seeing this as a new life stage. Our concern in this chapter has been with the transition into this stage, particularly with the first step in that process. According to the rites of passage framework, that first step involves a ritualised process, albeit an uncelebrated one (Hallman, 1999), by which an individual is separated from his or her former self through the social exchanges which accompany the assessments to establish eligibility for formal care services. It is described as an excruciating experience for the older person, and one he or she negotiates from a position of little power. In it, the older person is defined in terms of his or her unmet need. The assessment is the key social encounter in the separation experience, signalling the start of the rite of passage and of entering a new phase of life. The social exchanges involved contribute to the reframing of the older person's identity and the transmission of the philosophy and normative terms of receiving home care. Meeting these terms involves adjusting to the new rules and roles of the home care recipient. While there is a subtle process of negotiation, the power of the assessor and the institutionalised process for assessment reinforces the particular social script of ageing that characterises this life transition.

There are many elements of ritual practice in the process—the clear sense of purpose, the repeated activities, the standardised criteria, and, in terms of the first step of the rite of passage, the stripping of formal social status and the laying bare of the older person's life, leading to the erosion of the older person's authority over tasks at home and to the loss of autonomy and privacy in a once autonomous and private area. In fact, in Victor Turner's terms, it constitutes a signifier of an 'interstructural and invisible' identity (Turner, 1969, p. 93). It is generally accepted that autonomy and privacy are compromised in hospitals and residential care facilities (Dalley, 2002), but through this process of assessment and consequent provision of care, we argue that it happens also in the home. This experience, then, is a major biographical disruption. The extent of the disruption, though, is influenced by the scripts that give such events social meaning, pointing to the possibility of reframing the narratives and images of ageing to accommodate and normalise this process.

These observations lead to our reflections on liminality, the period of disconnection, anxiety and uncertainty, which we examine in subsequent chapters. Our discussion of liminality leads to questions about how the experience can be resolved to achieve a degree of reconnection and the reclamation of a preferred identity. Before addressing questions of reconnection, though, we consider in the next chapter just what it means to become frail and/or disabled while still living *at home*.

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Chapter 3
Space and Liminality

3.1 Introduction: Older People at Home: Identity, Continuity, Stability

In this chapter we move from outlining the processes involved in the first step of the rite of passage into supported independence, to explore the significance of the home setting and the lived experiences of change. We begin by outlining some of the essential meanings of home which are critical in creating and maintaining a sense of personal identity. Following this, we identify the often microscopic spatial alterations within the home made because of the bodily changes associated with the onset of frailty or disability. We place in the foreground the personal experiences of ageing and disablement, such as deteriorating mobility, loss of function, and challenges in managing the 'saggy baggy bits' of the body. Increasing dependence does not follow a set time frame, but it is a passage from one status to another in which micro-level processes and broader structural forces shape the older person's experience. We present here the idea of transition in terms of these bodily and spatial changes, and consider what they mean for the older person who must negotiate them when they move into receiving care in the home.

Beginning with a review on meanings of 'home', we highlight the important elements of identity derived from the spatial environment of the home, viz autonomy and independence, and the idealised characteristics of the home as being a site of security and warmth. Having noted these generally recognised characteristics of the home and their significance for older people, we consider the spatial disruptions that occur when the home becomes a place of formal care, especially when modifications are required to compensate for loss of function and disabilities. We consider the implications of disability on bodily space and care within the home. Our concluding discussion examines the experience of discontinuity and liminality with a focus on living 'in the home'—home being the setting, situation and the context in which older people age-in-place (Hazan, 1984, p. 3).

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3.2 Home and Space

The assumptions behind ageing in place imply that remaining at home, particularly in one's long-term dwelling, is an important means of accommodating physical losses and facilitating adaptive responses to the physical challenges that can accompany old age. Home is, across all cultures, one of the most taken-for-granted concepts, generally characterised by warmth and stability, continuity, independence, security and autonomy, safety and familiarity. However, the accepted nature of home for older people has been the subject of considerable research over the last two decades. Since 1983, when Powell Lawton commented that we knew little about the functions and applications of space at home, there has been increasing interest in how older people use their home space and, with the advent of sheltered care (Percival, 2001) and home care (Rubinstein, 1989, 1990a, 1990b, 1999; Gubrium & Sankar, 1990; Twigg, 2000), a growing interest in spatial adaptations and the meanings of those adaptations.

Perhaps the most up-to-date discussions of the meaning of home for both independent and more dependent older people come from the European ENABLE-AGE[1] project. This research has examined the home environment and its contribution to the wellbeing, autonomy and participation of older people. It found strong correlation between good health and a firm bonding to home, and lower levels of wellbeing and a higher number of reported symptoms among individuals with 'weaker physical and behavioural bonding to home.' Basically, the fitter the individual, the stronger the attachment to home and enjoyment of the place. Even for the less fit, home is seen as the best place to be. Parks (2003) comments:

> There is a strong tendency towards the positives of home, increasing with age. As we grow older, the concept of home stays with us; yet, its meaning expands to encompass more intangible qualities: cultural norms, social values, and personal memories. Ultimately, home seems to be a word whose meaning is enhanced with the passing of time: the older we become the more enriched and fulfilling our notions of home become. By the time we reach our elderly years, our sense of home is more than place: it has been integrated into our personal identities (p. 24).

Autonomy, independence and identity are central both to the meaning of home and to ageing at home with care. There is a general sense of independence and identity connected with 'doing things for yourself, doing what you want and nobody tells you what to do' (Hale, 2006, p. 179). To remain at home, despite difficulties, is to show to families, friends, neighbours and others that you are capable of being independent. It implies, as Collopy, Dubler, and Zuckerman (1990) say, 'self-determination, freedom, independence, liberty of choice and action' (p. 10). Dahlin-Ivanoff, Haak, Fange, and Iwarsson (2007) echo these observations when they state that:

> Home means having the freedom to come and go as one wishes and being able to do things in one's own way, and decide when and how to do things. For example, to have the freedom

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[1] See http://www.enableage.arb.lu.se

> to decide how clean and tidy the home has to be, and how to keep things in order, all this creates feelings of home. One can close the door and be alone, or open it to friends when one wants to. Being able to decide when to lie down, if one wants a rest during the daytime, or to go to bed late, without interference from anyone else, is important (p. 28).

Presenting the personal identity to family, friends and neighbours is accomplished through home arrangements and the activity of home making, as Canadians Dyck, Kontos, Angus, and McKeever (2005) observe: ‘home is a crucial material and symbolic source in the construction of personal identity’ (p. 175). Home arrangements express this identity through the way in which the home is maintained, clean and tidy, or otherwise, how rooms are organised, furniture arranged, artefacts displayed. Identities are constructed through emblems on the walls, such as paintings, photography, and needlework, and through household activities requiring commitment and skill. Not only do these activities demonstrate a particular morality of home making, they are also used as a model or as a deliberate action in teaching the skills and knowledge required for women’s daily tasks to the next generation. This is particularly relevant in the in-home care scenarios, where often the older women clients teach the visiting care workers how to accomplish certain tasks. Becker’s (1977, cited in Appleyard, 1979) observation that ‘the cleanliness of a home is a reflection on the family and more particularly, the wife’ (p. 75), reflects the view that having a tidy house and being a quick and efficient worker so that the place was ‘spick and span’ has been a source of pride for the current generation of older people. Davidoff (1976, p. 129 cited in Craik, 1989) observes that the same type of pride is derived from being well-organised, a good cook, and in having a clean home. Cleanliness is associated with a moral identity, and expressed through caring and home management. Darke (1994) agrees with the positive view of housework, and comments that housework was work in the sense of labour, a source of pride, and control over one’s space. Hale’s (2006) participants articulated these values:

> *. . . a clean home can reflect on the children and it teaches them in the future to have a clean home and also not only that, but in the moral sense as well, and I think that doing that and trying to abide by that, well, my work has not been in vain, because they’ve all got lovely homes and clean homes and [are] morally good themselves* (p. 86).

It must be remembered that we are dealing here with the generation of women who made home and housework the focal point of their lives. For this generation of women, certain areas were particularly important, as one of Hale’s (2006) participants stated:

> *I’m in the kitchen – I’m still running my own home. You can’t give up. You can’t give that up really. Somebody’s ALWAYS got to do that* (p. 83).

Craik (1989) insists on the importance of the kitchen, ‘not just in terms of specialised function but also in terms of articulating domestic patterns in general’ (p. 57). Howarth (1993) elaborates that ‘the kitchen . . . [becomes] the site of many other activities and the focus of the local social network’ (p. 7), making home, in Swenson’s phrase (1998, p. 389), the ‘center of reach’ where women relate to the communities outside their homes. This occurs in a variety of different ways—the kitchen being the centre of food preparation for social activities, and a point from which to observe the yard and connect with the neighbourhood.

This common conception of home, the ideal of a controllable space, ownership, security, permanence, stability, familiarity, and identity, serves as a model for us to achieve. But it can also act as a screen which conceals what happens behind the closed doors, such as abusive practices. Changes brought on by ageing processes and disability, too, which challenge the meanings of stability and security associated with home, tend to be overlooked, unnoticed or hidden within the dominant script of 'living at home'. Such changes as the formal delivery of care services disturb 'the established meanings and routinized activities that constitute the lived home' *(*Dyck et al., 2005, p. 175).

It is important to examine these changes, given the implications for identity, activity and relationships. To quote Dyck et al. (2005) again, in reference to the experience of becoming frail or disabled in later life in Canada, 'the fit between a biography and the materiality of the home is also likely to be challenged' (p. 175). It is precisely such a challenge to this 'fit' which we suggest places older individuals, and their families, within the liminal stage of a rite of passage.

3.2.1 Spatial Disruption: Transition

Reorganisation, modification and adaptation of space suggest an autonomous decision on the part of older people, made with due regard to their abilities. However, decisions on spatial changes are sometimes made by other people, especially when 'bodies become the defining element in a person's life' (Gilleard & Higgs, 1998, p. 19), defining what can and cannot be done, and also where, and how.

> *Nothing prepares you for old age. When you can't get about, up and down steps* (Barrett, Kletchko, Twitchin, Ryan, & Fowler, 2005).

To maintain an increasingly disabled body at home requires conscious spatial decisions. A complex mix of factors come together and affect these decisions: the size, design and condition of the house, the degree of modification to suit the particular needs of individual conditions, the location of the property and its proximity to facilities, whether the house was warm (especially for those who were severely frail), and the sense of safety and security. We might refer to this as the 'livability' of the home. The design of the housing stock in most countries means modifications are required to help achieve a person-environment fit, allowing the older person to remain in their own home and include assistive devices such as handrails for toilets, showers, stairs, raised toilet seats, and additional furniture like stools for the shower, walkers, and lifts.

House modifications and visible assistive devices are material indicators of the change the older person experiences. Place and space take on new meanings, as individuals are moment by moment confronted with physical reminders of their need for assistance. Former meanings and identities associated with home are threatened or compromised. If we are to understand the full meaning of this biographical disruption, then, we need to appreciate it in terms of this ‘spatial disruption’—the experience of liminality at home and the implications of change in the reorganisation of space. In fact, Turner (1969) claims that in a rite of transition, the material possessions which mark a social identity are often removed as the individual makes the transition into a liminal stage and that the individual becomes ‘invisible’ as the people they used to be (p. 93). Possessions, such as the home, cease to have their former meanings but take on new meanings; for example, the use of assistive devices at home reveals an identity of dependence.

3.2.2 New Landscapes at Home

Old age and disability require special spaces, or, in in-home care, spaces organized to become special. Laws’s (1997) comment that residential care represents ‘new landscapes . . . created to house ageing bodies’ (p. 25) can also relate to home care. Twigg (2000, p. 77) observes that the spatial ordering of care is part of the significance of the ordinary and the mundane in community care, and it should be recognized as part of the reframing of identity, to create a new personal identity of remaining as self-managing as possible while acknowledging disabilities. Wiles (2005) comments:

> Spatial reorganizing by the individual provides a good example of the home as a place of meaning and emotion to the occupants, compared with the home as a space which is convenient (or not) and cheaper for those providing formal care (p. 85).

Percival in his United Kingdom study (1997, 2001) considered the implications of interior space remodeling for the older person. Percival’s participants reported the following types of reordering of space in response to the onset of frailty and disability, such as: re-modeling of the kitchen to allow for the comfortable reaching of items; reorganizing of the downstairs part of the house into a bedrooms/living area; closing off spare rooms or rooms not accessible or in use; parts of the house becoming chilly, musty and out of bounds; and using conveniently created space, such as the kitchen, re-created to provide sitting, entertaining, cooking and eating spaces.

Another example of reorganizing space (Swenson, 1998) is that of placing necessary items conveniently to hand, on small tables on either side of the individual’s chair, to ensure as little movement as possible, or in response to living mostly in one room—for example, in one case in Hale’s (2006) study this was the kitchen, where the respondent sat between two tables, with her walking frame in front of her. The left hand table held the impedimenta of disability such as telephone with big figures, emergency phone numbers and numbers of contact people in large figures, and a medication tray. The table at her right hand held her magnifying glass, books, and magazines. Modified chairs, greater emphasis on heating, large print books and magazines, a magnifying glass, and medication are the types of changes in space in response to reduced function. Further practical aids to assist reduced function are grab rails, ramps, raised toilet seats, and special grab poles for getting in and out of bed. Aids, such as walkers, provide assistance to move around the home, and increase reachable space. Such adaptation helps maintain control and independence, but it also makes the disability clearly visible, a defining feature of the space, a constant reminder.

The familiarity of space is important: ‘Knowing’ and ‘observing’ are other features of living at home. Godfrey and Townsend (2008) quote a near-blind participant getting herself back into a home routine after hospitalization.

> *I try to go to the shower on my own... I can make my own toast... I put it in and wait until it jumps, then I know the electric is off... I know when the kettle is boiled, too... and there’s a little gadget that I put in my cup, which bleeps when the water is near the top so I don’t burn myself... I was very afraid of getting burned... They showed me all that in the residential rehabilitation unit* (p. 947).

When such familiarity is challenged by spatial changes, then the older person has to re-learn his/her environment, which could be a challenging task, fraught with strangeness, anxieties and uncertainty.

3.3 ‘Becoming’

The spatial changes, the sense of strangeness and unease, the anxiety caused by changing space to suit new needs, and the loss of control over the organisation of space, are an important part of the liminal experience of the older individual, when taken in conjunction with other changes. The assessment process for in-home care, which we have discussed in more detail in Chapter 2, is a major marker in the transition from ability to increasing disability, leading to, as it does, a new official identity with the designation of ‘disability’ requiring assistance.

Assessment also often involves the older individual having to demonstrate how they cope with functional tasks in the home. In New Zealand these assessments are undertaken by occupational therapists, or other health professionals. The older person may be asked to show how they can cook, dress and undress, or toilet, these being required to demonstrate the actual need for assistance. They can result in the installation of ramps and handrails, or the reorganisation of furniture and rooms. But as noted in the second chapter, the older person tends to have little control in these decisions. Assessment in the home, then, can involve a redefinition of space by outsiders, with little input from the older person. This experience is an important part of the transition from home as a place of independent living to home as a place of care (Taam, 1999; Efraimsson, Hoglund, & Sandman, 2001; Janlov, Hallberg, & Petersson, 2006).

3.4 The Ageing Body

Research into questions concerning the ageing body raises a number of issues that have implications for ageing at home with care. The process of entering late life and the onset of age-related frailty and disability does reduce physical capacities for activities and engagement (Katz, 2000; Mansvelt, 1997a, b). There is, therefore, a need to critique the understandings of independence and control (Secker, Hill, Villeneau, & Parkman, 2003; Featherstone & Hepworth, 1991); there are concerns about self image and the masking of age (Featherstone & Hepworth, 1991; Williams & Barlow, 1998, in Nettleton & Watson, 1998; Mowl et al., 2000; Hockey & James, 2003); management of the ageing body (Kontos, 1998); power and medicalisation (Powell & Biggs, 2000); and concerns over the ageing, damaged body (Tulle-Winton, 1999).

Physical activities and interactions within the home—movement within and use of home spaces—do take on a taken-for-granted quality. Given this taken-for-grantedness, it can be difficult to 'know' or be aware of how our bodies interact with these spaces (Corbin, 2003, p. 258). It is difficult to assess just how people experience their bodies except through a focus on presentation and activities (Turner, 1996; Shilling, 1993; Nettleton & Watson, 1998; Faircloth, 2005). Yet this is a crucial subject when contemplating the home and independent bodies at home. One possibility is to consider dependent experiences (Williams & Barlow, 1998, p. 131 in Nettleton & Watson, 1998; Secker et al., 2003; Corbin, 2003). As Juliet Corbin observes,

> My dad wants to die. He has advanced Parkinson's. He now measures himself by what he can't do, how he appears when he tries to do something – weak, unsteady, painfully slow (p. 258).

Others expressing a need to consider the ageing and independent body have commented similarly. Wahidin and Powell (2003) remark on the sociological neglect of the ageing body until it begins to break down and Powell and Biggs (2001) comment on the:

> linkage of autonomy, independence and dependency... through the importance of techniques for maintenance either via medicalized bodily control or through the adoption of "golden-age" lifestyles (p. 97).

3.4.1 The Extended, Altered, Damaged, Limited Body

We can consider the body in terms of mobility and independence, and its relative ability to use and reach spaces. Such functional concerns, however, are only one facet of the bodily change in this transition. There are other facets, such as bodily care and hygiene, which can require the help of caregivers for washing and dressing; the *extended body*, a term which we use to describe the body when it is dependent on assistive devices, such as crutches, a walking frame or a wheelchair; the *altered body*, with, for example, a mastectomy or limb amputation; and the *dying body*. Kvigne and Kirkevold (2003) also use the term, '*extended body*', to describe the prosthetic tools or remedies which extend or replace the function of damaged limbs. Such extensions, they suggest, take on a new meaning for the older person who becomes dependent on them and they begin to be seen as extensions of the body—such as one woman who described her wheelchair as her feet (p. 1303) or the person dependent on crutches describing herself as having four legs.

Such bodily changes affect a person's self-image and identity. Murphy (1987) conveyed this when reflecting on his loss of the full use of his legs:

> *I had also lost a part of my self [note the split of my and self]… I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence* (p. 85).

Some physical damage to the body can be masked (Featherstone & Hepworth, 1993) by clothes and make up. What cannot be masked, however, is the *extended body*. The assistive devices (such as crutches, a walker, a wheelchair) which change the physical presentation of the body, from upright on two legs, to the bent over position which is adopted with the use of crutches and walkers, tends to bring the head below the level of others, making it difficult to retain eye contact. An upright body shape and posture seems to be linked with self esteem and a positive identity. The altered and extended body, with physical signs of stooping, shaking, paralysis or amputation, challenges that esteem and identity, and this can be reinforced by the way other people interact with the older person. As Robert Murphy (1987), says, 'Damage to the body, then, causes diminution of the self, which is further magnified by debasement by others' (p. 93).

Other damaging disabilities such as rheumatoid arthritis (Bury, 1982) or stroke lead to extensive physical changes (Kvigne & Kirkevold, 2003). In their article on living with the 'bodily strangeness' caused by a stroke, they refer to the resulting disabilities as evidence of a 'limiting body', and the enormous struggle to regain power to accomplish basic activities (Kvigne & Kirkevold, 2003, p. 375). In these situations, close attention is required to work with 'problem' parts of the body so it re-learns skills such as putting on socks and shoes (Godfrey & Townsend, 2008, p. 946).

3.4.2 Bodily Space: The Liminal

Between the revealing of the damaged, extended, limited and altered body to oneself, and the presentation both to self and others, is a journey of reflection, emotion, poignancy and often humour, but also often grief and self-disgust. It is a liminal process. For people with bodily disabilities, the body is a problem. It cannot be taken for granted but must be made 'the object of conscious thought' (Murphy, 1987, p. 12). Am I the same person or am I a different person?

Part of this conscious thought is a deliberate reorganization of space which, while making living at home easier, also makes frailty and disability even more visible, especially the reorganisation that occurs with the introduction of practical aids. These grab rails, ramps, raised toilet seats, and special grab poles for getting in and out of bed as well as aids for assistance to move around the home increase usable reachable space. Reference to these as 'necessary' but 'not beautiful' captures, in part, the way the functionality in design takes priority and that prosthetic devices can seem out of place in the home. On the surface it appears to be a simple matter. Percival's (2001) observations are that people reorganize their home space to assist in managing the slower pace and decreased mobility of ageing. But such reorganization reframes the meaning of the space, from independent space to a space which indicates dependence for support and mobility, thus making the disability visible. Less visibly, it also reframes the identity of the resident, both to the individual concerned and to outsiders.

Though the emotions engendered by changing spaces in the home are similar to those feelings already discussed on receiving care, we mention them here in this context and reframe them through a definition of spatial intrusion. Such feelings consist of conflicting emotions over the visibility of disability and the relief in having help which makes activities of daily living and moving round the house much easier. At the same time, such devices draw attention to the disability and are a constant reminder of the changes in functioning. The material possessions of disability devices mark the new social identity, and make it visible. Reversing Turner's comments that the removal of material markers of identity were an indication of liminality, we suggest that the addition of disability aids are markers of the liminal stage in the rite of passage into supported independence.

Our review of research in the United Kingdom, Canada, Scandinavia and New Zealand suggests three important processes in bodily changes are a part of the liminal experience: (a) re-presenting the body and identity to oneself, (b) re-presenting the body to other people, and (c) the impact of the care worker on the perceptions of the identity and the ageing body.

3.4.3 Re-presenting the Body to Self

Consciousness of the ageing and the damaged body occurs when faced with the inability to move around quickly, to bend and stretch, reach, stride or walk easily, to continue the fine finger and arm movements, to hear and to see. Hale's (2006) participants commented that the struggle to maintain function actually emphasised the loss of former abilities. In re-presenting the body to oneself, the literature makes much of the 'mask of ageing' (e.g., Featherstone & Hepworth, 1991), the attempt to refute and change visible signs of ageing, such as wrinkles, grey hair, and even the slow gait. Not so easy to change, however, are the signs of the ageing body with disabilities. Murphy (1987) describes this as like coming into contact with a foreign identity. He suggests an individual becomes:

> *alienated from his [or her] old carefully nurtured and closely guarded sense of self by a new foreign and unwelcome identity* (p. 109).

Kvigne and Kirkevold (2003) focus on stroke survivors, especially women, recognising that in western cultures women's bodies are important capital, they are subjected to a particular type of gaze which has expectation that they must be made attractive. A stroke can significantly affect the ability of an individual to meet such expectations (p. 1294). Ageing and damaged bodies elicit strong emotions: horror of a husband's disabled diseased body and greater awareness of one's own ageing, disabled body with the ‘saggy baggy bits’. The emotions often accompanying such self awareness are, as Murphy (1987) says:

> . . . anger, an existential anger, a pervasive bitterness at one’s fate, a hoarse and futile cry of rage against fortune (p. 106).

Exemplifying this are two of Hale’s (2006) respondents who regarded their bodies with despair and revulsion. Such feelings resulted in large part in serious depression, requiring many months of counselling. Kvigne and Kirkevold (2003) describe similar feelings in their post-stroke studies.

This response, though, was not universal and others had a different perspective on their bodies and were able to consider the body as something to be managed, for example, through a reflective, calculated approach to completing physical tasks. Godfrey and Townsend (2008) allude to this when they talk of the process of recovery, in intermediate care of ‘each day’ working on the rehabilitation of bodily function:

> *Every morning I tried to do more for myself . . . had to wash myself all over, and they helped dress me—under close scrutiny—how to do it—sock, shoe on the right foot. It’s working through with so funny learning to be independent in something [that] you’ve done all your life without thinking. . . You have to think through everything—an awful lot of concentration* (pp. 943–944).

Becker (1993) has shown that older people living with limitations often continue to regard themselves positively and in control, although they are in need of regular help and assistance. This supports the argument of Rubinstein and Parmelee (1992) that, with appropriate resources, the ageing self has an enormous capacity to cope. Nevertheless, however resilient people may be, there is still the break from the self and the lifestyle prior to the onset of frailty or disability that must be negotiated. Working with this disabled and damaged body and learning to accept and present it to oneself is part of a liminal experience and one’s changing self-identity.

3.4.4 Re-presenting the Body to Others

Reflections on how to present the body to others also places the individual in a liminal position. Murphy’s (1987) comment that the ‘diminution of the self’ can be ‘magnified by debasement by others’ (p. 93) refers to the way the sight of the older, damaged body evokes negative responses from the self and others. The types of bodily changes leading to the need for care in the home are often socially stigmatizing and degrading, for example, being unable to control the body, its ‘leakiness’, its unresponsive limbs, or its slowness of pace, or its inability to speak or take care of itself properly (Kvigne & Kirkevold, 2003). Responding to this ‘diminution’ and ‘debasement’, and re-presenting the changed, incapacitated body, involves the deployment of social ‘boundary maintenance strategies’ (Dyck et al., 2005). For women, for example, this can involve the performance of a social feminine identity, as distinct from a physically needy identity, marked through the careful selection of clothing, the wearing of a dress, careful grooming for visits, or the wearing of matching nightwear and bed linen.

Hale's (2006, pp. 96–98) respondents also deployed a variety of emotional responses, anger, irony, humour and assertiveness, in communicating to others an awareness of their own changed physical self and an awareness of the impact of that on the other person. Laughter over physical difficulties and dependence on prosthetic devices were intended both to reassure themselves that they are acceptable and to reassure others. Respondents expressed anger over patronising and dismissive responses from others: 'people who think we are one sandwich short of a lunch' (p. 108). Shaking a fist at the heavens in the presence of others in apparent triumph over a deceased elderly neighbour followed by the comments, 'Aye, aye Mrs Mackay, I'm still here' (p. 131), was intended to convey irony and determination. Acceptance of self and assertive demands for assistance from a husband and friends when sight deteriorated was another response.

Some of Hale's (2006) respondents had used clinical psychologists or counsellors to assist in their coping with the presentation of their disfigured bodies to themselves and to others. Their intense responses to the onset of a disability points to the way their experiences of separation and liminality were associated with being alienated from their own bodies. In part, their responses to their bodies originated in the social meanings attached to their disabilities. Having an opportunity to recognise this through a process of reflection with psychologists or counsellors, or through the acceptance of family and friends, assisted in the process of reconnection. This observation emphasises both the different ways liminality can be experienced and the need to recognise the importance of reconnecting with the self and with others following the onset of disability.

3.4.5 Re-presenting the Body to Care Workers

We suggest there is a quite different confrontation with the damaged body when the cared-for person interacts with caregivers, one which can reinforce a negative self-identity or one which can promote reconnection. Personal care and 'body work' that is carried out in a way that draws attention to the older person's lack of ability to perform very basic self care can be contrasted with caregiving that involves working alongside the older person in a way that supports their continuing abilities. The lack of personal privacy and the relative powerlessness of the cared-for individual in these exchanges result in a particular type of liminality.

The normal allocation of boundaries between different parts of the house for the performance of personal care is disrupted when space is reorganized to accommodate the delivery of formal care in the home. This can result in the private body care tasks, such as washing and toileting, being performed in the public areas of the house (Dyck et al., 2005, p. 181). Furthermore, undressing to receive personal care, especially in these more public spaces of the home, makes the damaged body visible and strips the various masks of ageing. Such masks of ageing are as much about presenting an acceptable image of the body to oneself as to others. Stripping off in private and viewing the damaged body challenges the image presented by the masks, and this is exacerbated in the presence of a caregiver. There are strong feelings of powerlessness where the care recipient is naked, such as when being showered, bathed or dressed by a fully-dressed care worker, who is in charge of the situation, moving well, and carrying out what are normally the private tasks of personal care. Physical care disrupts norms of social interaction and exposes the private body in intimate self-care tasks of bathing, toileting, cleaning teeth and dressing.

The cared-for person's experience in these intimate encounters is influenced by care worker perceptions of the ageing body. Hale's (2006) respondents found such encounters 'difficult' and described disliking 'being cleaned up by others . . . Well it's embarrassing . . . between the legs . . . underneath the breasts' (p. 132). One described disliking having her breasts being lifted to ensure drying underneath; another disliked undressing in front of workers and displaying her own ageing and damaged body; and another preferred going to a local rest home for regular showers. 'It's easier there'. Meaning, 'They're used to it . . . the staff, you know' (p. 132). As this final comment indicates, care worker attitudes profoundly affect the way the older person experiences their confrontation with their damaged body.

3.5 Summary

The reorganisation and modification of space in the home at this stage is undoubtedly an adaptation strategy designed to maintain function and restore loss, the basic purpose of which is to support the maintenance of autonomy and independence. On the surface, spatial reorganisation to create functional areas and to accommodate the introduction of formal care into the home appears straightforward. But such reorganisation contributes in an important way to the liminality that accompanies the transition to supported independence. The idea of supported independence suggests enablement and empowerment to continue to remain at home. Our impression, though, is that many people in this situation find that when home becomes a site for the formal delivery of care, there is a considerable disruption associated with the challenges to the new uses of space and the meaning of the home. While the receipt of care is greeted with relief, it is also a profound disruption as was indicated in the impact of the loss of control over key spaces such as the kitchen, or the conducting of private body care tasks in the public rooms of the house. Such handing over of spaces causes considerable mixed emotions and the major disruption comes with the entry of formal officials and carers.

On the surface it appears to be a simple matter: home space is reorganized by the occupant to help him/her in managing the slower pace and mobility of ageing. Home space is cleaned by someone else to assist the occupant to remain at home safely and comfortably. But such reorganization reframes the identity of the home's resident, and below this apparently simple surface are the mixed emotions engendered by changing, adapting, and handing over spaces in the home. Such feelings consist of uneasiness over the visibility of disability; the relief in having care and being able to put energies into other activities; the agitation that accompanies the care worker taking control, even for a short time, over private spaces; and the disquiet involved in having someone else work in your space. As Mrs S. said, '. . . but as long as I'm still cooking I think. . . well I'm still running my own home' (Hale, 2006, p. 108).

From the discussion on the ageing body and the individual identity, the start of the transformation towards the new identity is apparent. Features of this movement are: the presentation of disability both to self and to others; the increasing presence of assistive devices; public view of the changed spaces and changing use of spaces; experiencing through the presence of the care worker the emotions of physical dependence; and the changed meaning of touch. From these features, we suggest that the body becomes a site of multiple meanings: for the care recipient, her/his body represents a personal identity, including intimacy, privacy and self presentation; for the care worker the body is a site of care, and is a source of employment, income, sympathy, pity, and an area for power and control. Our contention is that those people in a situation of receiving personal care face experiences of liminality.

As we shall argue in the final chapter, such assistance has to have as its purpose support for the autonomy and choices of the older person. We suggest that our present model of task-focused service with low paid, often untrained workers, maintains dependency and reinforces passivity. The likelihood is that the recipient remains frustrated, angry and anxious. With a different model and philosophy, and with appropriately trained workers, in-home care has much potential to support directional autonomy. Having highlighted the notion of spatial disruption associated with the transition into supported independence at home, we move in the next chapter to examine issues of 'time'.

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Chapter 4
Temporality and Liminality

4.1 Introduction

The liminal experiences which we suggest are part of the passage into supported independence can be illuminated further by considering temporal disruptions and the various multiplicities of time which accompany the advent of government funded in-home care. This chapter explores the disrupted temporal experience which occurs with the transition into disability, frailty and the receipt of care in the home. Despite its abstract nature, there is considerable value to be gained by focusing on the issue of time and separating it from Chapter 3's observations of space, and from the observations of the social context in Chapter 5. It allows us to focus on the microcosmic processes of change that have an impact on older people living at home with care. We make the point that by studying moments in time, we can observe the changing involvement with the world, and we use these perceived changes to support our argument that they are associated with a transition into a new life stage.

To study the experience of time is to study how people's lives are constructed and framed through their temporal environments. As Westenholz (2006) observes,

> time identities are not, however, static. In practice, they are socially negotiated, and in the process the delineation between the individual and its environment changes (p. 34).

The process of social negotiation associated with the transition involves the negotiation of time identities as the relationship between the individual and his or her environment changes.

Our interviews with older people receiving in-home care in New Zealand revealed discontinuity and led us to question the assumption that ageing in place provides for stability and continuity. One of the aspects of discontinuity was the way in which time was experienced. While the transition into supported independence can be thought of as a broad life course disruption, or, in Bury's (1982) term 'biographical disruption', closer examination indicates there are many other temporal dimensions within that broader experience. Interviews with older people in Scandinavia and New Zealand demonstrate both the broad patterns of change and the more micro-level changes, such as the implication of multiple time frames which begin to have an impact on the lives of older people with the advent of care at home. As older people interact with service agencies they must reconcile their own slower

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‘disability time frames’ with those of service agencies and other family members. This dissonance can contribute to the disorganized and out-of-control feelings that comprise the experience of liminality. We consider these tensions in terms of liminality, the concept which, in our view, best describes the situation in which older people can find themselves and relate this to our proposal of a new stage in life.

As we age, our perspective of time shifts increasingly towards a position which sees our lives as a ‘temporary, transitional existence’ (Bond, Peace, Dittman-Kohli, & Westerhof, 2007, p. 280). Such a shifting perspective is often evident in conversations with older people in their references to time past, in their reminiscences, to a concern with maintaining their abilities, and their reflections on time left for the future. These preoccupations with and changing perspectives of time are also supported by research results from the German Ageing Survey.[1] Furthermore, Elisabeth Dittman-Kohli (2007), member of the German FALL, writing on temporal references in the construction of self-identity, comments that as we age, we make more and more reference to temporal matters—the continuation of life, preservation of independence and approaching decline and loss. These comments suggest an emerging preoccupation with time, and the implication that unless we consciously examine the temporal dimension, it may remain embedded in the taken-for-granted assumptions which imply stability and continuity in ageing in place with in-home care.

Older people’s narrations of their experiences reveal the significance of time, highlighting the temporal disruptions associated with, for example, a stroke. The temporal dimension was a sub-text implicit in every narrative, threaded through every story. Time and again, as researchers hearing about the experience of frailty or disability, we were aware that we participated in re-living the experiences of disrupting social dramas, where individuals face experiences of disconnection. During several interviews, we could only observe with distress, as participants re-lived their struggles to come to terms with their situation, often comparing their former state with their present condition. For example, Godfrey and Townsend’s (2008) participants’ references to the experiences of diagnosis, treatment and the after-effects of their conditions had a distinct temporal dimension. These referred to recovery as neither smooth nor linear (Godfrey & Townsend, 2008, p. 944) with the illness described as an ‘interlude’ and ‘its disabling impact as being limited by time.’ However, recovery was an uncertain process, and participants felt a disjunction between the self before and after illness, this varying according to the ‘hope of a return to “normal”’ (Godfrey & Townsend, 2008, p. 945). Hale (2006) found the same: not only did her participants express sadness, often weeping as they reflected on what they described as the ‘slow disintegration’ of the ‘damaged’ or ‘altered’ body, they did so in a way that included reference to questions about time. Such references included consideration of whether the time of autonomous, independent living was ended, as well as the reflections on the moment-by-moment accounts of the process of becoming frail or disabled. Comparisons were made with earlier times in their lives, sometimes even generational and epochal, referring to parents and grandparents.

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[1] See http://www.fall-berlin.de/fe1.htm?/fep7.htm

As we read the research of others and listened to the narratives of our own participants, we became increasingly aware of the importance (not only to the participants, but also to our argument of liminality) of the moment-to-moment struggles which characterise the transitional experience. Such change is similar to the microcosmic spatial changes identified by Percival (2001). They also tend to be invisible to the broader population, occurring within the privacy of the home and evident only to the individual and his or her family.

Focusing on such disrupting changes allows us to observe microcosmic processes experienced when living at home with care, and how the lives of people in this situation are constructed and framed through their temporal environments. Temporal disruptions require coping responses, including negotiations with others to restore established time frames or to create new time frames. When older people feel 'incapable' or 'restricted' and 'challenged' they have 'to be creative in both changing their environment and using different strategies to be able to accomplish their most desired occupations' (Haggblom-Kronlof, 2007, p. 199). Restoring or re-patterning their environment in temporal terms implies some control over the temporal dimension of one's life. This can be as simple as sitting down between activities and resting when required, or walking more slowly, or sharing an activity so that it runs to time. Or it can be, as Godfrey and Townsend (2008, p. 946) remark, restructuring daily routines around pleasurable experiences.

Negotiating with others to establish preferred time frames brings us to an examination of home care services. In examining the details of temporality in home care, we refer of course to Twigg (2000) who has already noted the pluralities and complexities of time in home care. To make sense of this sometimes confusing complexity of times we draw on Westenholz (2006) for her concept of 'time identities', these being derived from the experiences, position and background of each individual in the home care situation: the older person receiving care, family member, the *employed* family member, the care worker. We also draw on Adam's (1995) notion of timescape, the complex multiple times that impact on the home care situation. Indeed, if we consider 'time identities' of care recipients, family members and care workers alongside the notion of timescapes, we can identify complex multiple times in home care. Examples which we explore later are: the funding and service allocation times in health service policy guidelines; the service delivery times of the care work agencies; the care worker time; and the disability times of the cared-for person. Conflicting time frames create complex timescapes which can contribute to anxieties and tensions in home care, and, we argue, leave cared-for people and their families in a liminal situation.

4.2 Time: Continuity

Part of our sense of time lies in its continuous nature. Personal memories and reflections of inter-generational dynamics make us conscious of continuity, and leads to feelings of permanence and stability. Such memories are made visible in our homes through pictures, photographs, ornaments, displays of craft skills, and gifts received over one's life, created at different times, personalising the home and its identity, and revealing the individual's engagement with the world. For these reasons, Csikszentmihalyi and Rochberg-Halton (1981) describe the house as memory made visible. Even when the home is changed and an individual moves to sheltered or assisted living, these temporal markers continue to be created and displayed (Parks, 2003; Percival, 2001).

Such objects idealise time past (Hockey, 1999, pp. 108–109, quoting Spence & Holland, 1991). No sickness, no disabilities, nor unhappy times find a place on the walls of home. Such idealized times are part of the norm of presenting the positive to oneself and to others—as Mary Douglas (1991) says, happy times, when people were younger, in charge, in control, had some authority, and were skilled; and not the negativities experienced, deaths, failed relationships, incomplete activities or ambitions. Hale (2006) found reminders of happy times, maps of past journeys displayed on the wall, ornaments collected or given, skills displayed through photos and paintings, and even an urn containing a wife's ashes and a rose bush grown in her memory, all these as reminders of time past.

The notion of 'embodied memory' suggests that experiences of continuity with time past are deeper than the physical mementos on display within homes. This concept points to the interrelationship between the body and time—the notion of the past somehow being located in the body. French (1999) exploration of embodied memories invokes her experience as a hearing-impaired child reluctant to play outside because, as she recalled, 'the wind gets in my way'. As an adult, French was reluctant to venture outside. She found her memories of the noise, a memory of hearing the wind, was a part of her reason for not venturing outdoors. Her memory of the wind was the reason she could not hear other sound cues. Our physical selves and our homes, then, are repositories of memories of times past, and symbolize continuity.

Time, therefore, can be thought of as being carried within the body as well as being made visible in the individual's home. An individual's history accompanies that individual during his or her daily, monthly and yearly life. It is part of the personal rhythms of life. Moreover, objects remind the person of the positives in their past life and affirm a sense of continuing identity when facing challenges that can be part of the late life experience. In an important and significant way, time past is unchanging. Walking through home spaces, as Irving (2004) and Hale (2006) did with their participants, provides not only a perspective of current time for frail older people, their slower time of disability exemplified by taking longer to move through one room to another, but also a historical timescape, a perspective of reminiscence. When we walk with an older person at home we move through their space and through their time, slower because of age and disability, but larger in terms of the presentation of indicators of time past. The sense of an individual history—of time lived—is enormous (Irving, 2004). Their time preserved is part of their life course and brings the past into their present, emphasizing the continuity of identity.

'Continuity' also implies the individual maintaining his/her daily rhythm. Timing means personal organization, maintaining an acceptable temporal rhythm to the day, the week, or the month (Larsson, Haglund, & Hagberg, 2009; Haggblom-Kronlof, Hultberg, Eriksson, & Sonn, 2007). Daily rhythm is part of what has been laid down during the life course, and thus part of ongoing expectations. As Goffman (1959) indicated, such daily rhythms are established early in life and connected with the presentation of self. These continue as part of the adult role, as an employee, as a parent, as a host/hostess. Such daily rhythms structure the organisation of the self and the home, and provide markers for the experience of the day: for example, morning is for tasks, after lunch is either siesta or leisure time, then another meal, depending on the culture. Maintaining our own daily rhythm is part of continuity and self-determination, part of keeping life on track.

The importance of temporal patterning and its role in providing stability and continuity were examined by Larsson et al. (2009) and Haggblom-Kronlof et al. (2007) in research which considered the nature of everyday living of older old Swedish people. For a group of 99 year old Swedish participants, Haggblom-Kronlof et al. (2007) described such patterns in terms of rhythm, which they defined as 'a settled pattern of behaviour, based on needs and individual will, and following clock-time, day-to-day time or experienced time' (p. 194). Their days were also shaped by external factors such as service support, radio and television programs (for example the hour of devotion), news and weather broadcasts. One minute-by-minute analysis demonstrated a morning's occupational rhythm, formed by the informant's son's visit every morning to have a cup of coffee and a cigarette before work.

> *As I said, I get up at six and go... straight downstairs and heat up two cups of water in the micro, one at a time and drink them with honey in. It usually takes nearly half an hour... but while it's boiling... it takes two minutes per cup, I usually lay the table and make the coffee* (p. 196*).*

Appreciating the general patterns of time use and the significance of these patterns and routines draws attention to the importance of change and the significance of those changes for the older individual. Godfrey and Townsend's (2008) and Haggblom-Kronlof's (2007) participants made plans to ensure that environmental challenges, such as going downstairs, were met by different carefully timed tactics, to ensure meeting individual goals. Remaining at home required personal strategies, demonstrated in the moment-by-moment accounts of key tasks, such as bed-making and house cleaning, where those tasks were possible. Participants appeared to perform their daily occupations in a highly time conscious way. Any interruptions to this pattern were described as 'unpleasant' and were a cause of stress (Haggblom-Kronlof, 2007, p. 195).

Insights from work with younger people with disabilities show the same moment-by-moment, time-aware approach to organizing daily patterns of living. Irving (2004) describes such daily constructions through a moment-by-moment account of the timing and context for small actions at home, for example, in someone moving to the bathroom to brush teeth, or reorienting herself to her home, by taking time to move round each room:

> ... persons become more conscious of the entire chain of action involved in previously taken-for-granted practices. Simple tasks become fragmented and their constituent parts are made present by an inability to perform, revealing facets and temporalities that were previously hidden in an embodied memory once naturalized through practice but now degraded through disruption (p. 328).

4.2.1 Temporal Disruption

Regular patterns of daily life are interrupted by health problems in old age. Olaison and Cedersund (2006) have demonstrated how the initial assessment process to determine eligibility for care, discussed in Chapter 2, is a temporal disruption. It might have been considered as a temporary disruption and that, with the provision of additional care services, the balance and regularity of everyday living would be restored. However, more frequently, the delivery of care services in the home perpetuates the experience of temporal disruption. The individual's ability to maintain their own temporal rhythms is often described as absent in situations of receiving care at home (Richards, 2000), given the schedules and budgetary demands of care providers and the agencies they work for.

Various authors have identified breaks in the expected rhythms of the life course. For example, Bury (1982) uses the term 'biographical disruption' to classify the intricate connections between time and the experience of the onset of chronic illness and disability. Williams (2000) extends Bury's notion of 'biographical disruption' by examining issues of timing, context, norms and expectations at particular junctures of individual lives. Kingston (2000) elaborates on the notion of status passage and refers to the goals of this passage, viz that of a changed or, in Charmaz' (1987) terms, preferred identity, while Godfrey and Townsend's work (2008) recognizes the temporal-spatial dimensions in their discussion of a trajectory of illness-recovery. Andrew Irving (2004) observes that the onset of disability and increasing chronic illness poses a danger to a person's sense of continuity, commenting that:

> perceptions of time and space are generated through people's everyday activities, [but] the disruption caused by illness transforms pre-existing ways-of-being in time and place (p. 317).

Ageing slows people down, as Larsson et al. (2009) and Haggblom-Kronlof et al. (2007) observed in their different studies. So it is with late-life frailty and disabilities which interrupt the steady pattern of everyday activities. Taken-for-granted simple tasks are broken down and their constituent parts become obvious through the inability to readily perform them, revealing facets and temporalities that were previously hidden in an embodied memory, once performed effortlessly through practice, but now requiring concentrated attention.[2] One of the respondents in the 2005 study of Barrett, Kletchko, Twitchin, Ryan, and Fowler commented:

> *People must think, whatever does she do all day, because I think that myself. But honestly . . . If you don't get up till late in the morning, and you're slow dressing, slow eating and I don't have a shower then because I can't stand solidly enough, I shake you know. So it's quite late by the time I'm sort of finished that bit. And then there are the beds, the bed to make, and the washing to do and the ironing and this sort of thing* (p. 20).

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[2] Obviously different syntactic chains exist in each location. For example ablutions and brushing teeth are differentiated as people in New York don't fetch water from wells whereas many people in Kampala do.

A further example of this new awareness of time is provided by Irving (2004) who observed the process of brushing teeth.

> *It becomes apparent that brushing-teeth involves animating-the-body, raising-one's-head-off-the-pillow, getting-out-of-bed, walking-to-the-bathroom, opening-the-door, standing, leaning-over-the-sink, administering toothpaste, brushing, and walking-back* (p. 328).

That this action involved walking to the bathroom is something rarely recognized as part of the practice of everyday living. Hale (2006) observed a similar time issue with an 88 year old woman managing a toilet routine in a small flat: she got up from her chair, manoeuvred on to her walking frame, twisted the frame round to where she needed to go, walked slowly to the toilet a matter of thirty paces or so, opened the door just beyond the frame. By reaching over the frame, she manoeuvred into the toilet, dealt with her clothing, performed on the toilet, and repeated the process in reverse. The whole operation took 20 minutes or more.

This process of recognizing difficulties and the slower time of disability and ageing can be the trigger that leads to the recognition of the need for help. The slower time of disability, then, is in an important way a 'temporal disruption'. Corbin (2003) suggests that motivation to seek care is often 'an interference with the activities of daily living or a certain degree of acuity before persons conceive of themselves as ill' (p. 263). She quotes Karp (1996) who observed that people had to reach a crisis point, where they could no longer carry on with the normal functions of daily living.

The experience of becoming frail also raises questions about temporal dimensions such as, 'Will I be able to do what I used to do' (Grenier, 2005). When references are made to disability, chronic illness and the associated suffering, there is often an implicit allusion to time. Morse and Penrod (1999) for example, comment on how suffering is seen by those with chronic illness as 'enduring'. Such references feature prominently in discussions of care at home, indicating a consciousness of time and process in disability, possibly intensified by the receipt of care. References to being 'suddenly hit' with a condition point to very clear temporal disruptions and associated liminality.

Whenever people enter periods of decline, then, the time dimension becomes a significant factor in their experience. Further, the slowing down that accompanies frailty and disability takes time away from other activities to accomplish the small but important tasks of, say, teeth cleaning or toileting. Instinctive coping behaviours, with the purpose of preserving the self and being able to carry on living include focusing only on the present: 'one day at a time' is the implicit motto here. Living with such conditions is described as 'hard times' that are to be endured, but not 'dwelt on' (Pilkington & Kilpatrick, 2008 p. 231).

One further dimension of this is the manner in which the experience of frailty and disability in old age leads to changeability in health and wellbeing—and how the routines and rhythms of the day are often, therefore, disrupted by the fluctuations. This is captured in the notion of 'unstable disability' that is often used to capture the experience of frailty in old age. How one is feeling on the day often determines the ability to participate in family or social engagements outside of the home, interrupting plans, weakening social connectedness.

> *Well, I don't go out like I used to . . . and sometimes I think, 'Yes I'll go with the girls,' and then that day comes and you're not so good* (Barrett et al., 2005, p. 74).

4.2.2 Separation: First Rite of Passage

The biographical disruption, we suggest, is punctuated by the assessment process, which takes place at one point in time, which takes time to complete, and which includes checks on the timing of functioning and activities of daily living. The date and time of the assessment itself represents an important point in time in a person's life story; and within the assessment there is a focus on issues of time in terms of how long it takes for the older person to perform basic activities of daily living: how long it takes to get to the toilet, how long to dress or undress, to put on shoes, to get to the door, and other aspects of everyday life. There are important temporal aspects, then, within the assessment process, which itself is a point in time marking an official recognition of disability. To reiterate our observations in previous chapters, this assessment symbolically formalises the separation from a previous identity, as well as officially recognising a status of frailty or disability as a part of establishing entitlement to formally provided help.

Such a separation is further emphasized by the provision of formal in-home care, which also introduces a new element into the older individual's timescape. Such care is organised according to the time conventions of the ordinary working day and, in the New Zealand context where directive control does not lie with the older person, its delivery is managed by an external agency. The reorganisation of the older person's timescape, when employment times are not synchronised with individual expectations and wishes, has been shown to lead to uncertainty and anxiety. In the New Zealand context, the Care Plan drawn up by the needs assessor or care manager, in consultation with the older person, specifies tasks that have been timed to a regulation number of minutes, or parts of hours: for example 20 minutes for a shower, 10 for cleaning a particular size of toilet, more perhaps for a kitchen. The coordinators are charged with attempting to meet the care recipient's requests around the timing of care worker visits, but frequently they are unable to achieve this. As the older person *becomes* a client, so does home care *become* one of 'clock time', this determined by the hours allocated, by the agencies receiving the referrals, and by the worker undertaking the tasks.

No matter how skilled the assessor, how great the need, the assessment process is significant in its formal acknowledgement of a situation of dependency and loss of control (Richards, 2000; NZ Guidelines Group, 2003; Janlov, Hallberg & Petersson, 2006). And despite the negotiation processes that are recommended, these being intended to address the power imbalance (Olaison & Cedersund, 2006), the process is a significant disruption in the life course that leads to a reappraisal of identity and the experience we have described as liminality. It appears that the assessment process has two ends, a beginning, when the formal assessment begins with its specific schedule of questions, and with the completion of the assessment, when many older people describe the impact on them as ‘feeling torn apart,’ ‘uncertainty,’ ‘anguish,’ ‘anger.’ Concerns over possible costs and fear of the future lead to questions of identity: ‘Who are you really? You become a set of ticks in boxes,’ and lead some to draw on their spiritual beliefs, ‘the Lord will provide,’ and a ‘sudden awareness of what was happening’ (Hale, 2006, p. 96). Within the hour to hour and a half that it takes for the assessment, then, the older person’s view of their world and of themselves shifts from that of an independent individual functioning without formal assistance, to someone formally recognised as dependent on in-home care.

4.3 The Liminal Stage

The tensions between clock time, and process time, between the agency-defined tasks and temporal preferences of the individual, lead to liminal experiences. Once eligibility for home care has been established, the process in different countries is to offer a home care agency or group of agencies for choice of worker. Individuals who *become* clients, have distinct preferences for when they want the house and personal care work carried out, but this is often at variance with that of the agency. However, the practical issue of timing, as they are fitted into the care provider’s schedule, profoundly affects their daily experience. For example, having to wait for long periods in states of undress leaves the older person in a state of limbo. The following comment by one of Barrett et al.’s (2005) severely frail participants suggests this awareness is not necessarily shared by care workers. She explained that her care worker was:

> *… unreliable as to time. Time is nothing to her. She told me today she would be here at quarter to ten and she didn’t come ‘til twenty to eleven. And then you’re hanging around all that time…getting cold. And she said, ‘Oh I’ve got another one to go to.’*

Twigg’s (2000) participants had their preferred daily routines, of morning tasks and afternoon leisure. Hale’s (2006) participants preferred showers and personal care in the morning, as well as domestic tasks. Evenings were for tidying the living areas and going to bed. Afternoons were free. While most agencies would like to adhere to these wishes, the need to organise daily routines around the time of the regular working day in the formal economy tends to result in care recipients being allocated times by provider agencies and told ‘take it or leave it’. The choice is rarely with the recipient. The power lies with the agency.

While the resilience of older people to cope needs to be recognised, we highlight that such resilience is not universal, that for some what may be interpreted as resilience may in fact be behaviours underpinned by the words ‘accept’, and ‘manage’, a language designed to shrug off the difficulties and ignore them. We do not underestimate the potential for older people to cope, but we also want to bring these difficulties into the open for consideration and resolution, to ensure ageing is valued and is positive.

Part of ‘accepting’ and ‘managing’ is to accept that as care recipients, the routines of their lives must change to suit the time frames of care workers and care agencies. Whatever the recipients’ home schedules, with in-home care, their preferred routines become subordinate. A comment from one of Hale’s (2006) respondents captures this:

> *We don’t call the tune. It’s them at the hospital [the needs assessors] they tell us what we can have, and the government pays the caseworker. . .well, through [the agency]. We don’t pay and it’s those who pay who’re in charge* (p. 114).

In the New Zealand context where directive control over the use of funding is with the agency rather than the older person, the time of the care worker belongs to the agency as the employer, rather than to the care recipient. This observation was evident in the following comments by two of Barrett et al.’s (2005) participants:

> *The home help comes in – they say, ‘This is what we’ve been told to do.’ And that’s it. They’ve got a list of things with them, it’s written on there, and they don’t do anything which is not written down.*
>
> *My girl’s only allowed to vacuum clean, wash the toilet and clean the bathroom, but anything else that wants doing, she’s not allowed to do it.*

Hale’s (2006) participants pointed to this type of situation as an issue of control. They felt it was an important part of the slow dispossession of power, because the more valuable time, i.e. paid time, of the care worker dominated the preferences of the care recipients. Without exception they fitted their days around the schedules of the workers. When care workers were providing domestic work only, as opposed to personal care when they would by definition have to be present, none of her participants would go out and leave the worker on her own; nor would they encourage any visitors during the time the worker was in the house. Part of the reasoning for this was to maintain personal contact with care workers for companionship, as well as the usual reason given of ‘keeping an eye on’ the work and the worker. The tensions were expressed in Hale (2006):

> *Mrs S. wanted her day to begin earlier, as did Miss E. and Miss H. who did not criticize their workers because ‘they did their best’. But, wistfully, Miss E. said ‘I’ve always been an early riser’ and Miss H. said, ‘I just get dressed the best I can, and wait for her to come and put on my socks and shoes.’ Miss G. expressed concerns about her daily routine being compromised by care worker times. She found it very annoying to have her ‘help’ arrive late, and sometimes to change the hours of work. Miss G. had maintained a strict working routine all her life and, even in retirement, continued a very stringent routine* (p. 114).

Aronson (1999) describes the loss of control as a part of the process of ‘being managed’, where the problems of time have to be solved from the standpoint of the agencies and care workers. This is supported by Twigg (2000, p. 188) who describes how ‘making clients conform to time discipline. . . is a central element in the work.’ Care workers, too, face their own temporal challenges, given the generally poor conditions, casual nature of their employment and low pay (see Chapter 7). Typically, they are compelled to get through their work quickly and complete the assigned tasks to make the work pay.

Another temporal aspect in this situation is the interpretation of an individual's needs in terms of standardized timed care tasks (Szebehely, 1995). The current time standards for home care tasks, which provide the basis for time-budgeted home care plans, were developed before the government contracts were widely set in place. The care work tasks were defined in terms of number of minutes it would take to perform particular tasks, for example, 20 minutes for a shower, including undressing, washing and dressing again, and sometimes including hair washing. Ten minutes for cleaning a particular area, five for a smaller area. These times are subsequently translated into funding through a correlation of tasks and times. For example, showering may take 20 minutes, vacuuming the carpet 10 minutes, cleaning a toilet and bathroom 10 minutes.

Not only are the tasks dealt with through standardized times, but also the frequency with which they are performed. For example, if vacuuming once a week is allocated by the assessor, the care worker will vacuum once a week, regardless of the care recipient's views. One of Hale's (2006) respondents commented that, 'the house is never dirty. I wish she'd do the cupboards... windows... back doorstep, [instead of vacuuming]'. This captures the often-cited tension between the care recipient's views of what is required and the timed allocation of tasks by authorities external to the home. It points to an area of contest between the recipient's wishes and needs and the worker's and agency's abilities to meet those needs. To meet the needs through funded care, there is a depersonalization of the individual, an 'objectification' in Milligan, Bingley, and Garell's (2005) terms and an autonomous person who, instead of being supported to manage is managed (Aronson, 1999). 'Being managed' is how many individuals perceive their situation.

The situation of time and care tasks will be discussed further in Chapter 7. It is enough to indicate here the distinction between the standardized times which govern agencies' work, and the responsive, relationship-based time of empathic care work, where the needs and feelings of the care recipient are given priority. Just as the care workers feel these tensions, so do the care recipients whose autonomy is jeopardised by clock time of the agency. It is sufficient here to say that there are tensions for care workers in working under these conditions with older people whose times are the slow times of disability, the longue duree of reminiscence, and the leisurely time of socializing.

4.4 Summary

It could be argued that the liminal phase ends with the assessment procedure and care worker in place. For some older people, it is possible that passage through this liminal phase will be achieved with the acceptance of care. But, as Szebehely (1995), Aronson (1999), Janlov et al. (2006) and others have identified, acceptance of care is insufficient to alleviate the disorientation and challenge to identity that characterises this stage. Rather, in many cases it can increase the anxiety and reinforce the liminal experience. Our review of narrative accounts of the assessment process leads us to agree with Aronson (1999) in Canada and the Swedish researchers that the experience of receiving care leads to a life that is ‘managed’, implying, in the terms of this chapter, a loss of autonomy and control over when one gets to do things.

Assessment and the acceptance of care becomes an issue of time and can lead to the question of whether the rite of passage ever ends. Kingston (2000), quoting Glaser and Strauss’s (1971, p. 33) definition on temporality and passage, refers to the issue as one of the ‘rate, pace or speed of the passage’. When an individual puts questions such as: ‘Am I likely to fall again in the future? How long will it take before my health improves?’ to medical professionals, they are asking about when they will return to their former selves. As Glaser and Strauss suggest, such individuals wish to know not only where they are going, but approximately how soon they will arrive there (p. 35). It may be difficult to predict how long the passage of an illness will continue or what the rate of change will be, or whether there is any possibility of reversing the decline. The notion of a rite of passage, though, implies there is a chance for the passage to end when the individual finds a stable and valued identity, however this is defined. Kingston (2000) comments that the efforts in finding such an identity are part of a rehabilitation process, and also part of the status passage (p. 219). Our observation is that in finding, accepting and presenting a transformed identity, the individual makes some reconnections to the wider society, a point which we take further in our final chapter.

Evidence of liminal experiences are the disempowerment, anxiety and concern experienced following assessment for care; the concerns over the times when care is provided in the home; the lack of control over the amount of time and frequency allocated to specific tasks; and the anxiety caused by the mismatch between the slower time of frailty and disability and the clock time of the care agency, and between the leisure time of late-life and the busy time of care work. These all have an impact on how the older individual negotiates the new life stage following the onset of frailty or disability. Many writers implicitly refer to these types of experiences and even if they do not mention liminality, they identify passages, trajectories, biographical accommodation and movement towards a new identity. In so doing, they capture the processes of change and the remaking of the self. They capture the developmental stages of the illness experience, encompassing the physiological developments and the meaning and effect on the life and self-image of sufferers and their families, and the mobilizing of resources (physical, emotional, social, cultural, and economic) to manage the practical and emotional consequences of disruption.

How is time experienced and transformed within the changing social setting? Our data, and those of other researchers echo Andrew Irving’s (2004) comments:

> If, as generally accepted, perceptions of time and space are generated through people’s everyday activities, then the disruption caused by illness transforms pre-existing ways-of-being in time and place (p. 317).

Many time frames can be identified in home care. If we use the categories devised by Westenholz (2006) on time identities and Adam (1995) on timescapes as insights into the temporal dimensions of home care, then we can see such different time settings:

- The broad generational/demographic timescape which is leading to increased numbers of older people remaining at home with care;
- The time frames of governments which decide the policies which shape packages of formal care;
- The timed entitlements to hours of care, planned and budgeted at national and local levels;
- The time frames of needs assessors and their agencies;
- The hours of care which an older person is allocated following an assessment and the establishment of eligibility;
- The time frames of the care provider agency, its coordinator, and his or her phoning or visiting;
- The time frame which determines the availability of the care worker;
- The time preferences of the older person—usually mornings are preferred to afternoons for in-home care;
- The time taken to complete care tasks: a shower or bath so quick that the care recipient is scarcely dried;
- The time before and after care tasks: the home or body before and after the care worker's visits;
- The time of family visits, and the time of other visits from neighbours and the social network;
- The time given by the family carer to caring tasks;
- The timescape of the care recipient, both the historical memory of quicker task completion and the present slow time of disability.

With national policies of ageing in place, the home is the site where these multiple time frames intersect and overlap with each other, resulting in new timescapes which have underlying conflicts and tensions. At a macro level, we can refer to the historical trend of population ageing which has led to new approaches and philosophies, such as ageing in place. At a micro level, in the homes of older people, it is possible to identify the time frames of care workers, which are derived from their employing agencies and the hours of care allocated, as well as by their own personal situation. We can also identify the time frames of the older person receiving care, their daily rhythms and routines established over many years. These are disrupted by the onset of frailty or disability, by the slower pace at which things are done, and the need to fit in with the new demands associated with receiving care at home. These intersecting time frames result in the need to negotiate times and relationships with agencies and workers. In the end, the issue is one of control over time. Dependency on the home help service, suggest Haggborg-Kronlof et al. (2007), means a lack of control by the older person.

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Chapter 5
Relational Transitions

5.1 Introduction

Movement into a new life stage is typically accompanied by new forms of personal and social relationships. In this chapter we explore what that means for older people as they move into the stage of supported independence.

It is widely accepted that changes in personal and social relationships in later life occur following retirement, loss of a spouse or one's generational peers, movement into retirement homes, or movement into residential care. Such events often lead to experiences of social dislocation requiring some type of social adjustment. One of Wenger's (2002) insights was that the transition into frailty and disability at home also involves a change in the older individual's social environment towards support networks that are characteristically family dependent or private and restricted. These networks tend to be smaller and have lower levels of community involvement. Our own research indicates that frail disabled older people who remain at home with care first of all experience their disability and care as a social dislocation. This disruption of their social lives subsequently requires them to reorient themselves and renegotiate their personal and social relationships. While there may be a series of new relationships with health and allied professionals and with care workers, becoming frail or disabled at home reduces the size of the networks and leads to renegotiations in the relationships with family and friends, especially if one or more of this network becomes the informal carer. Jeggels (2006) discusses this in terms of 'role fitting', observing that the older individual's disruption also produces a disruption for family members too, something which we will discuss more fully later in this chapter. Given that these processes take place within the privacy of the home, they tend to be unseen, unnoticed, and, therefore, taken for granted.

For many such older people the disruptions caused by the onset of frailty or disability leave them in social limbo. The processes contributing to this are familiar. A combination of: physical mobility and transport problems; unstable and fluctuating health; feelings of not being able to keep up with the pace of other people; an unwillingness to inconvenience others; loss of confidence and fear of accidents or falls; an unwillingness to venture out at night; and shrinking social circles, all influence the ability to sustain community focused networks. The resulting social isolation can

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lead to loneliness and depression, and points to particular challenges faced by this group of older people. Because social contact is not typically considered an 'essential' activity as are visits to the doctor or shopping for groceries, people in this situation tend not to be offered and are often reluctant to ask for assistance to meet a primarily social purpose.

Our observation, supported by the research from Janlov, Hallberg, and Petersson (2006) and Twigg (2000) is that a further experience of disability and of becoming dependent on home care involves significant social challenges for not only the cared-for person but also their co-resident spouse and other family members. These challenges are little recognised and consequently there is a lack of understanding of the issues facing older people and their families. These challenges contribute to experiences of liminality and need to be understood if they are to be addressed through policies and practices that facilitate passage into the new life stage of supported independence.

In this chapter, we examine first the changing relationships with the care providers and the family members through the voices of older people. Many of these changes are initiated and formalised through, yet again, the assessment process. If eligibility for formal care is established, formal care agencies and non-family care workers come into the life and home of the older person. These are typically women, whose caring role is transferred from their own homes to those of other people. Care recipients, particularly older women, have a great deal to say about such care, and in our review of their experience we describe their various strategies for dealing with in-home care workers.

The chapter then turns towards examining the implications for families and family members who become carers. We describe the challenges faced by spouses and other family members who become informal caregivers; the motivations and identities of informal caregivers; the experience of responsibility without authority; the experience of 'dirty work' and other physical challenges associated with care work; the implications of challenges to the spatial environment; challenges to the social networks; some of the particular issues faced by men who become carers; and the sense of grief and loss often experienced by informal caregivers. We conclude by considering changes that are occurring in the caring industry as a whole, both historically and philosophically, and the implications for practice.

5.1.1 Relationships in Transition—An Overview and Background

Becoming an older person, with or without disabilities, leads to new social encounters and attracts social definitions which shape how individuals are treated, the style of relationships, and, eventually, we argue, leads to a transformed identity. The process of growing older itself influences relationships with family members, as adult children establish independent lives, set up their own homes and create their own families. Such interpersonal interactions are influenced by past patterns of behaviour (Lewis & Meredith, 1988; Finch & Mason, 1993; Fine, 2007). Typically, however, affection, caring and practical help tend to begin to flow in both directions—from parents to children and from children to parents. Even when ageing with disabilities, this dynamic in relationships continues, especially through the care role of daughters. Informal caring by spouses and adult children is defined in various ways—as an expression of familial care and duty, a burden, a stress, a joy, an expression of good will. Whichever word or set of words is used, it is clear that the relationship is transformed: from a spouse or an adult child to a carer. In one sense, the relationship is an extension of family care norms; in another, it exceeds those norms by becoming the primary responsibility that begins to redefine the individual aims and goals of the family member who becomes the caregiver.

With policies of ageing in place, the onset of disabilities in late life has meant that more formal care is required, partly because family members are today unable to provide the level of care to meet the increasing severity of need. New relationships are formed with needs assessors, care agencies, and care workers. These relationships, too, are influenced by the context of expectations about how older people should behave, and the ideologies of ageing and activity that structure the policies and system of old age care (Katz, 2000; Victor, 2005). For the older people with whom we are concerned, interactions with family members as well as the relationships with agency coordinators and in particular the care workers are underpinned by normative views, often ageist stereotypes, about how older people should behave. Often these relationships are conducted in such a way so as to reinforce passivity and dependency in older people and undermine their autonomy and agency (Szebehely, 1995; Olaison & Cedersund, 2006). As we have noted, Aronson (1999) refers to this as a relationship that involves the 'management' of the older person, and as such, it has particular features that require greater understanding.

To understand these widely experienced changing relationships and observe their development from their origins within the wider context of ageing and disability, we draw again on the framework of a rite of passage. This helps to focus on the situations which create these changes and to observe the changes as a developing process, as the disability increases and as caring increases. Examining these changes suggests that there is a process of transition. The experiences of fluctuating and/or increasing disability and the experience of in-home care move the individual along a status passage from independence to a status of increasing dependence.

The rites of passage framework implies the involvement of others and directs our attention to the importance of relationships and the significance of changing interactions. It begins our awareness of the process of change by clarifying an official, formal separation from the current identity. For older people with disabilities, we have suggested in previous chapters that assessment is the official separation point, the first stage in the rites of passage. While changing interactions begin during the early stages of disability they are brought to light during the assessment process, when questions around informal support are asked. The assessment documentation then officially stamps the identity as someone in need of assistance.

With the completion of assessment, the separation from the former identity is also complete, according to the rites of passage model. The next, second, stage is that of the liminal, characterised by removal or by a compromise of the individual's former identity, status and control over life. During this second, liminal stage, these challenges to the former identity and status of the older person confront the norms which have previously underpinned relationships, for example, those of affection, power, control, autonomy, and independence. Such a confrontation, then, requires the renegotiation of care relationships by the increasingly dependent older person and by the caregiver. In what follows, we explore these themes by considering evidence from our own and international studies.

5.2 Assessment and the Experience of Separation

The process of needs assessment carried out to establish eligibility for formal care services presents new relationships to be negotiated by the assessed person. At one level, the goal of assessment is to specify the level of need, to establish eligibility for assistance and to provide information upon which to develop a care plan. At another level, as we observed earlier, the assessment experience, with its needs-based questions, is accompanied by a variety of emotions: concern, anxiety, embarrassment, humiliation and anger, as well as acceptance and understanding. The following comment by Janlov et al. (2006) shows there are clear connections between these emotions and expectations by the older person about social changes likely to result from the assessment encounter:

> It [the assessment] also evoked anxiety because it meant facing a new, unknown and potentially unpleasant situation and having to let strangers into their home and private life, all of which was experienced as threatening. This brought on the fear of losing self-determination and control over daily life and becoming increasingly helpless and vulnerable (p. 333).

The assessment process is also described by Olaison and Cedersund (2006) as a form of institutional conversation, a discursive practice with the subtext that the assessed person will learn the philosophy, rationale and terms of receiving home care. The terms of care, in this sense, are communicated and constitutes a specific social script, one which spells out society's expectations in terms of activity and ageing. These scripts are evident in the assessments and decisions that emerge from them.

However, to be assessed and to receive care produces for the older person an awareness of disabilities and needs, and a learning of the system and how to suit the needs to the system. So when Olaison and Cedersund (2006) suggest that those being assessed for home care position their accounts in relation to '*category-based identities*', they are suggesting a process of action in accordance with the social scripts for care, and that these actions influence how individuals seek to have their needs recognised by the assessors. The encounters, then, involve a form of:

> implicit identity constructions that are created through locally ordered discourses where applicants' self-presentations are negotiated and adapted to what is available in terms of home care (p. 378).

They reinforce particular expectations about what it means to be at home with care. In these encounters power lies with the assessors, and those being assessed demonstrate an awareness of that by presenting themselves and their conditions within the terms of the care arrangements. There is a process of negotiation, implicit or explicit, but this ultimately requires conformity by the cared-for person to the social scripts associated with the receipt of care.

5.3 Agency and Worker Relationships

Older people who are deemed eligible then face new relationships with the selected service provider agency and their care workers. It is standard practice for care agencies to attempt to select care workers who are likely to be compatible with the cared-for person, but other criteria such as proximity and availability influence decisions. The importance of this relationship, in our opinion, is little recognised. The care worker—care recipient relationship, as we have indicated, is one where once the care contract is developed for the care agency, much of the power lies with the care worker. Their relative dominance within the relationship is reinforced by the fact that they are able-bodied and mobile.

Hale's (2006) study showed that from the cared-for person's perspective relationships with the workers were judged according to care worker attitudes, skills, friendliness and flexibility. Successful relationships were those where care workers brought all four qualities:

> *We do get on well ... they like to place people where they are getting on well with people. Well I look forward to seeing [the care worker] now, and I think it would be awful... if I had somebody every morning and think, 'Oh oh, what's coming?' you know, and not looking forward to it. ... I think it's her attitude. She's a very friendly type of person* (Hale, 2006, p. 100).

Further, positive relationships were those characterised by trust and a stance by the care worker of 'working alongside', supporting directional autonomy, without constant anxious supervision or passive dependence on the part of the care recipient. The most successful care relationships were those where the cared-for person was able to indicate what needed to be done and even teach or instruct the care worker in how to do it. Where this happened the older person felt an immense amount of satisfaction. 'Teaching' the care worker to do the job 'properly' or according to the preferences of the care recipient was a feature of good relationships, a positive reinforcement for the care recipient's skills, when the care worker not only accepted but also learned from the teaching in terms of performing the care as the older person wished.

Within these relationship contexts, cared-for individuals employ a variety of strategies to have their needs met. These range from, on the one hand, subservience, acceptance and appreciation, to, on the other, negotiation, struggle and assertiveness (Hale, 2006, p. 130). An example of the former is the way care recipients often show appreciation and gratefulness of the care worker's time and attempt to be as little trouble as possible, something, as we have noted before, Aronson (1999) calls 'managing' and allowing oneself to 'be managed'. Many hope in return to receive generosity in the way the care work is carried out. Twigg (2000) has described how care recipients handle workers ‘with gloves, velvet gloves, because care workers are very touchy’ (p. 185).

By being ‘nice’, not complaining, care recipients hope to receive ‘niceness’ in return as Twigg (2000) commented. This included tolerating and accepting the personal situations of the workers, for instance in their need at times to bring babies, toddlers and sick children kept home from school to the care work visits. As it was, care recipients in Hale’s (2006, p. 132) study were aware of the poor pay rates for care work and the care workers’ needs to fit in as many hours as possible during the day. It included showing support, being a listening ear to the worker, giving gifts, and indeed intimacy in the relationship, such as taking an interest in a worker’s family and friends.

Positive care relationships are also characterised by continuity. Hale (2006, p. 98) reported on the case of Miss L who had a long-term care worker with whom she had an ‘excellent’ relationship. However, when this worker left town, Miss L was ‘at the mercy’ of a series of temporary caregivers whose work was poor, but which she tried to tolerate. One of Barrett et al.’s (2005) respondent’s insightful comments emphasised the importance of the relationship and the significance of continuity of care. She said:

> *You deal with a lot of personalities and changes of personalities and that’s not always easy. If you have somebody that looks after you for quite a considerable time, they get to know you. They get to know you, your needs, better; and how you feel, and everything, and you build up quite a nice relationship. But with some people it doesn’t quite work.*

A lack of continuity in the care relationship is recognised as undermining the experience for the older person. References to a procession of care workers ‘coming through my door’ were a common complaint that Hale (2006) noted, and her participants conveyed that a large part of the stress this caused was linked with the need to repeatedly display personal need and the reiteration of particular requirements. The recipients’ feelings of vulnerability were emphasized with every new care worker, leaving them anxious, irritated and embarrassed.

5.3.1 ‘Fictive Kin’

The similarities between positive care worker relationships with the cared-for person and family member relationships with that person are recognised by Karner (1998) in the reference to their status as ‘fictive kin’. Such relationships can be very positive, but they are not unproblematic. Care workers can find themselves in the position of advocate for the older person: supporting them in situations where families are abusive, or encouraging and arranging meals on wheels, or further help, or different contact with family.

Care workers in Hale’s (2006) study used kinship terms to describe some of their employment situations. One example was of a care worker who lived in a small tight-knit community where the care worker’s family had considerable contact with older people through the local schools, shops and garages. She actually described care work as

> *a family situation... they are like family to us because of the contact with my husband, their son and daughter... but there again, I refer to all clients as family because they usually have family there when I am there* (p. 174).

'Fictive kin' is strongly suggestive of an approach to care giving that implies elements of affection and closeness, rather than a neutral, disengaged relationship where the personal assistant is under the command of the agency or client (Twigg, 2000, p. 193). From our observation, many workers recognise the importance of the warm interpersonal aspect of caring and this can contribute to the worker being seen as a significant person in the recipient's life. A situation reported in Hale's (2006) study was one where a care worker maintained long-term relationships with those for whom she provided care. Doing so gave rise to very close bonds to the extent that in one case she was nominated as 'next of kin'. In this case she was also asked by the cared-for person to be a conduit of information between family members—a type of family information broker. Given the long-term nature of the care and the additional kinship-like roles, this care worker did become like kin. The kin relationship, however, was fictive, for both the care worker and the care recipient. There was a degree of ambivalence by family members about this new role and it was frowned upon by the agency. According to the agency this care worker was acting beyond her legitimate role and there was considerable debate about the appropriateness of taking these extra responsibilities. From the agency's perspective, this was a situation requiring close monitoring. However, it reflects the liminal position of the care recipient and the worker, and raises important questions about supervision.

5.3.2 Struggle Within the Care Relationship

We have suggested that the introduction of formal caregivers into the lives of older people at home leads to experiences of liminality. Some care relationships are characterised by anger and frustration, often because of poor work, or because of feelings by the older person about disabilities and dependence. Such frustration may take the form of the constant telephoning and complaining by some care recipients to the care agency. Such battles, though, can be seen as an effort to maintain both the competent autonomy and authentic autonomy described by Collopy (1988) where the personality, history and norms of an individual are maintained.

Other methods of dealing with the relationship can be seen in times when care recipients do not feel their needs are being met. Some employ what might be described as negative methods of negotiation—the frequent complaints about the care work and care workers. This can be thought of as a part of the 'struggle' to assert influence on the care relationship, 'influence the ways their needs are understood' (Aronson, 2000, p. 63), and retain some directional autonomy (Collopy, 1988). Complaints about the work done, the time taken, the number of care workers who ‘come through my door’, and the regular phone calls to the agencies which raise other issues or requests exemplify attempts to maintain control and avoid passivity. Again, we relate this to Collopy (1988), and attempts to maintain agency.

Clearly, care recipients are required to employ a variety of strategies to achieve the care they need, given their subordinate position in relation to the care agencies and care workers. It is, as Twigg (2000, p. 184) describes, a ‘struggle for control’ and a ‘prime area of conflict’. These challenges in home care relationships are widespread. Studies from the United Kingdom (Walker & Warren, 1996; Twigg, 2000), Canada (Aronson & Neysmith, 1996; Aronson, 2000; Angus, Kontos, Dyck, McKeever, & Poland, 2005; Martin-Matthews, 2007) and Scandinavia (Waerness, 1984; Szebeheley, 1995; Janlov et al., 2006) all point to challenges to the building of positive care relationships on account of ‘factory’ model, task-focused care work processes that reinforce the systemic subordination of the cared-for person. The potential benefits of ageing in place are eroded in these circumstances and the experience can become one characterised by the emotions of frustration, anxiety, and repeated embarrassment and humiliation.

5.4 Relationships with Families: Informal Caregivers and Experiences of Transition

Experiences of social liminality are also evident as care recipients renegotiate their relationships with spouses and family members following the transition into frailty and disability while living at home. It continues to be the case in the English speaking family of nations that it is a spouse or daughter who takes on this role, but this is not the case in all countries. In Japan, for example, it has been the wife of the oldest son (Kono, 2000, pp. 182–183). Motivations for taking on the care of a parent include a ‘sense of duty, of affection’, and of reciprocity: ‘I couldn’t let him down; he’s done so much for me’. The influence of prior relationships and role modeling is clearly evident: ‘she’s done so much for others/for me’, ‘like my mother did’. Belonging to a kin group results in distinctive relationships with responsibilities amongst kin. Linking these responsibilities with the construction of identity, Finch and Mason (1993) suggest that if the caring role is a valued part of the personal identity then it becomes ‘too expensive to withdraw from those commitments through which that identity is expressed and confirmed’ (p. 170). The emotions and responsibilities of belonging have a ‘moral dimension’ closely related to identity. These identities are constructed and confirmed, they suggest, through the caring process: ‘. . . identities as a reliable son, a generous mother, a caring sister or whatever it might be’ (p. 170). Some of the family members in Hale’s (2006) study demonstrated this sense of duty and responsibility, often motivated by strong feelings of reciprocity and affection. A family history of caregiving, then, was influential on current carers, whom she quoted as saying they were merely acting: ‘like my mother did’; [I] saw my mother care for grandparents, and father care for her mother' (p. 148). The role models of family caring were usually women, but men were also referred to.

The recent proliferation of research into caregiving signals a growing concern for and awareness of the particular needs of caregivers. Understanding the caring experience as a transition process is consistent with the conclusions of Cameron and Gignac (2008) who highlight the changing experiences and corresponding support needs for family members when they become carers. They identify five different phases in the process of becoming a family caregiver, and the specific support needs at each stage: (1) event/diagnosis; (2) stabilization; (3) preparation; (4) implementation; (5) adaptation. The first two phases occur during acute care, the third occurs during acute care and/or in-patient rehabilitation, and the final two phases occur in the community. As Stoltz et al. (2006) suggest, support for carers is more complex than may be realized. Our understanding of their experience, and therefore our ability to recommend policies and practices, is enhanced by teasing apart the caring experience in terms of the stages caregivers go through.

Early analyses in the caregiving literature focus on stages in caregiving for carers of those with Alzheimer's Disease. Wilson (1989) identified 'taking it on' and 'seeing it through' as distinct stages (see also Schofield, 1996; Willoughby & Keating, 1991). For carers of older people with physical disabilities, Selzer and Li (2000), Hirst (2002) and Coleman et al. (2004) have all recognized the significance of identifying specific transition points for carers based around their coming into contact with sites of care and major health events.

The transition points involve significant role changes between the caregiver and the cared-for person. These begin for many caregivers when a partner or parent becomes disabled, such as following a stroke, or with the increasing recognition of greater problems stemming from conditions such as Parkinson's and Alzheimer's. The processes of role change can be sudden as when an acute health event triggers a disability, or more subtle and imperceptible as is the case sometimes in the development of late-life frailty. 'Caring can sneak up on you' as a respondent in Hale's (2006, p. 145) study commented. Finch and Mason (1993) suggest these transitions lead to changes in identity for the carer, especially when care responsibilities and tasks intrude into a family member's life and go beyond the normative kinship role, such as is the case when providing bodily care for a parent.

Families themselves, or family members who become carers, enter a state of liminality in the process of caring for a frail or disabled elder. As Efraimsson, Hoglund, and Sandman (2001) describe, the process of becoming a caregiver involves:

> life situations where natural caring was changed into patient-care-giver relations and the home became a public room... patients had to deal with decreased abilities and the family members with adjusting to caring (p. 813).

Somewhere between 'taking it on' and 'going through it' are important challenges that lead to liminal experiences. Such challenges involve role changes; temporal changes; spatial changes; changes in social and family networks, and an ambivalent social position that is poorly understood, little recognised, but one which leaves caregivers with much responsibility and often little support or authority.

5.4.1 Developing an Identity as a Family Caregiver: Separation

Hale (2006) argues that the rites of passage concept is as relevant for carers as well as care recipients. She proposes that the first stage of the transition process, separation, was evident in the lives of carers in terms of change in self-identification and a growing recognition that family members were taking on a new, and often unsought, role as a caregiver. Her study of in-home care dynamics included family carers as one of the three groups of people involved in caring at home. Like several other authors, viz Wilson (1989), who talked of three stages, Hale identified three major stages in caregiving: a point of recognition, experiences of liminality, and acceptance of the role. Wilson observed families 'taking it on', 'seeing it through', and connections, while Jeggels (2006) from South Africa, also recognises three major stages: 'role fitting', where the family member becomes a carer; maintenance; and reconnection. The three stages are evident in a beginning, a middle period, and an ending. However, it may not be sufficient for appropriate intervention, and Cameron and Gignac (2008) have organised a multi-stage model, which may provide practitioners with better material for interventions.

The beginning, or separation, is used here to mean a point in time where there is clear recognition the family member has taken on a new role, or expanded upon a role previously undertaken, to such an extent it has now become a primary responsibility which begins to define identity and life choices. The separation experience for caregivers was either sudden or an imperceptible sliding into the care role, as one of Hale's (2006) respondents indicated when she said, 'by the time you recognize what you're doing, you're into it.' (p. 145). A number of markers of this transition were noted in earlier research by Hale (2000), notably linguistic changes, where the caregivers who were spouses began to stop using the pronoun 'we' of couples, and began to use the 'I' of an individual, indicating, amongst other things a change in authority and responsibility for making decisions.

Recognition by others also indicated or marked to the family members that their roles were changing. When health professionals became involved and offered help in terms of respite care and caregiver support, family members *became more aware* their role had changed. Accepting responsibility and taking action could be seen as another marker in the move to a caregiver role: when 'he got sick and went into hospital', a daughter initiated contact with staff; ensured a discharge plan with care was put in place; initiated contact with the care agency, and initially kept an eye on the care worker. Accepting responsibility and taking action in terms of hands on body work was another indicator of moving into a new role. One of Hale's participants commented:

> *Holding my husband's penis for the district nurse to insert a catheter was the turning point for me* (p. 145).

The awareness was a turning point in recognising she had taken a new role and this signaled an important change in the relationship—a separation from what had been before.

5.4.2 Experiences of Liminality: Responsibilities with and without Authority

As a spouse or parent becomes increasingly dependent, the family carers are often expected to assume more responsibility for making decisions and/or to persuading the cared-for person about decisions. At the same time, though, many carers report that they are often excluded from decisions that affect their spouse or parent with decisions taken without consideration for the implications on the caregiver.

Carers therefore occupy a betwixt and between position, or 'interstructural' position as Turner suggests (1969, p. 95), in terms of their associations with the care recipient and professional recognition. Many carers report they have little input into decisions by health and allied professionals. There is often little recognition by professionals that family carers have an intimate interest in and knowledge of the recipient's situation. Such exclusions can result in a tentative approach to the work of caring with limited knowledge of the options available to them. Jeggels (2006) observed that a successful caring relationship required full knowledge and information, support, and upskilling, defining this as 'role fitting'. Hale (2006) found that without this, the role of carer can lead to an ambivalent relationship with health care and care professionals, and feelings of anxiety in carrying out their tasks.

5.4.3 Experiences of Liminality: Physical Challenges

Becoming a caregiver can involve new demands in terms domestic work and hands-on physical work. This often involves activities such as bodily care which can be physically challenging in terms of the weight-bearing and lifting tasks involved. It is also difficult in terms of the challenges it represents to the identities and roles of the parties involved. Body work, as Twigg (2000) described, was often distressing, both for the carer and the cared-for person. It can be particularly difficult when adult children are caregivers. Accepted boundaries of personal privacy are broken in washing, toileting and dressing, and this is a source of stress for both carers and recipients.

> *And it was something that I had to be aware of, too, that he absolutely hated his daughters having to do anything private with him. He absolutely hated it.... If he'd used the toilet and he couldn't clean himself... he never ever liked his daughters to help* (Hale, 2006, p. 151).

These comments point to the undeniable change in roles and relationships that occurs when family members become the providers of personal care with washing, toileting, dressing and grooming, and to the significant stress that can be a part of these changes. In such situations, the extent to which former identities, status and control over one's life, say, as a parent or partner, are challenged, is clearly evident. Such situations also illustrate the challenges faced by caregivers, who also need to reorient their identities and roles. Where the challenges to the identities and roles that arise from these new situations are such that they are not accepted by the older person, formal care is an option, or the responsibility falls on a similarly aged spouse.

5.4.4 Experiences of Liminality: The Changing Spatial Environment

Csikszentmihalyi and Rochberg-Halton (1981 in Saarenheimo, Nikula, & Eskola, 2004), in suggesting that the home can be thought of as 'shell of the self', observe that:

> changes in the domestic order can be interpreted as challenges to maintaining the continuity of the self. In this respect, the 'signs of illness', such as the presence of special hospital furniture, care equipment or particular odours and noises, get easily interpreted as obstacles for social interaction at home (p. 14).

The onset of disability or frailty by a spouse or parent leads to important changes in the domestic order and the way in which social interaction at home is conducted. Saaranheimo et al. (2004, pp. 14–15) refer to considerable research which shows that the social networks of carers undergo significant change. The spatial rearrangements and practical limitations influence the ability to offer hospitality and affects the wish and perceived ability to invite people to visit. New rules develop which regulate 'the visits of friends and relatives' (p. 13).

The spatial re-arrangements and improvisations referred to in Chapter 3 affects not only the cared-for person, but other family members living in the home, and not only in terms of the reorganisation of space, but in ways which affects the ability to interact outside the home. The paraphernalia of disability begins to shape the living spaces and lead to the spouses feeling their living areas are no longer their own. Hale's (2006) research found there was a sense in which the meaning of home was dictated by the disability needs of the care recipient, with the home becoming a place *of* care and a place *for* care.

Sleeping arrangements are reorganised—in one instance in Hale's study the care recipient had a hospital bed with sides and a lifting frame installed, leaving space for only a small single bed for his wife in a corner; living rooms are turned into bedrooms, and other rooms are reorganised to accommodate overnight carers; often the spouse moves into another bedroom altogether; equipment to assist functioning—the presence of a walking frame, a 'talking book', and a white stick; a wheelchair beside the bed, a bedpan on the seat—these are the types of concrete reorganizations of space and furniture, identified also by Saarenheimo et al. (2004), that fill and define the rooms of homes where frail or older people live.

For family spouses and other members, the impact of these changes is often a sense that their home space is becoming 'cluttered up'.

> *I used to think my house was not my own but the place was set up like a hospital anyway and I used to have wheelchairs [for my husband], walking frames, seats and bed with frames up the side and lifts, you know, overhead lifts, things over the top, and there was no room to turn around... I had no space, I lost my space* (Hale, 2006, p. 152).

Changes like this represented a ‘radical reordering’ (Twigg, 2000, p. 86), an intrusion.

> *It’s my space. But she [the care worker] takes it over* (Hale, 2006, p. 155).

The private space where a lifetime of personal memorabilia were accumulated was, for some, threatened—leaving a feeling that the private had become public, and in this environment, the home was not the same.

5.4.5 Experiences of Liminality: Mixed Emotions and Feelings of Grief and Loss

Finally, it is worth commenting on the emotional side of caring. Barusch (1991) observed the ambivalence in caregiving for a spouse or parent in terms of emotions of loss and grief for the person the caregiver has once known, of the knowledge that there are further health issues to face, fears for their own health, and an awareness of having to face the future. As we have also noted, providing physical care with toileting and washing is often distressing for the cared-for person and the caregiver. Drawing on Barusch (1991) we note that the emotions that accompany caring for a frail or disabled family member are mixed. They range from a steady and growing commitment to the cared-for person, that develops over time, to a growing objectivity and changed view of the relationship. As noted earlier, this is linguistically evident in the shift from the ‘we’ of a couple to the ‘I’ of the individual, responsible caregiver. For some this develops into a detachment as questions about the longer term prospects are considered. Conflicting emotions also accompany the making of plans for life after the death of the cared-for person, with feelings of not wanting to be disloyal to the current life of the cared-for person by contemplating living without him or her. The conflict can also be evident in becoming immersed in caring for the care recipient rather than continuing to live one’s own life.

5.5 Becoming an Informal Caregiver: The Experience of Men

The gendered nature of care is evident in the way it has traditionally been provided by women. Yet, as men’s life expectancy increases and as gendered norms around family and care roles open up, it is likely men will begin to play a greater role in the care of spouses, parents and other family members. Russell’s (2007) study of older male caregivers examines the specific experiences of older men as they become carers of spouses in the home. Russell conceptualizes the type of progression for caregivers indicated earlier as a general process of extending normal spousal care, through a period of transition, to a full commitment as a primary caregiver. He describes this in terms that also imply liminality: it is invisible, in an *unfamiliar* working location for many men of the current older generation, in an environment traditionally occupied and run by women. The transition from the visible world of the formal economy to care work at home was, says Russell (2007) ‘a journey into difficulty and unfamiliarity’ (p. 310).

For the current generation of older men, their roles in the formal economy had involved creating tangible goods or services that previously did not exist—they involved creative and visible acts that ‘added to the existing order’. Rewards from this environment were tangible and added to feelings of self worth among men. Work was invisible only when it was unfinished. Work was definable and easily described. Care giving, however, had different rules. It was an emotional economy, the nature of the work was different, it was described as non-creative by these men, and it involved sustaining, maintaining and restoring the status quo but not adding to it.

Their acceptance of the carer role, according to Russell (2007), challenged ‘the norms of masculinity.’ Given socially constructed gender norms, he states,

> men are not considered real carers who suffer the same social, emotional and physical consequences which women carers have been demonstrated to suffer (p. 299, quotation from Arber & Gilbert, 1989, p. 80).

A major cause of role challenge, says Russell (2007), is the invisibility of care work. Family caregiving is a part of the private and invisible world, as many of the men in his study pointed out. Even immediate family members failed to grasp the full significance for the men of their change of role. For these men, the transition from public marketplace to the world of caregiving represented an immense cognitive and psychological shift. As one of Russell’s respondents stated, ‘They think they know, but they don’t see it—what really goes on’. Statements such as, ‘I never knew how hard this was, because I never saw what she did,’ and, ‘nobody sees what we’re doing’ (p. 302), were common.

The invisibility of the care work caused enormous frustration. Completed care work, or much of it, reflected Douglas’s (1966) well-known comment on disorder being matter out of place. Successful care work is matter in place, is order. But the work to get that order is unseen, as Russell says. Completed care work is work that has, in effect, disappeared. Men felt invisible as men because their work was not traditionally associated with men, especially in retirement. It was especially troublesome to be, in effect, unseen at home in the very social location in which their care work took place:

> *Out of sight out of mind. . . . I guess that’s how it works. Whenever anyone comes over, they run right to Connie and see how she’s doing. Just the other day, some friends came over and Connie was sitting in that chair over there. . .and ah, you can see it from the door . . . like I wasn’t even there! It seems like that happens a lot* (Russell, 2007, p. 306).

Even when the care work has finished, there is this invisibility. ‘Sometimes, it’s as if I don’t exist anymore’ (Albert quoted by Russell, 2007, p. 306). Many felt unsupported and unacknowledged by family members especially, and there was minimal and sporadic contact with friends and neighbours who therefore lacked understanding.

5.6 Summary

In this chapter we have explored the changes in social relationships that accompany the transition into supported independence. We drew attention to the power dynamics within these relationships and the relative disempowered position of the cared-for person. The assessment encounters signal a separation from former identities, status and control over the direction of one's life, and are a type of institutional conversation through which the assessed person learns the criteria and behaviour that are a part of the receipt of care at home. In these situations, power to decide the future of the assessed person lies with the needs assessors. Once judged eligible, new relationships with care workers are encountered, and again, these are characterised by what Twigg (2000) refers to as 'the power dynamics of care' (pp. 179–208). For some people there is a transferring of authority for care at home which seems like a surrendering of power; but as older care recipients face the related experiences of liminality, they do employ a variety of strategies in their encounters with care workers and these can be seen as attempts to continue to exercise a degree of self direction.

We also examined the experience of informal caregivers and the process of becoming a caregiver to a spouse, parent or other older person. Becoming an informal caregiver, too, involves a process of transition and experiences of liminality within that. Liminality is taken here to refer to the period of anxieties, frustrations, the process of learning new skills, learning a new language around disabilities and care, and dealing with new social networks. Accompanying a growing awareness of this role are new or changing relationships with the care recipient, friends and health professionals. Alongside this recognition are the emotions of grief and loss, exhaustion, challenge in dealing with the physical needs of caring and concern for the future.

As the population ages, it is possible that informal caregiving will become a larger part of the typical activities at certain life course stages. We have seen the emergence of numerous carer organisations around the world, such as Carers UK, Carers Australia and Carers NZ, and a considerable body of research on family carers. As we saw in Chapter 3, recognition in the media and by academic researchers is also evidence of a new stage in life. Applying this, then, to the growth of organisations focusing on family carers, accompanied by media attention, and by policies focused on carer needs, such as the Carers' Strategies in the United Kingdom, Australia and New Zealand, and the recent (2008) involvement by the United Nations, suggests that there is evidence for a new stage in life.

When such acknowledgement takes place and caring is recognised as a distinct role, then we suggest that the third stage of the rites of passage is reached, that of reconnections in a transformed identity. This, however, is something which we will discuss in the final chapter and which we will link to our concept of the new stage in life: carers, both formal and informal, as part of the new personnel which contribute to ageing in place with care.

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Chapter 6
Separation, Liminality and the Potential for Reconnections at Home with Care

6.1 Introduction

We began by arguing that population ageing and the responses of governments to support ageing in place have seen the construction a new social category of older people at home with care, with their own special services and personnel. While there has been considerable research into the impact on individuals of physical decline and the threats to the independent self within the context of the residential facility, from the classic work by Timothy Diamond (1992) among others, we are only now beginning to become aware of comparable processes around the organisation of in-home care and the impact on the individual. In this chapter we restate our approach to examining the transition to a life stage of supported independence in old age, and we begin to consider the third stage in the rite of passage, reconnection, developing this idea further in the following chapter.

An underpinning assumption of ageing in place and in-home care is that it provides for the maintenance of independence in the community. Through the provision of assistance to carry out the essential activities of daily living, the individual is assumed to be able to maintain continuity in their living environment, in the organisation of their lives, and in their social networks. But as we have seen, the very introduction of care to assist in the attainment of these goals introduces challenges which compromise the achievement of autonomy and independence. The design and nature of that care is therefore critical. With this in mind, it is worthwhile repeating the point by Polivka and Longino Jr. (2004) that we noted earlier:

> It is precisely when the individual begins to experience the erosion of freedom and agency that often comes with impairment and frailty that public policies should be designed to provide the resources needed to resist the loss of agency and allow the individual to exercise as much autonomy as possible under conditions of impairment (p. 5).

The loss of agency as a consequence of impairment raises the challenge of developing appropriate remedial public policies which support and restore agency.

The rites of passage concept, recognised as a useful analytical device by other researchers in this area, such as among others, Moore and Myerhoff (1977), Hazan (1984), Shield (1988, 1997), Teather (1999), Hugman (1999), Twigg (2000), Parks (2003) and Hockey and James (1993, 2003), allows us to consider in detail the

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significant changes that are a part of the movement into frailty and increasing dependence in late life, while also taking account of the wider social context of ageing. Conceptualising the transition as a rite of passage suggests that individuals face an experience of separation, loss of status and movement into an ambivalent social space. The assessment procedure which establishes eligibility for publicly funded services is a signal point in these processes. The resulting experiences can be thought of as constituting a liminal state with a loss of social status, a compromised identity, and as a part of this, a loss of agency and autonomy. The rites of passage model also specifies a progression between the liminal stage and the third stage of reconnection.

Thinking of the transition as a rite of passage, therefore, points in the direction of the types of initiatives likely to address the liminality experienced by older people facing the movement into receiving care at home. Understanding movement into supported independence as a passage through each of the stages illuminates the way in which individuals become detached from an accepted social location, processed through intermediary experiences which have ‘features of neither the previous nor the successive social position, and then . . . [are] incorporated into a new set of rules, roles and obligations’ (Hockey & James, 2003, p. 25).

If we are to develop policies and care work practices to facilitate the passage from a liminal state into a new set of roles and obligations, we need to be clear about just what those roles and obligations are. We suggest they are implicit in the motivations behind the adoption by OECD countries in 1994 of the policy of ageing-in-place—that being the provision of support for the maintenance of autonomous and independent living in the community, as opposed to an aged residential care or institutional facility. The provision of in-home care should clearly be seen, then, as having the purpose of maintaining the older person in their own home, in the community, so they can continue to live independent and autonomous lives. Policies and practices of home care should facilitate these goals. If home care policies, and the care practices they establish, are to achieve their potential in facilitating the passage from states of liminality, they need to be aimed at facilitating autonomy and independence so that care recipients may maintain former roles, may move into other roles, but at least become more visible as social individuals.

On their own, the terms ‘independence’ and ‘autonomy’ can provide an unrealistic picture of the experience of ageing at home with care, one that ignores the difficulties of a damaged or frail body, an unclear social role and a compromised identity, and the impact of a subtle ageism which can underpin assumptions that inform policy and practice. Recognising the importance of autonomy and agency and considering how it can be supported in different models of service delivery, however, is required if we are to develop policies and practices that enable the older person to reclaim their lives and be reconnected with a preferred sense of self and the wider society. If we understand independence as something that occurs within the context of support, formal care services offer much potential to facilitate the third stage of the rite of passage process, that of reconnection.

With these ideas in mind, we continue the examination of the transition processes through the rites of passage model.

6.2 Separation: Trigger Processes and Assessments

As we noted in Chapter 2, the process of assessment constructs older people at home as 'disembodied packages of care... a new cultural text of met and unmet need' (Gilleard & Higgs, 1998, p. 19). The process occurs within the context of interactions between medical and allied professionals, carers, family members and the older person. This frailty process, as it was described, involves diagnoses and the development of intervention plans, and often leads to the older person becoming attached to or embedded within various services and agencies established to meet their needs. Entering the process leads to the start of an ongoing passage of frailty and increased vulnerability, as Janlov, Hallberg, and Petersson (2006) suggest: 'Registration in the files as a help seeker seemed to mean that there was no turning back' (p. 30). Together, these changes lead to fundamental alterations in the older person's life that are likely to include challenges to a person's sense of self and identity, increased surveillance, and loss of control over his or her affairs.

The assessment process is like a secular ritual. It contains many elements of ritual practice: a clear sense of purpose and repeated activities that follow an established pattern. Moore and Myerhoff (1977) have commented that secular rituals 'structure and present particular interpretations of social reality in a way that endows them with legitimacy ... [and they] structure the way people think about social life' (p. 4). This leaves us with the task of understanding the categorisations of older people who face the assessment experience, the nature of the social reality that is constructed for them. We need, too, to understand the implications of these in the lived experiences of the older individual, and consequently those of their family members.

In the case of the referrals and the assessment process, the purpose is to ensure safe ageing at home through home help in personal care and the maintenance of domestic hygiene. As mentioned earlier, in the assessment procedure, the personal and home situations are defined within the terms of the official questionnaire which constructs the individual's condition as a set of needs to be met. This formal procedure legitimises personal need and establishes entitlement to public assistance. It also legitimises the authority of certain positions, primarily medical and allied health professionals, and locates the older person in a subordinate relationship to those professionals (Efraimsson, Hoglund, & Sandman, 2001; Janlov et al., 2006; Olaison & Cedersund, 2006; Hale, 2006).

Trigger factors such as a growing personal realisation of health needs, a stroke with resulting disabilities and difficulties in coping, having few or no people to help, hospital admissions, or urging from others, such as families, friends and neighbours, usually direct people to the assessment, process. It can involve:

- sudden and gradual transitions into frailty with diverse trigger effects;
- medical events, and medical complications and errors, and falls or death of spouse or close friend;
- the compounding effect of health, social and emotional problems, often from a specific starting point;

- an encounter with medical professionals; and
- growing dependence on partners, other family members, neighbours and friends.

The assessed person is not passive and the outcome of the assessment encounter is influenced by his or her personal reserves—these being the attributes the person brings to the assessment, such as prior knowledge of the services that are available, personal background, education and life experience, the degree of disability, the ability to articulate and speak for oneself, and support from immediate family. Possession of such resources plays a significant role in determining the outcome of the assessment.

Assessment procedures, though, tend to subordinate specific situational factors, personal characteristics and individual needs to what can be seen as narrowly defined, predetermined physical and mental criteria. Instead of, as Kane (2004) has suggested, a more open assessment format, based on what a person values, which for example would ask, 'what would you prefer, what makes you comfortable?' the assessed person is thus defined in terms of his or her degree of need and ranked according to a standardised process which is used to ration the allocation of care services. As noted in the previous chapter, this has the effect of structuring individual perceptions of self, often with the effect of reinforcing passivity and dependence.

The elderly person thus becomes a 'client' or a 'case'. The required services are defined by the needs assessor, and although there are many situations where there is a requirement of consultation with the older person, from our observation, the extent of this is limited. The same observation is made by others. Janlov et al. (2006), for example, commented in their study of older people going through this process that 'older persons . . . have no actual influence over the decisions about their home help. The officer told them what was available' (p. 26). An extreme example is Hospital at Home schemes which turn a home into mini-hospitals with specialised equipment, 24 hour access, and relatives driven into the siderooms. In these situations, 'domestic time and space . . . become wholly subordinate to an institutional regime' (Twigg, 2000, p. 105). At the other end of the care continuum is the episodic care which provides for the older person to maintain control over a wide range of areas of home life (Twigg, 2000). Both of these examples, though, are outside the focus on support for activities of daily living, for which needs assessors in Australasia, Denmark and Sweden tell the older person what is available and for which agencies provide a worker whom they choose on availability, proximity and suitability. The need by care providers to ration resources and the availability of care workers constrains their allocation of time and service. As Parks (2003) throughout her work says, care recipients have to adjust to more than coping with their disabilities. They must also adjust to what professionals deem they require.

This procedure reinforces a script of dependency through a process of 'becoming' that is unconscious and subtle. Eligible older people are required to be *accepting* of what is provided and *manage* accordingly because their problems are portrayed as '*all to do with growing older*', and because they might not get the service if they complain. The physical changes tend to be taken for granted and the formulaic specification of legitimate needs in the assessment process and the development of care plans can work to seriously undermine the older person's agency, reinforce passivity, disengagement and a state of liminality (Tulle, 2004). These changes have a deep impact on the independent living of the individuals, their environment, and their networks and relationships.

So, despite widespread acceptance of philosophies of positive ageing and the valuing of older people, there continue to be barriers to older people retaining agency when supported to age-in-place. The use of the terms 'independence' and 'maintaining independence' need, therefore, to be questioned. Older people use language such as *accept*, *manage*, and *put up with* when commenting on living with formal care at home, but such language can subtly point to their dissatisfaction with care arrangements as currently offered. Chevannes (2002) advocates a shift in the balance of power from the providers to the care recipients, but as Paterson (2001) shows, professionals tend to be reluctant to let go of power, and attempts to empower people do not necessarily affect practice.

Dependency on public carers greatly restricts ability to exercise influence and causes feelings of powerlessness. Frailty, disability and dependency give a poor basis for making demands. These feelings are exacerbated by the daily demands of having to live with decreased abilities. According to Bauld, Chesterman, and Judge (2000), older service users tend to be afraid to express themselves and show their dissatisfaction with services or care. Being cautious and minimising the seriousness of one's needs in order not to fall into disfavour and risk being left without help is common (Strandberg & Janson, 2003). We explore aspects of this powerlessness in the following discussion of individual liminality which focuses on three areas: body and physical frailty; relational or network changes; and issues of autonomy or agency.

6.3 Personal Liminality: Dealing with the Damaged Body at Home with Care

To speak of personal liminality is to recognise that older individuals find themselves in an unclear social location, separated from a former independent self but not yet reconnected into a new role and identity of supported independence. The experience of liminality is perhaps easier to understand when older people are considering a move, say, from home to hospital or from either of those to residential care. The transition is visible and the unsettling impact on the older person obvious. However, there is also a powerful experience of liminality for older people at home with care. Insights from Godfrey and Townsend (2008) on the trajectory from illness through to recovery, from Kingston (2000) on status passages following the onset of disability, from Bury (1982) and later Williams (2000) on biographical disruptions, and Charmaz (1987) and others (Backe, Larsson, & Fridlund, 1996; Becker, 1993; Becker & Kaufman, 1995) on the loss of self all point to the experience of older people facing this transitional experience.

Additionally, three recent Norwegian studies by Kvigne and Kirkevold (2003), Kvigne, Kirkevold, and Gjendgal (2004, 2005) have provided insights into the personal experience of liminality. Their studies have shown that the world of the stroke survivor is grounded in a life of loss and effort to compensate for that. Bodies no longer have a taken-for-granted, smooth functionality (Doolittle, 1992, 1994) and the mind has to become more active to make the body work. These studies of stroke patients, their feelings about bodily strangeness, and the struggle to continue life after a stroke, portray experiences which relate closely to those of the older people in our studies. Like many older people receiving care at home, stroke victims struggle to reconcile new tensions in three key areas: between independence and dependence, being in control and being out of control, and being connected with others versus being disconnected from others (Secrest & Thomas, 1999). The same tensions around independence, control and connectedness are a part of the experience of liminality. Struggling to continue life after a stroke involves passage through a liminal state, a loss of social status, a compromised identity, and accompanying this, a loss of agency and autonomy. Ellis-Hill and Horn (2000) discuss changes in identity and self-concept, following a stroke, concluding that many develop a negative self-identity and increased psychological morbidity, resulting in excessively diminished activities, and a more restricted life than necessary, despite efforts at rehabilitation.

The ageing, lived body is the bearer of cultural and social meaning. In a world where younger bodies are more socially and culturally accepted, being confronted with one's own frail, disabled and damaged body contributes to a negative self-identity and psychological angst. In circumstances of physical impairment which for Murphy was a slow paralysis, Murphy (1987, p. 106) suggests that individuals recognise the body as a 'foreign identity', this experience often accompanied by 'an existential anger, a pervasive bitterness at one's fate, a hoarse and futile cry of rage against fortune':

> ... the individual... [becomes] alienated from his old carefully nurtured and closely guarded sense of self by a new foreign and unwelcome identity (p. 109).

Another aspect of the body as a bearer of social and cultural meanings is the notion that it is an expression of a moral condition. The notion of self-control implies self-restraint and discipline over bodily impulses and urges. 'Good' bodies are kept under control. Bodily changes are therefore interpreted as expressions of a moral condition, because, for example, it is a moral weakness, as well as degrading, to be unable to control urine flow, or a foot, or an arm; to be unable to speak or take care of oneself properly; or to work very slowly.

Loss of control of the body interrupts both the way it is ordered and the normal and acceptable forms of interaction in society. Kvigne and Kirkevold (2003), describing this in terms of the experience of stroke survivors, define such loss of control as an interruption in the 'order of the body' and 'the order of interaction' (p. 1307). Further, interruptions in the order of the body are magnified through the norms of social interaction. Inability to comply with those norms in the presentation of the damaged body to others, be they family, friends or general social networks, and especially in the care work situation, contribute to what Murphy (1987, p. 93) has described as the 'diminution of the self'.

With the care worker, there is a specific type of personal confrontation with the ageing, damaged body, one which can reinforce dependency by emphasizing to the older person his or her inability for self care at a very basic level, or one which can facilitate an acceptance of the ageing and damaged body. The uncovering of the physical self that occurs when personal care is provided makes visible the aged body and strips the masks used to present positive images of ageing. As Aronson (2002) says:

> While the entry of home care may prove helpful, it also lays bare the reality of people's neediness and slipping capacities (Aronson, 2002, p. 402, citing Gallivan, 1992; Hurst-Rojiani, 1994).

The undressing to receive personal care creates strong feelings of powerlessness associated with the loss of control over the presentation of the self. Where the care recipient is naked, with their disabilities visible, and the care worker is fully dressed, in charge, moving well and with some power over the physical tasks of cleaning the body (Twigg, 2000), the older person is particularly vulnerable. As noted in Chapter 3 , Hale's (2006) respondents reported ambivalent feelings about subjecting themselves to being cleaned up by others. In these encounters, meanings are communicated not only verbally but also through touch—'gentle, not rough', or 'firm, but not rough', conveys care for the older person and their bodily needs. However, certain types of handling of the older person's body do not convey such care. Furthermore, certain areas of the body are particularly sensitive: private areas including genitals are areas older individuals prefer to manage themselves; arms, back, shoulders are neutral areas, while for women, breasts are particularly sensitive. The care workers in this context are in a powerful position to either debase the individual through the way in which they work with the body or facilitate reconciliation with the new physical state.

The body is thus a site of multiple meanings: for the care recipient, it represents a personal identity, a site of intimacy and privacy; for the personal care worker the body is a site of work, a source of employment and income, and an area over which they do have some power and control. Comments by older people capture an awareness of these different meanings. When one of Hale's (2006) respondents says, people '*think we are one sandwich short of a lunch*' (p. 108), and laughs about her physical difficulties and prosthetic aids, she is responding to her own interpretation of her body and the interpretations of her listener. She is both reassuring herself that her body, and therefore herself, is acceptable and accepted and she is reassuring her listeners, as Murphy has highlighted.

Learning to accept, manage and present one's body to oneself is part of a reconnection experience. It involves dealing with the 'diminution' of self and the social 'debasement' that contributes to the liminal experience, and re-presenting the self as one who has a changed body. Kvigne and Kirkevold's (2003) description of the post-stroke rehabilitation process as 'a journey from agonizing to owning' (p. 1305) seems apposite to the experience of older people at home with care.

As we shall see further in the next chapter, older people can be guided through the experience of liminality by the care worker. Transformation towards a reconnected identity involves managing the emotional responses to the new body; the presentation of frailty and disability both to oneself and to others; experiencing through the presence of the care worker the emotions of physical dependence; and the meanings of care.

6.3.1 Liminality and the Relational Landscapes Through Time and Space at Home

Care at home leads to change in family relationships and introduces a new set of relationships with care workers and with agencies. These relationships are critical since, as Walker (1982) observes:

> An individual may be incapacitated, but his dependency rests on the interaction of incapacity and environment, particularly the interpersonal relations surrounding the person with an incapacity (p. 52).

The relational landscapes change, however, as we saw in the previous chapter, with the onset of frailty and the introduction of in-home care. Family relationships and roles change and it becomes very difficult to maintain active friendships and social networks outside the home, unless there is appropriate support, such as accessible transport services. Additionally, with the physical challenges of frailty and disability, and when the home becomes a place of care and for care, it ceases to be a place where it is easy to maintain social links. For example, difficulties preparing meals, the reorganisation of rooms and space to accommodate disability, and sometimes an unwillingness to be seen with a disabled body mean many are reluctant or unable to entertain guests.

Relationships with care workers present opportunities for supported independence but, as was outlined in the previous chapter, this is not straightforward. The review of issues around temporality and spatiality in Chapters 3 and 4 points to how the incapacitated self is continually revised through relating to others and in particular to the formal care worker. When these relationships are simply task-focused, rather than person-focused, care services can be seen to reinforce passivity. As Morris (1995), quoting a study participant in reference to officials overseeing models of in-home care work in the United Kingdom, observes:

> They seem to think that community care is about someone being cosy and comfortable, being kept clean. To me that's a step back into the situation of residential care – living in the contained environment of your own home (p. 83).

It is possible to deliver services which ensure basic survival but which provide little support for the individual to make choices and when this is the case there is little opportunity for retaining a sense of autonomy.

Related to questions of autonomy and agency are the meanings that are attached to the home. The meaning of home changes for the older person and his or her family following the introduction of formal care services. The disruptive impact of home care and the need for 'improvisatory practices' (Angus, Kontos, Dyck, McKeever, & Poland, 2005) leads to disconnections in a number of ways that include:

- the disconnection from self associated with the loss of an independent and functioning body, for example, through restricted movement and the need for prosthetic aids and help from a care worker;
- changed expectations about self-care, self-presentation, and home care;
- feeling apart from others in way that is experienced very much at an individual level and not understood by those outside the experience;
- social disconnection through, for example, changed capacities to maintain social roles such as those of a visitor, host or hostess; and
- loss of social connectedness and therefore social participation, and the isolation of being at home, unable to share experiences with others, unless through formally organised day care activities.

Different uses of space make the disablement visible, and assistive devices can be seen as re-markers of social identity. Turner (1969) pointed out that in a liminal stage the material possessions which serve as markers of a social identity are often removed. As we have seen, for care recipients, markers are *added*, rather than removed, and in this situation these identify the older person as a liminar. Nowhere is the changing identity more obvious than in the additions to the body of crutches, walking frames, and wheelchairs. These mark the beginning of a transformed identity and are often accompanied by regret and, initially at least, some distress. Further, private spaces become public: bathrooms and toilets, once the most private areas of the home, become public areas where there is the greatest intrusion of personal territory and dignity (Higgins, 1989). The most private of actions can also take place in customarily public areas, where for example lounges become bedrooms with a commode beside the bed; laundries became shower rooms; special furniture is brought in, such as hospital beds with potential for adjusting positions; and sleeping arrangements are changed. Often parts of the house become shut off and much of the living begins to occur in only one or two rooms, such as the kitchen. And compensatory devices, such as rails and walking frames, begin to dominate the spatial arrangements.

Being at home with care also involves encountering and negotiating multiple time frames which intersect and overlap with each other. Temporal disruptions signal important changes that influence the way relationships are conducted, with, for example, more time needing to be taken to complete tasks. The slower time of disability has particular implications for formal care work, requiring more time to be with, to walk and talk with, the users of such support. These increase the amount of time needed to complete tasks and place special challenges around the process of providing care and support.

Tensions exist between the different time frames and this is perhaps most evident in the negotiation for the timing of formal visits by workers. Morris (1995) has commented similarly:

> Elderly service users and the practitioners who work with them have potentially conflicting perspectives. Practitioners work within complex legal and organizational frameworks and limited time scales. Elderly people typically structure their lives through domestic and social routines and perceive time and priorities differently (quoting Biggs, 1993; in Richards, 2000, p. 37).

Because of the competing claims of numerous clients and the need to coordinate efficiently the care worker times, preferred times are rarely available and the times of the day and the days for care are most often not negotiable.

6.4 The Potential for Reconnection

What is clear in the philosophies of ageing in place and in-home care is that home as a place of care is intended to provide continuity of environment. There is a related assumption that it leads to continuity of social role and identity. There is a particular type of discontinuity experienced by those who remain at home with care. Despite the challenges to the individual, however, there is potential for the achievement of the goal of supported independence. Hugman's (1999) comment that with care at home 'the degree of personalisation and individuality in daily life is... greater than either residential care or the congregate life of retirement communities' (pp. 202–203) points again to the core rationale for ageing in place in old age. He adds that home and community care services provide for passage through the transition into a new life stage in a way that promotes integration 'with a sense of normality' (p. 203).

Reference to the potential for the maintenance of a 'sense of normality' points to the opportunity for continuity and reconnection following the disruption caused by frailty and disability. But as we have indicated, achieving the continuity implied in the policy of ageing in place is not straightforward. Baldwin, Harris, and Kelly (1993), for example, found that the daily experience of the frail or disabled elderly at home was similar to those in residential care. They found that:

> the proportion of people who sat for hours on end doing nothing . . . was almost identical to the proportion of people who did so [in residential care] (p. 75).

The implications for the maintenance of autonomy are significant for the potential for reconnections and the reclaiming of the sense of continuity—of a life that is continuing to be lived. However, a lack of socially accepted activities and roles, and a form of care that promotes passivity certainly undermines the potential for this. In failing to appreciate the erosion of autonomy that occurs through assessment and care practices, there is a lack of awareness of the impact on older persons and a risk of promoting their further marginalization. This raises questions about current models of service delivery, something we turn to in the following chapter.

6.5 Summary

In this chapter we have reviewed the argument of a transition through a rite of passage into supported independence. Triggers lead to experiences of separation, signalled through the assessment process, and passage into experiences of liminality. If we consider liminality in terms of being ‘set apart’, this allows us to consider reconnections and how these are to be made. Health professionals by promoting task-focused care, rather than relationship-based care, both manufacture and contribute to sustaining the disempowerment and social exclusion experienced by older people at home with care. Care workers need not only the hands-on skills of care working, but also the ability to appreciate the older person’s needs, relate to them with empathy and help them rebuild and restructure their world. Focusing on supporting the ‘agency’ of older people through empowerment enables them to make reconnections and be incorporated into new roles. It requires a unique set of skills and human qualities including the capacity to build effective personal relationships. We suggest, therefore, that professionals should reflect on their mode of practice rather than expecting the care recipients to adjust...

As participants in the policy community around community care, we can advocate for the type of policy and practice which supports the reconnection to the new life stage. This would include expanded policies to support ageing in place and would emphasise support for the autonomy of the older person through enhancing the training requirements of care workers and the training and support of family carers (Barusch, 1991). It would include the adoption of preventive strategies directed towards preparing older people for this stage and responding to their needs in a way that supports their autonomy.

The review of the disruptions associated with the transition into receiving care at home leads to a discussion of the structures within which older lives are conducted and the services which come from these structures. Tulle (2004) talks about agency (p. 187) in terms of dealing with the discourse of ageing, and a critique of the structures within which older lives are conducted. From the New Zealand work and from a number of studies in Scandinavia (Szebehely, 1995; Taam, 1999; Efraimsson et al., 2001), in Canada (Aronson, 1999, 2000, 2002) in the United States (Shield, 1988, 1997; Gubrium & Sankar, 1990; Frank, 2002; Parks, 2003) and in the United Kingdom (Twigg, 2000) there are sufficient recurring elements within care policies and models of care to raise questions about ageism and older people receiving care who ‘live on the edge’ (Aronson, 1999). The value of remaining at home with a limited task-focused model of service delivery is a questionable value to many recipients. Our review leads us to the conclusion that there needs to be a more holistic perspective applied to remaining at home with disabilities, a greater note of the issues connected with disability, of the invisibility of that care environment which can hide the disempowerment of the older person. This sector needs to be strengthened, and reference by decision makers to the value of ageing-in-place should not be seen as a rationale for reducing spending on support for older people dependent on care in the home and on training and support for care services.

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Chapter 7
Care Work and Reconnections

7.1 Introduction

In this chapter we explore the care relationship from the viewpoint of the care worker, and consider the extent to which it can achieve its potential of sustaining independence and autonomy within the context of the philosophies, policies and practices of ageing in place. We have seen that becoming dependent on care in the home is a significant disruption, initiating a transformative rite of passage with significant implications for the affected individuals and their families. Individuals and families respond by mobilizing resources (social, economic, physical, emotional and cultural) and employing strategies to cope. Paterson, Thorne, Crawford, and Tarko (1999) describe a distinct structure and process of transformation in living with particular conditions, as does Williams (2000). For the older individual, 'coping' includes managing the practical and emotional consequences of disruption and the process of redefining the self, what Corbin and Strauss (1988) refer to as the making of 'biographical accommodations'. Godfrey and Townsend (2008) describe 'recovery trajectories', these being cure and restoration, adjusting to discontinuity and establishing markers of continuity, getting back and keeping going, and managing uncertainty. Such recovery trajectories can include, at one end of a continuum, the acquisition of a 'preferred identity' (Charmaz, 1987) and a socially valued role, and at the other, a sense of alienation and ongoing liminality. Each of these insights complements the overarching framework we have adopted, the notion of a rite of passage into a new life stage, the third phase of which is reconnection.

Ageing in place is accepted as the preferable approach to housing an older population, but it is not yet clear that this is matched by an appreciation of the crucial role played by in-home care work in achieving this core purpose. A part of the appeal of ageing in place policies to governments is that it is seen as a cheaper option than hospital or institutional care, given its greater reliance on unpaid family caregivers and lower paid workers in the community, these predominantly being women. In narrow economic terms, the reductions in costs achieved by this policy have appealed to governments attempting to cut public spending in health care. Some also suggest that the devaluing of home care work may be compounded by its location within a particular part of the health sector, with chronicity, and with elderly and disabled (Schmid & Hasenfeld, 1993; Waerness, 1984).

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This is not to say that there have not been attempts to recognise the importance of professionalising the care work sector and developing improved opportunities for career progression, as Doyle and Timonen (2007, p. 34) note in regard to Denmark. Rather than enter into an already well debated subject of whether the work is low status because of gender, the people who receive it, or the nature of the work, we approach the issue of care work with a view to recognising the value of its potential within the caring relationship as a catalyst in the resolution of the state of liminality. Drawing on her research and her experience in the care work sector, Hale (2006) has argued that care workers have potential to act as 'guides', assisting individuals as they negotiate transitions into this new life stage of supported independence. She suggests the role can be similar to that of the instructors referred to by Turner (1969) in analyses of rites of passage in pre-literate societies.

We begin, then, by drawing attention to the different meanings of care and the often untapped promise of in-home care practice and the care relationship. We ask whether the commodification or bureaucratic control of care work undermines its reconnective potential, before considering problems with current care policy and practice. Policy and practice settings play an important role in constructing what is possible in the care relationship. They routinise the process and frame the interactions between the carer and cared-for person. There are other factors which influence reintegration, but as it is care work practice which is so essential to supporting the goals of the policy of ageing in place and the maintenance of independence and autonomy implied in that policy, we conclude by reviewing characteristics of reconnective care practice.

7.2 Meanings of Care

Studies of the meaning of 'care' have pointed to the way the language of care is complex, involving a duality between, on the one hand, the intimacy of care and home, and, on the other, the language of employment and contracts. Words, their meanings at one level, and their use at another, tell us a great deal about caring, the family, workers and the industry (Ungerson, 1990, 2005). Starting with the word 'care', we draw on the early work of Hochschild (1995) who says it is:

> an emotional bond, usually mutual, between the caregiver and the cared-for, a bond in which the caregiver feels responsible for others' well-being, and does mental, emotional and physical work in the course of fulfilling that responsibility (p. 2).

As important as the physical work, is the mental and emotional work. In Chapter 5, we drew attention to the mutuality in care relationships: a good care worker and satisfied client have strong bonds between them. In so doing, we aimed to draw attention to the importance of compatibility between the care worker and the care recipient. The notion of compatibility underscores the mental and emotional dimensions of relationships. Compatibility is identified by Eustis and Fischer (1991) as one of the implicit connotations within the word 'care'. Compatibility can be more important than actual care work skills in providing for the wellbeing of the care recipient. It implies that the emotional bond, the inter-personal connection between the carer and the cared-for person, is an essential component of care work, and that 'excellent care' is something more than the precise execution of care work tasks (Eustis & Fischer, 1991).

The word care also implies 'help', this being a more active interpretation of 'care' with its connotation of 'caring for' and 'caring about'. Care workers in Aronson and Neysmith's (1996) Canadian study used the word help to describe the character of their home care work (p. 7). By help, they meant a wide range of tasks as well as concern for the broader security and wellbeing of the cared-for person. As one worker put it, 'I want to be sure that when I leave he is in fairly good spirits, is clean, has enough food and supplies to hold him until the next visit'(p. 7). Helping involved addressing the material and physical needs as well as the mental and emotional needs—leaving the person in 'good spirits'. Help as they described it was a complex, negotiated phenomenon accomplished by means of observation, particular knowledge of the individual, a careful according of self-determination to clients and a large degree of flexibility on the part of the home care worker. It becomes an active, motivating form of care. As another worker in this study put it, 'I encourage her to try. I might say to her, 'We have not a lot of time. I will do what you cannot, but try to dust' (p. 7).

Within current modes of practice, the care relationship develops alongside the carrying out of domestic and personal care tasks which are performed in a programmed and timed manner. Carrying out the tasks themselves, it would seem, requires little training. The care relationship begins when the agency sends a worker to a client at a time determined by the agency. The intuitive appreciation of the centrality of the 'relationship' and of emotional connection in this type of work that many care workers have was observed by Hale (2006) who noted that workers often made a special effort, at their own expense, to meet with their clients at a separate time before beginning the care work tasks. They did so because they believed the client would be more at ease with having them in their homes as well as performing personal and intimate work when they needed to.

Their actions point to an awareness of the need to build a relationship for the work to be effective. Amongst other things, this also indicates that effective care work requires time for such relationship building, but, as we will discuss, care plans typically weaken the potential for this. Instead, many care workers are in such need to work as many hours as possible that the tasks are rushed through and the worker is under pressure to move to the next client. Low hourly rates of pay mean the care workers are required to work quickly to earn a meaningful wage and this is an important factor in undermining the potential for reconnective practice. Nevertheless, we maintain that the opportunity exists for an empowering relationship, which encourages and supports the older person through the transition into socially valued roles and identities.

7.2.1 Care . . . and Its Potential

Support for independence assumes that once the scheduled care tasks in support of the older person are completed, he or she is then able to continue as an autonomous and independent individual, connected with former roles, relationships and identity. Throughout the book, though, we have argued that the experience of late life frailty and disability, the associated assessment procedures and the subsequent introduction of care programmes in the home of the older person constitutes a fundamental discontinuity. The organisation of home in temporal, spatial and relational terms is disrupted, affecting both the cared-for person and his or her family members. As Efraimsson, Hoglund, and Sandman (2001, p. 818) note, the changes affect 'well-being, habits, relationships and the home.' As home becomes a place of more intensive health, body and care work carried out by formal care workers and family members (Kellaher, 2002, p. 23), a 'struggle between the normal and the strange' sets in (Efraimsson et al., 2001, p. 818). The idea of home is fundamentally challenged under these conditions.

Losing function and developing disability is a major disruptive experience. It restructures everyday life and the taken-for-granted meanings and identities upon which it is founded (Williams, 2000, p. 43). Being unable to manage and control bodily needs and functions and care for oneself disrupts the normal self-management associated with independent adulthood. Added to this is the personal care—the private and personal washing, toileting, and management of physical symptoms—which deals with personal body matters that society does not want to think about: 'decay, dirt, death, failure' (Twigg, 2000, p. 145). She suggests, 'care workers manage these aspects of life on behalf of the wider society, ensuring they remain hidden or tidied away into the obscurity of ... private homes' (p. 145). However, the non-private attention, the involvement of another, the caregiver, that is regularly given to the state of the body and its needs 'effects a transition from our normal phenomenological modes of bodily "dis-appearance"—i.e. a body which "passes us by in silence" in Sartre's terms—to a state of corporeal "dys-appearance" (i.e. a dysfunctional appearance)' (Williams, 2000, p. 43). These experiences lead to the conscious questioning of taken-for-granted meanings, identities, beliefs and attitudes towards oneself and one's body.

Remaining at home does contribute to the potential for retaining this sense of normality and continuity, and healthy transitions in home care are described by Meleis et al. (2000; in Efraimsson et al., 2001, p. 818) as being characterised by processes that enable the individual to feel connected and interact, and are 'associated with collaboration within the family unit and with professional carers'. 'Reaching a new sense of identity ... [however, is] difficult' (Efraimsson et al., 2001, p. 818) given the challenges in managing this new life situation, given the threats to coping capacities presented by frailty and disability and the impact of these on confidence levels. While many strive to master the new demands and skills required to cope, 'because of the constant changes in conditions and an unpredictable future... [it can be] impossible to predict when the transition would be complete.'

While the official language of in-home care work concentrates on the performance of specific tasks in a timely fashion, it is the qualitative, emotional connections in caring for another person, the listening and talking that are a part of it, that allows those receiving care to 'express who they are and to preserve their identities as something other than sick, declining persons' (Stone, 2005, p. 283).

Hale (2006, p. 168) found that receivers of care were less concerned with the performance of practical, physical care tasks than with the personal connection implicit in the care relationship, and this was captured in the comment by one care recipient who said: ‘Will they really care about me or will they just be there for the work.’ It is these inter-personal characteristics where ‘excellent care in terms of good practical skills is less appreciated by recipients than poorer physical care from more compatible workers’ (Eustis & Fischer, 1991). It is the conversations which envelop the practical, physical tasks of caring that allow for the establishment of intimacy and for in-home care workers ‘to give clients their lives back and to make a difference—which is far more important to them than, say, giving a bath or a meal’ (p. 283). This is why the cared-for person often tracks the caregiver through the house while domestic and other tasks are performed.

In fact, it is this emotional engagement itself that provides much of the motivation and satisfaction for caregivers. Twigg (2000, p. 216) comments that ‘despite the low status, care workers are in general very positive about their work’ and she cites Feldman, Saienza and Kane’s (1990) to high overall job satisfaction among care workers. The high rate of satisfaction reported by in-home care workers, an occupation with typically very low rates of pay and poor conditions, is explained by the direct nature of the contact with the cared-for person and the rewarding feelings of being needed and appreciated (Eustis et al., 1994). Other studies also find that in-home care workers have high rates of satisfaction when compared to other caring aspects of this type of work—social workers, managers or residential staff (Eustis et al., 1994; Balloch et al., 1999; Denton, Zeytinoglu, Webb, & Lian, 1999)—this being seen as a reflection of the ‘direct nature of the interpersonal rewards’ (Twigg, 2000, p. 127).

These relationships have the potential to preserve hope in the face of the loneliness, isolation and disorientation caused by the onset of disability and late life frailty and need for in-home care. As Stone (2005) says:

> Care is a way of fighting. It is how we fight when we are so powerless that defeat is certain, when fighting is the only thing that will preserve hope, and preserving hope is the only possible victory. It is the way we do whatever we can to make life better for the people we love, for the world, and for ourselves (p. 286).

Coming to terms with frailty, disability and dependence has been shown to be related to an individual’s ‘values and beliefs and their self image’ (Efraimsson et al., 2001, p. 814). Coming to terms or ‘accepting’ the losses in function and ability is certainly a part of the reconnection process with which we are concerned here. However, we suggest that the goal of assisting an individual merely to come to a state of acceptance of their situation without an awareness of the deeper issues of identity, meaning and value can be an unsatisfactory response to more complex issues. This can stem from a glib desire to ‘quieten down’ or silence those presented with inadequate in-home care and living arrangements. At one level, the notion of reconnection implies a return to what was before, the re-establishment of continuities in the person’s life. There are of course, other forms or levels of reconnection to the wider society than a return to the former state. To suggest a type of reconnection does not deny the reality of difficulties faced in the ongoing struggle to cope with loss of function, disability and the related challenges of negotiating change in the meaning of self and the home. It does involve, though, a reaffirmation of the sense of self and a reconnection with the identity that existed prior to the transition or the adoption of a preferred identity in a new life stage.

Another means by which the older person is assisted in reclaiming their identity and being socially valued is obvious in certain small but effective programmes, where workers ask the client what is to be done, or where the client is in charge of his/her own funding and can state what is wanted. Such wants can be as simple as going to the library or the shops, going for a drive or working a little in the garden. The idea of the tasks is expanded, and the authority belongs with the client, with whom the worker will have a direct relationship, rather than an agency-employer relationship coming between the client and worker. Certainly not every client will want this type of help, and for some it may be quite unsuitable. Nor is every worker able to undertake such tasks. But it is in such tasks where workers can be used to assist in some form of reconnection.

7.2.2 Does Paying for Care Change Its Essential Nature?

The emergence of formal home care arrangements, as described in Chapter 1, has added a commercial dimension to what has historically been a non-economic domain of life, and introduces economic motivations of self-interest that would seem to contradict the altruism assumed to underpin the care relationship. There is a tendency to hold on to the idealised assumption that altruism underpins all aspects of care relationships, but there are other less selfless motives such as duty, adherence to family norms and social responsibilities. Stone's (2005, pp. 275–276) analysis of the politics of caring and of the commodification of care concludes that even when provided on a commercial basis, an emotional response that could be described as love develops. Payment for care, therefore, does not diminish the essence of the relationship and its potential to support the older person through the transition to increasing dependence. These bonds become profound and paid carers develop relationships that are built on mutual trust, reciprocity and respect.

Providing care on a formal, paid basis, therefore, does not necessarily displace other motivations for the care relationship. As it is, formal caregivers tend not to discuss the financial basis of their work with those who receive their care. Instead, their talk with clients about their work portrays it as if it were unlimited and provided as if by a family member (cf. Stone, 2005, p. 277). Aronson and Neysmith (1996, p. 7) concluded that workers in using the word help conveyed that they did not approach the relationship on a purely commercial basis. Karner's (1998) suggestion that care workers become like 'fictive kin' also points to this aspect of the care relationship. Formal caregivers develop such close bonds with their clients that they become like family members, which may be the reason that so many caregivers act beyond the specified terms of the formal care contract. Hale's (2006) care workers, for example, would 'pop back' after hours or early in the morning just to put out the dustbin or to hang washing.

Our focus here, then, is on those relationships encompassing intimacy and reciprocity, the give and take of close relations. Our proposition is that a warm and helpful relationship is a good foundation for rehabilitative/reconnective work, although Ungerson (2005) has created a sophisticated typology of relationships which could be of considerable value in supervising and training workers in reconnective work. The reciprocity implicit in relationships, however, is not necessarily obvious, even though the term 'caregiving' implies a one-way form of interaction. Stone (2005) addresses this:

> It seems as if the caregiver ministers to physical and emotional needs, and perhaps even decides exactly what help the cared-for person needs before ministering. What then does the cared-for person give? Care is reciprocal in a different way than tit-for-tat exchange. . . . The cared-for person gives to the caregiver a sense of being needed and appreciated, and of making a difference—not a trivial gift (p. 273).

She quotes a care worker to illustrate her point: 'You're working here. You're saving someone's life. They can't feed themselves, dress themselves. I feel I'm helping them.' The response that 'I get more out of this than they do,' is typical and indicative of a common view that caregiving is a reciprocal process.

Reciprocity in relationships is often practical. Hale (2006) reported an example of a care worker who would cook her own meal in the older person's home while she was cleaning. Other workers often took their young children, especially if they were sick and home from school, to the client's home. This created the potential for inattentive work, as well as the risk of infections for the older person, and was perhaps an example of using care work time poorly (Twigg, 2000). However, many older women welcomed this as part of a friendship network; they saw themselves as still having a role to play, value as a hostess, able to support younger women.

Further, Efraimsson et al. (2001, p. 814) describe how care recipients play an important role in the care process, acting as encouragers and motivators of the carers. While typically prohibited in arrangements for formal caregiving, such reciprocity is evident in the gift giving that sometimes characterises in-home care provided to older people. Agencies typically see this as problematic and seek to manage it by blanket rules banning it, but items or money are given by older people to their carers, reflecting the mutuality of the care relationship.

7.2.3 The Care Relationship and Agency Control

The potential of the in-home care relationship is threatened by the bureaucratic or organisational controls which influence how the worker carries out her tasks. The need for agency control means the locus of authority in the care relationship lies outside the home, with the agency, care service coordinators, and needs assessors. The care recipients for the most part have to live with the rules of the agencies, and the policies which govern these rules. We suggest that these policies and bureaucratic arrangements which frame particular service settings can undermine the likelihood of reconnective practice.

The relational aspect of care work sits uncomfortably alongside managerial or bureaucratic demands for accountability, impartiality, predictability and efficiency (Twigg, 2000, p. 162). As noted above, paying for care does not necessarily diminish that care, but it is the organisational control of funding to meet agency goals that restrains and limits how in-home care workers care for their clients. As Stone (2005) comments, when cared-for people

> become the raw material out of which profits are made, the entrepreneur is dedicated to keeping costs down . . . keeping costs down means suppressing care. When care is a market good, its essence—the human component, the relationship—has to be minimised because it is an input, and efficiency requires getting the most output for the least input (p. 282).

The same dynamic plays out with publicly provided care, the pressure being accountability for the use of taxpayer funds. The organisational dimension of the care relationship thus introduces requirements that it be counted, monitored and limited.

What does this mean for the way in which care is given and received? If care is to be managed, it needs to be transformed into something that can be measured or counted. It needs to be transformed from the vague relation of care into something society can underwrite; it has to be precisely defined, unambiguous and limited—a type of contract. This requires taking what are the unseen, fluid and dynamic qualities of relationships and reducing them to basic elements that are observable and countable. Doing so shapes the nature of the caregiver contract with the agency or whoever is paying the agency, as well as the contract with the people they care for. It means constraining the relationship between the caregiver and the cared-for person in terms that are acceptable between the caregiver and the agency. This results in caregivers being less able to respond flexibly to changing needs and requests, or even entering into dialogue with the cared-for person about what tasks are wanted.

The contract takes the form of the home care plans, the lists of tasks the care worker is required to carry out, and typically none of these plans include talking to or listening to the older person. But care relationships usually imply being responsive to the situation and to expressed requests, to perceived needs at the time. One of the characteristics of an effective care relationship, once established, was the receivers of care felt they could ask for additional tasks to be done, outside of those provided for in the assessment process: letters to be posted, washing to be hung out, dustbins put out or taken in, or even extra cleaning or preparation of food. One example is the coaxing to eat of a depressed older person by the care worker taking in a meal cooked in her own kitchen, and eventually cooking in the older person's kitchen, where the smell of food cooking encouraged the older person to move out of bed. Such flexibility, however, is discouraged or prohibited in contracts to avoid the risk of incurring greater costs, or even to avoid any risk of hygiene issues.

What is most important is the way in which the bureaucratisation of the care relationship transfers power outside of the caregiver-care receiver relationship, to a third party. Because those who pay fear the cost of unrestrained care or compassion, they seek to contain that care and compassion by mechanisms that include limits on reimbursement. So caregivers say, 'I'd like to do that for you but can't, given the terms of the care plan.' The caregiver cannot make the decision. The point, as Stone (2005) says, is:

> [w]hen care is paid for by third parties, instead of by care recipients themselves, the recipients also cede power to the payers. They lose power to shape and define the care they receive. In all the goal setting and rule-making by payers, recipients' goals count for little (p. 286).

Hale's (2006) review of first hand accounts of in-home care work show clearly that caregivers and the cared-for can become emotionally engaged. Making connections and developing a warm relationship, often over a 'cuppa,' is known as critical, but it is formally unrecognised in the hours allotted to care working. The relational aspect of the care relationship receives limited acknowledgement in in-home care policy and in agency support, except for efforts to limit it, but it is well known that the relational side of the care relationship—getting to know the older person and build rapport and trust—needs to be established before the practical, physical work can begin. Hale (2006, p. 168) found that in-home care workers spent time, at their own expense, building the relationship when beginning to care for an older person, making phone contact, making preliminary visits, and sharing something of their own personal lives (for example, talking about their hobbies) with the goal of establishing a relationship from which physical care could be given. The fiction that care workers do not become emotionally connected is most evident in reports of the feelings of grief they experience when a cared-for person dies. Many attend funerals and find they are as grief stricken as family members, many often having had closer relationships in the preceding years than family members (Stone, 2005). They experience similar feeling of loss when an older person moves into institutional care and many maintain contact when this occurs.

Our point here, then, is that in-home care is delivered within the context of contradictory language which on the one hand frames the work within the formal limiting language of contracts and on the other within the intimate language of relationships. This duality between the intimacy of care and home and the language of paid work, accountability and contracts (Ungerson, 2005) captures the essential tension in seeking to promote reconnective ways of in-home care work.

7.3 Issues with Current Care Policy and Practice

Different national policy settings influence the level of centralised authority over care. Programmes based around self-direction do have benefits. New Zealand and Denmark are beginning to develop programmes which give greater control to the care recipient to determine the care that is delivered. This freedom to choose, as Rostgaard (2004) observes, can result in poor choice and risky choosing (p. 13). However, it maintains agency for the older person. These types of initiatives do have important implications for how the care worker approaches her tasks and it does locate the authority for decisions about care within the home. While these programmes have promise, the majority of home care services continue to require recipients to accept what they are given.

Care workers would prefer greater autonomy, time to cultivate relationship and flexibility to carry out tasks not specified in the contract between the caregiver and the agency. However, the factory model (Szebehely, 1995), where workers need to perform as many task-focused hours of work as possible, continues to be the basis upon which care is delivered across New Zealand and Australia. This pressure is exacerbated by the low pay in the sector, with workers needing to rush to complete what is typically a large list of tasks for their wages to be worthwhile (Denton et al., 2002).

Task-focused and rigidly time managed approaches work against the adoption of rehabilitative strategies that support the autonomy of the care recipient. Care recipients want reliability and flexibility (Francis & Netten, 2004) and care workers want autonomy so they can manage with flexibility the requirements of the client (Doyle & Timonen, 2007). The result is the stifling of opportunity for the 'getting alongside,' relationship focused practices that reinforce the independence and autonomy of the cared-for person, and instead the reinforcing of compliance, obedience and passivity.

This has led to widespread dissatisfaction with this way of working, among both caregivers and the receivers of care. Care recipients commonly criticise the lack of opportunity for flexibility and control over the tasks performed and care workers report insufficient time to complete specified tasks. The fact is that agency specified tasks are often exceeded, but this is not recognised and compensated given that the work is carried out in the invisibility of the home. Given the dissatisfaction, we might ask, then why is the flexibility and potential for relational practice constrained by the policy settings that have developed around in-home care? As Stone (2005) notes, the need for accountability is real. She refers to the fear that care stifles real work, that care itself is somehow not an arduous activity—that is, the loving, friendship, trust, companionship and intimacy that develops—and that payment should be on the basis of 'doing, not being' (Stone, 2005, p. 281). So the caregiving relationship is expected to involve only the task-focused doing of physical, domestic work rather than listening, closeness and caring—roles often associated with social work. A factory model of care also aspires to ensure impartiality and predictability in service provision—that everyone will receive that to which they are entitled.

There is also the argument that such provisions lead to the prevention of abuse of the care receiver. Parks' (2003) conclusions, based on her personal experience as well as research observations, recognise the benefits of the relational side of caregiving, as well as the potential for over-involvement and abuse. Close emotional engagement, she suggests, does provide potential to manipulate and withhold warmth. Warm relationships are those where there is a mutual flow of support and are ideal. 'Warm' relationships can be contrasted, according to Ungerson's (2005) typology of in-home care relationships, with 'cold', 'cool', and 'hot' relationships. Cold relationships are those that are angry and resentful and of limited duration; cool relationships are professional with a detached focus by the care worker only on the work; and hot relationships are those where relationships are volatile but longstanding and often involve co-residence of family or worker.

The fear of abuse through over-involvement is a fear that workers will use their greater power to maintain control over their work and the cared-for person. Lachs and Pillemer (2004) discuss the potential and actual abuse of care recipients by both formal and informal home caregivers. Current estimates of the frequency of elder abuse are now available from several international sources, and these do note that 'a shared living arrangement is a major risk factor for elder abuse' (Lachs & Pillemer, 2004, p. 1265). One in four vulnerable elders are at risk of abuse and only a small proportion of this abuse is currently detected (Cooler, Selwood, & Livingston, 2000). The potential for abuse in poorly resourced and supported care work environments is real. The fact, too, is that the work is also carried out in the home where the actions of the caregivers, who work on their own, are unseen and less able to be monitored by colleagues as is typically the case in other service sector settings. Further, recognising the relational side of relationships can present challenges to family members, especially when aspects of reciprocity and mutuality are allowed. Family members can become suspicious about relationships that develop between an ageing parent and a caregiver and often resent the giving of gifts, items or money.

The low status of the care work occupation despite its growing importance as part of the service sector, also explains the persistent use of tightly specified bureaucratic rules and a lack of recognition of the need for greater discretion to be devolved to care workers (and care recipients). In 2001 care work was one of the most rapidly growing occupational titles. While this is the case, there is not a career structure in the New Zealand context, and only recently have there been indications of governmental recognition of need for more funding and a more comprehensive training system. Denmark, however, has instituted a career structure, as have certain areas of California.

Care work continues to be predominantly seen as 'inexpensive, semi-skilled, practical labour' according to Aronson and Neysmith (1996, p. 1), involving 'low-tech, custodial tasks that were once the domain of family members, housekeeping, shopping, meal preparation, and personal care' (Karner, 1998, p. 71). Feminist writers have drawn attention to the extent of the skills in care work and have located the cause in gender relations:

> A standard feminist complaint is that care work is regarded as lowly work, and for a long time, the standard feminist answer has been to recast care work to reveal its essence as highly skilled labour. . . . based on the premise that if social scientists show how much skill and knowledge go into caregiving, society will recognise the value of care work and pay up. . . . This literature assumes that care work is devalued in part because women are devalued in general, and in part because the men and few women who hold the power to value work don't appreciate the difficulty and complexity of care work (Stone, 2005, p. 279).

Karner's (1998) comments mirror the dominant discourse about the low-tech nature of care work, which focuses on only the practical physical tasks associated with it, and portrays it as an extension of women's family work. Hale's (2006) study found care workers choose this work because it fits in with other obligations—parenting, spouses' work and family responsibilities. The fact that this work is carried out within the invisibility of the recipient's home contributes to its lack of formal recognition, low occupational status and, therefore the persistence of problematic policy and practice settings. The part-time and flexible nature of the work is an important factor that hampers the establishment of a career structure (Maloney, 2005, p. 34; Twigg, 2000, p. 127).

Seeing this as the performance of basic physical, practical tasks without recognition of the higher level working associated with the role, is in part a consequence, at least in New Zealand, of the relatively young nature of the occupation and the view that it is an extension of the female domestic work role. There is little doubt that the status of care workers is low (Bartoldus, Gillery, & Stuges, 1989; Burns et al., 1999; Denton et al., 2002). In fact, the idea of liminality can be applied to the care work sector. The occupation has an ambivalent status, somewhere between domestic family work and a public service. Care workers, most often untrained women, work as public agents in the privacy of the home of the older person, using skills that are seen as an extension of domestic and housework skills. These staff are neither formally qualified nor formally recognised.

7.3.1 What Needs to Happen to Provide Reconnective Practice?

It is our contention that the care work sector is still in its development and that there is potential for it to be shaped in positive ways that will promote the type of practice we have suggested leads to better outcomes for older people. The challenge is to promote the development of governance arrangements and models of practice that enhance the interactions between older people who receive in-home care and those who care for them. As Bernard (1991) asserts:

> It is high time that policy makers, planners and professionals began a proper dialogue with older people concerning their needs and wants for leisure as well as with other areas of their lives. It is no longer sufficient to go on adopting a 'we know best' attitude (p. 12).

The promotion of greater 'directional autonomy'—the power to set the course of their own lives—is a key principle. Consultative and inclusive ways of working lead to processes of negotiation that enable the care worker to give power back to the older person and reinvigorate their engagement in managing the organisation of their home and personal life. The care task in this way of working extends beyond ministering to the clinical and functional limitations of the cared-for person to include actively giving them greater autonomy. Flexibility, then, is also a key principle that should underpin practice models and extends to flexibility with budgets and task selection to allow for greater client involvement in goal setting and the development of care plans.

There needs to be a strong rehabilitative focus in supporting client direction. In many respects the care worker should work to rehabilitate the power of the older person within the domain of their own home. As it is, one of the signs of effective care work relationships is that the cared-for person often feels as if he or she can ask for additional tasks outside of those they are assessed as being eligible to receive. Support should be given to the choices made by older people themselves, beyond domestic and personal care, and in the area of social and recreational activities. It is well known that the importance of social participation is critical for the wellbeing of older people and the tasks should extend to cover this.

This method of practicing does demand a high skill level, not least in relationship management skills. Home care, perceived in minimal terms as compensating for the loss of function in the older person, may have been intended as a basic domestic and personal care service, returning the cared for person to a hygienic state of living and positive routine, but it requires very much in terms of skills and knowledge as our references here have indicated. Caring is a complex phenomenon and it tends to be the concrete, observable tasks that are used to define and describe it. But our contention is that care working involves emotional engagement and it is this which reinforces the identity of the older person and the satisfaction or motivation for caregivers. Managing the emotional dimension to the relationship—Hochschild's emotional work—requires workers to have an additional set of skills to allow them to deal with the emotional connection in a professional way.

Good staff attitudes were the factor most commonly cited by care recipients as crucial to a high-quality service. Appropriate attitudes identified by service users included respect, friendliness, cheerfulness and understanding. When asked to identify the most crucial attitudes, the three most commonly cited were being 'obliging,' 'friendly,' and 'understanding.' However, other common views were that care workers should be 'happy-go-lucky,' 'jovial' and that they should treat people with respect. While initial motivation was seen as important in generating the type of attitudes service users valued, the main practices that managers employed to ensure appropriate attitudes were induction training that emphasized respect and dignity in care, ongoing supervision, and monitoring of standards (often through questionnaires to service users). These could have substantial cost implications in terms of direct expenditure and managers' time. More than one respondent identified that recruitment of staff of the right calibre in the first place was an increasing problem. The clear cost implication for improving recruitment was to increase rates of pay although providers felt restricted from doing this because of the inadequate fee levels paid by the commissioning Local Authorities (Francis & Netten, 2004).

The risk of abuse or poor forms of engagement is greater when workers are untrained and have limited skills or personal resources, and this is only exacerbated by the invisible nature of the work. Skills for this sector, therefore, need to be defined more carefully, formally recognised, and demanded of those who work in the sector. It is clear that training is required to promote quality care for the older person, and training is also a way of caring for the care worker (Aronson & Neysmith, 1996; Twigg, 2000). Denton et al. (2002) point out the often high degree of physical strain in care work situations, with risk of physical injury for the worker, and at the same time, the emotional stress associated with the role (see also Twigg, 2000; Burns et al., 1999).

7.4 Summary

Our review in this chapter has drawn attention to the importance of the role of formal care workers in the home to achieving the goal of supporting the independence of care recipients. In doing so, we seek to draw attention to the policy settings which frame in-home care and determine what is possible in the care relationship.

The transformative potential of a positive care relationship is linked with the qualitative, emotional connections that are a part of caring—the personal connections that are established. Such relationships provide hope in the face of loneliness and isolation, and can support a passage into new, accepted identities. Our review suggested that the fact that such care is provided on a formal basis, for pay, does not necessarily undermine its restorative potential. Formal home care can address both the physical and the emotional needs of the cared for person. It is agency control and the limiting language of contracts which is a significant threat to the potential for reconnective practice. Task-focused and rigidly time-managed forms of care undermine the potential for flexibility and responsiveness that is the essence of a caring relationship, and therefore the potential of the care worker to support the transition into the new stage of supported independence.

Care is more than the mere performance of domestic and body work tasks. It is the relational aspects of care that facilitate a passage from experiences of liminality to a stage of supported independence. Our argument is that the recipient of care is not being well served by systems that reinforce their passivity and maintain the discontinuity in their lives brought on by the development of disability and frailty. Workers need to be valued through support, supervision, and improved pay. Colleagueship, the opportunity to discuss cases, the opportunity to work in a team, and improving the support given by agencies to care workers have all been identified as factors that will contribute to improving the quality of home care (Burns et al., 1999; Willner, 2000; Stone, 2005). And as we noted in Chapter 2, many countries will face significant challenge in simply meeting the growing demand for home care workers (New Zealand Department of Labour, 2009; Hugo, 2007; OECD, 2009). We turn to the consideration of such issues in the following chapter.

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Chapter 8
Reconnections—Supported Independence and Agency in Frailty

8.1 Introduction

Our purpose has been to consider the current experiences of a growing number of older people who now find themselves supported to remain in their own homes with care. As we examined these experiences, we found ourselves rethinking the context of these older people, and their families. Are their experiences different from those of the independent older person, and if so, in what way? Through the voices of the older people and their families, in our own research and that of other authors, we have found considerable differences from the independent older individual, to the extent that we suggest a new stage in ageing. Combining these experiences with the demography, and, further, with the growth of new personnel, agencies and public recognition for this time of ageing, suggested to us that there is a new group of older people with a common experience of frailty and care, and these experiences have yet to be examined in the context of the subdivision between the third and fourth ages. In fact, the position of these older people fits in with both ages—the independence of the third age and the support given within the fourth age. Therefore, we suggest separating this group into a special stage in life, highlighting both major features, the support and the independence.

In so doing, we have sought to provide a critique of the policy of ageing in place and the care work policies that have developed to support it. We have approached the study of this stage of life in a way that gives precedence to the subjective experiences of older people and we have used the rites of passage concept as a framework for analysing the experience of transition into becoming a home care recipient. A part of our critique has been to show how not all care services facilitate transitions into a stage of 'supported independence.' Many instead tend to reinforce the experience of liminality. Appropriate home care, though, has considerable potential to support the older person through the final phase of the rite of passage into this stage. Such care we suggest is informed by an awareness of the relational context of care and is characterised by support for the agency and independence of the cared-for person. These are the defining features of our proposed new life stage of the Age of Supported Independence.

We move towards a conclusion, therefore, by considering the implications of these ideas for policy. The goal is the development of policy which facilitates

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reconnective practice: e.g. to encourage more social workers to become involved in the field of care for older people; to develop rehabilitative approaches to care work and equip care workers to deliver them; to promote the development of housing arrangements for older people that will provide additional support and assistance to those who need it (Reid, 2008); to promote stronger communities which value older people and which are richer sources of neighbourhood support; and to support the work of informal caregivers. It includes promoting environments where this life stage is socially valued, where ageing and disability is seen as part of the normal process of living, is visible, normalised, and accepted. We emphasise that achieving these goals is a social responsibility.

In conclusion we offer the argument that there is a new stage in the ageing process; that the years after age 65 are as interrupted and discontinuous as the years before, and that by separating the group of frail, vulnerable people betwixt and between full independence and full dependence, we can highlight the specific issues they face. We suggest we need to distinguish this group from Laslett's (1996) earlier Third Age and the later Fourth Age if our policies are to assist older people to remain engaged with society, consistent with the accepted principles of 'ageing in place.' We summarise the evidence for our hypothesis of a new life stage, consider the data on experiences of liminality, and the potential for passage into supported independence. Subsequently, we examine the potential of policies to stimulate the independence through a different interpretation of the word 'support' and, finally, we reflect on the usefulness of our portrayal of this issue.

8.2 New Life Stage?

The first two chapters have shown the growth in the size of older age groups and associated with this, growth in the number of older people with disabilities receiving in-home care. There has been a corresponding growth in policies for in-home care in line with the principles of ageing in place, and an increasing number of agencies and personnel involved in delivering services. These chapters also outlined the greater public recognition in these areas—in media attention and in academic research. These features indicate an area of population growth and change within the experiences of people in their years after retirement. By drawing attention to these findings and combining it with new insights from qualitative research into individuals' experiences, we suggest there is evidence to consider a new stage in life for many older people. The value in such a definition is that it promotes a focus on the combination of the experiences of individuals at this time of life, to ask whether policies take account of their expressed needs, and to consider whether the implementation of policies is sufficient to ensure such needs are met.

From these chapters we proceed to outline the experiences which we suggest define the characteristics of this new stage in the life course. These are the focus of our next sections in this chapter.

8.3 Care Services and Experiences of Liminality

In the preceding chapters we have asked, as did Room (1999), whether the policies that have developed around home care really do offer 'stepping stones back into mainstream society' (p. 172), or whether such services merely assign people to an existence at the margins. We have shown that the experience of remaining at home with care is not necessarily accompanied by the independence and autonomy implicit in the core purpose of the policy of ageing in place. In fact, for many older people home care can intensify the experiences of liminality—disconnectedness from self, from family and from the broader community. Further, the transition into frailty and disability at this stage of life tends to be accompanied by a weakening or denial of individual agency.

The notion of liminality as we have used it has similarities with the idea of social exclusion. Social exclusion is a multi-dimensional phenomenon and occurs as a consequence of exclusion in a number of areas that include: exclusion from material resources, exclusion from social relations, exclusion from civic activities, exclusion from basic services and exclusion within neighbourhoods (Scharf, Phillipson, & Smith, 2005). Room, writing in 1995, commented that:

> Social exclusion focusses on relational issues: in other words inadequate social participation, lack of social integration and lack of power. Social exclusion is the process of becoming detached from the organizations and communities of which society is composed and from the rights and obligations that they embody (p. 243).

Social exclusion does occur within relational contexts. It involves a lack of social integration and a lack of power to influence the course of one's life. It involves becoming detached from communities and organisations and from the roles, rights, obligations and opportunities they provide. This detachment influences and increases the social isolation of individuals. Disability and ageing certainly lead to one important form of social exclusion and this was demonstrated by Scharf, Phillipson, and Smith (2005) whose study of deprived neighbourhoods in three English cities found that ageing in place and increasing rates of chronic ill-health were linked with and contributed to social exclusion.

It is generally the case that people who experience social exclusion in mid-life find it difficult to break the cycle of exclusion in later life: indeed it can often become more acute. The impact of the development of disability and frailty contribute to this, and these effects are compounded by the impact of age discrimination and the devaluing of older people with chronic disabilities on both the aspirations of individuals and the environment within which they live (Social Exclusion Unit, 2006).

Social exclusion implies being pushed to the periphery of society and for older people at home with care this involves, according to Aronson (1999, p. 174), the precariousness of *living on the edge*. The notion of living on the edge refers to the often uncertain and fragile care arrangements that are made to sustain people in their own homes. The experience of life on the edge, they say, is characterised by pervasive anxieties and tensions that are centred on spatial matters and relationship matters. For older people ageing in place with care, social exclusion can include spatial exclusion and confinement behind closed doors in the hidden geographies of homes. These forms of spatial exclusion make it difficult to engage outside of the home and reinforce social isolation. As it is, social relationships at this stage of life become more restricted and circumscribed with significant implications for the wellbeing of the older person. Victor, Scambler, Marston, Bond, and Bowling's (2002) loneliness studies have consistently reported proportions of between 7 and 10% of older people being very lonely. Ageing in place, even with home care, does not avoid the disconnectedness and exclusion from neighbourhoods and society.

8.3.1 The Potential of Home Care to Address Liminality

Despite this, we suggest home care has much potential to support reconnection. While living with a disability within the home can contribute to social exclusion, living at home does provide opportunity for sustaining a sense of normality. Home care workers are potentially the most important resource for facilitating independence and autonomy and for achieving social reconnection. Additionally, community development approaches have potential to promote neighbourhoods that avoid social exclusion. However, a limited view of what home care is, with care merely being the completion of practical tasks, is less likely to facilitate the transition into supported independence. Taking care of domestic chores and assisting with personal care will not on their own provide care recipients with the wherewithal to make the transition from experiences of liminality and disconnection into supported independence. As we have outlined earlier, a simple task-focused approach to care work that focuses on ensuring the house is clean and the person cosy and comfortable as Jenny Morris (1993) pointed out, can reinforce the conditions typical of residential care, except in the more isolated environment of the home.

All too often exclusion is compounded by the failure of services to react to the complexities that create the experience of exclusion, both at earlier stages of the life course and in old age. We need better ways to re-connect older people with their communities. For most people and particularly for older people, living in a strong, open community is desirable. Knowing your neighbours, being able to trust people, and being able to rely on others are all important for quality of life. Yet growing numbers of older people are living isolated, lonely lives.

Our challenge is to find ways of ageing that address these forms of exclusion and which do not result in the loss or denial of agency. The focus should be on adding life to years as well as years to life (see WHO goals for health in 'Health for all in 2000'). We need to avoid, therefore, developing programmes to support older people at this stage of life that focus solely on compensating for the loss of physical functioning, without regard for agency and independence. While normative expectations of agency in old age may forbid it, especially in circumstances of frailty and disability, Tulle (2004) suggests our challenge is to find ways of ageing 'which are not premised on its denial' (p. 175). What we are advocating is an approach to policy and practice that promotes successful ageing beyond the third age, and recognises the importance to wellbeing of being able to continue to act in one's own interest, direct one's own affairs despite becoming frail or disabled. Polivka and Longino (2004) capture this:

> *It is important to focus on the frail elderly in the context of cultural changes that have tended to valorize individual freedom and agency. We think these changes are at least as significant for the less than fully independent elderly as for the robustly youthful third-ager . . . [P]ublic policies should operate to support those who require assistance in order to maintain their freedom and agency. We do not, in short, see frailty and impairment as the antithesis of agency* (p. 5).

Our focus, then, should be on supporting the agency of older people who become frail or disabled at that very point where they need it the most. Community care should involve enabling people to participate in decision-making processes about services, and more broadly, in social, economic and political life (Barnes & Bennett, 1998, p. 172). This involves the careful design of both formal and informal home care programmes, the development of a variety of supported housing arrangements, and wider community development initiatives.

The approach to developing care programmes needs to be informed by the subjective experiences of older people and their assessments of what they require for wellbeing. This involves a focus on the actual experience of the older person and not simply on their objective conditions. Subjective experiences of wellbeing are, according to Tanner (2003, p. 504), consistent with the notions of reconnections:

- Personal and social relationships based on notions of reciprocity;
- Maintenance of a sense of purpose, meaning and competence;
- Continued involvement in those aspects of life that are valued;
- Engagement in meaningful activities;
- Preservation of continuity with both place (home and community) and relationships;
- Provision of adequate income; and
- Practical, social and personal care that preserves a sense of autonomy and control.

Supporting older people to actively fashion their life course (Marshall, 1986, p. 13) involves valuing their voices and resisting the unjustified privileging of other voices. Our emphasis on the voices of older people and their families should become the basis of an alternative interpretation of the knowledge of old age and of the programmes to support older people at home. As Kontos (2000, p. 258) paraphrasing Gubrium (1993) observes:

> The goal is to make visible variety, contingency, and inventiveness in old age, while resisting the temptation to produce an analytically consistent text that privileges certain voices and silences others.

8.3.2 The Passage into Supported Independence

Tulle (2004, p. 175) has challenged researchers to approach questions of inequality and social exclusion in old age with greater imagination, especially the study of questions about the recovery of agency. Framing the transition into the receipt of care at home to support ageing in place as a ‘rite of passage’ into ‘supported independence’, we suggest, offers a different vocabulary from that of health care and service delivery with which to consider these experiences. It goes beyond the commonalities already identified as a basis for policies and practice, to consider the shared, transformative events and encounters which characterise the experience of those who pass through this transition. Further, the rites of passage approach recognises the social context of these experiences and avoids the individualising tendencies of the medical model. The approach gives attention to the impact of all actors in the world of the older person. The notion of a status passage offers a social model which offers a broader view than that provided by the medical model which tends to locate the problem and solutions within the body of the individual.

The notion of stages of progression in response to the onset of frailty and disability in late life as described here might be thought of as a variation of other approaches to understanding change and adjustment to change. There is perhaps a parallel to be found with accident victims, whose experience is described as comprising an initial period of anger, denial and frustration, followed by some resignation, then rehabilitation where possible.

The notion of reconnections is not about ‘resisting old age’ (Tulle, 2004, p. 180). We take it to mean finding identities in late life that are meaningful, preserving a sense of social continuity, maintaining a sense of purpose, and sustaining self-directed engagement in valued activities. The third phase in the rite of passage, then, is conditional on being given access to resources and support for independence and the realisation of socially valued roles. Meeting these conditions requires an approach to supporting ageing in place which sustains independence, and where people are supported through the provision of information and services to make choices. It means support to enable the reclamation and ongoing fulfilment of roles as spouses, parents, grandparents, neighbours, friends and citizens. Policies, therefore, need to support independence and agency, and be focused on providing assistance beyond merely carrying out basic domestic and personal care tasks.

8.4 Implications: Policy and Practice for Reconnections

The principles underpinning Danish policy goals for older people are an example of the direction we believe policy for in-home care should take. Doyle and Timonen (2007, p. 21) summarise the policies of the Danish Ministry of Social Affairs of 2002. These are support for continuity in the individual’s life; the ongoing recognition and use of personal resources; and support for autonomy and influence on one’s own circumstances. Policies also need to recognise the importance of the relational dynamic of care work for these principles to be upheld. As we have discussed, care relationships respond to changing needs and require flexibility and time, and a significant policy challenge is to develop formal systems of care that provide for this. Stack and Provis (2000) quoted by Doyle and Timonen (2007) follow this line of the autonomy of the care recipient:

> From the perspective of both the care recipient and the care worker, quality has been found to correspond most closely to the amount of time the care worker is allowed to spend with the client and the ability of the care recipient to direct the work of the care worker. The amount of time allocated to a client and the ability of the care recipient to influence the care duties of care workers is not a reflection of the service provider mix, but an outcome of public financial commitment to the long-term care sector overall, which translates into the amount of time/money awarded to care recipients (p. 118).

Time and directional control should therefore be critical policy objectives.

Different country systems vary in terms of the degree of leverage given to the care recipient to direct the actions and determine the tasks of the care worker. In countries where there is greater directional control by the older person, it is generally thought to improve the quality of care and strengthen the autonomy of the recipient. As we discussed in Chapter 7 , however, constrained budgets and predetermined pricing contracts tend to make it difficult for care workers to spend the amount of time they would like with their clients. The fact that care workers often work beyond the terms of their job description at their own expense, and carry the costs of doing so, shows the intuitive awareness many of them have about what is needed to assist the older individual to negotiate the challenges of this life stage. The need to work within predefined budgets and strict time-frames undermines the potential to provide the type of care that promotes reconnections. In these contexts, there is less potential for the care worker to perform the role of guide in terms of the rite of passage.

There is also a case for the delivery of services to meet what are commonly perceived as lower level needs, prior to the onset of acute conditions that disable and incapacitate. Lower-level services such as advice, information and advocacy, and telecare, should be considered as mechanisms by which older people can remain in their homes for longer, thus saving on higher acute treatment costs and higher dependency in later life, as Bernard (2007) discusses in a report to Counsel and Care *Real Choice, Real Voice*. Examples of these policies and practices can be found at the other end of the life course—early childhood. As there are a variety of home care services with the potential to enhance the quality of life of the older person, there is a case for a type of information or brokering service. This could be made available to the older person at certain age milestones, as is the case with the provision of such services by, for example, the different Child, Youth and Family Services in New Zealand, Australia, and the United Kingdom, to families with young children. Alternatively, such a service could be referred to the older person when he/she accesses primary health care. An information or brokering service could play an important role in linking older people to the various services available to them to facilitate low level preventive measures that will enhance the maintenance of functioning, quality of life and social participation. Such a role could be played by community groups or a public agency. In the United Kingdom, the Sure Start model works in this manner and provides an opportunity for bringing the right kind of services together in the right place, so that older people are enabled to participate fully in their community.

8.4.1 Strengthening the Capacity of Care Workers

If the goal of reconnection is to be achieved, there is a need also to strengthen the capacity of care workers. In the New Zealand context it is generally accepted that there is a need to provide better training for home care workers, along with improved work conditions, professional support and rates of pay (Health Workforce Advisory Committee, 2006). This is especially important given the increasing severity and complexity of client needs requiring greater skills of in-home care workers. As it is, there are widespread concerns about the low level of training of workers in this sector, especially when they are increasingly being asked to carry out tasks beyond their scope of practice and training. They work, largely, in isolation and there is limited opportunity for monitoring and supervision.

There is, however, some debate about this training issue. Doyle and Timonen (2007) observe there are those within the disability movement (p. 119) who identify advantages in systems that do not enforce minimum training standards. Proponents of this view sometimes argue that non-skilled persons are better able to deliver companionate and basic domestic care and that an enforcement of minimum standards could have negative ramifications in terms of recruitment. These arguments also recognise that training is costly, in terms of providing it, monitoring its effectiveness and enforcing minimum standards. Furthermore, more highly skilled workers demand higher wages, and in a sector renowned for underfunding, this is seen as reducing the amount of care that can be provided.

We suggest, though, that reconnective care practice demands more than merely basic knowledge about the performance of domestic work tasks and simple personal care skills. Carrying out the complex duties of care and managing the relational aspects of this work requires a specialised knowledge and skills. Further, it needs ongoing support for care workers in terms of monitoring and ‘supervision’ in the social work sense, that is the opportunity to reflect on care work practices, and to discuss issues and problems and how best to deal with them.

The importance of professionalising care and ensuring some sort of progression and structure within the sector implies greater recognition of the significance of the workforce in in-home care. As it is, many care workers report feeling that their work is not valued. The Care Work in Europe report by Cameron and Moss (2007, Chap. 2 and 6) suggests that while care workers themselves realise the importance and significance of their work they feel that, in general, most people undervalue this work. Further, there is wide agreement that employment in in-home care is not generally viewed as attractive. Difficult work arrangements in terms of strict time control, poor salary, often inferior management practices, the ‘dirty’ nature of some of the work, the physically demanding tasks that are required, and a lack of autonomy are reasons for a high turnover and for many leaving employment in the home-care sector.

Training can at least ensure the workers know how to provide enhanced basic domestic and personal care. In Denmark the home care workforce, say Doyle and Timonen, is relatively skilled in comparison with other countries. They quote Korczyk (2004) who observes that Denmark has recognised the importance of professionalising care work and ensuring career progression in the sector. As well as figures demonstrating the increasing number of workers completing training, Doyle and Timonen (2007, p. 34) observe that the municipality of Copenhagen has initiated training programmes which pay a prospective carer a full salary while undertaking training for up to 3 years. Despite these enticements, however, there was agreement that home care employment is less attractive than other areas, and such a negative perception does influence recruitment and retention. Reasons given for the low status of the work included its association with low qualifications, the invisibility of the work and lack of promotion opportunities. It is also suggested that it may be linked to low social valuation of old people, so that working with them is seen as 'care work without any result' which is treated as work of low priority.

8.4.2 A Community Development Focus

A community development approach emphasising the inclusion of older people in the carrying out of research (as in Barrett, Kletchko, Twitchin, Ryan, & Fowler, 2005), and in planning and advocacy, has much potential to contribute to change in the broader community environment. Research, advocacy and lobbying by organisations which work with this particular group of older people needs to continue. Further, since older people are the experts on their own situations, a community development approach will seek to include them as colleague researchers. Barrett et al. (2005) did draw on older volunteers in their analysis of the experience of the transition into frailty in later life. This mirrored the approach of Older People Researching Social Issues (OPRSI)[1] with the mining of their own experience:

> Older people want real or purposeful involvement... they want to know that the time and energy they put into the research is recognised, that their views are taken seriously, and that they will be informed about the outcome of the research. Many older people will benefit from the support of universities and, if training for research, involvement in ongoing research (OPRSI, 2007).

Much of community development is a matter for local planners and has the potential to benefit not only older people but us all. Lobbying to promote town plans that provide accessible public transport, the creation of accessible public spaces, and neighbourhoods that support vulnerable, lonely individuals within the community

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[1] Clough, R. Older People Research Social Issues (OPRSI), ARVAC www.arvac.org.uk/docs/info_bull95e.html, Downloaded 1.5.09.

are all examples of community development approaches (Barlow, Bayer, & Curry, 2005). A community development approach could also work to realise the potential for a greater contribution to care of older people in the community by older people themselves and their families. Older volunteers, providing they were properly trained, are often more naturally engaged with their local community and are likely to integrate well with those in receipt of care. Established services such as adult day care centres can be developed further as they have potential to play a critical role in maintaining social relationships and avoiding problems of social isolation. Day centres are also a point at which an array of services ranging from exercise skills, legal advice, health checks, intergenerational and outreach work can be provided. In New Zealand, for example, as well as providing independent, assisted and residential care living, the Selwyn Foundation[2] has created a community care system within parishes, with day centres, parish meals, visiting services and home care. This ensures a strong community with wide local knowledge, rather than a centralised system somewhere ‘out there’.

A community development approach could also address issues around mobility and transport as this is critical to the promotion of inclusion. These may be accessible public transport through accessible bus or rail services, Dial-a-Ride schemes, concessionary taxi schemes, or disability mobility services. There is a need to ensure ageing in place does not leave older people with mobility problems isolated in their own homes. There are real challenges in achieving this given the challenges to mobility caused by frailty and disability.

8.4.3 Coordination Between Sectors

There is a need for the coordination of services in the home so the most relevant kind of services are brought together. Mutual coordination between the sectors is especially relevant to meet the often multiple needs of elderly people in this stage. We have suggested service models should be flexible enough to respond to the particular needs of individuals. While there is a need for flexibility, there is also a need to ensure care programmes are well integrated and coordinated. There is often a need for the appointment of a lead carer to oversee the integration and coordination of services. Lead carers can have an enduring presence in the life of the older person, especially where there is inadequate informal family support available. Lead carers could oversee the management of health problems and ensure other needs were met. Lead carers could play the role of a coordinator to ensure the mix and integration of services is appropriate to the needs of the older person or household. The role of lead carers could be broad and extend to tasks such as acting as a broker for broader services which affect the wellbeing of the older person, such as services which oversee and advise on decisions about house repairs and maintenance.

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[2] http://www.selwyncare.org.nz

When providing care to older people in their own homes, continuity of service is important. Continuity allows for the lead carer to get to know the older person and their living situation—their particular health problems and functional limitations, the family and social network situation, and other needs the older person may have around transport, shopping, and housing.

Decisions about home-based support need to take account of not only the cared-for person but also, in couple households, the caregiver, and ensure respite care is made available, given the compounding negative effects of caring for an unwell spouse on the caregiver. The interdependency that develops over a lifetime of living together requires agencies delivering services to one partner to regard both partners as equal clients of their service, whether or not both partners fall within the parameters of the qualification for service. Adult children, most often daughters, caring for unwell parents also need to be supported. Recognition and support for spouses and families at times when they are vulnerable and under stress may take the form of respite care, income assistance and training.

8.4.4 Supported Housing Arrangements

We turn now to housing arrangements and their potential to contribute to care that supports the wellbeing of older people. Retirement villages are growing in number and provide the opportunity for community involvement and informal support, but here our attention is directed more towards supported housing arrangements which can play a great role in promoting contact, connection and communication. Such models can take a variety of forms, and range from village environments of co-located privately owned residences, to complexes consisting of purpose built residences available for subsidised rent. The defining feature is the availability of an on-site care worker or care team available to provide timely assistance to people in their own homes in a way that recognises the need for security, supports people's autonomy and independence, and maintains their quality of life.

Reid (2008) refers to the growing evidence that accommodation plays a significant role in improving the wellbeing of individuals and households—and, in particular, that 'supported independent accommodation' can help to maintain the physical, mental and social wellbeing of older people. Indeed, the notion of supported independent accommodation has now gained wider currency and it has implications for three key determinants of health and wellbeing for older people—the nature of their accommodation, the nature of the support they receive, and the level of independence that their accommodation and support affords them.

Satisfaction with sheltered housing is linked to the wish for small, warm, easily run accommodation, rather than the provision of an alarm and warden (Tinker, 1997, p. 174). But she suggests extra warden cover and the provision of meals for elderly people in sheltered housing who are, on average, more physically and mentally disabled than those in the community. She mentions programmes such as 'Care and Repair' to assist older people should they wish to remain in their own homes. Relocation to sheltered or assisted housing means for a majority of participants that their self-image changes from being self-reliant and independent to becoming dependent and perceiving themselves and their care to be a burden. As Parks (2003) and Frank (2002) observed, it was less like a home than it was intended to be.

Extra-care sheltered housing has the potential to act as a hub for services for older residents, as well as the broader local community. Services can be delivered to older people by those who live close by in their own homes. Such programmes have the potential to maintain the connectedness of older people within their wider community and facilitate their integration within the local environment.

8.5 Areas for Further Research

Little managerial attention is paid to the evaluation of home care services from the perspective of the older person and there is a need to examine further the experience of receiving care, the type of care that promotes independence and autonomy, and the types of policy settings that promote wellbeing among older people in this life stage. There is a need for more research on the impact on caring families and those who take on the role of a primary caregiver. What forms of support services are most able to sustain them in these roles? Such research will have important implications for work in this sector as populations continue to age and as tax bases diminish.

There is a need to understand the experience of social isolation of those at home with care and the role of the care worker relationship in moderating the impact of that. At the same time, if care workers visit in short bursts, we might consider the use of telecare, the innovative approach outlined by Barlow et al. (2005). Not only are there assistive devices to assist with increasing functionality in the home, such as visitor access, door opening and closing, communications equipment, but there is the possibility of other telecare. Barlow et al. (2005) discussed two main systems of telecare, for information provision and for risk management, where a system will take measurements from an individual's body or surrounding environment such as the home, transmit these to a control centre which will then access help, for example by referring to a relative or neighbour. Key policies and research towards implementation of telecare have been carried out in the United Kingdom, by endorsement from the Department of Health (Barlow et al., 2005, p. 444). Further research needs to be carried out into the technology, its ease of use and its impact on supporting the independence of older people receiving home care.

Further research could also be carried out into the socio-economic situations of people who receive care in the home. There is evidence that the financial means to pay for your own care is linked with greater levels of satisfaction and control (Barrett et al., 2005). The challenge is to achieve the same level of satisfaction among those dependent on state care and there is a case for ongoing research in how to achieve that.

There are also potential gains from examining the spiritual aspect of ageing associated with the stage of supported independence. Little attention has been paid to the 'sage' in the ageing population and even less to the spirituality of ageing with a disability and receiving care (Atchley, 2008). This new life stage of supported independence is a potentially rich area for research for considering the stages of wisdom, reflection and the interconnections of knowledge in creating a spiritual position.

8.6 Summary

Taking care of domestic chores and assisting with personal care will not on its own, we suggest, provide older individuals with the wherewithal to make the transition towards the final stage in the rite of passage, that being reconnection within the wider social setting in valued roles. Our concern is that, for many older people, home care can intensify disconnectedness from self, from family members, and from the broader community, and our review of this time of life shows that the transition into frailty or disability tends to be accompanied by the denial or weakening of individual agency. Packages of in-home care, precisely programmed in terms of tasks and time, tend to reinforce passivity, undermine autonomy and limit opportunities for reconnection—instead of supporting independence, they can reinforce dependence and undermine agency.

We emphasise that the purpose of these types of services should be to assist the process of reconnection following the disruptions caused by the onset of frailty and disability and the need for in-home care. The demand for such care is going to increase, but the capacity to respond appropriately to that demand remains in question (New Zealand Department of Labour, 2009). Reconnection, in our opinion is concerned with ensuring older people are not isolated, but continue to be able to maintain socially valued roles and purpose and continue to populate the streets and the community. It is also concerned with ensuring that the anxieties and precariousness are shared, understood, and solutions supported.

Like any conceptually framed study, this work has its limits. The rite of passage is a model from classical anthropology, yet we have used it in a secular situation. Moore and Myerhoff (1977) and Hockey and James (2003) among others have indicated the value of the concept, without necessarily applying it in the way we have. Others have used the notion of 'biographical disruption' (Bury, 1995; Williams, 2000) and 'status passage' (Kingston, 2000). Our application, we like to believe, has allowed us to look closely at the detail of the experience of the transition into frailty in late life in a way that provides for the consideration of the final stage of reconnections and the implications for policy. Our aim has been to reveal the problems older people and their families face at a particular time of life in a way which brings to light issues, to provide an explanation of the process of ageing and vulnerability in care, and to emphasize the value of pursuing an inclusive approach towards older people in society.

The value, then, of our hypothesised new stage in life, is to bring attention to the experiences of older people, whose primary connection is the shared experience of receiving in-home care. By an artificial construct such as this life stage of supported independence, we demonstrate the commonality of these experiences, thereby grounding individual experiences in a demographic and policy context, and showing them as features which belong to this group of people. By revealing these characteristics as issues and problems of a particular time in life, we challenge those involved with elder care to consider solutions. This is the value of our proposed new life stage.

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