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THE LAST NEW HOME:  
RESIDENTIAL CARE FOR THE ELDERLY  
IN NEW ZEALAND

A thesis submitted in partial fulfilment of requirements

for the degree of

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## The Club

Welcome to the club, they said  
when he turned eighty;  
the entrance fee is pretty steep  
and you will find  
that every year  
subscription rates are higher,  
and can't be paid by cheque.

But there are compensations.  
The grass, if you can still see it,  
is a richer shade of green;  
the birds, if you can hear them,  
sing more sweetly;  
victory is sweet and you will find  
the battle of just living  
has its glory;  
though friends be few  
there is a closer tie  
that links them heart to heart.

So welcome to the club my friend  
and may you find  
that life can still be sweet  
though you are eighty.

Ida Stokes (1900-1995)

## Abstract

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The primary assumptions of government policies for the care and support of older people in New Zealand are that home based care ('ageing in place') is the best option for the frail elderly, and that 'home' and 'rest home' are mutually exclusive concepts. In this context I interviewed eleven rest home residents about their experience of 'home' in relation to residential care. What I found was that, for most of these participants, frailty and increasing dependence on family and friends had meant their own home was no longer the seat of identity and continuing independence, or indeed of close relationships and intimacy, security, comfort and control. Rather, moving to a rest home provided greater independence from family and friends and, for many, increased security, comfort and companionship. For these older people 'home' was not associated with a specific residence and was indeed transferable to a rest home setting. These findings therefore contradict and call into question the primary assumptions on which current ageing in place policies are based.

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## Introduction

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In March 2005, the *Sunday StarTimes* ran an article on 'ageing in place', the new buzzword in ageing care that is 'sweeping the world, and gaining ground in New Zealand' (Laugesen, 2005:C1). In the article, Mathew Parsons, senior lecturer in gerontology at Auckland University and 'an influential thinker in the development of aged care services in New Zealand', predicted the end of rest homes within the next ten years. This bold and probably deliberately provocative statement is based on what has become an inarguable 'fact', that all old people wish to live, and die, in their own homes, and that this is therefore what should happen. It is, say the politicians, 'about trying to give the elderly what they say they want – to stay at home' (Pete Hodgson, Associate Minister of Health, quoted in Laugesen, 2002:C2).

Currently however, something like 40,000 older adults live in rest homes and continuing care hospitals in New Zealand. While the average stay is approximately two years, a significant proportion will spend five years or more in such homes. Their move there will almost certainly have been made with reluctance (because of failing health or major disability and the unavailability of family caregivers) and most will have very negative preconceptions about rest homes, at worst seeing them as little more than dumping grounds for the old and the useless. What is the reality though, and is the rest home experience necessarily as bad as some would paint it?

The research on which this thesis is based was designed to explore the experience of rest home life through the stories of some of the people who live there and to address what Gubrium (1993:56) calls a 'prominent cultural tension of nursing home life', the question of whether or not a nursing home can be experienced as home. The thesis focuses particularly on meanings of home and how they can be accommodated within the rest home model, and on the 'ageing in place' discourse that currently dominates government policy around aged care. Its aim is to critically examine some of the assumptions on which that discourse is based, with particular

attention to the assumed dichotomy between 'home' and rest home, and the associated negativity towards residential care.

## The current situation

Over the last three or four decades researchers in the field of ageing have taken an increasing interest in the experiences of older people in residential care. In the UK in particular, the cultural attitude to residential care has traditionally been very negative (Booth, 1985; Townsend, 1962; Willcocks et al, 1987). Moving into a rest home has been seen as signalling a 'failure to achieve the central value in our culture, namely independence, epitomized by living and managing on one's own' (Groger, 1995:137). At the same time, it has also been seen as signalling a kind of moral failure because it 'violates filial responsibility, creating feelings of disappointment in the older person and guilt in family members' (ibid).

This negativity towards residential care is not confined to the UK. Lee (1997), in a study of community dwelling older Chinese people in Hong Kong, found that most had negative views of residential care (based on stories from relatives and friends) and that that negativity was potentially important in shaping their own experience. When they did enter residential care however, their experience was often more positive than expected, influenced by feelings of relief and security and a strong wish not to be a burden on their families (Lee, 2001).

Negativity about residential care has also been a feature of community concern and media reporting in many countries, including New Zealand (Glasgow and Mackay, 2001; Richardson, 2003), with the result that residential care homes have become increasingly regulated in the hope of improving the 'quality of life' of residents and their experience of residential care (Fiveash, 1998). What some more recent work has suggested, however, is that enforcing higher staffing ratios, individualised care plans and a minimum level of social interaction may not make residential care homes better places to live in. A number of researchers (Baldwin et al, 1993; Oldman and Quilgars, 1999; Reed and Roskill-Paynton, 1996) have challenged both the totally negative view of life 'in a home', and the associated tendency to romanticise the alternative of remaining 'at home', arguing that what is often ignored is the quality of older peoples lives prior to moving into residential care and the problems associated with high levels of care at home.

In New Zealand, research into residential care for the elderly is limited, and tends to come predominantly from the health sector (Bland, 2004; Kiata et al, 2005; Robertson and Fitzgerald, 2004; Smith et al, 2005) with some work on retirement villages and other housing options from geography (Grant, 2003; Joseph and Chalmers, 1995, 1999; Mansvelt, 2002) public health policy (Ashton, 2000; Davey, 2006; Howden-Chapman et al, 1999) and sociology (Dupuis and Thorns, 1996, 1998). Generally however, there has been little work on the experience of rest home residents themselves, or indeed on residential care from a qualitative interpretative perspective.

## My background

As a researcher, both my interest in and my approach to this subject are very much shaped by my background and experience as a doctor working in the field of geriatric medicine. In that role I have been well exposed to the rhetoric that surrounds care for the dependent elderly and to the recent shift in policy focus away from residential care and towards supporting elderly people in their own homes. I have been responsible for assessing individual older people's eligibility for rest home entry, and have accepted, almost without question, that rest home care should be restricted to those who cannot be managed at home with support. That acceptance has been in large part because of the 'unnecessary' cost to the taxpayer, but also because of an assumption that 'home is best' and is where all older people wish to be. For those who cannot be managed at home, I have looked to rest homes to provide 'high quality care' in as 'home-like' an environment as possible, and have discussed with families the relative importance of ensuite bathrooms, attractive gardens and activity programmes.

As a result, my initial focus for this project was on the concept of 'at-homeness' in relation to rest home care. As time passed however, I found myself increasingly aware of its limited relevance. Here were older people, in many cases relatively independent and by my definition supportable at home, who, for a variety of reasons, were now living in residential care facilities. They seemed content, but less because the rest home was what they would consider 'home-like' than because it was a pleasant enough place that met their current needs. What was becoming apparent was that 'home' is in fact a complex and dynamic interaction between older person and place. Whether considered in the context of a rest home or one's own

home, it is perhaps best viewed as an ideal type, a hypothetical construction of defining characteristics not all of which are ever likely or expected to be present in the real world, 'at once fantasy, memory and longing' (Wright, 1993:214).

## Overview of the thesis

In Chapter Two of this thesis I provide the background to my research. I review the literature pertaining to meanings of home, for the population in general and the elderly population in particular, and outline a number of alternative models of home and its essential attributes. I look briefly at the influence of gender and of housing tenure, and examine more closely the importance of various aspects of home in later life.

In Chapter Three I concentrate more on the context of the study in terms of the ageing in place debate, the normative assumptions around ageing on which it is based, and the history and development of residential care for the elderly in New Zealand. I raise a number of issues around 'successful' ageing and the experience of support in the community, and how current policies fail to recognise the heterogeneity of the elderly population and the world in which they live.

In Chapter Four I introduce the study itself by describing the methodological stance I have taken and the methods chosen. I then outline some of the specifics of how the research was carried out, including data collection and analysis techniques, before ending the chapter by providing a brief profile of each of the participants.

In Chapter Five I summarize the results of my interviews with the eleven study participants, and what I have discovered about their experience of the move to residential care and their lives there. I highlight how they have been able to adapt their ideas of home to new and different situations, and how they have redefined independence in often unexpected ways. I then look more closely at their experiences of rest home transition, by means of a typological classification based on four different approaches to rest home life, and how a combination of life stage, gender and generation might go some way towards explaining them.

In Chapter Six I discuss my findings and the issues they raise in relation to what is already known about meanings of home in later life and to policy discourses about

ageing and residential care. I look at the ways in which both home and independence can be renegotiated by older people confronting frailty, ill-health and disability, and how conflicting beliefs about living, dying and growing old can make the promotion of community care for all older people particularly problematic.

Finally, in Chapter Seven, I make some concluding comments about the significance of my findings in the context of policy and practice around residential care for older people, arguing that the ageing in place imperative is ultimately misguided and that what is really needed is a policy that offers older people genuine choices between a range of supported living options including residential care.

# Home and 'homes' in later life

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[Understanding home] is like trying to describe an onion. It appears simple on the outside, but it is deceptive, for it has many layers. If it is cut apart, there are just onionskins left and the original form has disappeared. If each layer is described separately, we lose sight of the whole. The layers are transparent so that when we look at the whole onion we see not just the surface but also something of the interior (Rybczynski, 1986:230).

A main focus of this thesis is the question of whether or not a rest home can be experienced as home. Fundamental to that question is at least some examination of how the meanings we attach to home might develop and change to accommodate changing needs and circumstances, particularly in the latter part of our lives.

The concept of home, its particular meaning for older people, and the problematic of merging home and care in the residential care setting, has been the subject of sustained interest and research in fields as diverse as architecture, geography, environmental psychology, sociology, anthropology, nursing and allied health sciences over the last two decades. In this chapter I review some of that work, beginning with a brief history of the concept of home and the development of place theory before focussing more specifically on the meaning of home in later life and in relation to residential care. I outline a number of alternative models of home, and look at how those models have been applied in attempts to provide 'home-like' environments in residential care.

## Where do I belong? – The meaning of home

The 'domestication' of the term 'home', from place of birth to something more akin to a family dwelling, is a relatively recent development. Prior to the 17th century, in Europe at least, dwellings had been very public places, with large households of mostly unrelated people occupying multi-use spaces. It was not until the Dutch, restricted by boggy soil and limited space, began constructing smaller, multi-storied buildings, with separate business and living space and smaller households, that the

idea of the home as we know it today was born. What followed was a whole new emphasis on family, intimacy and domesticity, and on comfort, a concept that would come to be seen as the essential ingredient in making a house a 'home' (Rybczynski, 1986).

In the early 19th Century, in many parts of the English-speaking world, including New Zealand, the term 'home' also came to have charitable and moral associations. 'Home' with a capital H came to denote an institution that provided an alternative residence for those whose own home life was deemed deficient, such as orphaned or impoverished children and the indigent elderly. Auckland's Costley Home for the Aged Poor, opened in 1890 and by 1920 catering for 442 people, was hardly cosy or intimate, with its restrictive rules intended to promote order, temperance and cleanliness among residents deemed to have little acquaintance with such values. In 1909, the then Inspector General of Hospitals proposed the appointment of women, preferably trained nurses, to take charge of such institutions in order to provide a 'firm, capable mother figure', and such women did, in many cases, manage to create an environment not dissimilar to the family home of the time (Tennant, 2000).

Whatever the context, a 'home' is something more than a roof over one's head. Houses, some more so than others, are seen as providing for the basic human needs of shelter from the elements, while dwellings that become 'homes' for their inhabitants also provide a space for belonging in modern social life. Home is the place where we feel most comfortable and at ease and where most people experience their primary relationships. It is associated with familiarity, both in a physical and emotional sense, and contributes to our sense of identity through memories and associations with the past. In popular usage 'home is where the heart is' and 'there's no place like home'.

A considerable volume of academic literature has explored the meaning of home to the general population, much of it by attempting to break the concept down into its component parts and generate models or lists of essential attributes. Moore (2000), for example, identifies three facets of home. *Place attachment* emphasises the process by which people and home places develop relationships, and is influenced by such factors as social integration, long-term residence and place in society. *Place identity* is more concerned with how people use places, through display and affiliation, to situate their self-identity. *Theory of place* sees all 'place' as the result of the relationship between actions, concepts and physical attributes.

Kenyon (1999), on the other hand, offers four elements that constitute home. *The personal* is associated with meaningfulness, memories, independence and belonging; *the temporal* with stability, permanence and familiarity; *the social* with support and intimate relationships with significant others; and *the physical* with possessions, comfort and safety. Kenyon acknowledges however that not all have to be present now, in this home, and may relate instead to past or future homes.

Fogel (1992) focuses more on the benefits of home. Home, he suggests, provides benefits related to *independence*, such as privacy and control over the physical environment; to *familiarity* with a specific environment; and to residence in a particular neighbourhood or *community*. It also offers activities of housework and home maintenance that provide a source of both physical and mental exercise and of *purpose and meaning*; opportunities to reciprocate *hospitality* by entertaining relatives and friends; and a *locus of meaning* and site of memories and important life events.

All three, and others (Lewin, 2001; Dupuis and Thorns, 1998), also note that the significance of each component of home is influenced by factors such as age, gender, personal characteristics and social and cultural background. In respect to gender, it seems to be generally agreed that, although in many respects men and women have similar views on the meaning of home, men are more inclined to perceive of home in terms of status and achievement. In the gendered spaces of modernity men are still more likely to work and socialise outside the home than women, who may see home more as an emotional retreat or protective shelter (Somerville, 1997:228). Other studies have suggested that women care more about and derive more satisfaction from home (Mason, 1989), and 'tend to be more intimately linked to the dwelling in terms of their self-identity' (Rapoport, 1981:23 quoted in Somerville, 1997:228). At the same time however, the idea of home as a place in which to relax away from the stresses of the outside world may in fact be more true for men than for women, for whom home remains a place of work and, for some, of oppression, imprisonment and even violence (Madigan and Munro, 1999:65).

Studies of migrant communities and their concepts of home, position home as both a social and cultural construction, suggesting that ideas about what constitutes a 'home' are formed during childhood but influenced by the culture and life experiences of adulthood (Lewin, 2001). A distinction between 'home', with its

implication of comfort, well-being, and stability, and the rather more inert notion of the 'house', seems to exist in most languages and through many very powerful cultural shifts (Rykwert, 1993:49). Indeed every culture seems to approach both home and family with an implicit ideal about both, and with definitions of home that acknowledge the residue of sentiment which persists in their cultural memory for 'imagined havens of warmth with fathers and mothers in their place' (Trachtenberg, 1993:211).

In New Zealand and the United Kingdom at least, home ownership appears to play an important role in the concept of home, particularly for the middle class. A key component of its meaning can be expressed by the concept of ownership as a sense of belonging, in which the house belongs to the person, and the person belongs to the community in which it is located (Brookes, 2000; Dupuis and Thorns, 1998). Historically New Zealanders have a strong ethic of home ownership with, in the 1996 census, more than three quarters of adults as owner-occupiers. Among older New Zealanders (those aged 65 and over) that figure is even higher, with most living in their own homes and the overwhelming majority of those mortgage-free (Ministry of Social Development, 2001:44). For them, home is often closely associated with inheritance, as 'a complex interweaving of the quest for security and identity with the accumulation of assets and other markers of achievement, and the transfer of these to subsequent generations' (Dupuis and Thorns, 1996:499).

Saunders (1990:302) argues that home ownership generates what Giddens (1984:50) called 'ontological security', the confidence that most human beings have in the continuity of their self-identity and in the constancy of their social and material environments. This sense of security, Giddens suggests, has been eroded in the modern world, and it is to the private realm that we now look for a sense of belonging and purpose. Saunders' contention is that home ownership is one expression of that search, and that it both builds ontological security and reinforces self-identity (Saunders, 1990:293). In the New Zealand setting, Dupuis and Thorns (1998) implicitly support Saunders thesis. For them ontological security has four aspects, all manifest in home ownership: constancy in the social and material environment; a spatial context for the establishment of routine; the site where people feel freed from surveillance and in control of their lives; and a secure base for constructing identity. Home, they conclude, can provide a locale in which people are able to create a sense of ontological security in a world that is at times experienced as threatening and uncontrollable (Dupuis and Thorns, 1998:43).

Holloway and Hubbard (2001) refer to the increasing cultural significance of 'home' in contemporary western society, as indicated by the plethora of home improvement programmes, magazines and businesses. In such an environment a 'home' has become something to be invested in, in time, money and emotions, and at the same time a place for segregation and exclusion, the privacy of which has become almost sacrosanct. It has also been progressively transformed into something of an ideal that, while universal, exists simultaneously as both a deep-rooted individual concept and as a cultural norm (Wright, 1993:214).

What seems to be emerging as a consistent theme is that although 'home' is always located in space it does not have to be a fixed space, 'for home starts by bringing some space under control' (Douglas, 1993:263). It also seems clear that home is not only a space, but also has structure in time and aesthetic and moral dimensions, and that how it becomes a home is only through experience as a resident.

## The meaning of home in later life

Home was the old armchair by the hearth, the creaky bedstead, the polished lino with its faded pattern, the sideboard with its picture gallery and the lavatory with its broken latch reached through the rain. It embodied a thousand memories and held promise of a thousand contentments. It was an extension of personality (Townsend, 1962:38).

Until the early 1990s, the literature on the meaning of home in later life tended to focus on three common themes: that home is of greater importance to older people than to 'not old' people; that old age is a time of shrinking horizons; and that focusing on home in later life reflects a kind of spatial disengagement (Heywood et al, 2002:30). Perhaps most important however was the widely accepted notion that home is, for older people in particular, a repository of memories, a locus of control (Wilcocks et al, 1987, Rowles, 1987), and a private refuge in which disability can be hidden (Peace, 1993).

Rowles (1987) looks at many of the accepted attributes of 'home' and their relative importance in the face of advancing age and disability. He concludes that, while it is important to guard against romanticism 'in the unequivocal acceptance of the link between attachment to home and well-being' (ibid:349), and to acknowledge the constantly changing residential needs of older people and the stress associated with

those changes, it is still possible to mitigate some of that stress by sensitivity to the meaning of home for particular individuals (ibid:349-350). For elderly people in particular, he suggests, home is a setting that maximises a sense of personal competence. Intimate familiarity with the physical layout of a house and the spaces within it generates what he calls a body awareness, which is in turn linked to a feeling of protection and enclosure or 'physical insideness' (ibid:339). Home can also generate a feeling of 'autobiographical insideness' (ibid:341) by providing a sense of continuity – with the past as a repository of memories, and with the future as something to be passed on to children. As such it plays a crucial role in maintaining a sense of self-identity. What happens over time, however, is a subtle weaving of self and place such that home as a symbol of identity can become a composite of accumulated experiences in all the residences of one's life, and thus a concept that transcends place (ibid:340).

This idea of a dynamic and evolving concept of home has been a prominent feature of recent research, the findings of which have been summarised by Wahl and Weisman (2003). They are

- that older people's meaning of home is multifactorial and reflects personal, social, and cultural dimensions
- that there are differences in meaning of home, depending on the competence status of ageing individuals
- that cognitive-affective ties to the home can be an important psychological resource for coping with age-related losses
- that development of positive attachments to planned environments is possible, but is influenced by person as well as institutional factors
- that motivations to leave one's home in later life are multifaceted and more complex than the simple push-pull dichotomy and
- that some older people are better environmental problem solvers than others, for reasons that are (and perhaps will remain) poorly understood.

In the New Zealand context, the Mosgiel Longitudinal Study of Ageing<sup>1</sup> gives some attention to meanings of home. Started in 1988, this study set out to sample the entire population in the Mosgiel community aged 70 and over. At the six-year follow-

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<sup>1</sup> An ongoing and high profile investigation of the health, nutrition, functional ability and social networks of the elderly population of a small semi-rural community in New Zealand.

up in 1994-96, an anthropological component was included, involving extended open-ended interviews with a sample of participants. Among the topics covered were meanings of home. What was found was that participants talked about home 'in a variety of literal and figurative ways, suggesting that spatial connections are particularly intense for older people, in light of their long duration' (Keeling, 1999:104).

In a more specific study of the concept of home in relation to later life, Dupuis and Thorns (1996) showed that, for older New Zealanders, the meaning of home reflects specific sets of historical and social circumstances, and is both multifactorial and generation specific. For current older homeowners, they relate the experience and mythology of the depression (with its legacy of mistrust of a 'fickle economy') post-war housing policy, and a culture of saving, to a quest for security for oneself and future generations in home ownership.

## Rest homes: a home or my home?

The use of the word 'home' in relation to residential care homes for the elderly has for some time been the subject of increasing interest and debate, much of it very negative about the potential for rest homes to ever be satisfactory homes for those who live in them. Prominent in research from the United Kingdom in particular, has been the concept of 'institutional care', defined as a situation where individuals spend the bulk of their sleeping and waking time in a setting which is not their home (Higgins, 1989). The pivotal assumption in such a definition is that residential homes lack the capacity to be a home, and that living in such an environment represents 'an assault on self and on feelings of personal autonomy and control' (Willcocks et al, 1987, quoted in Heywood et al 2002: 31).

Higgins (1989) looks at both the characteristics that differentiate 'home' from 'institution' (private versus public space, family versus strangers, intimacy versus lack of intimacy, owner/tenant versus client/patient, choice and freedom versus limited choice and freedom, familiarity versus strangeness, and individual versus 'batch' or communal living) and at the structures, relationships and facilities that institutional providers seek to replicate when they set out to create a 'home-like environment'. The eight principles of care referred to in British local authority guidelines (fulfilment, dignity, autonomy, individuality, self-esteem, emotional needs,

risk-taking and quality of experience) tell us a lot, she suggests, about the way in which home is viewed by policy makers. Unfortunately, attempts to create a home-like environment according to such principles typically fall short, hindered by such obstacles as image, environmental discontinuity and, for women particularly, the loss of role as a 'homemaker' (Higgins, 1989:171).

Hammer (1999) in a phenomenological investigation of home that, like many of the previous studies, set out to find the core or invariant features of the idea of being at home for older adults in residential care, identifies seven themes or elements. These encompass the usual staples of privacy, security and autonomy, but also include respect, affection, commonality and significance (Hammer, 1999). What Hammer also identifies is that older adults who move to residential care struggle to reconcile their sense of who they have been with a sense of who they may become in older age, and that the best way of achieving that continuity is by active engagement with their new environment (ibid:17).

Along similar lines, Kontos, drawing on research done in a Canadian assisted living facility, proposes a dynamic relationship between the body, meaning and place (Kontos, 1998:181). That relationship, he suggests, is a dialectical process in which cultural beliefs that influence the interpretation and experience of physiological changes associated with old age, inform the cultural construction of the place in which old age is experienced and interpreted. Home can, in this way, serve as a resource in adjusting to the physical decline and loss of independence that comes with old age (ibid:167).

In recent American literature, a number of ethnographic studies have begun to focus more on nursing homes as places in which people must live and experience their lives (Groger, 1995; Gubrium, 1993; Savishinsky, 1991). Groger (1995) looks specifically at the question of whether or not a nursing home can be a home, rather pragmatically concluding that it really depends on the criteria that individuals use to define 'home'. In her view, residents have basically two options; either to conceive of home as a metaphor for independence and health and therefore as irretrievably lost, or to define home in terms of family and social relationships and therefore as potentially more transferable (ibid:138). Both home and nursing home, she says, need to be viewed simultaneously as both abstractions and concrete places. Home as an abstraction embodies the cultural ideal of independence, autonomy and comfort, and only by redefining those concepts can a nursing home be seen as

home. Home as a concrete place where people live however, is more easily transferred, particularly to more 'home-like' environments with single ensuite rooms furnished with residents personal possessions. It is, Groger suggests, the abstract idealisation of home that nursing home residents must be encouraged to let go of if they are to establish 'a sense of satisfying connection between self and environment akin to feeling at home' (ibid:152).

Hockey (1999) makes a similar point, in examining the notion of 'home' as 'an edited representation of idealised domestic life' (Hockey, 1999:113). Such idealisation highlights positively perceived beliefs, ideals and values but tends to ignore the more negative aspects of family life and ageing such as violence, neglect, loneliness and isolation, disease and disability. Life in residential care, she points out, will always fall short of our mythical representations of the ideal home, both because of the unpredictable nature of the human body and because for many residents it will have been entered into as a direct result of their failure to maintain a domestic environment in a culturally appropriate manner (ibid).

What seems apparent is that this idealisation of 'home' is sometimes more a creation of planners and providers of elderly care than the elderly themselves, and that the expectations of rest home residents can be quite different to those of their relatives, and indeed the staff. The belief that rest homes can be made more 'home-like' by offering more choice in such things as menus and mealtimes (Abbott et al, 2000), involving residents in meaningful activity (Cutchin et al, 2003), and maintaining contact with the past through visits from family, friends and neighbours (Rowles, 1987) is entrenched in regulation and nursing culture, but may not in fact be shared by residents themselves. While rest home staff often have unrealistically high expectations of social participation and harmony, residents are on the whole more realistic and generally satisfied (Abbott et al, 2000) or even pleasantly surprised (Allen et al, 1992).

A further area of interest has been around issues of relocation for frail older people, particularly relocation to a care home setting. As a starting point, Rowles (1987) sets out to 'place the experience of moving in longitudinal context' by viewing it as a series of moves over time 'in which each relocation is linked to moves that occurred previously and to those that are anticipated to follow' (Rowles, 1987:342). To understand the issues of relocation, he first describes three overlapping groups of elderly people. The *active old*, who are generally healthy and living with a spouse,

relocate for practical reasons of reduced household size and an inclination towards a more leisure-orientated lifestyle; while the *vulnerable old*, often widowed and increasingly reliant on their children or neighbours, do so more because they need some degree of practical or social assistance and are beginning to acknowledge their own mortality. For the *frail old* however, relocation is likely to be to a 'last new home', often a residential care setting. Along this continuum, individuals tend to become less competent, both physically and psychologically, and less able to actively transform a new setting into a place that can be called home. For the last group in particular relocation is often made with reluctance because 'it represents clear acknowledgement of mortality and a final break with home and the possessions of a lifetime' (Rowles, 1987:346).

While some attention has been given to ways of easing this transition (Abbott et al, 2000; Cutchin et al, 2003; Morgan et al 1997), the focus of rest home planners and designers has often been on the physical environment and provision of amenities. Studies have suggested that making a residential care facility more home-like can be facilitated by being surrounded by personal possessions (both artefacts and memorabilia that provide a link to the past and treasured items to be passed on to children that provide a sense of continuity and a link to the future) and by 'enhancing residential permeability' through design features such as windows that facilitate surveillance of outside space (Rowles, 1987). The creation of an environment in which an older person can function effectively does not, however, make a 'home'.

A number of interesting analogies of rest home life have appeared in the literature in the last few years, providing some thought-provoking challenges to conventional wisdom about rest homes and 'home'. At the University of Toronto Nursing School, Dr Dorothy Pringle, when introducing students to the organization of life in a nursing home, asks them to 'imagine living on an airplane'.

...not having a choice of whom one sits beside and risking that this seatmate may smell, slurp food, chatter endlessly or refuse to participate in even occasional exchange of pleasantries; having to stuff the few allowable personal belongings away so they do not encroach on one's neighbours or aisles; eating on the schedule imposed by the airline not when one is hungry and, moreover, having little choice over what one eats; having to use and wait for communal facilities, such as bathrooms, and not being able to get to the toilet when needed because there is a cart in the aisle or the seatbelt sign is displayed; having television sets turned on regardless of one's interest in watching them; having to wear a restraint to protect against the rare

possibility of injury; and having nothing to do and nowhere to go (Andrews et al, 2005:110).

While the image is deliberately provocative, the idea of 'airplanes as flying nursing homes' is designed to draw attention to the way residential care homes are tightly managed in time and space. The analogy is intended to highlight the powerlessness of residents, the limitations in choice and services for reasons of efficiency and economies of scale, and the way in which freedom is curtailed and restrictions imposed in the name of safety.

Douglas, on the other hand, reminds us of the common refrain that home is not a hotel (Douglas, 1993:274). As she points out, homes of all sorts generally involve compromise and coordination in the use of facilities and the sharing of chores, consideration of others, and a certain amount of conformity to routine and to letting other members of the household know where you are going and when you might be back. In most family homes individuals have their usual place at the table or chair in the living room, and privacy is in reality limited and dependent on the same sort of conventions of behaviour (knocking on doors, averting eyes and not listening to private conversations) that apply in other forms of communal living. Limitations to freedom are, Douglas suggests, part of the experience of home for most of us (ibid).

Bland (1999) takes the analogy further by suggesting that, while homes are not like hotels, perhaps rest homes should be. In an article which explores two different models of residential care for the elderly, 'service' and 'social care', she describes a home set up and run along entirely different lines by a couple from the hotel trade. Utilising a 'service' model, they made no attempt to make a 'professional' assessment of residents needs and simply provided services and applied the normal social conventions of privacy as in a hotel. What they were able to create was a care home in which residents were treated as socially competent adults who are paying for (or contributing to the cost of) a service and were able to have greater control over their lives because those running the home had no sense of their own professionalism or role as 'carers' being undermined or threatened (ibid:557).

In the New Zealand context, two recent unpublished interview studies, one from nursing (Bland, 2004) and the other from allied health and anthropology (Robertson and Fitzgerald, 2004) have addressed the issue of home in relation to residential care. While both conclude that rest homes are 'unlikely to ever be a home away

from home' (Bland, 2004:79), they also acknowledge that 'homeliness is not essential to the provision of a high quality and enjoyable residential care environment' (Robertson and Fitzgerald, 2004).

Bland's thesis focuses on the competing demands on rest homes, which fall 'betwixt and between' the roles of home/hotel, hospital/hospice and business, and the conflicting expectations of owners, funders and regulating authorities, residents and their families, and society in general. She draws attention to the mixed messages in the Code of Practice of the New Zealand Rest Homes Association, which calls on its members to provide 'a warm, homely atmosphere' that offers 'a supportive, *safe* and *therapeutic* environment in which residents feel free to be themselves'. She reports how she came to realise that the rhetoric of individualised care was little match for deeply entrenched work practices or geriatric routines designed primarily to promote efficiency and minimise risk (Bland, 2004:110). While quite pessimistic about the prospect of changing the culture of rest homes to make them more 'comfortable' for residents, she does acknowledge however that she saw remarkably little passivity or 'acceptance' among residents, who actively worked at 'making the best of it' and being content (ibid:136).

Looking for a model for the transformation of rest home to home then, requires some exploration of the processes by which home comes to have meaning at a personal level but also in social, cultural and political contexts. It also requires acknowledgement of both the complex mythology of the 'ideal home' and the negative aspects of the home experience (Moore, 2000). What Moore argues for is a move away from creating lists of meanings of home, 'under the misconception that one authoritative set of meanings is a realistic goal', and towards a more context-sensitive focus on the experience and meaning of home as a word and an idea. Understanding 'home', she suggests, requires a greater focus on the social, cultural and political contexts within which it is framed, on the 'complex ideology that surrounds it', and on 'the ways in which it disappoints, aggravates, neglects, confines and contradicts as much as it inspires and comforts us' (ibid:213).

### *Summary*

In this chapter I have reviewed the literature pertaining to the concept of home and the meanings we attach to it, with particular reference to older people. I have outlined a number of alternative models of home and its essential attributes, looked briefly at the influence of gender and of housing tenure, and examined more closely

the importance of various aspects of home in later life. I have also looked at the issue of providing 'home-like' environments in residential care, and raised some questions about the assumptions on which attempts to provide such environments are based. I have shown that home is a cumulative and experiential concept that is context-sensitive and prone to idealisation and romanticism, but is nonetheless important to any discussion of the place and structure of residential care for the frail elderly.

In the next chapter I look more specifically at the ageing in place debate and at some of the assumptions around ageing that have contributed to it. I also provide some background to the development of residential care for the elderly in New Zealand and a snapshot of the sector as it exists now.

# Ageing in Place

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Forget the retirement home – stay put and grow old gracefully in your own home. That's the philosophy behind new trends in care for the elderly, but does it make sense?  
(Laugesen, 2005:C1)

The current social policy focus on supporting older people to 'age in place' rather than entering residential care, in many ways reinforces the idea that 'home' and 'rest home' are mutually exclusive concepts.

In this chapter I examine the ageing in place debate, looking first at where the concept has come from and why, and at some of the normative assumptions around ageing that contribute to the debate. I then briefly outline the history of aged care provision in New Zealand, both in residential care homes and in the community, and some of the wider social and political factors that have influenced that development.

### Ageing in what place?

In recent years, the ageing in place debate has moved up the social policy agenda in New Zealand and other developed countries, including Australia, the United Kingdom and the United States, for two key reasons: 'demographic alarmism', and the escalating cost of residential care. The perception is that as the population continues to age unprecedented numbers of older people will flow into residential care, creating a huge financial burden for the taxpayer, when they can and should be staying in their own homes (Callahan, 1992:5).

Even in very late life, says Davey (2002) 'the majority of Australians and New Zealanders live at home and want to remain there for as long as possible'. But what precisely do we mean by home in this context? While the answer might be assumed to be a long-term private residence, in some cases the original family home, full of

treasured possessions and memories and part of a familiar community of supportive friends and neighbours, the evidence is that for many that is not the case. Government reports on Positive Ageing (Ministry of Social Development, 2001) and Ageing in Place (Ministry of Health, 2002) acknowledge that maintaining independence often requires a move to a smaller more convenient house. Many older people, particularly women in the over-85 age group, live in flats that they own or rent, often from local authorities. Over the last decade too, retirement villages have grown in number and size to now accommodate around 5 percent of the older population, making them the largest single specialist provider of older people's housing in New Zealand (MSD, 2001:47). In terms of housing then, the older population is as diverse as any other in our society and moves almost as often. Between the 1991 and 1996 Censuses just over one-quarter of elderly people changed their address (Statistics New Zealand, 1998:29). Very few of those will have gone to residential care.

Definitions and perceptions of ageing in place vary greatly, from 'to remain in a familiar setting imbued with various meanings' (Cutchin, 2003:1077) to simply 'maintaining older people in their home environment' (Richmond et al, 1995:1) or 'the ability to make choices in later life about where to live and to receive the support needed to do so' (Dyson, 2002:78). The way the term is used most frequently however is as a policy ideal with little sense of the very complex interaction between older adults and place on which it draws (Cutchin, 2003:1078). While implying a fundamental of continuity and security, the maintenance of independence, and a certain degree of competence and control over one's environment, ageing in place tends to ignore the fact that change and uncertainty are ever-present components of later life, often requiring creative thought and action by both ageing individuals and their families (ibid).

Richmond et al (1995), in their report to the New Zealand National Advisory Committee on Core Health and Disability Services, talk of older people being 'encouraged to remain in their own homes and communities for as long as possible ("ageing in place")' in order that 'the proportion of them receiving long term institutional care is decreased to the essential minimum'. While clearly accepting that residential care is *institutional* and only to be considered when absolutely *essential*, the report does note the concern of some commentators that perhaps 'the balance of care is now swinging too much towards home care and that protagonists are overemphasising its advantages' (Richmond et al, 1995:47).

What seems apparent is that, whether as policy, choice or ideal, the promotion of ageing in place is underpinned by a number of fundamental assumptions.

- that all older people prefer to live 'at home'
- that 'home' and 'rest home' are mutually exclusive terms
- that rest homes are 'institutions' and somehow not part of the community
- that it is cheaper for older people to live at home
- that institutional care is an option of last resort to be considered only when support at home has 'failed'
- that the need for institutional care can and should be determined only by means of a 'comprehensive needs assessment' by a suitably qualified 'expert'.

The current policy focus on ageing in place is certainly not unique to New Zealand. Noro and Aro (1997), in a study undertaken to assess the potential for success of an active policy to deinstitutionalise elderly residents of long-term care homes in Finland<sup>2</sup>, found that, while older people living at home generally preferred to remain there, very few of those already in residential care actually wanted to leave. Although it could be said that their seemingly successful adaptation to and acceptance of rest home life reflected a process of institutionalisation, the study found that no longer having to undertake normal daily activities such as 'home chores' had 'eliminated a considerable physical and mental burden for many' (Noro and Aro, 1997:318).

## Approaches to ageing and old age

'You are old, Father William', the young man said,  
'And your hair has become very white;  
And yet you incessantly stand on your head -  
Do you think at your age it is right?'                      Lewis Carroll

The field of gerontology, the multidisciplinary study of ageing and old age as a synergistic product of interacting biological, behavioural and social factors (Maddox and Glass, 1999:191), encompasses a wide range of disciplines all interested in old

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<sup>2</sup> A policy motivated by a perceived high rate of inappropriate placement in residential care and the economic burden associated with it.

age and the problems of the elderly. Social gerontology, or the sociology of ageing, has traditionally focused its attention on the welfare needs of the elderly within a social policy framework and on the impact of social policies around ageing on the health and well-being of older people. In more recent times however, that attention has shifted somewhat, first to the social construction of the concept of age and later to the experience of ageing and the meanings attached to it (Lynott and Lynott, 1996:758).

Within sociology, the first formal theory of ageing was that laid out by Cumming and Henry (1961) as disengagement theory. Their premise was that ageing could not be understood separately from the characteristics of the social system in which it is experienced and that, if ageing involved a gradual but inevitable process of individual decline, then the way in which the social system could deal with that decline was by institutionalising mechanisms of disengagement. As a result of such mutual withdrawal or disengagement between the ageing person and society, the individual was able to move towards a 'settled' old age and the equilibrium of society was maintained. Prior to 1961, the sociological understanding of ageing had centred on the concept of adjustment and the then unformalised but widely shared 'activity theory', the idea that if older people were active and involved they would be happy (Lynott and Lynott, 1996:750). Both concepts were treated essentially as descriptions of the 'facts' of growing old, and as problems to be overcome by individuals in negotiating a satisfactory old age.

By the early eighties however, the so-called 'facts' of ageing were beginning to be questioned and the focus of social gerontology was moving from the individual to society. Particularly prominent in early research on residential care for the elderly (eg: Townsend, 1981; Walker and Phillipson, 1986) were the political economy perspectives which argued that ageing is not a mere condition of growing older but rather part and parcel of the structure of a capitalist society (Lynott and Lynott, 1996:754). Such perspectives are still reflected in the concepts of ageism and structured dependency, and to a certain extent in the 'crisis' approach to an ageing population (ibid:755).

The late eighties saw the appearance of a plethora of new theories, falling broadly within the realms of critical gerontology and humanistic and biographical approaches to ageing. While still acknowledging the importance of social and economic processes in marginalizing old people, these theories were equally concerned with

how individuals cope with and respond to those processes. As such, they reflected a resurgence of the primacy of the individual, but with a greater focus on identity and the self and the struggle to retain physical and mental integrity in the face of the challenges of old age (Heywood et al, 2002:25).

Many of the earlier theories (notably disengagement theory, activity theory and structured dependency) seem to live on in everyday discourse about old age (Heywood et al, 2002:22), perpetuating the image of 'old people' as an homogenous group and ignoring how varied they are in gender, social class, ethnicity and state of health but also in attitudes, personality and life experience. At the same time, the policy discourses of Positive Ageing<sup>3</sup> and Ageing in Place are creating a whole new repertoire of concepts and images for constructing meaning around ageing and health.

### *Success or failure*

The first of these concepts is that of successful ageing – the idea that by looking after ourselves and living according to the rules we can all be fit, active and independent in our old age.

The 'kitsch idyll in the evening sun', as a cultural model of old age, has found a modern variant in the effective media staging of fit, happy and active seniors skipping in the park.... Such images are not completely false, but even less are they completely true; they depict only part of the whole and all too often the reality may be quite different. (Beck and Beck-Gernsheim, 2002:133)

Clinical gerontology has, since its inception, questioned the notion that there is an inevitable link between old age and failing health, and has looked for alternative ways of defining old age. While undoubtedly motivated by a commitment to fighting ageist discrimination and promoting the health and well-being of older people, such approaches also risk promoting an ideal that is not necessarily achievable by all, and imposing a moral judgement on those whose lifestyle choices have meant they have aged less 'successfully' (Jolanki, 2004:501). The result is what Oliver (1990,

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<sup>3</sup> New Zealand's Positive Ageing Strategy, launched in 2001 by the Minister for Senior Citizens, 'is not simply about being positive about older people – it is about being positive about the ageing process as it relates to ourselves' (Ministry of Social Development, 2001:3)

quoted in Arber and Evandrou, 1997:11) calls the 'personal tragedy theory of disability and ageing', which centres on concepts of normality, able-bodiedness and able-mindedness. Within such models, older people who are sick or disabled are treated with sympathy, but are at the same time viewed in somewhat negative terms by virtue of not having achieved the 'normal' ideal.

Within New Zealand, the last decade has seen a proliferation of government reports, strategies and action plans promoting healthy independence and active ageing (Ministry of Social Development, 2001; Dyson, 2002; Ministry of Health, 2002). Driven by images of an ageing population and rising health care demands and costs, the strategies appeal for 'a society where people can age positively, where older people are highly valued and where they are recognised as an integral part of families and communities'. At the same time, the action plans are heavily weighted towards health promotion and disease and injury prevention but noticeably lacking in implementation detail (Glasgow and Mackay, 2001:9). What is often not acknowledged however, is that while identifying risk factors for disease and encouraging healthy lifestyles may well be beneficial at a population health level, and may help reduce the incidence of disability, medicine still has a limited capacity to restore the irrevocably damaged or infinitely defer the impact of progressive disease. Such limitations are particularly relevant for the 'old-old' who, by definition, are rapidly approaching the end of their lives. It is this group in particular who are increasingly being constituted as the ultimate 'other', not just by the non-old who care for them, but even more by the 'young-old' – those for whom the presence of old age homes looms large in their lives, even though they do not (yet) inhabit them. The message of successful ageing, suggest Featherstone and Wernick (1995:10) may be ultimately one of denial.

### *Independence and the autonomous self*

Another of the concepts associated with ageing in place policies is the idea that independence is the primary goal for all, and that dependence is 'an abyss into which each of us must avoid falling, rather than an aspect of the human condition' (Lloyd, 2000:175). This focus on independence reflects, at least in part, the values of capitalism and the privileging of the individual in a society increasingly focussed on image and the 'project of identity' (Heywood et al, 2002:27). What it also reflects is the recasting of older people as active consumers, encouraged to plan ahead for a lifestyle of leisure and consumption and to turn to the private sector for income,

housing and support. What Higgs (1995) suggests however, is that policies such as Positive Ageing effectively present older people with two distinct images – one physically frail and dependent and the other active and healthy – with no middle ground. Ironically, he says, reforms to health and social services that promote greater choice and informed decision making relate to the first while only being meaningful to the second, because 'frailty and dependence are not ideal circumstances from which to exercise consumer sovereignty' (ibid:547).

Johnson (1993) questions the dichotomy between dependence and independence and asks who of us is really independent. We live, he suggests in an interdependent world in which most of us would find our lives significantly altered if those who support us withdrew. That such a world is reliant on reciprocity is simply the nature of society, and to understand dependency it is necessary to take into account *what* services or resources people need and on *whom* they are dependent (Arber and Evandrou, 1997).

### *Concepts of safety and risk*

Perhaps the greatest challenge to ageing in place might well be the contemporary obsession with safety and risk. While retirement villages and rest homes market themselves to potential residents and their families as places of safety and security that can 'take the worry away' for older people, media stories of violent crime and 'home invasion' serve only to emphasise the risks of independent living for the old and frail. It is not only physical risk either that can be minimised by fenced communities, security systems and modified environments. Health risk too is often over-stated for marketing purposes, with older people all too easily convinced of their need for alarm systems, 'safe' environments and the medical supervision of trained staff.

Bland et al (1992), attempted to measure the quality of care provided in residential homes for older people in Scotland against the 'core values' adopted by local authority inspectorates: privacy, dignity, autonomy and fulfilment. What they found however was an inherent and largely unresolvable conflict between commitment to such values and the 'risk assessment' focus of the social care approach, whereby overall responsibility for the safety, security and welfare of residents lies with the staff. As long as the prime function of the residential home was seen as providing 'care', by taking responsibility for or taking charge of people deemed unable to care

for themselves, then normal social conventions around privacy were considered at best inappropriate or impractical and at worst dangerous. The belief was that residents needed to be under constant staff surveillance if their welfare was to be safeguarded.

Kane (2001) raises similar concerns in relation to long-term care policies in the United States that are becoming increasingly focussed on health and safety outcomes at the expense of quality of life domains. The high expectations of the policy makers and regulators are, she suggests, quite unrealistic, encouraging long-term care providers to expect too much from themselves by aspiring to eliminate all bad outcomes for their residents, and families to expect too much of the providers. What American society has failed to do, says Kane (ibid:296), is confront what it expects of long-term care, and what tradeoffs it is willing to accept if exclusively good outcomes are impossible. By leaving policy makers to set their own priorities, what people are left with is the belief that long-term care should aspire to the best possible quality of life *that is consistent with health and safety*, when what residents and their families might prefer is the best health and safety outcomes *that are consistent with a meaningful quality of life*. The urge, says Kane (ibid:303) is to protect, but risk is a normal part of ordinary adult life, and long-term care is no exception. At a regulatory level, efforts to minimise risk and to displace risk management responsibility onto individuals (who must exercise informed choice and follow expert advice to avoid risks) and providers (through increased accountability procedures, assessments, service contracts and the promotion of 'evidence-based' practice) serve only to standardize and direct the activities of hands-on care staff in order to limit formal responsibility and the risk of blame for adverse outcomes (Fine, 2005:258-259).

According to the risk society hypothesis advanced by Beck (1992), as science, rationality and democracy have led advanced societies to find new ways of controlling nature and advancing individual rights and responsibilities, life has in fact become ever more uncertain and risk-filled. As areas previously considered to be beyond our control become subject to deliberate decision-making, risks must be balanced and responsibility taken, with sometimes contradictory outcomes. Those contradictions are of particular relevance to the frail elderly.

Frailty, argues Kaufman (1994:45), is a concept socially produced in response to powerful discourses about surveillance and individualism within the conflicting

frameworks of medicalization and autonomy. Medicalization encourages older people and their families to look to medical care and doctors as 'the locus of expertise and resolution as they attempt to control and solve the problems associated with debility in later life' (ibid). The promotion of autonomy on the other hand, places supreme value on self-determination and the right to choose, often at the expense of seemingly old-fashioned values such as community, interdependence and mutual obligation. The result, says Kaufman, is that 'the very old become the field on which the discourse on autonomy and freedom of choice competes with the discourse on intervention, surveillance, safety and risk' (ibid:47).

### *De-institutionalisation and disabled rights*

In New Zealand from the 1970s onward, the provision of care for people with all forms of disability has come to be dominated by the discourses of de-institutionalisation and disabled rights. From the late 1960s, Erving Goffman's influential work on asylums (Goffman, 1968) had popularised the concept of the 'total institution' at a time when residential care for the elderly was expanding. While the research on which it is based was done in a psychiatric hospital, Goffman's work specifically included in its five types of total institution those set up to care for people, 'like the aged', who were felt to be incapable of looking after themselves. It created an image of 'batch' living in an environment characterised by isolation from the outside world, rationalisation of everyday living, bureaucratic organization, and erosion of social and personal identity. Such images were perhaps not too far removed from the large rest home of the popular imagination.

What these discourses created was a move away from large institutions, and the promotion of care in the community for disabled people of all ages. Underpinning such moves was the Social Model of Disability (Oliver, 1990), an approach that challenged the orthodox view that the problems faced by disabled people are caused by their own flawed mind or body. The social model suggests instead that it is the way in which society creates and perpetuates barriers to the inclusion of people with impairments that makes them 'disabled'. While previous models had portrayed disability as a 'personal tragedy' and disabled people as in need of care, the social model promoted the idea of 'differently-abled' individuals entitled to live normal lives alongside their able-bodied peers. Despite questions about the applicability of purely social models to frail older people, they became very influential in this country within the newly formed Disability Support Services Section of the

Ministry of Health following its reorganisation in 1992 (Richmond et al, 1995:17), and resulted in a dramatic change in expectations around how the state should respond to and provide for older people.

## Ageing in residential care

### *Terminology*

Throughout the international literature, and even within New Zealand, a diverse range of terms is used to describe the various facilities providing residential care for the elderly. In New Zealand these facilities fall into four groups. Two provide specialised care for individuals with dementia and two cater to a wider dependent elderly population. Of the latter, the first group, which I refer to as rest homes and which are the focus of this research, provide residential care for elderly people (and small numbers of younger people with chronic disabilities) who require twenty-four-hour care and supervision. Most of that care is provided by minimally trained but often quite experienced staff, with regulations requiring oversight by a registered nurse. The second group, known variably as 'hospital level' or 'continuing care' facilities, or as 'long-stay', 'private' or 'geriatric' hospitals, provide a higher level of more skilled nursing care for sicker and more dependent individuals. Regulations require a greater number of trained staff and the availability of more specialised equipment, but actual medical input is limited.

The United Kingdom has roughly comparable levels of care, provided in 'residential homes' and 'long term care' facilities, but much greater provision of rental units providing various levels of supported living. In Australia the term 'nursing home' equates roughly to New Zealand continuing care facilities, with 'hostels' providing what we term rest home level care, and in North America it is 'assisted living facilities' that provide lower-end rest home care and 'nursing homes' the higher level rest home and hospital level care.

### *The history of residential care in New Zealand*

Prior to 1898 and the passing of the Old Age Pensions Act, many of New Zealand's elderly poor, although fit, lived in 'hospitals' or 'refuges' attached to hospitals. Very

different to the hospitals of today, they were grim establishments for the incarceration of the old and sick, not unlike the poor houses of the time but without the moral overtones. With access to government pensions however, the 'deserving poor' became able to pay for their care, and the concept of homes for the frail elderly was established. Most were publicly funded, with a few operated by church organizations and private trusts, as a means of relieving hospitals of some of the 'aged, infirm and chronic cases' whose presence was 'seriously crippling' hospital resources (G W Gradham, Inspector of Hospitals, 1883, quoted in Salmond, 1976:7). The 1938 Social Security Act saw the introduction of a standard benefit for everyone over the age of 65, as well as new housing policies including the construction of pensioner flats in cities and towns throughout the country.

In the early 1950s, pressure was again being felt in the public hospital sector, particularly in Auckland, and the government offered subsidies of up to 50 percent of capital costs to religious and welfare organizations willing to build residential homes for the care of the frail elderly outside the hospital sector. This move would effectively discourage hospital boards from establishing or expanding residential homes, while still keeping the costs of residential care within the means of elderly people on pensions. Originally conceived as 'residential care for the frail ambulant', these homes would essentially provide a lifestyle choice for the active elderly with relatively minor care needs. In 1960 building subsidies were increased to 100 percent, and by 1978 staff salary subsidies were introduced to enable residential homes to take on the care of more dependent residents without the need to increase the cost to residents beyond the level of the old age pension.

It was at around this time that the focus of residential homes for the elderly began to change from care of the frail ambulant to that of the aged sick, a group who until the late 1970s had received 'nursing care' in private hospitals and in the geriatric wards of public hospitals. This change was soon followed by a trend away from the admission of 'senile' old people to 'mental hospitals', and some time later by the closure of psychiatric hospitals and residential facilities for the physically and intellectually disabled, both of which resulted in the transfer of significant numbers of older residents to residential homes for the elderly. By the mid 1990s, most public hospitals had exited long stay elderly care entirely.

As early as 1961, pressure on both public hospital and residential care beds in Auckland was such that the first scheme for subsidising individuals in private care,

the Auckland Rest Home Scheme, was set up. This continued through the 1970s and 80s, along with various other schemes to encourage the private sector. With such subsidies came a need for standards and regulation, and in 1965 the first Old People's Homes Regulations were introduced, requiring all homes with six or more elderly residents to be licensed and setting out standards of accommodation and care. Despite the misgivings of many (Salmond 1976:52), the subsidy scheme was extended to the rest of the country in the 1970s, and to the religious and welfare homes in 1989, putting the latter on an equal footing with the private sector for the first time. Although guidelines on bed numbers were introduced as part of the expansion of subsidies, they were not adhered to. As a result, the decade between 1978 and 1988 saw a tripling in the number of private rest home beds in the country as a whole (Green 1993:159).

Escalating costs, generated by readily available subsidies and a rapid increase in bed numbers, were soon followed by the introduction of funding criteria based on individual need rather than lifestyle choice. In 1987 the first attempt was made to introduce standardised assessment as a form of 'gate-keeping' to residential care. As early as 1976, Salmond (1976:22) had suggested that one third of elderly in residential homes were 'inappropriate', and later reports (Bonita et al, 1989, Richmond and Moor, 1997) continued to refer to the high proportions of 'functionally independent' rest home residents. The clear implication of such reports was that such residents should not be there. It is this idea of inappropriate placement that seems to have been an early driver of the push to support older people in the community.

It is worth noting that despite the policy statements extolling the virtues of 'ageing in place', the number of residential care homes for older people increased by a third between 1986 and 1996 (Howden-Chapman et al, 1999:17), with a trend towards increasing ownership by corporate business and entrepreneurial groups. More recent developments within the sector have also included an increase in the number of hospital level beds, catering to the more dependent elderly but also attracting a higher level of state funding, and of serviced apartments. The latter, usually bed-sit or one-bedroom units purchased by residents on a licence-to-occupy basis and serviced by rest home staff, are often promoted as a more independent living option. As such they are attractive to funders because they operate on a more user-pays model, and to those who can afford to buy them because they are not subject to entry criteria and are often seen as a means of protecting assets. As an owner-

occupier option, they might also be seen as more home-like, and indeed as something akin to 'ageing in place'.

### *Who are the occupants of rest homes?*

At the time of the 2001 Census, 12 percent of the New Zealand population were aged 65 and older. This proportion is expected to rise to 20 percent by 2026, and will bring with it increasing diversity in ethnicity, health, interests and expectations. While in 2001, the vast majority of those aged 65 and older were of European origins (only 3 percent of Maori and a similar proportion of Pacific Islanders were 65 and older), this is projected to change as the 21st century progresses. For the next few decades however, the biggest growth in numbers will be in the old old, who will continue to be predominantly white, female and widowed<sup>4</sup>. While more than half of people aged 65 and over will have a disability<sup>5</sup>, with the rate rising to around two thirds in the 75 and over age group, most will remain independent and at home, close to one third of them alone (Statistics NZ, 2004).

What this means is that for the next 25 years or so there will be at least two distinct generational cohorts of over-65-year-olds in the New Zealand population. The younger cohort will be the baby-boom generation, born between 1946 and 1965, raised at the peak of the welfare state, and entering retirement fit and active, with comfortable lifestyles and high levels of home ownership and supplementary income. The other will be their parents, old enough to have experienced war and depression (whether directly or through the experiences and stories of their own parents) and with much higher levels of ill-health and disability. While the former will undoubtedly become increasingly prominent in older people's organizations and political lobby groups such as Age Concern and Grey Power, it is the latter who will in fact be the ones affected by ageing in place policies, and will continue to make up the bulk of the rest home population

In most developed countries, the percentage of older people in residential care at any point in time is low, at around 5 percent of all older people. It is estimated

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<sup>4</sup> In New Zealand in 2001, nearly 70% of those over the age of 85 were women and less than 2% were Maori.

<sup>5</sup> Defined, for census purposes, as any limitation of activity resulting from a long-term condition or health problem.

however that 25-30 percent of those who survive to age 65 can expect to spend some time in a long-term care institution before they die (Kinsella and Velkoff, 2001, quoted in Statistics New Zealand 2004:94). Comparative figures from the mid-1990s show New Zealand to have one of the higher rates of residential care in the developed world – at 6.7 percent of those aged 65 and over, significantly higher than the United Kingdom but on a par with Australia, Canada and most of Western Europe. As might be expected, rates of residential care increase with age<sup>6</sup>, and are also affected by such variables as gender and marital status (Howden-Chapman et al, 1999:17). At the time of the 2001 census, 95 percent of those living in residential care facilities in New Zealand were of European or New Zealand European (Pakeha) descent. Close to 50 percent were over the age of 85, and nearly 70 percent were women (Ministry of Health, 2002:94). Of the around 870 facilities in which they lived, almost half were owned and operated by not-for-profit religious and welfare organizations, with the remainder privately owned either by individual 'owner-operators' or, increasingly, by large holding companies (Clarke, 2001).

As noted earlier, the residential care sector is currently divided between long-stay hospital, specialist dementia care and rest home beds, with many facilities providing more than one option. While the balance is moving more towards the higher levels of care, it is still rest home beds that make up some two thirds of occupied beds. Entry to long-stay hospital and dementia care is by specialist medical assessment and attracts a top-up government subsidy regardless of means, while eligibility for government subsidies for rest home level of care is means tested. Current estimates suggest that nearly half of those in rest home beds are paying the full cost of their care (Ministry of Health, 2002:93).<sup>7</sup> Despite this however, the clear message of public policy around residential care is that only those whose needs cannot be met in the community should be allowed to enter rest homes. Indeed, in most parts of the country potential residents are required to undergo an assessment by staff from a Needs Assessment and Service Coordination (NASC) agency to establish that they are unable to be supported by in-home services.

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<sup>6</sup> In 1996, only 1.3% of those aged 65 to 74, but 10% of those aged 75 and over and close to 50% of those aged 90 and over, were in residential care (Statistics New Zealand 1998).

<sup>7</sup> With significant changes to funding eligibility introduced in July 2005, the proportion of private payers is already falling and is likely to continue to do so.

What is it that distinguishes those in rest home care? It is difficult to establish with certainty why some older people enter communal care whilst others with comparable degrees of disability remain in the community. What is clear however is that it is not simply a question of need or level of disability. A number of factors that affect the 'ability' (and perhaps the inclination) of older people to live 'independently' have been identified (Davey, 2002; Dwyer et al 2000). These include practical issues such as income, housing and access to transport; but also personal factors such as attitude to life, self esteem, optimism and sense of security and control; as well as regular engagement with meaningful social activities and social networks and, perhaps most important of all, the availability of informal care and support from family and friends. What is consistently found is that the single most important factor in keeping older people at home is the existence of a spouse. Current figures suggest that by age 85, 50 percent of men but only 10 percent of women will be living with a partner (Statistics NZ, 2004). For many of the rest 'ageing in place' will equate to ageing in place alone.

The institutionalised elderly population is composed of three distinct elements: those who die shortly after admission, those who return to the community after a short stay either for convalescence after an acute illness or to give informal caregivers a break, and those who are long-stay (Higgs and Victor, 1993). In New Zealand, MOH statistics show that 20 percent of rest home residents die within 3 months (some within days) and 40 percent within 12 months of entering rest home care (Ministry of Health, 2002:94). For many of those people the role of residential care, whether at rest home or hospital level, will have been to provide 'terminal care'. The focus of this study however is the remainder, those with more stable health for whom the rest home may be their home for several years.

## Staying home and being supported

Only at the highest levels of dependency, where there is a need for continuous nursing care, is there little opportunity to substitute other (community-based) care options for residential care (Ministry of Health, 2002).

Services that support older people in the community could be said to include anything from income maintenance provided by Work and Income New Zealand and housing assistance provide by Housing New Zealand, to social and community services such as libraries, community centres and swimming pools provided by local

authorities and the voluntary and welfare sector. What is generally meant by 'community-based care' as an alternative to residential care however, is the range of support services provided by the District Health Boards through Needs Assessment and Service Coordination (NASC) agencies.

As early as the 1970s, hospital boards throughout New Zealand were providing support services for older people in the community (including nursing care, social work, home aids, laundry service, meals on wheels, equipment loan, artificial aids and domiciliary physio and occupational therapy) while subsidised domestic support was available through the Department of Social Welfare (Salmond 1976:9). Until the 1990s however, services in most areas were limited, inflexible, and sometimes difficult to access, and the relatively easy access to residential care subsidies provided what many saw as 'perverse incentives' to residential care.

With the introduction of Needs Assessment and Service Coordination (NASC) agencies in the mid 1990s, the focus of support service provision was set to change from entitlement to need. The original concept of NASC was to put the person in need of support services at the centre of the equation, assessing their needs (as defined by themselves and their family) on an individual basis, and actively securing the best possible package of services to meet those needs. What that would do, the planners hoped, was reduce the number of new rest home placements and enable more people to remain at home.

While many older people have indeed been able to access a higher level of community support as a result of those changes, and have been very happy to do so, what does not seem to have been allowed for is that no matter how good the services are there are still some older people who *want* the comfort and security of a rest home or simply do not want to live alone. As Richmond et al (1995) point out, when failing health, loss of confidence, loneliness, and the 'mental and physical burdens of day to day living' lead to a need for care for older people, family and friends may not be available, or older people may not wish to call on them to provide that care (ibid:28). Ideally in such circumstances, various levels of 'supported living' would be available and would at least offer an alternative to residential care for the less disabled. In New Zealand however, such options have been, and remain, very limited. Although the last decade has seen a significant increase in housing built and marketed specifically for older people (because of special features such as low maintenance construction, location, size, 'disability friendly' internal design and

access to support services and facilities) most of that development has been in the private sector and little of it has been designed for 'sheltered' or supported living<sup>8</sup>.

Despite the implication then, from some of the earlier critics of residential care homes, that rest home residents have been in some way rejected or abandoned by their families and society, the experience is much more complicated. As more people live into their nineties and beyond, they may well have outlived friends (and often family), their children may be becoming old and frail themselves, and their extended families have often become geographically spread. With more women in fulltime employment, and the 'sandwich generation' often involved in caring for grandchildren while mothers work, it is not only families but also neighbours and other community members who are less able to provide either the support or the practical day-to-day assistance needed by some elderly people to manage in their own homes.

### *Summary*

In this chapter I have examined some of the normative assumptions about ageing that have contributed to the ageing in place policies currently dominating the planning and provision of care for the frail elderly in New Zealand. I have focused particularly on concepts of successful ageing, independence and autonomy, and safety and risk, suggesting that what they represent is an unrealistic ideal that many older people will fail to achieve. I have also provided a brief history of residential care and community support services, and looked at some of the factors that influence whether older people remain at homes or relocate to some sort of aged care facility at the end of our lives.

In the next chapter I describe the research design and methods used in this study, and introduce the study participants.

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<sup>8</sup> Defined in The Health of Older People Strategy (Dyson, 2002:82) as accommodation for older people that provides an explicit focus on privacy, autonomy and independence, including the ability to lock doors and use a separate bathroom; an emphasis on apartment settings in which residents may chose to share living space; and the direct provision of, or arrangements for, home support, personal care and some nursing services, depending on need

# Research Design

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Good qualitative research ought to confound issues, revealing them in their complexity rather than reducing them to simple explanation. If I have learned one thing from the experience of qualitative research – and the experience of life itself – it is that human behaviour is overdetermined. Our studies should underscore that observation. Let researchers of other persuasions pursue single-issue answers to complex questions (Wolcott, 2001:36).

Gubrium and Holstein (2000) have been strong advocates for more research on the everyday lives of older people and 'how they interpret and discern what it is like to grow older and old in today's world' (Gubrium and Holstein, 2000:3). With that in mind, the aim of this research was first to explore how older people in rest home care interpret their experience of home in relation to their present situation, and then to juxtapose those experiences and interpretations against some of the normative assumptions about ageing on which the planning and provision of elderly care in New Zealand is currently based.

The key questions to be answered were:

- What does home mean for rest home residents and how can those meanings be reconciled with resident's experience of rest home life?
- What do these meanings suggest in the context of 'ageing in place' and its primary assumption that home based care and support is the best option for the frail elderly?

To answer those questions I have used a qualitative methodology within an interpretative perspective, utilising data collected through semi-structured interviews with eleven rest home residents to illustrate both the heterogeneity of the elderly population and the commonalities of experience among a group of older people living with the experience of increasing frailty and the need for care and support.

This chapter outlines the methodological stance I have taken, the methods used, and the specifics of how the research was carried out, including ethical

considerations, data collection (with particular reference to interviewing older people in general and rest home residents in particular) and analysis techniques. It ends with a brief introduction to each of the eleven older people who participated in the study.

## Methodology

Because home is such a complex concept, it can only be researched using experiential methodologies – a perspective which acknowledges that 'home' does not have an unambiguous meaning (Lewin, 2001:360).

Researching housing and old age via quantitative cross-sectional studies is very limiting, and says little about how and why older people have reached their current housing position (Clapham et al, 1993). What qualitative and particularly interpretative approaches aim to do however, is to uncover the complexity of human experience in context by learning from participants rather than subjects.

In trying to uncover some of that complexity of experience in relation to rest home life in New Zealand, my initial approach was broadly influenced by the research experience and perspective of social worker and family therapist turned social researcher Anne Opie. Her approach emphasises both the complex, contradictory and serendipitous nature of qualitative research and the importance of the researcher's 'location' within her work (Opie, 1994). While positivist researcher's might be concerned about representative sampling, informant reliability and researcher bias, Opie embraces subjectivity, suggesting that the quality of representation is in fact strengthened by the wide knowledge and experience, extensive reading, and ideological positioning that an involved researcher can bring to her subject.

the quality of my representations [of joint custody] and my ability to explore the implications of behavioural and textual data derived from my own ideological positioning, from a close reading of the texts, and from the breadth and nature of the reading I was able to bring to the research; each element interrogating/affirming/ extending the others....My approach to the literature and orientation to the questions that concerned me were grounded in many years of clinical experience of families and family dynamics as well as reflection on and experience of my own families (Opie, 1994:67).

Following Opie's example, I introduced this thesis by outlining my background as a medical doctor working with the elderly and how it has contributed to my interest in the experiences of older people in residential care. What that history has also contributed however, is both a wide exposure to the positivist traditions of scientific research, strengthened in the last two decades by the growing dominance of 'evidence based medicine', and a nagging doubt about the applicability of such approaches to understanding or addressing the well-being of older people.

As a result, I began my research as a qualitative study from an 'interpretive practice' viewpoint (Holstein and Gubrium, 2005), interested in how people make sense of and give meaning to their own experience of rest home living. Over time however, I moved towards a more critical perspective, conscious of the insidiousness of dominant beliefs about old age and frailty (particularly in relation to independence and security) and the power of government departments and policy makers to promote a particular position or world view in such a manner that it becomes internalised by individuals and accepted as common sense. This is an approach very foreign to many researchers from health and health-related disciplines, even those who utilise qualitative research methods. Perhaps influenced by what Prasad (2005:4) calls 'positivist anxiety' – an eagerness to measure up to conventional positivist standards – such researchers frequently employ qualitative methods of data collection such as interviews and observation, but within a positivist framework that assumes reality to be concrete and knowable through the application of 'objective' methods of data collection.

Another influence on the development of this research project has been the life course perspective as described by Arber and Evandrou (1997). From this perspective, all age groups, including those approaching the end of their lives, are engaged in actively creating and recreating their lives and in adjusting to changing circumstances in different ways depending on their values, attitudes and biographical experiences (ibid:9). Life course approaches focus on both change and continuity. They acknowledge that present generations of older people are likely to retain many of the attitudes and traditions that were prevalent in their formative years and to be heavily influenced by having lived through historical periods that differ radically from contemporary society. At the same time however, they also emphasise the diversity of biographies within each generational cohort, and the effect of such factors as gender, class, occupation, marital status and ethnic background on the experience of ageing and the meanings attached to it (ibid:10).

## Methods

With a focus on meaning-making and how older people talk about their lives and experiences, my choice of method was a qualitative interview-based study involving in-depth interviews with a relatively small number of participants. Qualitative methods in general, and in-depth interviews in particular, are useful in addressing research questions that require explanation or understanding of social phenomena and their contexts. They provide an opportunity for detailed investigation of each participant's individual perspective within the context of their personal history and experience and, as such, are particularly well suited to exploring complex issues that occur over time (Snape and Spencer, 2003:5). Perhaps more importantly however, they also allow social researchers to explore how history, society and biography intersect (Mills, 1959), and how both broader social relations and historical context pattern 'individual experience'.

Wolcott (2001:96) suggests that, over the last two decades at least, qualitative research techniques have become sufficiently widely known and accepted that there is no need for researchers to describe and defend them anew. In the context of this particular study however, which may be of interest to readers outside of the social science arena, I think it is worthwhile to provide some brief explanatory comments and 'delimitations' (ibid:9).

Firstly, qualitative research uses non-probability samples for selecting the population for study. Such samples are not intended to be statistically representative of the older population in general, and this affects the type and degree of generalisation that is possible. While a range of different approaches to non-probability sampling is described (Ritchie, Lewis and Elam, 2003:79), that used in this study is a criterion-based, convenience sample.

The second comment relates to the generalisability of qualitative research and the thorny concepts of reliability and validity. The view taken by Lewis and Ritchie (2003:263-269) is that the findings of qualitative research can be generalised, but that the framework within which this can occur needs to be clarified for each research case. What they suggest is that generalisation involves three linked but separate concepts. Representational generalisation is the question of whether or not the views and experiences of this particular group of rest home residents can be held to be true for all rest home residents in New Zealand. Inferential generalisation

is whether the same findings can be inferred to other groups such as elderly people receiving care at home. Theoretical generalisation is whether issues raised by this study can contribute to a wider understanding of ageing, home and the ageing in place debate. While the latter can only be judged in the context of existing theories and evidence, and inferential generalisation must ultimately be a matter of judgement (with the role of the researcher being to provide sufficient detail of the research context and the phenomena found to allow others to assess their transferability to other settings) it is the issue of representational generalisation that is most often challenged by the proponents of quantitative research paradigms.

The basis for representational generalisation in qualitative research is very different from quantitative research. Qualitative research cannot be generalised on a statistical basis – it is not the prevalence of particular views or experiences, nor the extent of their location within particular parts of the sample, about which wider inference can be drawn. Rather it is the content or 'map' of the range of views, experiences, outcomes or other phenomena under study, and the factors and circumstances that shape and influence them, that can be inferred to the research population. Although individual variants of circumstances, views or experiences would undoubtedly be found within the parent population, it is at the level of categories, concepts and explanation that generalisation can take place (Lewis and Ritchie, 2003:269).

Without going into too much detail about the arguments as to whether or not the concepts of reliability and validity as developed in statistical research have any value in determining what Lewis and Ritchie (2003:270) call 'the quality or sustainability of qualitative evidence', I can only reiterate that the aim of this particular qualitative study was not to provide data of the sort that can be generalised across all rest home residents, but rather to describe and analyse some of the ways in which individual residents, with particular experiences of life, home and family, think about and relate to the place in which they live.

## Data collection

### *Recruiting participants*

Using the Eldernet website<sup>9</sup>, which provides a comprehensive listing of residential care facilities throughout New Zealand, I selected a small number of homes of

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<sup>9</sup> [www.eldernet.co.nz](http://www.eldernet.co.nz)

different types and locations within one provincial region. I then approached each home by letter and follow-up phone-call seeking the permission of the owner/manager to access potential participants. Once permission was obtained, I asked the manager or care manager of each rest home to distribute an information sheet<sup>10</sup> to all residents who fit the criteria for participation and to identify those who were interested in taking part. Criteria for inclusion were broad. Essentially any permanent rest home resident who was interested in the project and willing to take part was eligible. The only groups specifically excluded were those with significant cognitive impairment, significant language impairment (eg difficulty speaking following a stroke) or poor command of English, very poor hearing or very poor health (acutely ill or unable to tolerate a long interview).

At that stage, one participant contacted me directly by email expressing interest in taking part in the project and an appointment was made for a first interview. For the rest, an appointment was made with the rest home manager/care manager who then introduced me to those who had expressed interest in taking part. After further explanation of the study and what it would entail, those who were still interested were asked to sign a consent form<sup>11</sup> and a time was arranged for a first interview, often later the same day or the following day. At one home, a resident who was sitting in the rest home foyer and overheard my conversation with the care manager asked to be included and was.

Initial interviews were conducted with a total of eleven residents in six different facilities, four in a New Zealand provincial city and two in semi-rural locations. One of the facilities was part of a quite new retirement village owned and operated by a national chain, and two were moderately large purpose-built homes run by a religious and welfare organization and a community trust respectively. Another was also purpose built but well-established and privately owned, and two were privately owned facilities which had begun as modified private homes and been added to. Participants included three men and eight women with a median age of 87 and age range from 67 to 97. All were New Zealand Europeans and all but one had been homeowners.

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<sup>10</sup> Appendix One

<sup>11</sup> Appendix Two

Initial interviews took between 45 minutes and 1½ hours. Six participants, one man and five women, were interviewed a second time, with follow-up interviews lasting between 20 minutes and one hour. All interviews took place in the participant's room or, in one case, in a small private lounge at the rest home. One participant was happy to be interviewed but did not wish to be tape-recorded and interview data is drawn from notes taken at the time and my additional observations written after the interview. Although an interview guide<sup>12</sup> was used, participants were encouraged to talk about anything they wished to, and were generally directed back to specific topics only when the interview was clearly deviating well outside the scope of the research. The interviews focused on life course events, experience of home and community, and decisions about, as well as experiences of, rest home life. Most participants were very keen to talk about their experiences and many had read my information sheet in advance and given some thought to what they might say.

## Data analysis

All interviews were transcribed in full, and analysed thematically utilising Framework – the matrix-based method for ordering and synthesising data described by Ritchie, Spencer and O'Connor (2003). This was a continuous process that involved defining the key elements within each individual's account and looking for both differences and similarities between individual accounts in terms of emerging themes. By this method, the data was first classified and organised into a thematic framework, then reduced and synthesised into a combination of descriptive typologies and key themes in order to preserve both the depth and breadth of the original data set.

While the data did not lend itself to the strictly defined typologies described by Ritchie, Spencer and O'Connor (2003: 244), in which each individual participant fits clearly into only one category, it did however generate four quite distinct categories or 'ideal types' of rest home resident. These ideal types in turn, provided a means of summarising and presenting the data in a way that was able to convey both commonality and diversity with equal importance. What must be emphasised at this point is that the typology created, while adequate in encompassing the data

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<sup>12</sup> Appendix Three

produced by this particular study, should in no way be considered complete and comprehensive for all rest home residents.

### *Issues of ethics and consent*

Rest home populations include a large number of cognitively impaired residents, but for the purposes of this study those with significant cognitive impairment were specifically excluded. This was done because of the greater vulnerability of those residents and the problems of obtaining informed consent as much as for 'accuracy' of information. It was also done because of a deliberate decision to collect data only from elderly residents themselves and not from family surrogates who may well have had a quite different view of rest home life from that of the resident themselves.

Despite that exclusion however, Health and Disability Ethics Committee approval was considered necessary for this study because it would involve 'Participants who are patients/clients of...an organization providing health services...disability services, or institutionalised care'<sup>13</sup>. The implication was clearly that, as 'patients/clients of an 'institutionalised care' facility, these were potentially vulnerable people in need of protection. Recent controversy around the publication of photographs of elderly rest home residents in the May 2006 issue of *Kai Tiake Nursing New Zealand*, the journal of the New Zealand Nurses Organisation, has brought these issues to public prominence, with much discussion around whether or not the people involved should have been able to give consent to publication without the involvement of their families. As one commentator pointed out however,

If consent was knowingly given in good faith, there's possibly another irony here. By speaking on behalf of the allegedly photographically-abused elderly, albeit well-meaningly, those who decry the publication are also tacitly conspiring in another form of geriatric oppression, that of denying them their own voice – or even that they might still have minds of their own (MacDonald, 2006:C9).

Although no formal assessment of cognition was done, participants in this study were all considered by the rest home staff to be competent enough to take part and to give informed consent and were treated as such. The possibility that some residents may not have felt free to refuse when approached by the care manager

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<sup>13</sup> Massey University Human Ethics Committee Screening Questionnaire, Revised 28/01/04

was considered, but the manner of both those who were eventually interviewed and two other potential participants who had initially agreed to take part but changed their minds on the day, suggested that they did so voluntarily and without pressure. In fact, as has been observed by other researchers, those who took part seemed keen to record their stories. That may have been so that 'a bit of themselves might be carried beyond the nursing home walls, to rejoin the conversation taking place in the outside world' (Henderson and Vesperi, 1995:20) or simply because the interviews provided 'an opportunity for intelligent conversation and a welcome break from nursing home routines' (Higgins, 1998:863).

## The participants

In introducing the participants in this study, a number of limitations must first be pointed out. Firstly, elderly people are relatively unaccustomed to analysing experiences and feelings and may instead, in an interview situation, tend to focus on physical complaints and concrete subjects and to give the impression that those things are more important to them than they actually are (Svidén et al, 2002:15). They may also want to show themselves in a good light, by making the best of their situation and convincing themselves and others that they made the right decision in choosing to enter residential care. Both these points were considered at all stages in the research. Secondly, the participants in this study were undoubtedly atypical of rest home residents as a whole. Their selection was very much dependent on the judgement of the care managers involved, who would almost certainly have approached only those who they felt would be able to provide information of value to the study. As a result, the group interviewed were largely the more able and alert in their respective homes, but also perhaps the most suitable candidates for 'ageing in place'.

*Beryl*, aged 97, had had a long association with the rest home she was in and had first spent a short time living there after a fall. She returned to her own home for several months, but found it a struggle and decided to move back permanently. One daughter had died, and the second was ill and able to provide only limited practical support although they spoke on the phone each night. Beryl had had the same room in the rest home for seven years and spent most of her time there, walking to the dining room at morning-tea time to catch up with the news, and again for dinner, but

otherwise taking part in few of the organised activities. She tried to be as independent as possible but found she was needing more assistance as she got older.

*Gill*, who I first met just before her 91st birthday, had lived in the family home with her husband until his death eight years earlier. Since then she had lived happily in her own unit until two heart attacks and a series of hospital admissions left her too unwell to return home. She had been in the rest home for nearly six months but was still having a few health problems and was limited in what she could do. Her two sons both lived in the same town several hours away, but she had chosen to enter a rest home in the area where she had grown up and spent most of her life. Fellow residents included old friends, a sister-in-law and even some people she had been to school with. At my second visit her health had improved but she was still happy and now 'used to being spoilt'.

*Gladys*, 82, had also moved to the rest home for medical reasons. Like Gill, her health had improved since she had been there but she still felt the need to have skilled people around if she needed them. She had moved a lot during her life, for some years buying houses to do up and sell again, and had had her last house built just eight years before moving into the rest home. She liked things 'nice' and had put her own mark on her room with new curtains, shelves and cushions. Her daughter and several grandchildren lived nearby and visited regularly but she had declined her daughter's offer of a home with them because of 'the age gap'.

*Joan*, 79, lived with her two cats in a bed-sit style rest home room opening onto a shared deck where she kept a large collection of potted plants. She had come to the rest home from hospital two years earlier after a stroke, and said the move was her children's idea. Prior to the stroke she had moved house a number of times to be nearer her family, but was now back in the area where she had grown up. She likened the rest home to boarding school, where there were 'all sorts' and you had to 'make an effort to fit in'. She had recovered well from the stroke and was now quite independent, taking daily walks around the streets and entertaining groups of visitors regularly. She was too busy to take part in the rest home activity programme but happy to have the security of staff around and the freedom from daily chores.

*Mary*, 92, had been through hard times and lived in many different places throughout her life. Widowed for fifteen years, she had sold up and moved to a unit soon after her husband's death and lived there for nearly twelve years. After a bout of ill-health she had gone to stay short-term with her only son and his wife in another part of the country. Living in their home had not worked out and it was decided that she should sell her flat to another family member and convert a sleep-out at their home into a granny flat. She found that very lonely and isolated and eventually convinced her son that she wanted to move back to her hometown. She had no wish to return to her flat, where neighbours had died or moved on and she no longer felt safe, and moved straight into the rest home where she had been for six months at the time of our first interview.

*Madge*, 89 had been a rest home resident for nearly three years. Married with three children – two sons and a daughter who she described as 'deaf and dumb' – she had led a busy life of social engagements, service to the community and looking after her own children and anyone else's that needed care. When first her husband and then her older son died, she and her daughter had lived briefly with the younger son until Madge herself became sick and was admitted to hospital and arrangements were made for her daughter to go to a group home in a nearby town. Although she admitted she 'took it hard for a long time', and was clearly a little hurt at how easily her daughter had adapted to the move, she was also quite relieved. From hospital she moved to a flat in the grounds of the local rest home, but after a second hospital admission followed by convalescence in the rest home itself, decided that was where she wanted to stay. Giving up her home was, for Madge, as much about relinquishing her own role as caregiver as it was about accepting care herself. She had never really lived on her own, and did not enjoy the short time she spent in the flat, preferring the company of staff and residents in the home despite its inconveniences.

*Sally*, 86, had had a stroke a few years earlier that left her with some memory problems, but had remained at home with her husband until he had become ill and been admitted to hospital. She had gone into the rest home because 'I had to go somewhere', and he had joined her there from hospital but died soon afterwards. Sally had grown up in a rural area and always enjoyed the outdoors, spending all her spare time in the garden. She was not one to sit down, and enjoyed assisting

other residents (often against the wishes of the staff) and weeding the rest home's extensive gardens.

*Treene*, 88 and the most physically disabled of the participants, had, like a number of the others, had several moves since her husband's death. She had initially moved to be closer to family who then moved on again themselves, and had shifted back to her hometown five years earlier 'to die where I lived'. She had suffered a stroke, which limited her mobility, but had returned to her own home and managed quite well until a further stroke caused her to fall and fracture her hip. She was now wheelchair-bound and unable to get to the toilet without assistance.

*Jim*, the first of the men interviewed, was 87 and had been living in the rest home for eight years. He had never married, and had never owned a home or formed a strong attachment to any one place. Home for him was 'a wife I suppose, but I'm not married', and his fondest memories were of the time he spent in the army. He too had entered the rest home after breaking his hip, but could still walk independently with a walker. He was self-sufficient and used to his own company, but felt the staff and other residents were mostly 'good people'. He lived with his memories and kept a suitcase full of old documents and photographs that he spent his time sorting through.

*Francis*, at 71, was one of two younger men who participated in the study. He had entered the rest home four months earlier under pressure from his doctor because he was not looking after himself, and admitted that things had not been going well at home because 'the memories [of his wife and children] were killing me'. His two cats had come to the rest home with him, and had helped to make the new place feel like home, and he was enjoying more regular meals than he had had at home. He had major health problems, for which he was receiving treatment, and although unwilling to give up the idea of returning home acknowledged that it was unlikely that he would make it.

*Joe*, at 68 the youngest participant, had lived in three different rest homes by the time I met him. Diagnosed with a degenerative neurological disease in his early sixties, his frequent falls and blackouts had been very stressful for his wife. After many trips to hospital, doctors had advised that he needed twenty-four-hour care.

He and his wife had lived in a number of different places, not all of which had felt like home, but just before he became sick they had purchased a rural property that was to be their retirement home. Neither of them knew much about, or had given much thought to, rest homes before that time. His wife had died suddenly a year ago, and at the time of our first interview he was still grieving for her, but appeared reasonably settled and happy. By the second interview however, he was feeling increasingly out of place among people mostly twenty years and a whole generation older than him and was seriously considering going back out to live on his own. He had a computer with internet connection, and had enrolled in a computer course at the local polytechnic.

### *Summary*

In this chapter I have described the research design for this study, positioning myself as a qualitative researcher working from an interpretative perspective, but heavily influenced by my background as a medical doctor working in the field of elderly medicine. I have outlined my reasons for choosing an in-depth interview based study, and the limitations associated with that choice, and have provided a brief overview of how the research was carried out. I have also examined the ethical issues involved in working with elderly rest home residents in this way, before briefly introducing the participants themselves.

In the next chapter I present the results of the study, highlighting some key findings around home and independence.

# Security and independence

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Five-year-old children differ from one another more than newborn babies do because they have lived longer. Seventy-five-year-old people differ from one another even more because they have lived even longer (Isaacs, 1992:6).

Older people are not homogenous. They have different lives and experiences that, depending on the definition of old that is used<sup>14</sup>, can encompass an age span of 30-plus years and at least two, and possibly three distinct generations. The cohort effect is however strong, not just in terms of a common history but also, to some extent at least, in shared beliefs, values and expectations.

In this chapter I summarize the interviews with the eleven participants in the study, outlining both the commonalities and diversity of their experience in relation to the move to residential care and their lives there. I start by highlighting two key findings: firstly, how these residents have been able to make sense of 'home' in new and different situations, and secondly how they have redefined independence in often unexpected ways. I then describe the diverse experiences of rest home transition for these participants, by means of a typological classification with four distinct categories. Each category is introduced with an illustrative quotation from one of the participants and the discussion that follows focuses particularly on how each group has dealt with the experience of 'home' and 'independence' in the rest home setting. I conclude with a closer look at what differentiates the four groups and why, with particular attention to the three key variables of life stage, generation and gender.

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<sup>14</sup> In age-related disability terms usually over 65 years of age.

## Two key themes

### *Reinterpreting home*

The key research question of this study is whether and how older people might adapt their own personal meanings of home to accommodate the move to residential care and the experience of rest home life. What it has shown is that as people age their relationships with the places around them are constantly renegotiated and that 'home' becomes progressively more focussed in on what are seen as its most important elements.

Home may, for example, become a nostalgic memory of family relationships and singalongs round the piano on a Sunday night, pleasant to look back on but no longer valid or relevant to rest home life. Alternatively, it might become a more concrete concept concerned with aspects of comfort and aesthetic appeal, involving nice furniture, good heating with individual controls, a pleasant outlook and places to walk and sit outside. It might equally however come down to emotional warmth, and relationships characterised by friendliness, companionship and care.

For participants in this study, home was commonly associated with friends and 'people you know', and with 'nice feelings' of 'warmth', 'homeliness' and 'being happy'. These were often interwoven with other attributes such as animals (pets), 'nice things' or a garden, and with the concept of a retreat, 'somewhere to come in and shut the door'. For others, home involved freedom and the absence of restrictions, and feelings of ownership and control over a room that was theirs for as long as they wanted or needed it.

For most however, these requirements could be readily adapted to the rest home environment. Many had stayed in, or returned to, the town in which they grew up, where friends could visit and fellow residents included those they had grown up and gone to school with and others they had known through friends or neighbours. Others had taken treasured pets to the rest home with them, or adopted new ones, and had established small gardens or managed to 'still go out pulling weeds' even if 'the men here reckon that I'm not allowed to garden'. While they did not 'own' their rooms, they or their families had often chosen them specifically and they had all, to varying degrees, personalised them with their own furniture, photographs and treasured items, as well as with fridges, curtains, shelves and computers. Most had

their own private telephones and several had locks on their doors or signs they could put on the door requesting privacy.

While most had been happy in their previous residence, none expressed the strong attachment to place described in earlier work (Fogel, 1992; Moore, 2000; Rowles, 1987). Indeed reference to home as a repository of memories was often in the negative.

*there were too many memories [at home]...But when you think about it, the memories were killing me.*

Francis

More positive memories endured in the form of photographs, mementoes and treasured items and the stories they generated,

*The only precious one is that jug, it was my grandmother's, over a 100 years old that is. What else? That painting on that dish was a friend of mine who went over to Australia to live and she died, and she hand-painted that cake dish there. And the shaving mug back in that corner was my eldest son's. He won bike riding... Well, little bits like that... as I say each little thing is a memory to me.*

Madge

but also in the communities to which many had returned in later life and the people they had grown up with.

*of course I had my sister-in-law here... and friends... a lot of friends, some I even went to school with, they're in here... So I didn't feel out in the big world on my own.*

Gill

It seemed, in fact, to be affective ties to family and community rather than to home itself that provided the meaning-making resources these elderly people needed to make sense of age-related losses of spouse and/or children, health and physical abilities.

What was also apparent was that the majority of these people had had a number of residences throughout their lives, with moves in later life particularly common. None expressed particularly strong attachment or ties of identity to their previous home. It appeared, in fact, that while a subtle interweaving of self and place may evolve through long residence in one place, it might equally be created out of an accumulation of life experiences in a number of different residences but within the social context of home. Almost all referred in some way to home being 'what you make it' and to making a home requiring a certain amount of effort and commitment.

In the end it seemed to be an atmosphere of warmth and affection, friendly staff who treated residents with respect, and the companionship of other like-minded people that, for most participants, contributed the most to making the rest home environment truly homelike.

### *Renegotiating independence*

Fear of losing one's independence seems to be an almost universal concern of older people facing ill-health and impending disability. What is apparent from this study however is that independence can be looked at in a number of different ways. It is not only about making one's own decisions, but also about not wanting to be under an obligation to others. Sixsmith (1986) makes the point that there is not a simple dichotomy between independence and dependence, but rather a spectrum encompassing three dimensions of independence – physical independence, autonomy and reciprocity. For the participants in this study it is the latter, reciprocity, which many thought about when they made the decision to enter residential care.

*Well, you can't live with your family coming and doing everything can you? Well, I felt I couldn't.*

Madge

For many of the participants in this study, staying at home meant relying on family, friends or neighbours, and the generosity and goodwill of paid caregivers, for practical assistance and support. As a result, the decision to enter a rest home became a way of enhancing rather than losing independence. Entering the rest home effectively freed them of an obligation they were unable to repay. It also enabled them to regain some control of their lives, by re-establishing a relationship of reciprocity where, either directly or indirectly, they were paying for the assistance they received. Almost all made at least some mention of the option of living with family and the fact that their own children had offered and were willing to have them. Most however, had declined the offer because 'they're busy' and 'have their own lives to live', or because 'I don't think it's right'. Becoming 'a nuisance', a 'burden', or even 'a worry', for their children was a major concern, and they were willing to accept a degree of inconvenience and restriction to prevent that.

What this suggests, and what many participants were able to express, is that the idea of 'maintaining independence' for older people is not as straight-forward as it

sounds. Indeed for those facing ill-health and disability, it is a matter of prioritisation, negotiation and compromise.

*They [rest home staff] told me I could do as I like, and you can't do as you like. ...[but] if you're living with your husband and what not you can't always do as you like either.*  
Beryl

## Four kinds of rest home resident

	<i>Reinterpreting Home</i>	<i>Renegotiating independence</i>
<i>The deserving resident</i> (Beryl)	<i>The last new home</i>	<i>Making an effort</i>
<i>The in-need resident</i> (Gill, Madge, Gladys, Jim)	<i>This'll do me</i>	<i>Not being a bother</i>
<i>The resigned resident</i> (Mary, Sally, Joan, Treene)	<i>Where else would I live?</i>	<i>You can't rely on family</i>
<i>The reluctant resident</i> (Joe, Francis)	<i>A home away from home</i>	<i>My own person</i>

**Figure 1: A typology of rest home residents**

For each of the participants in this study there was a unique biography and set of circumstances that had led to the move to a rest home. Although rest home had generally not been the only option, it did address a particular set of needs and had not been chosen lightly. What this study shows however is that while each participant's experience was different, they did have sufficient similarities to be loosely categorised into four quite distinct groups: those deserving of and ready for a rest home: those 'sick' and in need of rest home care, those resigned to rest home living; and those reluctant to accept rest home care.

## **1. The deserving resident**

*I fell and I broke both my wrists... I went into the hospital then, and then I came here because I couldn't handle things at home you see. And I was here three weeks and then I got a feeling of the place you see. So when I knew I had to come into a home, well, it was my own decision to come to the home... Because I only had a fracture of the bone of the spine... My daughter was sitting on the floor beside me and I moved, I think I put it out again, I said 'Oh I'm going into that home' I said 'you can sell this place'...*

*...I had quite a few people coming in, but you know nearly all my friends have died... So we're just on our own. You feel as though you get to a stage that no one else is alive. Never mind, I don't let it get me down...*

*...I used to do a lot of knitting and jigsaws, and ah, I always had something on the go, but ah, I can't do it now. I'm getting really annoyed now because I sit in this chair and I go to sleep. And I think to myself well I suppose at my age I'm allowed to... But I can't believe I'm 97 really...but I don't feel it altogether except when I'm walking and then I can't be bothered.*

Beryl

For Beryl, the time had come to give up the 'struggle' of living independently in the community and make the decision to move to residential care. Although perhaps capable of continuing at home with support, she had begun to feel tired, frail and deserving of care. She had reached an age when her husband was long dead and friends, neighbours and even one of her children had also died, leaving her increasingly alone and isolated in the community. For her, the rest home was a place where she could quite happily live out the end of her life in peace and comfort. She acknowledged that there were things she would like to do but couldn't, and was frustrated by, but realistic about, her lack of strength and energy.

### ***Last new home***

Her own space, to which she could retreat for rest or some time to be alone and out of view, was important to Beryl, and it was her room rather than the rest home as a whole that she now identified as home. With her world effectively narrowed down to the rest home and its immediate environs, a sense of ownership and security of tenure over a small part of it was important. What she actually expressed as of primary importance in terms of constituting a home however, was things like good relationships, 'being happy' and 'all getting on together'.

### ***Making an effort***

For Beryl, small things such as being able to 'do for yourself' by having 'a good wash down' at the basin, making the bed or doing a little dusting were important ways of retaining her independence. Having consciously chosen to give up the

struggle of life in the community, for her own benefit rather than anyone else's, she felt no threat to her autonomy and accepted that, while rest home life was perhaps 'a wee bit restricted' and one had to 'work in with them' and 'learn to wait', it was also comfortable and convenient. She acknowledged the goodwill of most of the staff and the need to 'make an effort if you want to be happy'.

## **2. The in-need resident**

*I thought I was quite good in my own home, and then all of a sudden I kept having falls...had two heart attacks...the Matron talked and that and she said 'Well, I think you'd better stay here for a while', and then they said 'Don't you think you'd be better staying here'...because they understood what my health was...*

*...I've got so used to being here and you feel more secure. If I was home, say you went to bed at night and something happened, well you sort of put off ringing a bell or anything and you think, well, here they pop in several times a night – the door often opens and, you know, you're awake. I say 'yes I'm awake', they say 'are you alright?' You know, well it gives you great confidence you know....*

*...It's all right if you can do for yourself, but when it comes to the point, um, there's quite a lot of danger attached to it. If your hands go you could scald yourself, you know, you could fall, and all these things. Well, you know, what are you to think. It's far safer to be where you've got company and help...*

*...And I think it's wise – some don't like to make the decision and sort of fight against it but I think no, if you've had a warning with your health, well its best to sort of think, and think sensible about it....*

Gill

For this group, moving to residential care was the 'sensible' thing to do in the face of recurrent ill-health. By accepting the opinions of others (generally their doctor or the hospital) that they were no longer safe or capable of being alone, they had been able to abrogate responsibility for the decision and to slide easily into a new and more dependent life. They considered themselves sick rather than frail, and so legitimate recipients of the care and supervision of trained staff, and entered into the rest home life with enthusiasm, often criticising other residents who made less of an effort to be happy. Life for this group had moved on to a new stage, with different needs, responsibilities and relationships, and they had moved on with it.

*I think I've got a new life. I mean, I don't feel I'm sitting here waiting for God. I'm hoping that I'm going to be able to keep going and do things.*

Madge

*It is a different way of living... its hard to explain really, but to me it's a new life, because I am doing a lot more things now... I've done a lot more here than I even started to do at home because I was losing interest.*

Gladys

### ***This'll do me***

For this group home was about the past, happy memories, and roles no longer relevant or important in the rest home context. These included family roles such as husband, wife or mother, and social roles such as driver, gardener, hostess, or pillar of the community. Although the rest home might now have become their home, it was a completely different kind of home, measured by different criteria and reflecting different needs and values.

*What really makes the home is the friendship and knowing that you don't have to do anything. Because you want to do it you know, and you try to do it, but you can't.*

Madge

The most significant change in role had generally been from caregiver to recipient of care. For some this meant 'having everything done for me', while for others it took the form of hands-on nursing care and supervision, and it was this group who were more inclined to have recast themselves as 'patients' unable to manage their own health needs.

### ***Not being a bother***

Participants in this group were also less concerned with maintaining 'independence' than with 'not being a bother'. They were often quite happy to be 'spoilt' by rest home caregivers, seeing it as a positive rather than a negative feature and a reward for years of caring for others. In relation to family however, independence was very much about self-sacrifice and not being a burden on children with their own lives to live. Even for family to 'have the worry of me' would be a burden, and they were quite ready to accept the need for rest home care in order to avoid it.

*I thought to myself, I'll get out of this, because they want to go and do things that I couldn't do, and I felt as if they felt 'oh grandma's here we can't go', you know, 'we can't do it'. That's why I got out. Well it was a big part of it.*

Madge

*We all get on so well I would hate to spoil a friendship... I don't say that it wouldn't work [living with family], but I don't think I'd take the chance*

Gladys

*I didn't fight against it...because you've got your family to consider to a certain extent...and they are busy...*

Gill

Good manners and tolerance seemed to play an important part in their identity and self-esteem, and they prided themselves on being model residents.

*They mightn't like it [in the rest home], and complain and that. But um, when you've been brought up the way I have, well those sort of things don't worry me you know.*  
Gill

### **3. The resigned resident**

*I wasn't well enough to go around the rest homes, so [son] went around... he said he wanted me to come, and I said 'no I'll take your word for it'. And ah, I came here and it was all very pleasant...*

*...Well I suppose, I thought about it, and it was what I expected [living here]...because I couldn't think of anything different to go by...*

*...There's no privacy in a home. You haven't got a lock on your door, but I don't think it would make any difference...it means you've to keep getting up to open it... I've had to get used to it – because you couldn't do otherwise... Some knock and some don't... What's the good of it bothering me? What do I do about it?*

Mary

For this group, the decision to enter residential care had been made with reluctance but also resignation. This may have been because of physical disability and the need for hands-on assistance with basic tasks such as mobility and toileting, the death of a spouse without whose presence home was simply not an option, or because of social circumstances that had left them essentially homeless. While very conscious of the restrictions and irritations of rest home life, they had made their decision and were going to make the best of it. Generally content, if not exactly happy, they were able to exert their independence in small ways and continue with life in rather straightened circumstances.

#### ***Where else would I live?***

This group, like the last, were unsure about whether they could really call the rest home 'home' but equally sure that it was the only home they currently had. Home for them was about 'just being happy', and as far as furniture and belongings were concerned they were content to have a few treasures and mementos but were otherwise 'past that now'. Although in many ways the most critical of the rest home's restrictions and routines, they were also the most appreciative of the respect and companionship to be found there, and were willing to acknowledge that rest home life was better than they had expected and that they were 'much better off'.

*Yeah not home, not like home, but I thought you can put up with anything if you like and they were nice...*

Sally

### **You can't rely on family**

This was a group who had made their own arrangements for care, both because they felt they couldn't depend on practical assistance from family (who perhaps lived at some distance or in circumstances that limited their input) and because they would not want to anyway.

*I couldn't bear to rely on them – it would be dreadful.*

Joan

*It's better than being...pushing yourself onto your family.*

Sally

Perhaps more than the other groups, they were realistic and pragmatic about their situation and did not expect an ideal world. They tolerated 'being rounded up like children' because 'the others are here and they say it to everyone', but stood their ground and retained a degree of independence and control over things that mattered to them.

*The first one that showered me was a man...I nearly died. He turned around and he said 'come on Mary, get in the shower'. And I didn't have any say in it. And the first time I've been showered by anybody and it to be a man. Could you imagine it? But he was very nice. But I stopped that. I put my foot down on that. I didn't want a man showering me.... I said to them I don't want a man showering me. So they did do something about it. So now I get a variety of girls.*

Mary

### **4. The reluctant resident**

*So they said well it would probably be best for me to come into a rest home, ah, so – my wife was still alive at the time – so I went into a rest home... I was quite devastated...Yeah. I thought you know, a rest home was for old people...but they thought it would be better for me to have 24 hour, 7 day... Well it was our decision, we discussed it and, it was a reluctant decision on both of our parts...*

*...I'm not sort of safe to be on my own all the time. Most things I can do myself you know. I'm pretty self-sufficient here. But there are things which I would be very wary about doing – cooking and things like that I would be pretty wary about...*

*...I'm not worried about growing old. Ah, it's just I think ah, I'm just not ready for it basically... If I, you know if things had maybe have been different, maybe I would have risked being at home... but you know, but then again, as the doctor said, it was taking its toll on [wife].*

Joe

This group were reluctant rest home residents who continued to hanker for what they had left behind. Although they too had entered the rest home for 'medical reasons', they had resisted the expert advice as long as they could and had remained at home through long or recurring periods of difficulty and concern.

*They didn't like how I lived, the way I wanted to live...It took them 12 months to get me to come here... I was more or less forced.*  
Francis

In the rest home they tended to keep to their rooms, with doors shut and in some cases locked, and felt out of place among people generally older than themselves and with different attitudes and needs. They related better to staff than to other residents (as friends or at least sparring partners) but did not like being told what to do.

*I still claim my independence. I don't allow anybody to tell me what to do...  
Do this, do that, do the next thing. And I says I'm my own thing. I says if you don't like it just tell me and I'll bugger off home again.*  
Francis

Although they tended to get out of the rest home environment as often as they could, they felt as if their lives had stopped but were not yet ready to 'just sit back and let the world pass them by'.

### ***A home away from home***

Home, for these people, was much more about ownership and control than it had been for other groups. They were very unhappy about being moved, even to a seemingly more suitable room, and liked to be able to 'come in and shut the door'.

*the room I went to was bigger, and it had its own toilet and shower and all that, so there was that, but it was still the fact that I have moved from a room I thought was mine into another room, and then I ... I always sort of had that little niggly feeling in the back of my head 'am I going to get shifted again?' I never really felt secure.*  
Joe

They admitted to being 'private' and 'possessive' and to 'needing control over my things' and liked to be able to lock their rooms when they went out.

At the same time, however, home was also about family and belonging, and about individual attention from staff members and knowing that their needs were being put first. They had had to learn to be tolerant of, and to make allowances for, others who did not measure up to their 'standards of communication' and to adjust to a more communal style of living.

### ***My own person***

It was autonomy that dominated discussions of independence with this group, who were adamant that 'I'm my own person' and did not like being told what to do.

*All I want to do is just be left alone and just get on with my life, and don't want to have people just sticking their nose in and you know... and minding my business for me.*  
Joe

They themselves, however, were not backward at making suggestions to management and expected to be listened to. They were vocal about perceived infringement of their rights and were very aware of issues around institutionalisation and independence.

*I went to a rest home up in [town]... and, I hated it..., it was too institutionalised for a starter., I referred to it as Alcatraz, that's how I felt, as though I was a prisoner... It was a new place and, you know, everything was done by the book sort of thing... They just did their job. They were there to do a job and that was it. They were thorough and they, you know, they looked after you, I can't complain about that... when I was up there this night I decided I wanted to come in [to town for a drink with friends] so I rang a taxi to come and pick me up, and the manager rang the taxi and stopped them from coming to pick me up. And we had a ding-dong go about it, and I said she was depriving me of my rights...*  
Joe

This group were significantly younger than the other participants in the study. They complained that they felt out of place in an environment where they were invariably 'the baby here' and where there was 'no-one I can communicate with apart from the staff'. In many ways too, although their own health was invariably not good, they were not yet ready to confront their mortality and found the continual presence of death in the rest home environment unsettling.

*Getting back to mates, there was two people I did have quite close relationships, one was an old lady, she had a... she was in a wheelchair, and ah, she and I used to get on quite well. We became very very close, and very friendly. She used to get the evening paper and when she'd finished with it, she used to get the girls to give it to me and that sort of thing. And ah, and then there was another chap who was ex-Army. I didn't know him in the Army, but we had a...he was blind, and you know we sort of had a bit of a relationship. But they both passed away, and so, yeah. That's one of the things I find a bit difficult handling.*  
Joe

## Life stage, generation and gender

Having identified four groups of rest home residents and described how they differ in terms of the key themes of home and independence, the next step in making sense of this data is to look more closely at why they might differ, and to suggest some possible explanations for these differences.

The first observation is that the four groups appear to fall into an intuitive order, from the deserving (those very much at the end of their lives) to the reluctant (not yet at

that stage and not wanting to be). Between the two are the in-need and the resigned, both ready to acknowledge the proximity of the end of life but not to the extent of the first group. While those at each end seem to divide quite easily by age, that is not so clearly the case either with or between the other two groups. Indeed it seems that it is 'life stage' and generational cohort rather than age per se that is the more important factor in determining how individual participants have perceived and experienced the move to residential care.

The majority of participants in this study, and indeed the majority of the residents of rest homes in this country, were over the age of 85. As such they had shared certain important early life experiences, attitudes and beliefs. What they also shared, however, was a particular stage in the life course. That stage was characterised by widowhood, a rapidly shrinking support network, declining physical strength and endurance, and an increasing prevalence of health problems and disability. For those people at least, the move to rest home seems to have been readily accepted as simply the logical consequence of surviving so long.

*I'm 91, it had to come sooner or later.*  
Gill

Well past their three-score-years-and-ten, they were not only finding the simple tasks of daily life an increasing struggle, but were also increasingly aware of their own mortality. This was perhaps in part because of the unavoidable presence of death and dying in the rest home environment, but also because of their own increasing frailty.

*I have been hoping I will pass on here. Because where else am I going to pass on?*  
Gladys

They had, it seemed, reached a stage in life at which 'you feel as though no one else is alive' and when both home and independence were about balancing different, and often opposing, needs.

Interwoven with both explicit and implied life stage references, there was a striking pragmatism, possibly related to age and experience but also perhaps to gender and generational effects. With a median age of 87, the participants in this study were predominantly the old old, members of a generation who had lived through the depression of the 1930s, and married and raised their families during and immediately after the Second World War. As a group they had learned to be hard-working, to save for luxuries and to 'make do'. Almost exclusively female, they had

spent most of their lives caring for others and few had ever lived alone except as widows. Theirs too, had been a generation for whom cooperation and lack of complaint were seen as constituting politeness and good manners, and for whom membership of any community was expected to involve a certain amount of give and take. They were generally tolerant of others, and were willing to make allowances for other residents and even for staff who were clearly 'doing their best'.

As women, they had been brought up to think of the needs of others first, and self-sacrifice and consideration of others played a significant part in their identities. This was important for many in influencing their decision to move to a rest home, but also in how they responded to the rest home environment. While their apparent passivity and acceptance of their lot could be interpreted as a reflection of acquiescence or 'institutionalisation', it might equally reflect simply being 'the kind of person that does not ask life to be perfect but only acceptable and liveable' (Gubrium, 1993:58).

It was a younger generation, more accustomed to the rights and interests of the individual, and perhaps to the prospect of living alone, that made up the group of reluctant residents. Not quite baby-boomers, they had none-the-less entered the workforce and raised their families through times of plentiful employment and relative prosperity and had been looking forward to the rewards of retirement. Interestingly this group of two were both men who, it could be said, had inhabited a different social world to their female counterparts. More used perhaps to expressing their needs and wishes, and to being listened to, they were at the same time not particularly skilled at doing for themselves and so faced a somewhat different reality in terms of support options. Less tolerant and accepting than the older women, they tended to be more aware of and more irritated by the inconveniences and restrictions of rest home life, and less willing to make the best of them.

### *Summary*

In this chapter, I have encapsulated the experience of the eleven participants in this study in making a rest home their home. In doing that I have identified two key themes (meanings of home and independence) and four different approaches to rest home life, and how a combination of life stage, gender and generation might go some way towards explaining them. I have shown that for the participants in this study home is a complex and evolving concept that is rarely associated with a specific residence and can indeed be transferred to a rest home setting. I have also

introduced two of the key findings of this study. The first is that maintaining 'independence' is not as straightforward as it seems and that moving to a rest home can, for some people, be a way of achieving it. The second is that how people view rest homes varies according to age, life stage and generation.

In the next chapter I discuss those findings in the context of existing knowledge about home and rest homes, and against the background of ageing in place policy and the normative assumptions about ageing and residential care on which it is based. I also introduce two new issues that have come out of the interview data in relation to age and life stage – frailty and end of life issues.

## Place, meaning and identity

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Old age is having been born a long time ago. It is also having lived for a long time. These are not the same. Having been born a long time ago means bearing the features of a cohort. Having lived for a long time means sharing the experiences of a cohort (Isaacs, 1992:5).

In the previous chapter I presented the key findings from my interviews with rest home residents. In this chapter I discuss those findings and the issues they raise in relation to what is already known about meanings of home in later life and to dominant policy discourses about ageing and residential care. I discuss the ways in which both home and independence are renegotiated by older people confronting frailty, ill-health and disability at the end of their lives, and how conflicting beliefs about living, dying and growing old can make the promotion of community care for all older people particularly problematic.

### The rich tapestry of life (and homes)

Much of the existing literature on meanings of home has focussed on creating more or less definitive lists of the features which make a place a home (Fogel, 1992; Hammer, 1999; Higgins, 1989; Kenyon, 1999; Sixsmith, 1986; Somerville 1997). What this study has shown however is that 'home' is a complex and, perhaps more importantly, dynamic concept, which changes over time at both a biographical, generational and societal level.

For most of the participants in this study, the motivation to leave home and enter residential care was indeed multifaceted and more complicated than a simple push-pull dichotomy (Wahl and Weisman, 2003). Although they had probably all been among those older people who 'generally prefer to remain in their own homes' (Koopman-Boyden, 1988 quoted in Richmond et al 1995:47), when actually faced with failing health and increasing dependence they had reconsidered their priorities and balanced a number of competing factors. They 'knew' that leaving home meant

giving up their 'independence'. What had to be balanced against that, however, was concern about being dependent on family and friends for practical assistance and support, and about being a 'burden' and a 'worry' to their children, particularly those living some distance away. In such circumstances it was residential care that could give them the greatest degree of 'independence'. Similarly, for those who had had recurrent health problems, home was no longer a locus of control (Wilcocks et al, 1987) or the place where their personal competence was maximised (Rowles, 1987). For these participants, they were able to feel more confident and secure in an environment where they knew skilled care was close at hand.

### *Accommodating frailty*

Frailty, suggests Kaufman (1994:48), is 'one of those complex terms – like independence, life satisfaction and continuity – with multiple and slippery meanings'. One way in which it can be understood is as a rather precarious state of being that is both a parameter of risk for institutionalisation and a medical/social service problem. Another is as a quality and adaptational process which forces older people, their families and care providers to reconsider the meaning of independence and dependence in advanced old age (ibid:56). It is that 'precarious state of being' – of reduced agility, strength, energy and activity tolerance, frequently exacerbated by reduced income, chronic illness and declining health – that must underpin any discussion of residential options for older people.

Rowles (1987:342) argues that, despite an almost universal reluctance to leave their current home, older people themselves are well aware of the increasing environmental vulnerability that comes with advancing age. As they gradually come to realise that their physical frailty and social and economic circumstances necessitate a change of residence, they will often have begun to weigh up their options well before their family or doctor have become involved in the decision or even voiced concerns. Such a change in residence will seldom be a discrete event. For many, including most of the participants in this study, it will involve a series of moves over time.

Rowles also suggests that, in the continuum of ageing, it is the oldest and most frail who are least able to 'actively transform a new setting into a place that can be called home' and more likely to view the move to residential care 'pessimistically and with foreboding' (ibid:346). What this study has shown however is almost the

reverse. Of the four groups identified in the typological classification, it was in fact the 'deserving' residents, the oldest and most frail in the study, who had most successfully made the transition from their previous dwelling to a new 'home' within the rest home environment. Those at the other end of the continuum, the 'reluctant' residents, were the ones who viewed the move most pessimistically and struggled most with the notion of the rest home as 'home'. For the 'in-need' and the 'resigned', the circumstances surrounding their relocation to rest home were seemingly beyond their control, and while some had indeed created a new home others had effectively left home behind as a happy memory and moved on to a new and different kind of life in residential care.

### *Home and identity*

While acknowledging the reality of frailty in advanced old age, Rowles (1993) and others (Dupuis and Thorns, 1998; Rowles et al 2004) have, at the same time, continued to emphasise the apparent importance of continuity of residence in one's own home to the preservation of self and identity, particularly for older people.

Although not exclusively an aging related phenomenon, our ability to develop and maintain a sense of attachment to place, to sustain a sense of physical, social and autobiographical insideness, and to organize the space within our home in a manner consistent with our needs and personality, may, as we grow older, become increasingly significant in preserving a sense of identity and continuity amidst a changing world. (Rowles, 1993:66)

It is this dichotomy – of home as the seat of identity and continuing independence, and its inverse the loss of self and identity that accompanies 'institutionalisation' – that has become a critical underpinning of the ageing in place imperative (Rowles et al 2004;175).

Kaufman (2000:103) suggests however, that the construction of a coherent sense of self is an ongoing process, and that we are all constantly reinterpreting our pasts and reshaping our identities. Whereas the popular perception is of ageing individuals struggling to maintain a positive self-image in the face of declining health, social status, power and mobility, Kaufman's observation is that elderly individuals do not define themselves as being old. Although they know they are old, and are aware of the limits imposed by old age (and live with them), they think of and describe themselves in terms of themes that have evolved throughout their lives. It

is these themes that can provide the continuity of identity that will carry them through their later years (ibid:104).

For the older women in this study in particular, for whom self-sacrifice and consideration of others played a significant part in their identities, what seemed to have been of most importance in preserving a unified sense of self was being able to help others. This may have involved helping their family by moving to the rest home and letting them get on with their lives, helping the rest home staff by not holding them up or being difficult, or helping other residents by assisting them when they could. Equally important for many was being 'sensible', considerate and 'well brought up', while for others it was being 'cheerful' and well thought of and perhaps even a little better than the rest.

*I'm usually ready for the girls because I don't like holding them up. So I go down there merrily... I love the nurses, I get on well with all of them.*

Gladys

*They're lovely [the staff] all of them. In fact, they love to get down here to me.*

Madge

Independence was another common theme, but often 'reinterpreted' to fit changing circumstances. For some simply wanting or trying to be independent seemed to be enough.

*Because you want to do it you know...and you try to do it but you can't.*

Madge

For others a degree of control remained important and they were able to achieve it in a variety of ways.

*At the present moment I rule my own life... I attend to all my own bank accounts...It's important to me because it makes me feel that I'm not like the rest of them.*

Mary

As a group though, these older women did not appear to have a strong sense of the self as an individual. Consequently they could and did continue to describe themselves as independent and caring, even in the rest home setting.

### *Home-like environments*

Although the rest homes visited in this study were varied in size, appearance, location and facilities, each of the participants had developed at least some degree

of positive attachment to their particular environment, sometimes surprising both themselves and the people involved in their care.

*When I came here they were taking me around showing me rest homes...and I says "this is going to be funny, they'll never be able to find a home for me"...and this was the second home I came to...and they said "right we'll go and have another look at another one." I said "don't worry." "Why?" I said "this one will do me." I liked it right from the start.*  
Francis

Some had history with the particular facility (generally the religious and welfare or community trust homes) while others had chosen their rest home carefully and took pride in that choice, recommending it enthusiastically to friends and other potential residents with whom they came in contact. Ultimately most were able to talk about the concept of home in relation to the rest home in which they lived. The definitions they used, however, tended to focus less on a particular place or set of attributes than on more emotional concepts such as happiness, comfort and companionship, that were both contingent and transferable.

Higgins (1989) is one of the few researchers to have directly addressed the issue of 'homeliness' in relation to institutional care and the social policy that surrounds it. Writing from a British perspective, she looked at how policy-makers and planners attempt to artificially re-create domestic environments in institutional settings by contracts and service specifications which include explicit requirements around those elements considered to constitute the core of 'home' life such as privacy, choice, autonomy, individuality, occupation and risk-taking. What comes through most strongly in British residential care contracts and policy documents, is the assumption that home is, above all, a private place where individual's have some control over who enters their personal space and on what basis (Higgins, 1989:164). What is also assumed is that those living at home will have some sort of occupation that is purposeful rather than simply occupying time, and some degree of choice about, for example, what and when to eat, when to sleep and who to spend time with. They will also have the opportunity to express their individuality, take risks and 'behave eccentrically' 'without the threat of sanctions or abuse' (Higgins, 1989:164).

New Zealand residential care contracts are not dissimilar. They address such issues by requiring providers to 'provide a homelike and safe environment for each subsidised resident' while at the same time promoting their 'independence' and 'quality of life'. Service specifications require that providers 'centrally involve residents in decisions that affect their lives', actively encourage them to 'maximise

their 'potential for self help and involvement in the wider community' and ensure that their needs are met 'in a caring, comfortable, safe environment that maximises individuality, privacy and health potential' (MOH, 2005:37). They stipulate that facilities must provide, for each resident, 'a written and implemented social and recreational programme of activities planned to meet the identified interests, stated preferences and level of ability/disability of the resident' and that that programme must 'include group and individual activities and involvement with the wider community' (ibid).

For most of the participants in this study such contractual obligations seemed to have little relevance. Unlike in the UK where, at the time of Higgins work anyway, shared rooms were commonplace and many residential care homes were still very hospital-like in design and décor, all the participants in this study had their own rooms, some with ensuite bathrooms, and access to a choice of lounges and sitting areas. As a result, privacy was not a major issue and most were quite comfortable with the degree of control they had over their private space. Keeping occupied was perhaps more of an issue, but the majority had in fact established their own habits and routines around group and community activities. Many too had found purposeful occupation in small domestic tasks or in assisting other residents or staff. Beryl, for example, dusted her room while Gladys sewed on buttons and name tags for other residents and Joe helped out on occasion by folding washing or setting the tables for meals.

Although there were plenty of complaints about food<sup>15</sup>, most participants were quite happy with the routine of fixed menus and mealtimes, and would probably have found it much less 'homelike' to be offered restaurant-type flexibility and choice. They were all offered alternatives to food they particularly disliked or couldn't eat, but otherwise were content with fare that, although not quite like what they were used to at home, had become familiar and predictable. They had all had the option of breakfast in bed, although some chose to go to the dining room, and Francis had managed to negotiate breakfast in his room when he was ready

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<sup>15</sup> Savishinsky (1995:100) observes that people will often displace their general discontent with life into specific complaints, particularly about food, and that care should be taken in interpreting such comments.

*I get myself up... I'm the last one to have breakfast, because everybody has breakfast at 7 o'clock, and I said "I'm not getting up at 7 o'clock for breakfast"... not for porridge and toast... They bring it here when they see me on my feet.*  
Francis

Several also chose to have evening meals in their room. While the more independent could choose when they wished to get up and dressed, or indeed to stay in bed all day on occasion, almost all had set shower times which had been agreed by negotiation.

Behaving eccentrically, and certainly risk-taking, were much less acceptable – although Francis again seemed to have negotiated a certain degree of tolerance of his eccentricity. Treene, who spent most of her day in a wheelchair, was toileted by staff but often 'tempted to try to do it myself'. She didn't however, because 'it would take too much paperwork for the girls here if I fell'.

What these findings support then is Cutchin's (2003:1083) concept of the value of 'space-time structure', rather than an over-abundance of flexibility and choice, in providing comfort and familiarity for rest home residents. Not only, it seems, can fixed dining times and seating arrangements be important markers of each day's space-time coordination, but other place-centred activities can help create meaning and purpose. Activities centred round expectation, obligation and responsibility (as a role or 'job', 'something to look forward to', 'being expected', or simply pleasing others who have 'gone to a lot of trouble') can also play an important role in creating and sustaining peer relationships. Likewise, compassion, camaraderie and cooperation can serve, at least in part, as a substitute for family and community by creating an overall sense of intimacy and belonging (ibid:1084).

### *Choosing not to be alone*

While the general tendency of older people to remain in place might appear to be well established (Fogel, 1992:15), individuals differ greatly in their willingness to move and in the specific reasons for their attachments to their homes. Although most of the participants in this study had entered rest home because of increasing frailty, a reluctance to be dependent on family, or because they felt they were 'sick' and in need of skilled care, there were a number for whom simply not wanting to live alone was a significant factor.

Madge, who had lived alone only briefly and found it

*horrible, especially when it came evening, I used to hate the evenings,*  
Madge

was equally reluctant to be a bother to her family and had chosen instead to move to her local rest home. Sally, similarly, had been living with her husband until he became ill but then 'had to go somewhere'. She too felt she did not want to 'worry' her family by 'pushing myself onto them', and was happy to be offered the option of residential care. Both were of a generation for whom living alone, particularly for women, would have been an option of last resort and they expected to have to make some allowances in order to find a suitable alternative.

The idyllic images of domesticity that underlie the ageing in place policies tend to ignore, or at least downplay, issues such as loneliness and isolation and the more negative realities of some people's lives. Although the majority of the participants in this study did have loving families who would have continued to support them in their own homes, a few, such as Jim, did not. For him, and others like him, a rest home may in fact offer a higher degree of physical comfort and personal attention than in any previous residence. For others too, who for various reasons were alone at the end of their lives, a secure home and nurturing family-like relations were gained again rather than lost in a residential care facility.

What the results of this study indicate is that, contrary to the assumptions of policy-makers and regulating authorities, rest homes do not have to re-create all the features of 'home' for residents to be content. For most of the participants, what they were looking for in a rest home, and what living alone in the community had been unable to provide, was a 'safe' and secure environment as much as a 'homelike' one, and that is what they found. For many, however, what they also found was a new, if somewhat different, home in which they had come to feel they belonged. Although this new home might be somewhat more restrictive in terms of privacy, choice and risk-taking, they were willing and able to compromise. They seemed too, to understand quite well the value of routine and programmed activities in the creation and maintenance of a caring community. In this last new home, all had been faced with the challenge of changing circumstances and the need to re-integrate with place, and most had done so very successfully.

## Conflicting beliefs

Home is a complex and dynamic concept that transcends place, and the relationship between one's home and one's identity is multifaceted and forged within the constraints of culture norms and social ideals. For those responsible for social policy affecting older people, but not yet facing the reality of advancing age themselves, those norms and ideals might include, for example, the contemporary ideal of unlimited independence and choice, or indeed the idealisation of ageing in the bosom of a caring, supportive family and community all ready and waiting to plug the gaps inevitably left by formal in-home support services. For the elderly themselves however, and for the participants in this study, their experience may well have differed from those ideals. What others might see as independent living in the community may have turned out to involve an unacceptable level of *dependence* on family and friends, and most participants had experienced the constraints and limitations of community care.

*I had a nurse coming in at half past eight in the morning, and I had to get up and open the door for her. And she got the breakfast and I had that, and when I had a shower she came and had to shower me, and then she could do the...I had a washing machine, I had everything, and um, getting ready for her to hang, but when I hung it at home on the line she hung I couldn't get it down afterwards... And then she would go at half past 11, I'd be sitting having my dinner at half past 11, and she'd have saucepans washed up and everything, just my plates. And then nobody came in til about six o'clock at night... Well I had all that time on my own... and all night on my own. You see that's...But I had enough of it, and I wanted to...and she'd come in at 5 o'clock and get my tea, and then she was gone at 6. Well, it was winter and I wanted a hot water bottle in. So that was too early to put it in my bed so I had to call the neighbour to come and get it, do it for me. Well that wasn't nice...*

Beryl

*Well I suppose it could be up to a point [more independent to be living at home] but then you've still got to rely on your home help and they've got limited time to... say they come three times a day well your times limited with them there and you've got to manage otherwise*

Gill

### *Health and safety*

The medicalization of ageing is well entrenched in our collective culture, as evidenced in the language we use. In a recent conversation about rest homes on Radio New Zealand<sup>16</sup>, both the Ministry of Health's Deputy Director-General of Clinical Services Colin Feek and presenter Eva Radich referred repeatedly to rest homes 'treating' all sorts of 'patients'. While they would almost certainly have used

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<sup>16</sup> Nine to Noon, 11/4/06

terms such as 'supporting' or even 'caring' for 'clients' had the conversation been about younger people with disabilities, they clearly accepted that the group of people they were talking about were 'sick' and in need of medical/nursing care.

What is evident from this study is that many of the participants shared similar beliefs. When asked why they had moved to the rest home, the most common response was 'because of my health'. Indeed the majority had in fact come directly from hospital following an acute illness. References to themselves and fellow residents as 'patients', to 'Matron' and the 'trained staff', and to being 'not well enough' to manage independently were common, particularly among the group of 'in-need' residents. For them, 'home' as they had previously known it was no longer an option because they were 'sick' and, by definition, unable to manage without the constant supervision of trained staff.

*I've not been a fit person physically, and I was in hospital several times actually, and they decided that um... someone decided that I should be here because I couldn't look after myself properly... but um, there is a time when you can't look after yourself, and they, whoever is responsible, decided I could stay here... They knew that I was not fit to be on my own...physically I'm incapable...*

Jim

Such responses fit well with Parsons's (1951) concept of the 'sick role'. Parsons argued that to be sick is to take on a particular social role with culturally determined rights and responsibilities. The person who is sick is, for example, exempted from the normal social obligations to earn a living and to care for themselves and others, and might equally perhaps be exempted from the obligation to strive for independence. In exchange however, a person who assumes the sick role is expected to seek and cooperate with 'technically competent medical help' (Nettleton, 1995:70). While that would usually involve seeing a doctor and complying with the treatment prescribed, it might also, in the case of the 'sick' elderly, be interpreted as submitting to the care and supervision of 'trained staff' in a residential care facility.

The participants in this study were also very conscious of the rest home staff's focus on minimising risk, and most accepted that the resultant restrictions on their own activities were necessary.

*No I don't [help other residents]... they don't like it because if anything happens... I don't think its... I mean I don't think its a good policy... because I don't know what I'm doing. They are trained, I'm not. So if one of them fell over I would certainly go and get somebody, but I wouldn't try to lift them or anything like that.*

Joe

Only Sally, who reported being 'growled at sometimes for trying to help somebody else...in case I cause injury', but persisted anyway, seemed to question that assumption.

### *The end of life*

While medicalisation has turned ageing into a disease to be treated, and ultimately prevented, 'institutional care' for the elderly has increasingly become the home of 'last resort' (Oldman and Quilgars, 1999:363), to be considered only when all other options have been exhausted. Part of the reason for this approach may well be that, for most of us, mortality and ageing are closely intertwined and one of the hardest questions we have to face is how we might wish our lives to come to a close (Kirkwood, 2001:2). While most of us have very limited knowledge of what is actually involved in the later stages of life, what we also tend not to appreciate or acknowledge is that our opinions about ageing may alter as our circumstances change. A degree of incapacity or a lifestyle that seemed intolerable when we were young, may well become much more bearable when in later life we come to experience it. There is indeed a growing body of evidence (Berlowitz et al, 1995; Sackett and Torrance, 1978; Tvesat, Dawson and Matchar, 1990; Tvesat et al, 1995) suggesting that, while people in relatively good health show a clear preference for quality of life over quantity, judgements made by those actually experiencing reduced health-related quality of life can be quite different (Lawton 2001:603).

What this study has shown is that, for those actually experiencing the frailty of advanced age, the prospect of living out the end of their lives in a rest home is more appealing than those planning care services for them might assume.

### *Growing old*

What then of ageing itself, and the different ways in which those who are old now and those who are not view it? While all of the participants in this study could, by the standards of current ageing in place policies, be considered to have 'failed' to age successfully (simply by virtue of having entered residential care) most did not in fact seem to see themselves or their circumstances in that light.

*When you get to this age, well, this is alright.*  
Madge

Joan, who was probably the most able, had needed a lot of care when she first entered the rest home following a stroke. She admitted she did not need that care any more, but had 'no regrets' and was pleased to know the care was there 'if I need it or for the future'. She felt she had aged successfully, 'no less so for being here', and said she had no sense of failure, although she did acknowledge that 'some might think that'. On her daily walks around the neighbouring streets she was 'the old girl from the home' but assured me she was 'fine with that'.

For this group, having reached old age and faced some sort of disruption to their previous way of life, the inevitable losses associated with ageing were here and now and they had found that indeed 'old age isn't so bad when you consider the alternative'<sup>17</sup>.

## About ageing in place

In describing their experience of moving to and living in a rest home, almost all of the participants in this study made at least some comment about the alternative of in-home care. Clearly aware of the dominant policy discourses around residential care and ageing in place, they all admitted to negative preconceptions about rest homes and most had vowed that 'they'll never get me out of my home'. What they had found, however, was that home was good while you were 'doing alright by yourself' but less satisfactory when things were going less well.

*When you're young you don't do you (think you'll be in a rest home). You're never going to get sick.*  
Madge

While rest home life was far from perfect (with most criticisms revolving around limited space, busy staff who left residents waiting and had little time to talk, and little choice of food) so too was being at home with supports. As well as having to get up early to let caregivers in, and call on family or neighbours for assistance with things that did not fit within the scheduled services, many felt lonely and isolated, particularly at night. At home, with no transport and limited mobility, they 'might not see anyone for days', and even if caregivers were coming in they were 'always having to go on to the next person, always in a hurry'. Although quite aware of 'all

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<sup>17</sup> Maurice Chevalier, *The New York Times*, Oct 9, 1960

the support you can get now', several commented that while the house might be spotless 'what's the good of that if you're worrying all the time that something will happen'.

*Life is good, because here I don't have to get my meals. I was finding that hard, and I used to get Meals on Wheels...and I had a home help...she used to come in for two hours on a Tuesday, and it was... it's much easier living here put it that way.*

Mary

Discourses of in-home care tend to assume that 'home', with its memories of family and loved ones, is the preferred ageing location. The majority of participants in this study however had moved house at least once after being widowed, and for one the problem with home was that 'the memories were killing me'. For others the problem was simply the strangeness and undesirability of living alone, and the loneliness of life with a rapidly diminishing pool of friends and family in a neighbourhood where they felt they could 'live and die and no one would know'.

### *Summary*

What I have shown in this chapter is that the 'at homeness' that ageing in place is predicated on is inconsistent with the experience of participants in this study. For most of them, life events such as major illness, death of a spouse or other family events had led to discontinuity of residence long before a move to residential care was even being considered. When they did move, what they valued most was not privacy and choice but security, companionship and belonging. Their experience of in-home care was dominated by increasing frailty, and by increasing dependence on family and friends for social contact and companionship as well as for practical support. As a result home was no longer the seat of identity and continuing independence and could no longer provide the sense of control and purpose, the close relationships and intimacy, or even the sense of comfort, well-being and stability that they had previously enjoyed. In such circumstances, residential care had actually become a practical and perfectly acceptable 'home'.

In the final chapter I look at the implications of these findings within the context of policy and practice around residential care for older people in New Zealand, and at how those policies might be broadened to accommodate a less narrow view of what constitutes a satisfactory home in old age.

# Conclusions

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During the years of alcohol prohibition in America, the late W C Fields, comedian and renowned alcoholic, used to joke that he would rather die than live in Philadelphia, bastion of the temperance movement. For his final joke – though perhaps it was no joke at all – he chose for his own epitaph the reflection: 'On the whole, I'd rather be in Philadelphia' (Kirkwood, 1999:231).

What I set out to do in this study was to explore the experience of rest home life through the eyes of some of the people who live there, to address the issue of whether or not a nursing home can be experienced as home, and to look critically at the ageing in place discourse that currently dominates government policy around aged care. What I have found is that older people enter rest homes for a variety of reasons and are not all happiest remaining in their own homes; that 'home' is a complex and changing concept that transcends place and time and is as much defined by warmth, affection and caring relationships as by bricks and mortar; and that, while rest homes can become 'home' for some residents, becoming 'home' is not always necessary or important.

In this last chapter I make some concluding comments about the significance of those findings in the context of policy and practice around residential care for older people. I argue that the ageing in place imperative is ultimately misguided and that what is really needed is a policy that offers older people genuine choices between a range of supported living options including residential care.

This is, of course, but one account of rest home life and must be considered in the context of the existing literature and the wider experience of rest home residents throughout New Zealand, their families and others involved in their care. What I hope however is that the experience of the participants of this study, many of whom would 'on the whole, rather be in a rest home', will at least give readers pause for thought when considering the future of residential care in New Zealand.

## Old age: what are we so afraid of?

Traditional scientific paradigms in gerontology are founded on the idea that age means nothing, and that illness and disability in later life are due to disease that is potentially reversible. While such an approach was undoubtedly beneficial in the early days of geriatric medicine, when older people were often consigned to the geriatric hospitals of Britain without any attempt being made to diagnose or treat their ailments, its unfortunate consequence has been a tendency to depict ageing rather negatively, as a failure of health surveillance and intervention. Today, despite the espousal of policies for positive ageing and independent living in the community, the negative attitudes remain and there is, suggests Heywood et al (2002:38) 'very little evidence of any real commitment to stop looking at old age so negatively or to listen to what (real) older people say'.

What is interesting about old age is the ambivalence we have about it. While most of us don't want to grow old, we don't want to not grow old either! Indeed what most of us probably want is to live actively and in good health until some unspecified age (at least a decade older than we are now) then to die quickly and painlessly while still in control of all our faculties and bodily functions.

One feature of being human, suggested a questioner at the 2001 Reith Lecture Series on Ageing<sup>18</sup>, is the ability to control or manage our environment. Another is the ability to accept our limitations and know when to relinquish that control. Do we, he asked, have an obsession with control and is it preventing us from facing up to our limitations? While the question was asked in relation to Kirkwood's comments about death and dying (Kirkwood,2001), it might equally apply to the limitations associated with increasing dependency in old age. By not accepting those limitations, or the need to relinquish control, we risk creating an environment in which those who have become less able to manage their bodies and their environment are tainted with all the negative connotations of 'institutional care'.

As Callahan points out (1992:6), everyone who will become 65 in the next 30 years is alive today and being influenced by both what they see happening to the current

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<sup>18</sup> BBC Radio4 Lecture Series presented in 2001 by Tom Kirkwood, then Professor of Medicine and head of the Department of Gerontology at the University of Newcastle, and accessible in audio or text form at [www.bbc.co.uk/radio4/reith2001/](http://www.bbc.co.uk/radio4/reith2001/)

elderly and what they are told about their own futures. While many of them will live independently in the community until they die, without ever facing chronic ill-health and disability or having to engage with the ageing in place debate, the rest will at some point have to face physical and mental frailty and the need for support and care. For their benefit, as much as for those who are old now, what are needed, suggests Minkler (1996:470), are new approaches that look more broadly at what makes a good life in old age and at how multiple alternative visions of a good old age can be supported.

### *The spectre of dependence*

Remaining 'at home' ('ageing in place' in a private dwelling) is widely seen as a key component of independence and as a marker of healthy and successful ageing (Davey, 2002). Health status declines however and disability rates and severity increase with age, and healthy and successful ageing may take on a different meaning for the very old. While the policy discourse of ageing in place dichotomises 'home' as *good* and 'institutional living' as *bad*, either setting can provide varying degrees of security, control and well-being, and of independence or dependence.

We need to be critical of this simple polarisation, and ask whether, from the point of view of the elderly person, living in an institution is preferable to continuing to live at 'home' or moving to live with a relative. For example, an elderly person living in their married child's home may be almost entirely dependent and lacking in autonomy. Similarly, a housebound elderly person reliant on state social care services may have a poorer quality of life than if they resided in an institution... They may live in their own home but lose control over it, becoming passive and dependent, as well as socially isolated (Arber and Evandrou, 1997:22).

One of the key findings of this study is that, for some older people, greater independence might actually be found in residential care than at home. For many of the participants home was no longer the seat of continuing independence, because of an increasing need to call on family (and in some cases friends or neighbours) for help with transport, household maintenance and simple day-to-day tasks, and for care and support when ill. For a generation for whom asking for help and being beholden to others, even family, was an anathema, it was the move to a rest home environment that enabled them to continue to be independent.

## Rest home as a place for ageing in

If remaining in one's own home is not essential for independence, and if indeed a degree of dependence on rest home or community support staff is more tolerable when we really need it than we might once have thought, where does that leave rest homes as a 'place for ageing in' for those confronting declining health and increased dependence in old age? In this study, and in discussion around residential care provision in New Zealand, the concept of home and its meaning to older people is a prominent issue. The fundamental premise of ageing in place policies is that older people *want* to stay at home, and that if they are unable to achieve that then alternative options such as rest homes, or indeed continuing care hospitals, should be as 'home-like' as possible. What has been shown by this study however is that many of the fundamental assumptions that underpin ageing in place policies are highly questionable, and that

- discontinuity of residence is very common among older people in the community
- older people do not all prefer to live at home
- home and rest home are not necessarily mutually exclusive
- rest homes can be, and are, part of communities
- entering rest home does not need to constitute failure
- reasons for entering rest home are complex and multi-faceted and do not necessarily fall within the 'comprehensive needs assessment' model.

Rather than being a discrete entity associated with a particular residence, home is a more imprecise and non-specific concept that changes to fit changing circumstances and is in fact more likely to be associated with a hometown or region and with people who share a common history and experience. At a more fundamental level it is associated with physical features of comfort and convenience, as well as with emotional warmth, companionship and caring relationships.

For the participants in this study at least, a rest home was able to provide most of those features, and in many cases more effectively than had been possible 'at home'. Furthermore those fundamental features of comfort, friendliness, companionship and a sense of belonging seemed to bear little relationship to the requirements for the provision of 'homelike environments' contained in residential care service specifications.

### *Different people with different needs*

In Chapter Five I outlined a typological classification of the rest home residents who participated in this study, dividing them into those deserving of and ready for rest home care; 'sick' and in need of rest home care; and resigned to or reluctantly tolerating rest home life. What that classification illustrated was that, while each individual's situation was quite different, there were certain commonalities in their approach to rest home entry that may help in understanding the limitations of ageing in place policies.

The 'deserving residents' for example, had done their ageing in place but now saw resting as an appropriate response to feeling profoundly weak, tired and slowed down by old age, and a 'rest home' as the appropriate place to do it in. For the 'resigned residents' too, rest home was an available and acceptable option in the face of either physical disability and the need for hands-on assistance with basic tasks such as mobility and toileting, the death of a spouse who had provided supervision and support, or social circumstances that had left them essentially homeless.

The other two groups on the other hand, may well have been candidates for community support. The 'in-need residents' in particular were the group most influenced by discourses of safety and risk and the medicalization of old age and frailty, reinforced by residential care home advertising focussed on safety and security, 'skilled staff' and '24 hour registered nursing supervision'. For them rest home was a matter of 'necessity', but only because they had accepted the advice of others that they were no longer competent to manage alone. Perhaps, given a different message and the kind of support that made them feel secure but without being a nuisance or a bother, they may have been quite happy to remain at home. The 'reluctant residents' too may well have been able to manage in a supported living environment where they could remain relatively independent but have a reasonable level of supervision and help on hand whenever needed. They were after all more concerned with practical support needs, and with issues of privacy and control, than with the affective features of care and companionship available in the rest home environment. While remaining in their own homes had not worked out for various reasons, they were ideal candidates for some sort of 'sheltered' accommodation.

With such diversity of population, it seems self-evident that any attempt to apply a one-size-fits-all model, even one as seemingly benevolent as ageing in place, will not meet everyone's needs. While many older people will indeed wish to remain in their own home with supports, even in the face of major disability, others will not. Future provision will need to be made for both groups. Not all older people are emotionally attached to a single place or home, and policies such as ageing in place risk romanticising that idea and overstating the negative consequences of a move which may in fact result in an increase in health, happiness and well-being.

### *Generational influences*

What this study has also illustrated is that social policy and planning for the care of older people is complicated by the problem of cross-cohort interpretation, of one generational cohort projecting their ideas and values onto another. In the mainstream media (Braunias, 2003; Ansley, 2006) and within health and social planning arenas (Quine and Carter, 2006), much has been made of the impending retirement and 'old age' of the baby boom generation. Very few baby boomers however will even need to think about residential care for themselves for at least another twenty years. Over that time the occupants of rest homes will continue to be predominantly the parents of baby boomers rather than baby boomers themselves, while at a social policy level decisions about the services available to them will increasingly be being made by another generation again. Each group will undoubtedly have quite different life experiences, priorities and beliefs, which will be reflected in their approach to and expectations of aged care services.

In the current environment the 'Grey Power' lobby is becoming increasingly politically active, but is dominated by the young old. These active 'Third Agers' and their vocal support of Positive Ageing initiatives may well be having a negative influence on our general approach to ageing and to the planning and provision of support services for older people. While they advocate for such things as increased access to elective surgery, prescription medicines, and subsidised transport, they seem less interested in the provision of care and support for frail 'Fourth Agers' with failing physical and/or mental health. Whether that reflects the concerns of the majority, or indicates an underlying reluctance, particularly on the part of the 'Third Agers' themselves, to confront the possibility of frailty and increasing dependence at the end of life, its likely result is the further marginalisation of those who, by virtue of

entering residential care, have become 'the failures' of the ageing in place imperative.

### *Is it, in the end, all about money?*

Originally conceived as 'residential care for the frail ambulant', the New Zealand rest homes of the 1950s and 60s, set up and run by the religious and welfare sector utilising government subsidies for capital and later staffing costs, effectively provided a 'lifestyle choice' for the frail elderly with relatively minor care needs. With fees set at no more than the old age pension, those who, for whatever reason, entered residential care did so without formal assessment or recourse to additional government funding. The current situation is very different. Fees now average \$665 per week for rest home residents (more than double the current 'pension' level including living alone and maximum disability allowances) and all those wishing to enter residential care must first meet specific 'needs-based criteria'. As a result, the 'lifestyle choice' option has effectively gone, except for those able to pay for their own care. The problem with 'needs-based criteria' of course, is that older people are not a homogenous group. The older we are the more likely we are to differ in physical and mental health, abilities and disabilities, strengths and weaknesses, and also in life experiences and opportunities, financial and social resources and sheer good or bad fortune.

It is the latter, the contexts and conditions under which decisions are made, that research of this type can usefully draw attention to and that current social policies tend to overlook. Ageing in place policies for example, and the models of community care on which they are based, are heavily influenced by concepts such as individual agency and 'consumer choice' but pay little attention to the role of structure and the social and biographical constraints it imposes. By emphasising the 'fact' that all older people wish to continue to live in their own homes, and enter residential care only because of limitations in the availability of support services, such policies downplay the importance of the history and biography of individuals and families and the wider society to which they belong. In New Zealand at the beginning of the 21st century the neo-liberal political rhetoric of individual responsibility and choice, market forces and consumer sovereignty dominate. Discourses that celebrate individualisation and consumer choice, and tacitly promote autonomy and independence as the ultimate goals for individuals, make it very difficult to publicly

address the experience of old age and interdependence, and the interactions and interconnectedness of individuals within communities.

In practical terms, the concept of ageing in place assumes that frail older people will be the recipients of effective and high quality supports, both formal and informal (family, friends and neighbours). With a worldwide labour market however, families are becoming increasingly mobile and geographically spread, and recruiting appropriate people who are willing and able to provide quality in-home care (particularly for the low pay they are offered) is becoming more and more difficult. At the same time the residential care budget is blowing out<sup>19</sup> and District Health Boards, who are now responsible for managing the budget, are looking hard for ways to save money. With the average cost of support for people at home in the vicinity of \$46 per week (Access Ability Taranaki, personal communication) the active promotion of ageing in place seems an obvious move.

## The last word

In a 2002 lecture at The Leveson Centre for the Study of Ageing, Spirituality and Social Policy, Malcolm Johnson, Director of the International Institute on Health and Ageing at the University of Bristol, made a call for the re-valuation of collective living arrangements for older people and a return to 'the beneficence of the asylum' as a place of refuge, safety, shelter and support (Johnson, 2002:17). Despite what Johnson refers to as 'the derailing effect of the Goffman/Townsend<sup>20</sup> assault and the consequent public wariness of old people's homes' (ibid:11), there is, he suggests, a need to acknowledge that residential care homes have both improved and changed. They have improved in terms of providing single rooms that are more spacious and personal, more inviting communal areas and better food; and have changed in their primary role, increasingly becoming a place for the very old and dependent to live out the end of their lives in security and comfort.

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<sup>19</sup> For the 1998/99 financial year, 63% of DSS expenditure for older people was for residential care and less than 15% for home support services including caregiver support and respite care (MOH, 2002:86)

<sup>20</sup> A reference to the influence of the work of Peter Townsend (1962, 1981) and Erving Goffman (1968) on the prevailing negativity about 'institutional care' for the elderly in Britain.

'But the prevailing ideology, in its full blown state of anti-institutionalism garnished with postmodern concepts of the centrality of the disconnected self, presumes that the privacy of the personal living cell remains a dominant ideal in all circumstances.' (Johnson, 2002:11)

In New Zealand 'anti-institutionalism' is evident in the policy discourses surrounding the ageing in place debate, and the widely accepted view that rest homes are places to be avoided at all costs. What Johnson suggests however, and what this study reinforces, is that the lived experience of some people at the far end of life is characterised by increasing frailty and physical decline. For those individuals, a collective living arrangement which can provide a combination of supported private space and the security and companionship of a caring community may be 'the least worst way of living at the far end of life' (ibid:17).

The current policy focus on ageing in place in some ways reinforces the idea of rest home as the normative final destination for the elderly, to be changed only by proactive social policy aimed at keeping people at home. However, contrary to the message created by retirement village marketing that emphasises a continuum of care from villa to rest home or hospital, ageing at home has always been and remains the norm. For a minority of older people, for whom remaining at home is either too hard or too stressful and who need the level of care and/or security that a rest home can provide, the promotion of independence in one dimension, through a static emphasis on ageing in place, risks depriving them of that choice. What it also risks is the reinforcement of our general negativity towards residential care, and its portrayal of rest homes as 'institutions' that somehow represent 'an assault on self and on feelings of personal autonomy and control' (Willcocks et al, 1987, quoted in Heywood et al 2002:31). Such negativity cannot help but rub off on the residents of those 'institutions' themselves and to worsen the dilemma of all those faced with the realities of frailty and increasing environmental vulnerability in older age.

By continuing in the pursuit of the 'ageing in place' imperative we are in danger, suggests Keeling (1999:106), of trying to make simple and straightforward something that is complex, highly personal and dynamic, and in effect forgetting the people doing the ageing. Our attention indeed might 'be more fruitfully directed at exploring the management of interdependence, and identifying those characteristics of particular places and community settings which promote a sense of belonging, security and identity in later life'. It might also perhaps be more productively applied

to looking for alternative options for both the provision and funding of supported communal living for the frail elderly, and at promoting them as important and respected parts of our communities for those whose needs they suit – part of a diverse range of options for diverse individuals with diverse lives, families, needs and aspirations. While increasing the provision and quality of community supports for frail and disabled older people who wish to remain in their own homes is without doubt an appropriate and worthwhile goal, it should not be at the expense of other options. Rather than dismissing residential care out of hand, we should perhaps heed Johnson's plea to reconstruct our thinking about residential care homes for the elderly and 'put them back in the valued spectrum of human living arrangements' (Johnson, 2002:17).

*Well I felt terrible to start with. And then I became... I liked the place, I liked being here and I liked the people here. So I made up my mind from that day on that I was going to make this my home...*

*So I did, and I've never looked back... I went for a drive up past the house... Cos it was new when I went in it, and ah, I never thought about it, from that day on I haven't thought about it.*

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### Appendix One: Introductory letter and information sheets

The Manager  
\_\_\_\_\_ Rest Home

Re: *A home away from home? The experience of rest home life in New Zealand*  
– a social science research project.

Dear

My name is Dianne Stokes and I am a postgraduate sociology student undertaking a research project for my Master of Philosophy (Sociology) thesis on the subject of living in a rest home. My particular area of interest is in how different residents define 'home', and whether a rest home can come to be their home.

As part of the project I would like to interview a number of rest home residents in your region about their experiences, and have used the Eldernet website to select a range of homes of different size, type and location as possible research sites. One of those I have selected is \_\_\_\_\_, and the purpose of this letter is to introduce myself and the project and to seek your permission to approach your residents as potential volunteers.

The project has been reviewed and approved by both the Massey University Human Ethics Committee Palmerston North and the Manawatu/Wanganui Health and Disability Ethics Committee, and will be supervised by Dr Allanah Ryan, Sociology Programme, School of Sociology, Social Policy and Social Work, Massey University.

I enclose an information sheet about the project, which I hope you will read and discuss with relevant people within your home/organisation, and will contact you by telephone within the next two weeks to see whether you are interested in taking part and, if you are, to arrange a time to visit and talk to you about it. If, at that stage, you are agreeable I will ask you to give formal permission in writing for me to access participants from your rest home.

I look forward to discussing the project with you.

Yours sincerely

Dianne Stokes

A large black rectangular redaction box covering the signature and contact information of Dianne Stokes.

*A home away from home?  
The experience of rest home life in New Zealand*

**INFORMATION SHEET**

**- Residents -**

**Researcher Introduction**

- I am a Postgraduate Sociology student undertaking this research as part of my thesis for a Master of Philosophy (Sociology).
- My name is Dianne Stokes, and I can be contacted at PO Box 6085, New Plymouth, ph (06) 7586316, email [dstokes@globe.net.nz](mailto:dstokes@globe.net.nz)
- My supervisor is Dr Allanah Ryan PhD, Sociology Programme, School of Sociology, Social Policy and Social Work, Massey University, ph (06) 356 9099 ext 2625, email [A.M.Ryan@massey.ac.nz](mailto:A.M.Ryan@massey.ac.nz)
- The aim of my project is to describe, and hopefully develop some understanding of, what it is actually like to live in a rest home, by asking some of the people who live there.  
My intention is not to make judgments about how well people are looked after, or about whether rest homes are good or bad places, but I would like to find out something about what it is like to live in a rest home – and about whether, and how, a rest home can come to be seen as ‘home’. To do that I would like to interview a small number of residents about their experiences, and am looking for volunteers.

**Participant Recruitment**

- I have asked the rest home manager/care manager to let residents know about the research, and to distribute this information sheet for me. Please let them know if you would like to take part and I will arrange to visit to discuss the details with you.

I will not be upset or offended if you then decide not to participate, but if you are still keen will arrange a suitable time for the first interview. As this sort of research is quite time consuming, I will only be able to use 2 or 3 volunteers from each rest home I visit.

- If you are interviewed, I may ask you some questions about your move to the rest home that bring back unpleasant memories or cause you some distress. If that happens I will be happy to stop the interview, and will arrange for the care manager or another appropriate person to come and be with you if you wish.
- Although your name will not be used on tapes or transcripts of the interviews, or in the research report that I write, it is possible that other people within the rest home who read the report may be able to identify you from what you say. As my final report/thesis will include information from residents in a number of different rest homes, none of which will be identified, this risk should be very small.

### **Project Procedures**

- The information you give me about your experiences of rest home life will be used in writing my Master of Philosophy (Sociology) thesis, and may also be presented in summary form to a conference or meeting of people involved in social research and the care of older people.
- Following the interview/s you will be given the opportunity to examine and amend the transcript/s, and to ask for any part you do not wish used to be removed.
- Data from the research, including tapes and transcripts, will be securely stored for five years in accordance with Massey University research policy, and after that time can be returned to you or your family, destroyed, or placed in a research archive. This will be discussed with you when you agree to take part in the project and again when the transcripts are reviewed.
- A summary of the project findings will be sent to you once the research is complete, and the final thesis will be available, once examined, from the Massey University library.
- At the time of the first interview you will be asked to choose a pseudonym, which will be used on all tapes and transcripts. Your identity will be known only to me, and you will not be identified in any reports or presentations.

## **Participant involvement**

- Interviews and follow-up visits will probably take up between 1½ and 3 hours of your time, over 2 or 3 sessions, and will take place at times that suit you. Interviews will be tape-recorded and will normally be conducted in private.
- If you agree to be interviewed, you will be asked to sign a consent form confirming that you understand what the project is about, and that you are willing to take part. You will have the right to withdraw that consent at any time.

You have the right to:

- decline to participate;
- decline to answer any particular question;
- withdraw from the study at any time;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the audio tape to be turned off at any time during the interview.

## **Project Contacts**

- Please feel free to contact me and/or my supervisor if you have any questions about this project. If it is easier for you the care manager will pass on your name and contact details, and I will contact you.

## **Committee Approval Statement**

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Application 04/94. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email [humanethicspn@massey.ac.nz](mailto:humanethicspn@massey.ac.nz).

This project has been reviewed and approved by the Manawatu/Whanganui Ethics Committee.

Contact: Sheryl Kirikiri, Administrator, telephone 06 350 8199, email [centralethics@xtra.co.nz](mailto:centralethics@xtra.co.nz)

*A home away from home?  
The experience of rest home life in New Zealand*

**INFORMATION SHEET**

**- Rest Home -**

**Researcher Introduction**

- I am a Postgraduate Sociology student undertaking this research as part of my thesis for a Master of Philosophy (Sociology) through Massey University.
- My name is Dianne Stokes, and I can be contacted at PO Box 6085, New Plymouth ph (06) 7586316, email [dstokes@globe.net.nz](mailto:dstokes@globe.net.nz)
- My supervisor is Dr Allanah Ryan PhD, Sociology Programme, School of Sociology, Social Policy and Social Work, Massey University, ph (06) 356 9099 ext 2623, email [A.M.Ryan@massey.ac.nz](mailto:A.M.Ryan@massey.ac.nz)
  
- The aim of my project is to describe, and hopefully develop some understanding of, what it is actually like to live in a rest home, by asking some of the people who live there. My intention is not to make judgments about how well people are looked after, or about whether rest homes are good or bad places, but rather to find out something about what it is like to live in a rest home – and about whether, and how, a rest home can come to be seen as ‘home’. To do that, I would like to interview a number of residents of different homes about their experiences.

**Participant Recruitment**

- Participation will be entirely voluntary.
- I will provide an information sheet for informants which I will ask the manager/care manager to distribute to residents they consider eligible to participate. Those who wish to take part will be asked to put their name forward so that I can be introduced to them and provide further details.
- Eligible participants will be permanent residents of the home who are considered competent to consent to participation, and who do not have significant cognitive impairment, significant language impairment (eg difficulty speaking following a stroke) or poor command of English, very poor hearing or very poor health (acutely ill or unable to tolerate a long interview).
- As this sort of research is quite time consuming, I will only be able to use the first 2 or 3 volunteers from each home.
- Potential risks to participants are listed in the accompanying information sheet for informants.

**Project Procedures**

- The information from participants in this rest home will be pooled with data from other rest homes for use in my Master of Philosophy (Sociology) thesis and may also be presented in summary form to groups involved in social research and the care of older people.
- Data from the research, including tapes and transcripts, will be securely stored for 5 years in accordance with Massey University research policy, and after that time will be returned to participants or their family, or disposed of according to their wishes.
- A summary of the project findings will be sent to you once the research is complete, and the final thesis will be available, once examined, from the Massey University library.

### **Participant involvement**

- Interviews and follow-up visits will probably take up between 1½ and 3 hours of each participants time, over 2 or 3 sessions, and will take place at times that suit them. Interviews will be tape-recorded and will normally be conducted in private.
- Participants will be asked to sign a consent form confirming that they understand what the project is about, and that they are willing to take part. They will have the right to withdraw that consent at any time. Their rights are listed on the accompanying information sheet for informants.

### **Rest Home involvement**

- I would like to use this rest home as one of the sites for my project, and to pool the information collected with data from 2 or 3 other rest homes in my final thesis.
- I would like the assistance of the manager and/or care manager in identifying suitable participants, informing them about my research and distributing information sheets, and introducing me to those interested in taking part.
- My timetable will be arranged to suit residents and home routines, and I will endeavour to cause as little disruption as possible.
- During interviews, I may ask some questions about a resident's move to the rest home that bring back unpleasant memories or cause some distress. If that happens and the resident wishes to stop the interview, I may ask the care manager or another appropriate person to give support.
- Although neither participants nor the rest home will be named in any research data or in the final report, and I will not include any potentially identifying characteristics of the home – location, bed numbers, affiliations etc – it is possible that people within or close to the rest home may be able to identify some informants from what they say. Inclusion of participants from 3 or 4 different rest homes should minimize that risk.
- It is possible that during the research some participants may express concerns about their care. Should this happen they will be advised to discuss the problem with the rest home manager or care manager, or with another appropriate person who can act on their behalf – family member, GP, social worker or independent advocate. If necessary, and if that is what they wish, I may make initial contact with that person for them. Any such concerns will be treated in confidence, and will not be included in the research report.
- It is also possible that I may observe inappropriate staff practices or behaviours, or other things that could reflect badly on the home. Any such concerns I may have will be discussed with the rest home manager, will be treated in confidence, and will not form part of the research data.

### **Project Contacts**

- Please feel free to contact me and/or my supervisor if you have any questions about this project.

### **Committee Approval Statements**

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Application 04/94. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email [humanethicspn@massey.ac.nz](mailto:humanethicspn@massey.ac.nz).

This project has been reviewed and approved by the Manawatu/Whanganui Ethics Committee.

Contact: Sheryl Kirikiri, Administrator, telephone 06 350 8199, email [centralethics@xtra.co.nz](mailto:centralethics@xtra.co.nz)

## Appendix Two: Consent form

*A home away from home?*

*The experience of rest home life in New Zealand*

### CONSENT FORM

**THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF FIVE (5) YEARS**

I have read the Information Sheet: Version 2 and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree / do not agree to the interview being audio taped.

I understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I understand that I have the right to see and edit the interview transcript

I agree to my interview tapes being returned to me / destroyed / archived at the completion of the research project.

I agree to participate in this study under the conditions set out in the Information Sheet.

**Signature:**

**Date:**

**Full Name - printed**

## Appendix Three: Interview guide

### *A home away from home? The experience of rest home life in New Zealand*

## **Interview Guide**

### *Questions*

1. Tell me about how you came to move here
2. Tell me what the word home means to you
3. What is it like to live here and does it now feel like home?
4. How do you think things could be different to make living here feel more like home?

### *Themes*

1. past experiences of home
2. leaving home
3. settling in
4. everyday life
5. autonomy/individuality
6. being looked after
7. relationships
8. fitting in/making it work
9. at homeness

### *Prompts*

1. Tell me more about that
2. Can you be more specific
3. Can you give me an example
4. Why do you think that is?
5. What do you think about that?