A Place to Call My Own – Understanding the Experience of Home for Young People with Disabilities Living in Long-Term Residential Care

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Abstract

This exploratory study was based on a new model of residential care that was designed specifically to provide a home-like environment to young people with severe disabilities and complex chronic healthcare needs (i.e., Multiple Sclerosis (MS) and Acquired Brain Injury (ABI)) to allow them a more appropriate and dignified lifestyle. In 2006, there was an estimated 6,500 people with disabilities under 65 years of age living in residential aged care in Australia (Australian Bureau of Statistics; ABS, 2008). These living environments have been found to be inappropriate and inadequate for young people with disabilities (Cameron et al., 2001; Winkler et al., 2006), particularly given that they may not require 24-hour nursing care.

It is important to consider the nature of home in more detail when thinking about living environments for marginalised groups of people (e.g. people with disabilities), especially as it has been found that the nature of home can impact on the quality of life (Annison, 2000). In order to understand the meaning of “home” for a group of people who live within a particular environment, it is essential that we seek to understand the perceptions of those individuals. In order to provide optimal services, the subjective experience needs to be heard and understood.

The current research was conducted in accordance with Interpretative Phenomenological Analysis (IPA). This method allowed the research to retain the voice of the service users at the forefront and ensured that their views remained paramount. Multiple domains of home, as they were experienced over time, were examined through a series of semi-structured personal interviews conducted with seven residents with either MS or ABI at their residential care setting. The study aimed to understand the residents’ ‘lived experience’ within the residential apartments, and specifically to answer the following questions:
1) How do residents experience home within a residential care setting? and;

2) What influences their sense of home?

Two core themes emerged from the data, namely *Perceived Qualities of Place* and *Identity*. These themes seemed to be inextricably interlinked with each other, and to the extent that they overlapped, a sense of *Home* was created. These two core themes were influenced by a core process that took place for this group of residents, namely, *Deconstruction and Reconstruction* of their sense of home. The core process was influenced by the theme of *Connections*. *Connections* was constructed from three sub-themes: *Interactions with the physical environment, Relationships with family and friends*, and *Relationships with staff*. These themes influenced the way in which deconstruction and reconstruction occurred as well as the nature of identity and the perception of place.

The current study produced four major findings. First, connections appeared to be paramount to the development of a sense of home having an influence in multiple ways. Although previous research has linked the importance of social relationships to general well-being and quality of life, the current study has found that these perceptions of relationships also impacted on the participants’ sense of home. Positive relationships, particularly with staff, created a sense of belonging and comfort that assisted in the reconstruction of their sense of home. Interactions between participants and family were especially critical to the participants’ sense of home.

Second, the sense of home emerged as an important concept that is comparative, temporal, tenuous and vulnerable to deconstruction, and needs to be considered by service providers. Deconstruction appeared to take place more rapidly than reconstruction, highlighting the importance of prevention. Home was a vulnerable
construct that could be easily destroyed through negative interactions with the physical environment and/or interactions with others. Third, the construct of home was intimately linked to the sense of identity. It is important for service providers to appreciate these linkages and respond accordingly. This type of information is rarely used in relation to the design and provision of services in environments that provide long-term care for young people with chronic and complex health needs. Finally, this study has built a theory that shows the link between the existing models of home proposed by Despres (1991). Although these models have been proposed as four distinct conceptual approaches to home, this study has highlighted that they do not operate in isolation. Instead, home is a multi-dimensional construct that is influenced by many factors. It can be influenced by connections, perceived qualities of place and identity. However, identity needs to be congruent with a sense of belonging. Identity needs to be a construct that becomes more focal in service delivery.
Originality of Thesis

I hereby certify that this work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

______________________________
Hayley Danielle Quinn
September 2012
Publication Arising From This Work

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Chapter One: Overview

Many young people with complex disabilities find themselves living in residential aged care facilities (Cameron, Pirozzo, & Tooth, 2001; Gilmore, 2002; Winkler, Farnworth, & Sloan, 2006). This situation arises due to the lack of suitable accommodation options, inadequate funding (Cameron et al, 2001), and the normal ageing process of parent carers. Most families will eventually find themselves unable to continue caring for their disabled relatives, particularly if they have high levels of need for medical support. These families often have no choice but to seek the placement of their relative in residential aged care facilities, a decision that causes a great deal of distress for all parties.

In 2006, an estimated 6,500 people under 65 years of age were living in residential aged care in Australia (Australian Bureau of Statistics; ABS, 2008). This situation occurs despite a legal requirement for aged care residents to be over 65 years of age. The aged care living environment is inadequate and inappropriate for young people with disabilities (Cameron et al., 2001; Winkler et al., 2006), particularly given that they may not require 24-hour nursing care. They are more likely to require services that are not available through aged care funding packages, such as appropriate social engagement; access to rehabilitation or therapy services (Wales & Bernhardt, 2000); and assistance to tackle and learn the tasks of daily living (Strettles, Bush, Simpson, & Gillett, 2005). Residential aged care is designed to accommodate older people who are at the end of their lives, and as such, is resourced and staffed to meet the needs that might be expected at this stage (Fyffe, McCubbery, & Honey, 2003). Further, status as a nursing home resident excludes younger people from receiving appropriate disability services that could assist them to access the community (Strettles et al., 2005). Thus,
these environments may not only be inappropriate to the life stage of younger residents, but may also prevent their involvement in community participation (Cameron et al., 2001; Stringer, 1999).

In February 2006, the Council of Australian Governments (COAG) announced the Younger People with a Disability in Residential Aged Care initiative. This joint initiative between the national, state and territory governments aimed to reduce the number of younger people currently living in, or at risk of moving to, residential aged care (Disability Services Queensland, 2006b). The Australian Government provided new funding of up to $244 million, and the Queensland Government made a financial commitment to the initiative of $47.8 million over a five year period. The specific five year objectives of the initiative were:

- To assist younger people with a disability in residential aged care to move to more appropriate accommodation, where available and if the person chooses to do so.
- To divert younger people with a disability who are at risk of admission to residential aged care to more appropriate accommodation.
- To improve the delivery of specialist disability support services to younger people with a disability who choose to remain in residential aged care or for whom residential aged care remains the only available option.

Funding was provided to establish new appropriate living environments for younger people with disabilities. One proposed model of service was the Integrated Living Model, the aim of which was to facilitate the independence and mobility of younger people at the same time as responding safely to their high level of physical support needs. These residential support services were designed to accommodate between 10 and 20 young people with high and complex levels of physical or health
needs. Provision was made for private living areas, and spaces that encouraged family involvement or visitors. The residents’ individuality and choices were encouraged and supported in order for them to create a comfortable, homely environment. The design and construction of new residences also had to take into account the effective use of aids and equipment to support people with high level complex physical and health care needs (Disability Services Queensland, 2006a).

It was assumed that these accommodations would enable younger people with chronic and complex health care needs to live in environments that promoted a sense of choice and control, addressing not only their functional needs, but also their social and psychological needs. However, in reality, very little is known about how these environments are experienced by young residents. Some research in the general population has informed us that the experience of home can impact significantly on psychological well-being. However, we have limited understanding about what home means for this population. This study is exploratory and aims to gain an understanding of the experiences of young people who are living within this environment. Specifically, it will seek to answer the following questions:

1) How do residents experience home within a residential care setting? and;
2) What influences their sense of home?

**Why Residential Aged Care is an Inappropriate Environment for Young People with Disabilities**

Young people with disabilities who live in residential aged care are likely to experience social isolation and limited opportunities to participate in recreational activities (Winkler et al., 2006). For instance, a survey of Directors of Nursing at certified residential aged care facilities in Victoria (Winkler et al., 2006) revealed that social isolation affected many of the residents. Only 24% of the residents received daily
visits from relatives and over 40% of residents reported being socially isolated from their peers. Although family relationships were more likely to be maintained than non-family relationships, up to 11% of residents received family visitors less than once per year (Winkler et al., 2006). Over 50% of residents were engaged in recreational activities or travelled outside the aged care facility less than once per month (Winker et al., 2006). Even more surprising was the fact that 21% of residents went outdoors less than once per month. For large numbers of residents, some activities were undertaken less than once per year, including shopping (55%); leisure activities such as movies, sport and dining out (56%); visiting relatives in their own homes (58%); and visiting friends (83%). It was found that 34% of residents under 60 years of age almost never participated in community-based activities, effectively excluding them from the community (Winkler et al., 2006).

Although many aged care facilities endeavour to meet the specific and complex needs of younger people, they are hindered by inadequate funding, insufficient resources and lack of appropriate staff training (Cameron et al., 2001). When surveyed about their experiences in providing care for young people with acquired brain injury (ABI), only 18% of the 493 Commonwealth-funded aged care facilities reported difficulties providing the necessary physical care. However, the majority (86.6%) reported that the needs of young residents with ABI were different to those of other residents, causing them to encounter difficulties living in an aged care environment. Young residents lacked space and privacy (19%); interaction with peers (32%); cognitive, emotional and physical stimulation (26%); and sexual activity (6%). They reported difficulty living in close proximity to older residents who were frail, terminally ill, or suffering from dementia (17%) (Cameron et al., 2001). Research has shown that this situation may not only be dissatisfying, but may have a detrimental impact on other
outcomes. For instance, some young people living in residential aged care have been found to experience a continual decline in independent living skills and physical abilities (Kelly & Winkler, 2007).

Placing young people in residential aged care is incongruous with the philosophy of the Disability Services Act (2006) which mandates that young people with disabilities should have the maximum possible inclusion in community life. The Act states that people with a disability have the right to: (1) receive services in an accessible and safe built environment that is appropriate to their needs; (2) to be respected as individuals; (3) to realise their individual capacities for physical, social, intellectual, emotional, religious and cultural development; (4) to actively participate in decisions affecting their lives, and to have access to information and support that facilitates their participation in such decision making; and (5) access to services that promote quality of life and support their relationships and participation in the community.

In June 2006, the discrepancy between the Act and the conditions within which many young people were living led to a Queensland Government review of young people (under the age of 50 years) who were living in State-funded residential aged care facilities. The primary aim of the review was to investigate a range of accommodation options (Disability Services Queensland & Queensland Health, 2006). Based on a review of de-identified care plans collected by the Aged Care Assessment Team (ACAT) during 2003 to 2004, the review concluded that the overall support needs of young people were greater than those of older residents. Most of the social and emotional needs of young people were not being fully met, irrespective of their level of need (Disability Services Queensland & Queensland Health, 2006). Younger people experienced boredom, did not participate in community activities and were not able to...
access appropriate therapy services (Disability Services Queensland & Queensland Health, 2006). As a result of the review, the State Government determined that there was an urgent and critical need for alternative accommodation options that were in line with the principles of the Disability Services Act (2006). It was clearly stated that accommodation options for younger people with complex medical needs must translate the principles of the Act into practice and minimise any restrictions of residents’ rights or opportunities.

**Moving People Out of Institutional Care**

The deinstitutionalisation and relocation to the community of individuals with intellectual disabilities (ID) has been taking place for many years in Queensland. Young people with congenital disabilities have been moved from large scale institutions to smaller residential accommodations within the community under the assumption that the non-institutional environment will improve their quality of life. Indeed, some research has demonstrated the positive impact of these relocations. For instance, a systematic review containing 13 studies of deinstitutionalisation to community living for people with ID in Australia found that community placement was associated with increased levels of community participation, adaptive behaviours, and contact with family or friends (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). More extensive reviews conducted in the USA and UK (Emerson & Hatton, 1996; Hatton, Emerson, & Kieman, 1995; Lakin, Braddock, & Smith, 1995, 1996; Larson & Lakin, 1989) have confirmed these conclusions.

In subsequent Australian research, Young, Ashman, Sigafoos and Grevell (2001) assessed 95 individuals with ID who were relocated to community-based group homes following an institutional closure programme. The group homes were suburban houses that accommodated between one and four people. Behaviour, choice-making
and life circumstances were assessed for each individual six months prior to leaving the facility, and again at 1, 6 and 12 months after relocation to the new accommodation. Significant increases were found in adaptive behaviour, choice-making and life circumstances, suggesting that the environment of a community group home supported a more active and involved lifestyle compared to the institution (Young et al., 2001). Individuals also demonstrated increases over the 12 month period in self-care; independent or semi-independent money management, engagement in activities such as shopping, cooking and laundry; and in taking personal responsibility. However, the mechanisms of change remained unclear in that increased self-care may simply have been due to the fact that fewer residents shared the facilities, resulting in more flexible time schedules, better resident-staff ratios, or the presence of more opportunities for residents to participate in daily activities, such as shopping and money handling (Young et al., 2001). Irrespective of the causal mechanisms, the shift to community-based care was associated with positive outcomes.

In contrast to these self-care findings, relocation did not improve maladaptive behaviours, physical or language development, vocational activity, self-direction or socialisation (Young et al., 2001). This finding suggests that the mere provision of environmental opportunity is not sufficient to enable realisation of the full benefits of community living (Young et al., 2001). Young et al. concluded that active interventions and skills training were required in addition to a supportive environment, further highlighting the difficulties experienced in aged-care facilities where such intensive support is not available.

To examine some of these hypotheses further, Young (2006) studied a range of dependent variables within a sample of 30 pairs of adults with moderate and severe ID, matched on age, gender, level of disability (e.g., intellectual, communication, mobility,
sensory and behavioural), time spent in institution, and adaptive behaviour scored by staff prior to de-institutionalisation. Individuals were then relocated into one of two options: (1) housing within the community accommodating between one and four people, or (2) cluster centres situated on large parcels of land containing semi-detached and detached housing accommodating between 12 and 25 residents with 24 hour residential support (Young, 2006). Both community-based accommodation types were provided under the same residential service philosophy, namely to assist each individual to live life as normally as possible in the least restrictive environment. Each individual’s care needs were addressed and an individualised support package was developed.

Houses were self-contained and all aspects of daily life remained the responsibility of residents with staff support. Staff assisted where necessary with cooking meals, shopping, domestic cleaning, and gardening. Staff-resident ratios were higher compared to the institution and daily activity programmes were available, including at least 15 hours per week of support to access the community for recreation, leisure and domestic tasks such as shopping and banking. Choice was provided where possible. For example, evening meals were prepared according to residents’ likes and dislikes, in contrast to the institution where all meals were prepared in a central kitchen with no consideration for residents’ choice or preference (Young et al., 2001). In contrast, residents living in cluster centres had less choice, lower staff-resident ratios, and more rigid routines and restricted activities than those in community housing (Emerson et al., 2000). Although still a more positive environment than the institutional care setting, these residents had less control over their daily lives.

Choice making, adaptive and maladaptive behaviours and objective life quality was assessed prior to deinstitutionalisation, and then 12 and 24 months after moving to
the new accommodation. Following relocation, levels of adaptive behaviour increased for both groups (i.e., community housing or cluster centre); but there were additional significant improvements in domestic skills for the community group. The community group also gained prevocational and vocational skills, such as task completion and care of their own equipment. Although there were improvements in choice-making for both groups, the community group demonstrated significantly more involvement in everyday choice-making compared to the cluster centre group.

Both groups showed improved objective quality of life over time, measured by the Life Circumstances Questionnaire (Young, Ashman, Sigafous, & Grevell, 2000), but the community group showed greater increases in self-determination, community access, general achievements and residential well-being. Contact and social interaction with friends and family increased for both groups over time but there was no significant difference between the two groups (Young, 2006). This study demonstrated several positive impacts of community environments compared to large residential institutions on residents’ well-being including an increase in opportunities for choice-making and participation in social activities.

In demonstrating how home can contribute to quality of life, Annison (2000) utilised Maslow’s (1943) hierarchy of needs as a way of developing a multi-faceted approach to creating and maintaining home environments (see Table 1). Maslow’s three classifications of need are: (1) fundamental needs, such as the physiological needs for water, food, warmth and shelter; (2) intermediate needs, such as the need for security, safety, love and affection, belongingness, social acceptance and self-esteem; and (3) growth needs, including the need for creativity, self-actualisation, justice, goodness, beauty, order and unity. The home can meet fundamental needs through the provision of shelter and a place to engage in activities such as sleeping. Other elements
of the home can meet intermediate needs such as belongingness, safety, privacy and an emotionally supportive environment. Finally, individual’s growth needs can be met through the tasks associated with taking responsibility for the home, managing one’s behaviour in the home, and manipulating one’s environment to suit one’s needs, and providing opportunities for self-expression. Meeting these needs is integral to a person’s well-being, meaning that home can be one of the most important contributors to individual development and adjustment (Annison, 2000).

Table 1.
Relationship of attributes of home to Maslow’s need hierarchy

<table>
<thead>
<tr>
<th>A</th>
<th>Fundamental needs (physiological needs such as water, food, warmth/shelter)</th>
<th>Suitable physical/material structures and environment for the individual’s purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Safety – ensuring a safe environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extent of services as seen as a necessary part of the home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Spatiality – adequate room for essential activities and their separation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Centre of fundamental activities such as eating and sleeping</td>
</tr>
<tr>
<td>B</td>
<td>Intermediate needs (needs for security, safety, love/affection, belongingness, social acceptance and self-esteem)</td>
<td>Emotional environment – place where there is love and affection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Happiness – the experience of happy events and general feelings of happiness, positive atmosphere</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relationships – type and positive quality of relationships and the ability to control them and exercise choice over who one lives with</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Friends and entertainment – people visiting, the social core of the home, the opportunity and ability to offer hospitality</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Belonging – comfort, relaxation and familiarity contribute to this</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge – familiarity with the physical and social environment of the home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Permanence – the continuity of home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Meaningful places – because of the specific events which took place there</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Privacy – being able to have the level of privacy desired and the freedom to do what one desires</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Security and control – sense of security, control of the area – who enters and what they do or where they go, ability to create a refuge for oneself, choice of what is done and when it is done</td>
</tr>
</tbody>
</table>
Reflection of one’s ideas and values – view of self, and others’ view of self, indicator of personal status, recognition in socially valued roles, personalisation of the home

Meta-needs or growth needs (need for creativity and self-actualisation including the need for justice, goodness, beauty, order and unity)

Responsibility for the home, including homemaking tasks, home improvement tasks, and home ownership or tenancy

Self-expression – behaviour in and manipulation of the place; acting upon and modifying dwelling; opportunities for self-expression and development; choice of, and opportunities for new and different activities

Critical experiences – related to growth and development of the individual

Time perspective – relating the self to the past, present and future via home

Preference to return – as an ordering point in space

Architectural and decorative style – appeal to the individual’s sense of aesthetic

Choice of dwelling

Work environment – working at home

(Adapted from Annison, 2000, p.260)

Other research has generally shown the benefits of relocating people with ID from institutional care environments into community settings. However, the vast differences in the nature of the accommodation and service models to which they are relocated means that little is actually known about the qualities of the environment that contribute to positive outcomes and how that environment is experienced from the resident’s perspective. Subjective quality of life (i.e., residents’ own responses to their new lifestyle) has not been explored due to the potential of unreliable responses and the likelihood of acquiescence in this population (Young, 2006). Further, there are likely to be significant differences between the experiences of those with congenital ID and young people with acquired chronic and complex health needs (e.g. Multiple Sclerosis (MS) or Acquired Brain Injury (ABI)) who find themselves in aged care nursing homes following years of independent living.
Young et al. (1998) highlighted that relocation to the community is a complex process that must take into account the multi-faceted nature of home. Young et al. (1998) highlighted the need for research that systematically describes the physical, social and psychological features of the various residential settings within which young people with severe disabilities lived, rather than merely naming and categorising them (e.g., community-based housing, including cluster home, group home, shared accommodation). These researchers found that the nature of the residential setting was a key factor in determining the level of choice for residents, access to services and the community opportunities for social interaction, and responsiveness to changing needs (Young et al., 1998). Ultimately, therefore, the home setting is likely to impact significantly on the well-being of residents and their quality of life.

Thus, it is important to gain an understanding of how young people with severe disabilities experience their residential environment. This knowledge will then assist us to understand how best to provide living environments for this population. Home is a physical place, but it is also a social and psychological experience. Therefore, to understand the impact of supported living services on this population we need to understand the complete meaning of home, including physical, social and psychological. By understanding their ‘lived experience’, we are more equipped to provide suitable living environments for young people with complex health care needs.

Following on from the significant investment in relocation for people with ID, there is now considerable interest in the types of physical environments and models of care that could be provided to young people with acquired disabilities who currently reside in aged care nursing homes. Several new government initiatives have been established to provide more suitable community accommodation models for this population, most based on the partial lessons learned through the de-institutionalisation
initiative. Despite overwhelming community concern about the circumstances of young people and the popularity of these new community approaches, there is a lack of empirical evidence about how these environments will achieve their aims and no evidence about how they are experienced by the young residents. The current study aims to fill this gap in knowledge using a qualitative investigation of these multiple domains of home for a small group of residents during the first two years of operation of an Integrated Living model of accommodation. In the next chapter, I will explore the meaning of home in more detail as it pertains to this population.
Chapter Two: The Meaning of Home

For a long time, service providers have been linking the word home - whether it is home, homely, or homelike - to residential settings for people with disabilities (Annison, 2000). This connection is often made without a clear understanding of what home embodies for this population. When considering living environments for marginalised groups of people, the nature of home ought to be examined in more detail, particularly given that the nature of home can influence the quality of community living (Annison, 2000). It is, therefore, important to understand the perceptions of the individuals who live within a particular environment in order to understand what constitutes “home” for that group of people. Without this subjective knowledge, it will be difficult to provide services that optimise their quality of life.

Home will hold different meaning for different individuals and although research has provided different perspectives and a broad range of ideas, there is nothing that constitutes a precise definition of home. The difference between somewhere being simply a house or being a home has been explored to some extent in the literature. However, the majority of studies focusing on the meaning of home have involved individuals without disability. For a person with a disability, their experience may differ considerably due to the fact that many of them will require varying degrees of assistance from others (i.e., nursing and support staff) with activities of daily living (e.g., dressing, showering and toileting), domestic tasks (e.g., cooking and house cleaning), and in carrying out social roles within their home (e.g., entertaining visitors and engaging with neighbours) (Annison, 2000).

A number of researchers have found that people with mobility limitations are likely to find many residences unsuited to their needs (Borsay, 1986, Heywood et al.,
The inadequate physical design of homes can create barriers to self-management of impairments, ultimately contributing to the deterioration of a person’s conditions (Harrison & Davis, 2000). Due to their reliance on others for mobility, the lives of some young people with disabilities may lack spontaneity and choice about their preferred activities (Oldham & Beresford, 2000).

Research has rarely related bodily events to the personal meaning of home (Imrie, 2004). It has long been recognised that access to space in the home is made possible through the body (Merleau-Ponty, 1962). The physical body is seen by many as the major symbol of a person (Crossley, 2001; Ellis, 2000; Shilling, 1993). As Merleau-Ponty (1962, p.150) stated, “I am not in front of my body, I am in it, or rather I am it”. Home is the site that is most focused on the care of the body (e.g., washing, grooming, and dressing). The physical home environment can be separated into areas where particular bodily functions occur and are accommodated. Bathrooms function as places to wash and groom the body, lounge rooms provide space for physical interactions, and physical recuperation takes place in the bedroom (Imrie, 2004). Although these physical segregations can differ across homes, they represent a broad social and cultural message that speaks of appropriate and legitimate bodily use of space (Imrie, 2004). Thus, the meaning of home is produced through the body and its relationship with space, reflecting a complex interplay between the physiological and socio-cultural messages (Imrie, 2004). However, people with disabilities often experience physical places that do not accommodate their physiological needs, creating ‘disembodied spaces’ (Imrie, 2004).

When disability necessitates the provision of care services, particularly medical or adaptive equipment, in the home, routine activities and the established meaning of
home can be disrupted (Ruddick, 1995; Tamm, 1999 cited in Dyck et al., 2005). In this situation, the home space becomes a workplace for paid caregivers. Therefore, the provision of care services disrupts the meaning of home and challenges not only the person’s privacy, but also renders vulnerable their identity (Dyck et al., 2005). This complex dynamic highlights the need for ensuring that individuals have their care needs met safely at the same time as maintaining their control over the environment, and the sense of identity they gain through that place.

**The Subjective Meaning of Home**

There are a multitude of approaches to understanding the concept of home. However, most definitions acknowledge that home is situated first and foremost in physical space. In early research on home, Bachelard (1969) recognised the association between physical place and home, describing home as “a key element in the development of people’s sense of themselves as belonging to a place” (p. 72). Proshansky, Fabian and Kaminoff (1983) contended that “without exception, the home is considered to be the ‘place’ of greatest personal significance” (p. 60). Furthermore, Heidegger claimed that the home is “the key location in which a spiritual unity is formed between humans and things” (McDowell, 1999 as cited in Easthope, 2004, p.135).

Stedman’s (2002) research demonstrated that the meanings ascribed to a place are important determinants of attachment, satisfaction and behaviours. Thus, the physical place is a centre where meaning is constructed (Tuan, 1977). This sense of place can be seen as an individual’s or group’s collection of symbolic meanings, satisfaction with, and attachment to a spatial setting (Stedman, 2002). Satisfaction is derived from the functional capacity of a place to meet a range of basic needs including
services, sociability and physical characteristics (Stedman, 2002). As Ridgway, Simpson, Wittman and Wheeler (1994) stated:

Empowerment is often found in the details of the mundane world. It comes from controlling access to personal space, from being able to alter one’s environment and select one’s daily routine, and from having personal space that reflects and upholds one’s identity and interests (p.413).

However, it is believed that a person can be satisfied with the features of a place while not necessarily being attached to that place (Mesch & Manor, 1998). Indeed, home is not understood simply as a physical entity, dependent only on the structure of a building or the built and natural environment surrounding that building (Easthope, 2004). Although homes are located in particular places, it is not the location itself that is home, rather homes can be understood as significant places that hold considerable psychological, emotional and social meaning for people (Easthope, 2004). It is only when meaning is given to a place that it becomes a home (Easthope, 2004).

The meaning of home for the person relates to a combination of experiences, identity, relationships and a sense of belonging in the world (Korosec-Serfaty, 1985; Twigg, 1999 cited in Dyck et al., 2005). Meaning is obtained through the control of physical space in two major ways, personalising and defending (Porteous, 1976). Personalising the physical space allows expression of identity and a means of providing stimulation. The personalised space, in turn, further promotes identity, which is valued due to its implication of freedom and self-determination. The defending of space achieves stimulation and assures security. Not taking into account personal bodily space, more effort is spent by average citizens defending and personalising the home than any other fixed physical space. Both physical security and psychic security can be attained through the home. Generally recognised security measures, including rituals such as knocking on the door or ringing the bell when entering another person’s home, are seen as vital. The home is used for sleeping, grooming and sexual behaviour,
activities that divert attention from external threat, therefore leaving individuals more vulnerable to any negative actions of others. For this reason, the home becomes a protection during times of vulnerability (Porteous, 1976).

According to Dupuis and Thorns (1996), home can also provide the experience of ontological security when four conditions are met, namely, 1) the home is a constant place within the material and social environment, 2) the home is a space in which the daily routines of life are performed, 3) the home is a place where a person has the most control over their life due to being free from the scrutiny of the modern-day world, and 4) the home is a safe foundation from which identities can be constructed. Ontological security is seen as a sense of continuity and order in relation to an individual’s experiences, and is contingent upon a person being able to give meaning to their life (Giddens, 1991). Thus, although home is defined through its physical and social space, it is the psychological experience of that space that determines the extent to which a place is likely to be considered a home. A broad analysis of the literature on home was undertaken by Despres (1991), who identified ten qualities that influence the meaning of home (see Table 2). These ten qualities, when all present impact on a person’s sense of home. It is easy to see that home is the fundamental basis of a diverse and significant range of activities.

Home may become increasingly significant for people whose broader geographical and social worlds have decreased in size due to chronic illness or mobility issues (Dyck, Kontos, Angus, & McKeever, 2005). Annison (2000) noted that the concept of home contained many features. Although no single feature alone enables the realisation of a true home, the absence of any one of these features may transform the space into a non-home. Other researchers have also described the sense of home as having three components: the physical setting, human activities, and psychosocial
processes (Brandenburg & Carroll, 1995; Relph, 1976, 1997). Saunders and Williams (1988) posited that home was a mixture of the physical house and the social household, thus making home a socio-spatial entity. Porteous (1976), however, argued that a number of psychological territorial provisions are also satisfied through home, namely identity, security and stimulation. Sixsmith (1986) promoted a tripartite model of home encompassing three experiential modes; the “physical home”, the “social home” and the “personal home” (see Table 3).

The physical home takes into account the physical structure, architectural style, spatiality, extent of services and the work environment. The emotional environment, the type and quality of friendships, and friends and entertainment are components of the social home. The social home is a place to share with others, to relate, and to feel love and acceptance. Home as a centre of meaning is reflected in the concept of the personal home. At this level, home is seen as the reference point in life, fundamentally emotional in nature. The personal home encompasses feelings of happiness, responsibility, belonging, critical experiences, self-expression, privacy, permanence, meaningful places, time perspective, knowledge and preference to consistently return to the same place. Sixsmith’s model of home highlighted that it is the subjective experience of a place that transforms the physical and social features of the environment into a home.

Smith (1994) identified a number of attributes that contributed to a sense of home, as well as attributes that led environments to not be considered as homes (see Table 4). The ‘non-home’ attributes were the mirror image of those attributes that contributed to the sense of home (e.g., lack of personal freedom and privacy). These attributes confirm the dependence of ‘home’ on a safe and suitable physical
environment, positive social interactions and a personal sense of control and choice within that environment.

Table 2.
Despres (1991) 10 general categories of ascribed meaning of home

<table>
<thead>
<tr>
<th>Home as:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <strong>Security and control</strong> in the sense of the individual’s feeling in control of the area and physically secure</td>
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<tr>
<td>2. <strong>A reflection of one’s ideas and values.</strong> How people see themselves and want to be seen by others</td>
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<tr>
<td>3. <strong>Acting upon and modifying one’s dwelling.</strong> The extent to which the home provides a sense of achievement, a place for self-expression and/or freedom of action</td>
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<tr>
<td>4. <strong>Permanence and continuity.</strong> This meaning marries the concept of home with the time dimension whereby home may be a place of memories or an environment which has become intimately familiar over a period</td>
<td></td>
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<tr>
<td>5. <strong>Relationships with family and friends:</strong> i.e., a place to strengthen and secure the relationship with the people one cares for. Home is perceived and experienced as the locus of intense emotional experience, and as providing an atmosphere of social understanding where one’s actions, opinions, and moods are accepted. Ideas such as a place to share with others, to entertain with relatives and friends, and to raise children, are related to this dimension</td>
<td></td>
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<tr>
<td>6. <strong>Centre of activities.</strong> These activities may be related to simple physiological needs such as eating or they may include pastimes or the support of other activities conducted away from the home such as work or sport</td>
<td></td>
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<tr>
<td>7. <strong>A refuge from the outside world.</strong> This relates to the need for privacy and independence; the need to “get away” from external pressures and seek solace or at least be able to control the level and nature of demands upon one</td>
<td></td>
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<tr>
<td>8. <strong>An indicator of personal status.</strong> “Although ranked among the least important categories of meaning for the home, it is relatively important for people that their home show their economic status, status being mostly understood by individuals’ socio-economic position” (p. 99)</td>
<td></td>
</tr>
<tr>
<td>9. <strong>Material structure</strong> including not only consideration of the physical attributes of the actual dwelling and its aesthetic features, but also the physical characteristics of its surrounds and the neighbourhood</td>
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<tr>
<td>10. <strong>A place to own.</strong> Ownership is imbued with connotations of freedom, permanency, pride and significant economic investment</td>
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(Adapted from Despres, 1991, pp.98-99)
Table 3.
Sixsmith’s categories of interdependent meanings attached to the concept of home

*The “Physical Home”*
1. **Physical structures** - enduring physical characteristics
2. **Extent of services** - lighting, heating, household equipment, garden, telecommunications, etc., are sometimes seen as a necessary part of home
3. **Architectural style** - some homes were meaningful because of their architectural style
4. **Work environment** - working at home is sometimes a defining aspect of home
5. **Spatiality** - spatial properties, the activities that those spaces allow, and their location, are an important aspect of home for some people

*The “Social Home”*
6. **Type of relationship** - type of relationship and personal choice over being with particular people is the essential focus of this category
7. **Quality of relationships** - the quality of relationships
8. **Friends and entertainment** - people visiting the home who form the core of social entertainment in the home
9. **Emotional environment** - a place where there is love often signifies a home

*The “Personal Home”*
10. **Happiness** - the experience of happy events and general feelings of happiness are an integral part of home
11. **Belonging** - comfort, relaxation, familiarity contribute to a sense of belonging to home
12. **Responsibility** - stability arising from ownership and responsibility for the home
13. **Self-expression** - behaviour in and manipulation of the place are closely tied to ideas of home
14. **Critical experiences** - learning to be independent, formative experiences, lived through stressful periods generate deep associations with home
15. **Permanence** - the continuity of home
16. **Privacy** - being able to control your interpersonal world by having the level of privacy desired
17. **Time perspective** - places exist as home whether in the past, present or future
18. **Meaningful places** - because of specific but not necessarily critical events taking place there
19. **Knowledge** - tied to familiarity, this aspect of home emphasises physical and social knowledge
20. **Preference to return** - i.e. in terms of a locus in space

(Adapted from Sixsmith, 1986, p.287)
Table 4.
Smith’s (1994) contributors to (A) a sense of home and, (B) non-home

<table>
<thead>
<tr>
<th>A</th>
<th>Contributors to a sense of home</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Suitable physical environment</td>
</tr>
<tr>
<td>2.</td>
<td>Positive social relationships</td>
</tr>
<tr>
<td>3.</td>
<td>Positive atmosphere engendering feelings of warmth, care and cosiness</td>
</tr>
<tr>
<td>4.</td>
<td>Personal privacy and freedom</td>
</tr>
<tr>
<td>5.</td>
<td>Opportunities for self-expression and development</td>
</tr>
<tr>
<td>6.</td>
<td>Sense of security</td>
</tr>
<tr>
<td>7.</td>
<td>Sense of continuity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B</th>
<th>Contributors to non-home environments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Lack of personal freedom and privacy</td>
</tr>
<tr>
<td>2.</td>
<td>Dissatisfaction with the internal social relationships</td>
</tr>
<tr>
<td>3.</td>
<td>Poor physical environment</td>
</tr>
<tr>
<td>4.</td>
<td>Negative atmosphere within the home</td>
</tr>
<tr>
<td>5.</td>
<td>Lack of personalisation</td>
</tr>
<tr>
<td>6.</td>
<td>Lack of permanence</td>
</tr>
<tr>
<td>7.</td>
<td>Lack of security</td>
</tr>
<tr>
<td>8.</td>
<td>Lack of ownership</td>
</tr>
</tbody>
</table>

(Adapted from Smith, 1994, p.42)

Quality of life benefits have been found to only accrue when the full features of home were present. Therefore, it is necessary to ensure that service providers take into account this multi-faceted character of home when providing accommodation for people with disabilities. We need to understand the environment more in order to ensure a holistic view of home. Each of these environments (i.e., physical, social and psychological) will be reviewed in more detail below.

The Environments

**The physical environment.** For many decades, negative outcomes, such as declines in physical health, depression, and maladaptive behaviour, have been hypothesised as being a result of incongruence between an individual’s needs and desires and the environment in which they resided (Kahana, 1982; Lawton &
Nahemow, 1973). Following a relative hiatus in the literature, the physical environment is again emerging as an important predictor of psychosocial and health outcomes (Sloane et al., 2002). For instance, in long-term care settings for people with dementia, environmental factors have been related to intellectual deterioration (Annerstedt, 1994), agitation (Nelson, 1995; Sloane et al., 2002) and mobility restriction (Day, Carreon, & Stump, 2000). Although these areas are of importance, factors such as the social nature and meaning of a place can be overlooked.

The idea that architecture and the physical environment can influence a person’s behaviour is not new (Festinger, 1951; Ittleson, Proshansky, & Rivlin, 1970; Sommer, 1969). Many features of the physical environment have been investigated in terms of their contribution to the sense of home and the quality of life it can deliver. For instance, the arrangement of physical features may enhance adaptive competence and quality of life (e.g., appliances located in ways that increase ease of use), or decrease destructive behaviour (e.g., appliances that are easy to operate, but difficult to dismantle). Behaviour may also be influenced indirectly by the symbolic effect of certain physical features. For example, the physical environment can shape people’s interpretation of events within a particular setting (Robinson, 1986, as cited in Thompson, Robinson, Graff, & Ingenmey, 1990).

Thompson et al. (1990) investigated the degree to which residential settings were judged to be home-like or institutional to identify the important features. Participants (30 undergraduate psychology students) independently images of each setting in terms of home-likeness, on a scale from 1 (home-like) to 5 (institutional). The ratings differed significantly across the 11 residential settings, $p < .01$. There was a high correlation $r = 0.98$ between the residential capacity of a building and the overall home-likeness rating $r = .98$, with larger residences being more likely to be rated as
institutional. All but one of the disability residences were perceived as being distinct from the non-disabled housing. A university dormitory, two buildings for people with disability located on the grounds of a state residential facility, and an acute community hospital were rated as being most institutional. In contrast, two private homes, a private family apartment and an 8-person disability group home were rated as being most home-like. Furniture position was the feature most highly correlated with home-likeness \((r=.904)\). Given that furniture is the most readily changeable feature within most settings (Thompson et al., 1990), this finding indicates the importance of being able to modify one’s environment to create home-likeness. This study also highlighted the fact that people make rapid impressions of the physical features of home.

Smith (1994) argued that home is the most fundamental and powerful of all physical environments. To be able to achieve important personal and social activities that characterise ‘home’ and contribute to quality of life, people need to have near-total control over that physical environment. If this is the case, it is important for us to explore how we can provide home-like environments for people whose disabilities detract from the control they have over their environments.

**The social environment.** A consistent finding in the research regarding young people in residential aged care is their lack of social interaction and community participation (Cameron et al., 2001; Winkler et al., 2006; Winkler, Sloan, & Callaway, 2007). Studies have confirmed that social contact and human relationships are important predictors of the quality of life of residents in institutional care (Kelley, Specht, & Maas, 2000; Kelley, Swanson, Maas, & Tripp-Reimer, 1999). Patterns of behaviours that may have a direct consequence for physical and mental health can be shaped by the social context and social interactions in which a person engages (Mendes de Leon, 2005). A positive correlation has been found between different aspects of
well-being and the quality of one’s social relationships (Pinquart & Soerensen, 2000; Tomaka, Thompson, & Palacios, 2006). Regardless of setting, friendships have been found to be an important predictor of well-being among older adults (Aday, Kehoe, & Farney, 2006; Payne, Mowen, & Montoro-Rodriguez, 2006; Silverstein, Chen, & Heller, 1996). Indeed, it is plausible that friendships and social interactions may take on more importance when non-related individuals reside in the same place and have regular contact (Street, Burge, Quadagno, & Barrett, 2007).

A study conducted by Street et al. (2007) examined the impact of social relationships, among other factors, on measures of subjective well-being. Data was obtained from 384 cognitively-intact residents of a supported living accommodation, aged 65 years and over. It was expected that higher resident contact with outside family and friends would be associated with higher well-being, also higher well-being scores were expected for residents who had friends within the living environments and for those residents with positive staff relationships. Social relationships were split into two categories, namely external and internal. External relationships included: family contact, (e.g., “How often do you speak on the phone with family?” and “How often does a family member visit you?”); and friend contact (e.g., “Do you have regular contact with friends that do not live here?”). Internal relationships included five items focused on interactions with other residents and staff (e.g., “Have you met residents here with similar interests to yours?” and “Do you feel that you have friends among the staff?”).

Analysis revealed that although there was no significant impact on life satisfaction of contact with family and friends outside the living environment, significantly higher levels of life satisfaction were associated with positive internal social relationships (Street et al., 2007). Further, residents who perceived themselves as
having friends within the living environment and positive relationships with staff were more likely than those without to report stable or improved quality of life than residents without those relationships. The social relationships within the living environment were, therefore, important to well-being (Street et al., 2007).

Studies conducted with nursing home residents have found that new relationships are formed between residents and care providers within the new care environment (Bitzan & Kruzich, 1990; McGilton & Boscart, 2007; Nussbaum, 1991). Relationships that are established in long-term care environments between residents and care providers are likely to be complex at both the personal and professional levels. Depending on their quality, these relationships may significantly impact residents’ and care-providers’ satisfaction (Messier-Mann, 1995). In an informal, friendly and supportive atmosphere, where there is mutual respect, close relationships may develop (Messier-Mann, 1995) and it is believed that through these facilitative relationships, residents can be encouraged to exercise control and enhance their autonomy and self-esteem (Clark & Bowling, 1990).

Indeed, some studies have confirmed that therapeutic relationships are developed between residents and care providers (Li, 2004; Morse et al., 1992; Nussbaum, 1991) and that these relationships can demonstrate psychosocial care, mutuality (Li, 2004), reciprocity and commitment (Morse et al., 1992), and a level of closeness (Bowers, Fibich, & Jacobson, 2001). In contrast, other studies have reported that the relationships established between residents and care providers seem formal and tend to exist only out of necessity (Iwasiw, Goldenberg, Bol, & MacMaster, 2003; Powers, 1992). These relationships lack close emotional attachments (Pietrukowicz & Johnson, 1991; Robbins, Lloyd, Carpenter, & Bender, 1992). Although clinical observations have suggested the existence of meaningful relationships between
residents and care providers in long-term care facilities (McGilton & Boscart, 2007), mixed findings suggest that how these relationships are perceived by the different parties may be contradictory.

To explore how close resident-care provider relationships are defined within the long-term residential care setting in Canada, McGilton and Boscart (2007) interviewed 25 residents (majority over 86 years), 25 family members including spouses, sons and daughters and 36 care providers (mostly female (85%), including registered nurses (6), licensed practical nurses (15), and health care aides (15)). The majority of residents and care providers had been at the units for more than four years. The average age of care providers was much less than the residents (45 years), reflecting the expected age differential within the aged care setting.

Residents and care providers were asked whether they perceived themselves to be in a close care provider-resident relationship and why they felt the relationship was close or not close. Residents were asked to comment on the care provider who most frequently cared for them and care providers were asked to comment on each resident to whom they were permanently assigned (maximum of four residents). Family members were asked whether they felt their family member was in a close relationship with the care provider who cared for their relative most frequently (McGilton & Boscart, 2007, p. 2151).

The definition of a close resident-care provider relationship was different for residents, family members and care providers. Residents’ definitions were based on the behaviours and caring attitudes of care providers, whereas the extent to which care providers’ behaviours had a positive effect on their relatives determined the level of closeness perceived by family members. Care providers’ perceptions of closeness were linked to the emotional connection they felt with residents and the level of reciprocity in
the relationship. Although all groups raised the need for connectedness, care providers mentioned the barriers created by workload and inadequate staffing levels (McGilton & Boscart, 2007).

Although the quantity of interactions may be limited for residents, there is some evidence to suggest that the quality of the interactions may be more important. For instance, De Veer and Kerkstra (2001) found that negative social interactions can be detrimental to well-being. In their study of 686 residents and family members at 36 nursing homes, four variables were examined, namely having choice and control over one’s own activities and schedules, nurses’ attitudes towards residents, the amount of disturbance created by other residents, and the extent to which the physical characteristics of the building allowed privacy.

Residents who did not feel at home desired more opportunities to be on their own and felt nurses’ attitudes were less resident-centred than those who did feel at home. They also reported feeling disturbed by other residents more often. Residents who had the opportunity to spend time alone and personalise their own area within the environment reported feeling more comfortable (de Veer & Kerkstra, 2001). However, the quality of interpersonal relationships with nursing staff appeared to be fundamental to the overall experience of the nursing home.

Differences were reported between residents with physical illness and mental illness, the former reporting feeling less at home and wanting more privacy, flexibility of routines, resident-centredness and changes to the physical building. However, for the majority (95%) of residents with mental illness, data were collected through proxy-interviews with a significant other (usually children), which may have resulted in an underestimation of their needs (de Veer & Kerkstra, 2001). Nevertheless, this study raises the possibility that the social aspects of home may differ across disability groups.
Emerson and McVilly (2004) conducted a study of friendship activities among adults with ID and found that the residential setting was more significant than the characteristics of individuals themselves as a determinant of the type and content of activities in which people participated with friends. Robertson et al. (2001) found that a range of variables was associated with variation in the size and composition of a person’s social network, including the type of previous and current accommodation, institutional atmosphere, staff-resident ratios, and the existence of active support for residents to engage in social activities. Although the study was conducted with adults with ID, it draws attention to the relevance of the physical environment and its impact on their social networks. The social activities undertaken at home usually involve significant family rituals such as birthdays, celebrations of achievements and spiritual or religious holidays, making home a central place (Rousch & Cox, 2000). For people with severe disabilities who have no or limited capacity to go out into the community, the significance of home increases as it becomes the sole place for their personal and social life (Rousch & Cox, 2000).

Although most studies have focused on elderly nursing home populations, these findings may be even more profound for young people. Young people with acquired disabilities and complex health needs are likely to have regular and ongoing contact with their care providers. However, their contact with family and friends may decline dramatically after admission to long-term care (Winkler et al., 2006).

**The psychological environment.** Ginsberg (1998) believes that ‘human beings are home-makers’ and that home serves an important psychological function in how we live, as the following quote highlights:

We make our homes. Not necessarily by constructing them, although some people do that. We build the intimate shell of our lives by the organization and furnishings of the space in which we live. How we function as persons is linked to how we make ourselves at home. We need time to make our
dwelling into a home…Our residence is where we live, but our home is how
we live (p.31).

The psychological domain of home was explored almost two decades ago by
Giuliani (1991) who defined home as an emotional space with emotional connotations
that determined the extent of attachment (Giuliani, 1991). Gurney (2000) described the
home as:

An emotional warehouse wherein grief, anger, love, regret and guilt are
experienced as powerfully real and, at the same time, deposited, stored and
sorted to create a powerful domestic geography, which, in turn sustains a
complex and dynamic symbolism and meaning to rooms and spaces (p.34).

The home is symbolic of an individual (Sixsmith & Sixsmith, 1991). It is an
important symbolic source for the construction of an individual’s identity (Laws, 1997,
as cited in Dyck et al., 2005). Home can be seen as a reflection of an individual’s
values and views (Lewin, 2001) and holds biographical meaning for its residents, which
is found in decorative items, furniture, memorabilia, and personal belongings (Rowles,
1993). Emotionally charged memories of relationships with others and experiences
throughout life are held in the objects surrounding an individual (Csikszentmihalyi &
Rochberg-Halton, 1981). The symbolic value attached to the familiar objects in
someone’s home allows the past to be closely linked with the present (Tamm, 1999).
Rose (1995) stated that particular qualities of a place symbolise how individuals define
themselves and that a sense of place comes from the feeling of belonging and comfort in
a place (as cited in Easthope, 2004).

Molony [unpublished manuscript] conducted a study using an interpretative
phenomenological method to provide insight into the structure of the meaning of home
for older adults. Seven older adults provided rich descriptions of their experiences in
owner-occupied homes or congregate housing. Experiential narratives from the older
adults were analysed to reveal four key dimensions of the experience of home:
atmosphere, separation, connection and dynamic transaction. Atmosphere included feelings engendered by the experience of home, such as: relaxation, comfort, belonging, familiarity, understanding, acceptance, forgiveness, freedom, strength and identity.

Dynamic transaction referred to home as a place of dynamic interchange, anticipation and memory. A place where a person was cherished, cared for, respected, sustained, nourished, empowered and emancipated. Separation was provided by home, it was the boundary between public and private space, giving a person choice in who they invited in and who they kept out.

Home was found to be a place of connection and continuity. The provision of physical objects provided connections to personal history, family, friends and events. Home connected people to others with a shared language, shared experiences and shared history. It provided a connection to a sense of self. Molony posited that an understanding of the meaning of home may be useful in developing a model that can create a healing caring environment. She suggested that further development of the concept of home is warranted in order to build appropriate theories.

In the disability area, O’Brien (1994, as cited in Annison, 2000) defined the psychological aspect of home for people with ID as consisting of three components: 1) a sense of place, including comfort; choice about use of time, routines, money; personal security; safety; socially valued roles (e.g., neighbour or tenant); provision of privacy; physical and emotional base; opportunities for hospitality; 2) control over the home and the necessary supports for living there, including choice of place; choice in who you reside with; some control over number of residents; control over staffing and resources; 3) security of place through tenancy or ownership, including ownership pride; personal security and stability; valued social role of home owner. In contrast, O’Brien identified a number of residential setting characteristics that were non-home like, and advocated
for the removal of such features to enable residential settings to be transformed into homes.

**The Current Study**

In summary, the literature has highlighted the inappropriateness of accommodating young people with disabilities in residential aged care facilities, as well as the benefits of moving people out of institutionalised care. The physical, social and psychological nature of home has been outlined and links made to the influence on individual’s well-being. However, questions regarding the meaning of home, the essential elements of home, and how such elements can be incorporated to enable the provision of homes rather than care facilities remain unanswered (Annison, 2000).

This exploratory study was based on a new residential accommodation designed specifically to provide a more appropriate and dignified lifestyle within a homely environment to young people with severe disabilities and complex chronic healthcare needs (i.e., MS and ABI). The research was conducted in accordance with Interpretative Phenomenological Analysis (IPA; Smith, 1996). IPA has been developed to ensure that in-depth and rich information regarding individuals’ lived experiences is gained from naturalistic, unstructured data. It provides the ability to discern multiple perspectives on the same topic and to recognise the complexities and diversity of different experiences. By adopting this method, the study was able to give voice to the service users and ensure that their concerns remained paramount. Using the framework of IPA, the study aimed to explore residents’ experiences of the physical, social and psychological environment at the residential apartments. The study examined multiple domains of home as they were experienced over time through a series of semi-structured personal interviews conducted with residents at their apartments. The
The purpose of the study was to understand the residents’ ‘lived experience’ within the residential apartments, and specifically to answer the following questions:

1) How do residents experience home within a residential care setting? and;

2) What influences their sense of home?

The following chapter will outline the method of the study and provide information regarding the residential setting. Chapter Four will introduce the reader to the participants through the use of case summaries, and this will be followed by Chapter Five where the results that evolved from the IPA analysis will be outlined and discussed. Chapter Six will provide a discussion of the findings including implications for practice, limitations of the study and suggestions for future research.
Chapter Three: Method

To work collaboratively with service users and be committed to a person-centred approach, the stories provided by young people with disabilities need to remain at the forefront of research. Without an understanding of their experiences, we run the risk of delivering inadequate or unhelpful care and support (Cohen, 1991). Allowing individuals the opportunity to express their feelings, desires and beliefs, and understanding these expressions can provide an effective way to inform service providers, thus assisting them to be more responsive and flexible (Cohen, 1991; Keady, Nolan & Gilliard, 1995).

This qualitative study explored how the participants experienced home within a residential care setting and what influenced their sense of home. The framework of IPA was used to guide the study. In reporting these results, I chose to use numerous excerpts from the transcripts in order to give voice to the participants as much as possible. This allows the reader to clearly see the basis of my interpretations, a process that is important to interpretative rigour. Permission to present this information at this personal level was given by the residents. To enhance anonymity, participants chose a different name, and any identifying features were changed or obscured unless doing so had a significant impact on the results of the study. The name of the residential setting was changed to “Mei Domus” to prevent identification. Although effort was taken to preserve anonymity, the setting was likely to be identified by those working in the field. Thus, participants and the organisation were fully informed regarding the potential for identification.

Philosophical Approach

IPA was developed by Smith (1996) as a qualitative approach to explore in-depth how people describe and make sense of their personal and social experiences.
Initially used purely in Health Psychology, IPA is now being more widely used in diverse areas of research, such as disability, health and illness (Bramley & Eatough, 2005; de Visser & Smith, 2006; Howes, Benton, & Edwards, 2005; Reynolds & Prior, 2003; Swift & Wilson, 2001); mental health, bereavement, and loss (Chappell, Eatough, Davies, & Griffiths, 2006; Clare, 2003; Eatough & Smith, 2006; Harris, Pistrang, & Barker, 2006); identity (Lavallee & Robinson, 2007; Pearce, Clare, & Pistrang, 2002; Riggs & Coyle, 2002; Smith, 1999); counselling and therapy (Midgley, Target, & Smith, 2006; Schoenberg & Shiloh, 2002); reproduction and parenting (Harris & Lindsey, 2002; Johnson, Burrows, & Williamson, 2004; Seamark & Longs, 2004); sexuality (Alexander & Clare, 2004; Flowers, Duncan, & Knussen, 2003; Free, Ogden, & Lee, 2005); genetics (Chapman, 2002; Michie, Smith, Senior, & Marteau, 2003; Smith et al., 2006); and health professionals and practitioners (Carradice, Shankland, & Beail, 2002; Epstein & Ogden, 2005; Whittington & Burns, 2005).

The experience of living within a new environment cannot be fully understood from any perspective other than that of those who have experienced it. This research is based on an approach that emphasises the meanings participants ascribe to their experiences. IPA gives voice to the residents who are living the experience and whose concerns must stay at the forefront of the research (Auerbach & Silverstein, 2003; Grbich, 2007). In contrast to more structured approaches, such as content analysis where qualitative data is reduced to discrete categories and analysed quantitatively, IPA produces a detailed interpretative analysis of the themes alluded to in the data, retaining the importance of the narrative description. IPA can be particularly useful when the research is concerned with complexity, novelty and process (Smith & Osborn, 2008).

IPA is underpinned by phenomenology. Phenomenologists believe that an account of first-hand experience is necessary in order to understand the ‘psychological
essence’ of human phenomena (Giorgi, 1997). The philosophical ideas of Husserl (1936) generated the descriptive phenomenological approach to scientific inquiry (Cohen, 1987). He noted that little critical reflection took place as people went about their daily lives and believed it was important to develop a scientific approach that enabled us to understand the essential components of these lived experiences (Lopez & Willis, 2004). In order to understand the fundamental lived experiences of others, Husserl believed that researchers must discount their prior personal knowledge and suspend any assumptions (Lopez & Willis, 2004). Husserl viewed humans as free agents who were responsible for influencing their culture and environment. The impact of society, culture and politics on this freedom to make choices was not central to his theory (Cohen & Omery, 1994).

In contrast, Heidegger (1962) challenged some of Husserl’s assumptions about meaningful inquiry and, subsequently, developed a hermeneutic, or interpretative, research tradition (Cohen, 1987). In the study of human experiences, hermeneutics extends beyond the description of central concepts to the meaning that is derived from experiences (Lopez & Willis, 2004). Heidegger emphasised that individuals are always engaged in their world and, therefore, influenced by the world in which they live. He recognised that all subjective experiences were linked to the social, political and cultural contexts in which they occurred. Heidegger (1962) also recognised that it was unachievable for researchers to engage in research without having their own understanding and beliefs about a particular topic. Within IPA, prior knowledge and presuppositions brought to the research by the researcher are seen as valuable guides to the investigation of the particular phenomena (Lopez & Willis, 2004).

The underlying epistemological position of IPA is that whether or not something is “real” is not dependent on an individual, but on the meaning ascribed to each
experience. Thus, reality is entirely personal and subjective (Smith & Osborn, 2003). The meaning of an experience becomes fundamentally more important than its objective qualities. The key research questions focus on what ‘something’ is like for the individual and “the meanings that subjects with their acts of consciousness bestow on the referents” (Giorgi, 1995, p. 36). IPA recognises people as cognitive, affective, linguistic and physical beings and assumes a connection between what people say and their emotional and thinking states (Smith & Osborn, 2003). Thus, experiences should be accessible through narratives provided by those at the centre of the experience. However, IPA also acknowledges that this connection between experiences and their expression is complex and that people may struggle with or resist expressing what they are thinking. The researcher, therefore, has a role in accessing, gathering and interpreting a person’s emotional and mental state and making inferences from what is being disclosed (Smith & Osborn, 2003).

Within phenomenological research, the customary method of data collection has been in-depth interviews, providing a narrative account of the individual’s knowledge and experience of the topic under investigation. These accounts give us insight into the subjective experiences of each individual (Lopez & Willis, 2004). They are then analysed by the researcher to produce core themes that describe and interpret the collective experience across a range of participants. Qualitative interviews allow a deeper understanding from the perspective of the people within the environment, and an in-depth appreciation of subtle processes that would be hard to achieve through other methods. This approach provides a deep understanding of a particular phenomenon from the perspective of those most involved, as well as giving the ability to discover central themes and issues that affect the majority (Richards & Morse, 2007).
The IPA researcher has two aims in mind when approaching analysis, namely description and interpretation. There are fundamental differences between descriptive and interpretative approaches to the data (Lopez & Willis, 2004). The first aim of IPA is to understand and describe what the participants’ world is like from their perspectives, which leads to a focus on experiences of particular situations, relationships or processes (see Chapter Four). The second aim of IPA is to develop a more explicit interpretative understanding of the experience and to position the initial description in relation to its broader social, cultural and theoretical context (Larkin, Watts, & Clifton, 2006) (See Chapter Five).

This interpretative analysis allows the researcher to be more speculative when dealing with the data and to reflect on what it means for participants to have expressed their concerns and feelings about a particular situation. Interpretation is likely to be informed by the researchers’ own engagement with existing theoretical concepts or experiences (Larkin et al., 2006). IPA recognises the dynamic nature of the research process (Smith, 1996) and acknowledges that accessing the personal world of another individual depends on and is influenced by the researcher’s own ideas during the course of interpretative activity (Smith, Jarman, & Osborn, 1999). Therefore, IPA involves a two-stage process of interpretation, or double hermeneutic, in that the joint reflections of both participants and researcher influence the data during its collection and analysis.

The Setting

**Background.** This study focused on a specific residential setting, ‘Mei Domus’, that was established under the Younger People with a Disability in Residential Aged Care initiative. The residential apartment building that forms the basis of this study was amongst the first of its kind in Australia. The apartments were designed to provide long-term supported accommodation for young people, (i.e., less than 50 years of age)
with severe disabilities and complex chronic healthcare needs, such as MS and ABI (see Appendix A for a brief overview of these conditions). The intention was to provide suitable, dignified and appropriate living environments for young people, where they could receive the level of health care they required, yet retain control over their lives to the greatest extent possible.

According to central documents about the initiative, young people with a disability would be able to live their lives as other young people might do in the community, despite their need for high levels of nursing care. This outcome would be achieved through their engagement with family, friends, staff, volunteers, the community and the environment in a manner of their choosing. The young residents would be empowered through the provision of flexible and collaborative support from care providers. Residents would have control around mealtimes, sleep times, and care times. There would be choice and input into how their care was delivered, and what interests they wished to pursue. Support would be available to maintain involvement in these interests over time.

The service delivery model was designed to deliver the five key components identified by the Disability Queensland Accommodation Services initiative 2008, namely:

- to uphold the legal and human rights of each individual with a disability;
- to meet individual needs and goals through the promotion of personal independence and development;
- to encourage and support individuals with a disability to participate as fully as possible in decision making regarding activity choices and daily life events in relation to services received;
• to support and encourage individuals’ participation in the life of the community;
• to recognise individuals’ right to dignity, privacy and confidentiality in all aspects of life.

The residences were designed to be individual, private apartments with access to a number of communal areas. This design provided residents with the choice to maintain their privacy and remain within their own apartments, having all the necessary facilities for sleeping, cooking, personal hygiene and entertainment. Alternatively, they could access spaces within the building where they could spend time with family, other residents and staff. Compared to other residential environments where only a private bedroom area is provided, the apartments were designed to promote residents’ independence and provide a more “home-like” environment.

**The physical environment.** The apartments were built in the grounds of an existing aged care complex, giving residents access to on-site allied health services, such as hydrotherapy, physiotherapy and occupational therapy. However, the apartment complex was located at the far corner of the property with a distinct street address. The two-storey residential apartment building was designed by a commercial architectural firm in consultation with two individuals with MS and an occupational therapist. The building comprised 14 self-contained residential apartments (12 x 1 bedroom, 2 x 2 bedroom). There was a large communal lounge/dining area with plasma television and DVD player, and two communal television areas (one upstairs with a projector screen television and DVD player, and one downstairs with plasma television, DVD player, a Nintendo Wii, and a range of reading material). There was an indoor spa room, a covered outside deck area, grassed areas, herb garden, and a large outdoor barbeque area. The building was surrounded by landscaped gardens which were visible through
the many floor to ceiling louvered windows on the ground floor. In addition, there was an area for staff-use only that included an office, a tea room, a staff toilet and a commercial grade kitchen for preparation of resident meals (for residents who chose to eat communally).

Within the main building, each resident had his or her own private apartment, with the exception of two apartments which were shared. In these shared apartments, each person had a private bedroom and shared living, kitchen and bathroom areas. The private apartments consisted of a bedroom; bathroom with shower, toilet and vanity basin; lounge area; and fully equipped kitchen (oven, stovetop, fridge, microwave, and dishwasher); and an outside courtyard (or balcony for upstairs apartments).

**The social environment.** The intent of the apartment design was that residents could retreat to their own space, but could also engage in communal activities if they desired. The social environment was to be facilitated by both the structural environment (i.e., the presence of communal areas) and the service environment (i.e., commitment to community and family engagement, and support to engage in activities). Organised social events were to be a feature of the environment. For instance, a variety of regular planned activities were to be scheduled, including a session at the gym, an upper limb clinic, pottery class, and a crossword and trivia session. The majority of these activities would take place within the apartment building, except the gym session and the pottery class, which would occur in the community. The communal areas were designed to allow residents and their family and friends to meet for informal social gatherings outside of the resident’s apartment. Individual residents would be able to arrange access to activities occurring in the community by booking one of the apartment vehicles or a taxi. Residents were required to make prior arrangements with staff if their activities necessitated a support worker.
The apartments were to be serviced and staffed separately from the aged care complex, although both were managed by the same large non-profit organisation. During the data collection period, there were 36 staff members employed in the apartments, consisting of 1 manager, 7 registered nurses, 2 endorsed enrolled nurses and 26 assistants in nursing. Staff members were employed on either a permanent full-time, permanent part-time or casual basis. Agency nurses were also used when necessary. Eight staff members covered the morning shifts from 6am to 2.30pm or 7am to 3.30pm. The afternoon shifts from 1.30pm to 10pm or 2.30pm to 11pm were covered by six staff. The night shifts were eight or nine hours in duration (starting at either 9.30pm or 10.30pm) and were covered by two staff.

Services were designed to maintain or re-establish important and meaningful interactions between residents and their families and friends; and provide support for residents to access the surrounding community and resources. The service model was person-centred, family and child friendly, and it allowed individuals to determine their daily routines and activities, as well as allowing opportunities for family, friends and interstate visitors to stay at the apartments.

The residents. At the time of the study, the apartments had been opened for approximately 12 months and were occupied by 16 residents (11 female (69%) and 5 male (31%)). The mean age of residents was 44 years (range: 28 to 57 years). Female residents were aged between 33 and 51 years ($M = 43$ years) and male residents were aged between 28 and 57 years ($M = 46.5$ years). There were a range of diagnoses among the residents, including MS (10), and ABI (6). Residents varied in their levels of functioning and mobility. Six residents were fully dependent on another person to operate their wheelchairs, eight residents were self-driven, and two used a walking stick. Prior to moving into these apartments, ten of the residents had been living in a
residential care setting or a hospital setting. The remaining six residents had been living at home, either alone or with family, but could no longer remain in that setting due to their healthcare needs.

Individuals applied for a place in these apartments, and were accepted or declined on the basis of intake criteria established by an independent assessor in collaboration with the State government disability agency. The intake criteria were not available so it was not possible to determine any systematic bias in terms of how this group of people were identified.

Residents were selected on the basis of their capacity to articulate their thoughts, thus ensuring that they could offer rich information and insights into the phenomenon of interest (i.e., life within the new environment) (Patton, 2002). This decision is consistent with the IPA framework as it is concerned with a detailed account of individual experience rather than a generalised account from a large sample (Smith, Flowers, & Larkin, 2009). Consequently, the selection process was based on the likely contribution of each individual to the exploration of the phenomenon. A decision was made to purposively include residents with ABI in order to explore any differences based on different expected illness trajectories.

**Selection Process**

A purposive sample of seven residents (6 female, 1 male) participated in this study and all seven consented to participate. Five of the residents had a diagnosis of MS and two of the residents had an ABI. Only one male was recruited, as the other males at the apartments had severe communication difficulties. Two males were automatically excluded due to their communication difficulties and two males with ABI were initially interviewed, but they were not able to provide the necessary depth required for this study due to their cognitive disabilities. Three females were also
automatically excluded on the grounds of communication difficulties. Another two female residents declined to participate, and one female resident passed away just prior to the interviews.

**Participants**

The average age of residents who participated was 46 years (ranging from 34 to 58 years). Five of the seven participants had resided in an institutional facility prior to moving to these apartments (i.e., aged or community residential care, or hospital setting). Two participants arrived from a private home where they had been living with family members. Participants varied in their level of functioning and mobility. One participant was fully dependent on another person for wheelchair operation, and six participants were self-driven, with one of the six also being able to use a walking stick at times to aid mobility.

**Ethical Review**

Ethical clearance for the study was obtained prior to the recruitment process through the Griffith University Human Research Ethics Committee (GU Ref No: NRS/07/09/HREC).

**Measures**

Qualitative interviews can provide a useful method of gaining access to individual’s values, attitudes, experiences and understanding that cannot necessarily be revealed through formal questionnaires or observed by a third party (Byrne, 2004). Interviews also assist in the building of rapport with participants which can help maintain participation over time, as well as creating an environment that allows for open and honest answers to questions (Hoyle, Harris, & Judd, 2002). Semi-structured interviews were conducted with residents focusing on their views of the social and psychological environment at the residential apartments (see Appendix B). Semi-
structured interviews were chosen as they ensure coverage of important issues but also give the opportunity for questions to be modified according to participants’ responses. This enables the exploration of important and interesting areas that arise during the interview process. Semi-structured interviewing is flexible, sensitive to varied styles of expression, and provides the opportunity to gain meaning, interpretation and perspective whilst embracing individual differences (Willig, 2001). The interview protocols were developed as a guide rather than a strict structure. General questions were used followed by prompts for use if required. The interview process was led by the residents and I explored topics that were raised during the interviews, rather than following a strict format.

The first round of interviews focused on the new environment and the residents’ experiences within that environment. These semi-structured interviews were conducted during a two month period. The interviews took between 20 minutes and 55 minutes (mean = 36 minutes). The interview questions related to the residents’ experiences and relationships both outside and within the new environment. These questions explored contact with family (e.g., How often does a family member visit you?, How easy or difficult is that here?, and How has this changed since you moved to this accommodation?), contact with friends outside the new environment (e.g., Do you have regular contact with friends that do not live here?, How easy or difficult is that here?, and How has this changed since you moved to this accommodation?), and relationships formed within the new environment with other residents (e.g., Do you regard any of the people who live here as your friends? Why? How is that different from where you were living before?), or staff members (Do you feel that the staff shows affection and caring for you? In what way? How is that different to where you lived before?) (Adapted from Street et al., 2007) (see Appendix B).
The second round of interviews focused on the resident’s psychological meaning of home and their personal experiences of living in this setting. These semi-structured interviews were conducted during a two month period. The psychological environment interviews took between 20 minutes and 1 hour (mean = 42 minutes). The interview questions explored the residents’ thoughts and feelings regarding home (e.g., “What makes somewhere home?”, “What are the things in this environment that feel like home to you?”) and their experience of living at the residential apartments (e.g., I’d like you to tell me what it has been like for you living here over the past [number] months”, “Describe for me what a typical day would look like for you here”) (See Appendix B).

**Procedure**

Prior to conducting the interviews, I visited the residential apartments on a number of occasions and spent time talking with staff, residents and family members. Due to the variation in verbal ability of the residents, information was gained from the Manager regarding the most appropriate way of approaching and communicating with residents. This time allowed me to learn about the individual communication needs and styles of residents, without putting unnecessary expectations on them. Based on the nature of the interactions conducted during these visits, residents were excluded due to their inability to communicate.

Residents were approached individually and invited to participate in the interview process. The purpose of the study was explained to the residents and the opportunity to ask questions was made available. It was made clear at this stage that any participation was voluntary. Once an individual agreed to participate, a suitable appointment time was made; taking into account each resident’s scheduled activities and preferred time of day. During the first scheduled appointment time, participants were given the information sheet and consent form (see Appendix C). This information
was also given verbally to ensure understanding of the reason for the research and the consent process. Participants were then asked to sign the consent form. If a resident was physically unable to sign the consent form, a suitable person was requested to sign on their behalf. This proxy-consent occurred on only one occasion and, in this instance, the consent form was signed by the Manager of the apartments after verbal consent had been given in his presence.

Once consent had been signed, the participant’s permission was sought to audio record the interview before commencing the interview process. All participants were informed that they could discontinue the interview at any time, and that the interviews could be conducted over a number of sessions if required. This option was given to ensure residents were not fatigued by the interview process and also to be sensitive to the emotional state of some residents when discussing their current situation. The interviews with participants were conducted in a quiet area in each resident’s apartment. Participants were given the opportunity to discontinue the interview and continue at a later stage if they appeared tired or distressed. Two participants made use of this option and their interviews were completed over two separate sessions.

Two semi-structured interviews were conducted with each participant at different time periods. The initial interviews were conducted after the first year of operation when residents had been living in the new accommodation for between 6 and 14 months. The second interviews were conducted when all participants had lived at the accommodation for more than twelve months (14 to 22 months). Thus, each participant was contacted twice with a period of eight months in between interviews. This timeframe was chosen for the final interviews because previous research has found that it is only after a period of approximately one year of living within a space, conducting daily routines and arranging possessions, that it becomes a home (Vaughan,
Rousch, & Cox, 2000). Conducting interviews across this time span maximised the knowledge gained from the data about temporal experiences, and assisted in understanding broader contextual influences on the experience of home that are likely to occur over time, such as staff changes, legislative changes, and weather or seasonal variability.

**Analysis**

To ensure accuracy of data, all interviews were recorded on a hand-held voice recorder. In preparation for text analysis, the interviews were transcribed verbatim and entered into separate word document files for each participant. During the initial reading of each transcript, the recording was also listened to in order to ensure accuracy of the transcript, as well as reminding me of the emotional tone of the interview. Each participant’s two interviews were analysed one after the other before moving on to another participant’s interviews. Each randomly-selected set of transcripts was initially examined in-depth at least once, and usually repeatedly, during which time notes were made regarding the content of the interview (see Appendix D). Key points and phrases were highlighted and any questions that arose were noted. The analysis process began by searching for particulars and then gradually working towards generalisations (Smith, 1996). Following the initial basic coding, the transcripts, complete with notes, were re-read and emergent codes were generated and noted in the margins. Once emergent codes were generated, names and segments of transcripts that represented the codes were typed into word processing software.

After each participant’s interviews were coded, key interpretations for each participant were hand written into a notebook. Interpretations were then supported by participant quotes, which enabled repeated checking for accurate representation of participants’ stories. Case summaries were then prepared for each participant; using
quotes from their interviews (see Chapter Four). Throughout this process any emergent themes were discussed with my supervisor to ensure that my descriptions were in fact based on the participants’ interviews. All interviews were completed to this level of analysis before moving on to other participants’ interviews. This process allowed identification of any connections across themes within each case study. Once I became familiar with the codes, emerging interpretations were clustered together into master themes, giving attention to meaning as well as frequency, prior to looking for themes that were evident across all participants (i.e., master themes).

Following this extraction of master themes, a cyclical analysis process was created, where review of other interviews was conducted to seek confirmation or negation of the master themes. This process of contrasting and comparing narratives allowed a preliminary theory to be produced. Broader thematic categories were then produced across the entire dataset, enabling the identification of super-ordinate themes that could account for the majority of the data. At this stage, the process became more interpretative than descriptive, resulting in a theory of the experience of home (see Chapter Five).

Assessing Quality in Qualitative Research

There has been a growing dissatisfaction in the way that qualitative research has been evaluated using the validity and reliability criteria developed for quantitative research. Validity and reliability are considered important considerations within the field of qualitative research (Smith et al., 2009). However, the evaluation needs to be done appropriately to the method used (Smith et al., 2009). Although quantitative concepts, reliability and validity are equally important. In seminal work in the 1980s, Guba and Lincoln substituted validity and reliability with the concept of “trustworthiness,” which contained four sub-concepts: credibility, dependability,
transferability, and confirmability. However, researchers have continued to use reliability and validity in qualitative inquiry in Great Britain and Europe where they are considered highly relevant. As with any research, it is necessary within qualitative research to demonstrate rigour and validity. Yardley (2000) developed four broad principles for assessing quality of qualitative research, however, it should be noted that these are not considered prescriptive requirements (Yardley, 2000).

Yardley’s first broad principle is sensitivity to context. This highlights the importance of considering the socio-cultural environment, relevant existing literature, and the participant data. The current research attended to sensitivity to context in a number of ways. A review of the existing literature in the area of accommodation for young people with disabilities, as well as the underpinnings of the research methodology was conducted. The research prioritised the participants’ perspectives and acknowledged the interactional nature of the data collection. Further, my prolonged engagement with the participants and the resulting data allowed sensitivity to context to be addressed. I spent several hours a week over a prolonged period of time at the apartments, both prior to and during data collection, interacting with residents and staff. This extended time, together with my skills as a clinician, allowed me to establish rapport and show empathy and understanding to the participants. Following data collection, extended time was spent immersed in the data as the interviews were listened to and read over several times, resulting in a high degree of engagement and familiarity.

The second broad principle is commitment and rigour. There is an expectation with IPA that commitment is shown during the data collection and analysis process, in terms of the researcher’s personal investment and commitment to ensuring participant comfort and close attention to the participant’s narrative. At some stages of the research process, this demonstration of commitment can be tantamount to a demonstration of
sensitivity to context (Smith, 2011). Rigour should take into account the appropriateness of the sample used to address the research question, the quality of the interviews and the comprehensiveness of the analysis undertaken. The current study selected a purposive sample from a unique accommodation setting, interviews were conducted sensitively by a trained clinician, and analysis was conducted systematically and thoroughly. The idiographic nature of the data was respected and highlighted within the results, as well as a more interpretative analysis being conducted in order to develop a theory. There was sufficient sampling from the corpus to provide evidence for each theme.

The third broad principle is transparency and coherence. Transparency can be enhanced in IPA research through describing the selection of participants, construction of interview schedules and how interviews were conducted, as well as describing the steps used in the analysis process (Smith, 2011). There should be sufficient transparency for the reader to see what was done, and the analysis should be coherent, plausible and interesting (Smith, 2011). This study provides a description of participant selection, as well as noting why certain residents were not included in the research, information regarding the interview process and an outline of the analysis process. Coherence refers to the presence of a coherent argument and whether themes logically hang together. Coherence can also refer to the consistency between the research conducted and the philosophical assumptions underpinning the approach. The phenomenological and hermeneutic sensibility ought to be apparent in the reporting of the research (Smith, 2011).

In order to enhance rigour, my supervisor independently reviewed the interviews in order to confirm the themes that were derived from the data. Discussion then took place to confirm or disconfirm particular themes, allowing consensus to be reached
about the super-ordinate themes that existed across interviews. My own field notes were also used to verify the interpretations made from the analysis. Observational data was recorded during and immediately after visits to the apartments. These notes included descriptions of the physical environment, observations of social interactions made during the visits and notes about the observed reactions of residents during interviews. These field notes were used as an aide-to-memory during the analysis as they contained details that might otherwise have been forgotten or overlooked.

Yardley’s fourth broad principle is impact and importance, which refers to whether the research provides interesting, important and useful information to the reader. The current study provides a focussed, in-depth analysis of the experience of young people with disabilities living in long term residential care. It provides a detailed examination of the experience of the participants in the study and offers a way of assisting our understanding of this phenomenon, as well as offering some implications and recommendations for practice. The findings from this study have been presented to the sector and the results have been discussed at length with the key providers in the field.

Meet the Researcher

Given that the researcher is an important part of the data in qualitative IPA research and that it is not possible to discount the influence of the researcher on the data collected and analysed, it was considered important to record my own reflections as I conducted this study. Thus, notes were made regarding my thoughts and feelings during and after visiting the residential apartments, as well as any questions or ideas that arose while I was working with the data. Following each visit to “Mei Domus”, I spent some time in my car reflecting on the visit and noting observations of resident and staff behaviours and interactions. These notes became increasingly important as I
commenced the data analysis process and was led back to similar conclusions. They provided a source of collaboration and served to remind me of my own thoughts and feelings during the data collection process. In order to minimise the influence of previous literature on the analysis process, a cursory summary of the literature was conducted some time prior to the data collection. The full literature review was not conducted until after the analysis was completed. This was then considered in more detail and drawn together with the findings from the participant interviews.

Prior to analysis of the data, I spent time reflecting on my own personal experiences and values in relation to the topic under investigation. Within qualitative research it is imperative that any experiences, personal values and assumptions that may influence the data analysis process are identified (Elliott, Fischer & Rennie, 1999; Merriam, 2002). The following journaling was carried out prior to the analysis process.

I am a 41 year old female and a mother of a school-aged child. I was fortunate to have the stability of growing up in the same family home until I chose to leave home as a young adult. I left my home country and moved to Australia, aged 25 years. Following this move I rented various accommodations over the years and always had the sense that I wanted to settle in a place and provide the same stability for my family.

When I first visited “Mei Domus”, I remember thinking that it could just as easily be me living there if I had been diagnosed with MS or had suffered an ABI. I was a very similar age to one particular resident who also had a child of similar age to my own. It repeatedly occurred to me that anyone of us could find ourselves in a similar situation in a country where options for appropriate accommodation are limited. As I spent time at “Mei Domus” and observed the interactions between residents, family and staff and the way in which staff responded to residents, I kept asking myself “What
would it be like if this was my “home”, and I had to be separated from my child?” The thought of ever having to move into an aged care facility was a horrifying one.

I have had two friends diagnosed with Motor Neuron Disease. One friend, Tony, was living in the United Kingdom and was fortunate enough to be cared for by his wife, Maureen. Her love, strength and courage, and the access to adequate services to assist in managing his needs, enabled him to stay living at home until he died. The other friend, Michael, was living here in Australia and unfortunately found himself in the position where he had to move to an aged care facility. I can remember visiting him there in a small cramped room. The room contained a bed, bedside table, small table, chair and a television, and attached to the room was a small bathroom. It was a horrible feeling being there with him and I remember having the sense that I wanted to leave quickly when I was there. Very sadly, he chose to end his life, which I’m sure was impacted by the fact that not only was there no cure for his illness, but the thought for him of living the remainder of his life within that environment was unbearable. These experiences make this project one of personal importance to me. It is just not acceptable that we are accommodating our people in such inappropriate environments. Everyone deserves to be treated with dignity and respect and to live with the best quality of life possible.

Through my professional background as a psychologist, I have an interest in people’s experiences and how through these experiences they make sense of themselves and the world they live in. I also understand the impact that negative experiences can have on an individual’s mental health. I am interested in how we can increase quality of life for people and ensure they can remain connected to their important attachment figures, such as parents, children, partners and friends.
My training in quantitative research methodology, and the strong stance within the field of psychology that quantitative methods were best used to find and disseminate the truth, meant that I had to relearn a new method of analysis. I also had to hold strong to my belief that the words of individuals experiencing a particular event can show us greater depth and meaning than using quantitative methods to assess their experience, and really allow us to understand what is needed.

The influence of my own experiences and my knowledge of the literature on the present study are represented by the following assumptions: home is a subjective experience; home is a complex concept; and home is a place that gives us a sense of belonging (H D Quinn, Personal Reflections, 2011).

It was important for me to ensure that my own experiences, values and assumptions were not influencing the data analysis. I had regular face to face meetings with my supervisor where we discussed thoughts and ideas about the analysis and critically reviewed the themes that were evolving from the data. During these meetings, I raised any issues that I felt were coming from my own personal views rather than the participants’ interviews. Joint analysis of selected interview transcripts was also conducted to ensure that emerging themes were coherent and showed a level of transparency.
Chapter Four: Introducing the Participants

*Home is not where you live, but where they understand you* - Christian Morganstern

The following two chapters present the findings of the current study. In keeping with the two stage process of IPA, this chapter presents the descriptive case summaries for each of the seven residents who participated in the research. It provides important contextual and demographic information about each participant and maintains the essence of each person’s story. The inclusion of these case summaries ensures the idiographic nature of the study is maintained. Through this chapter, each participant is acknowledged as an individual and his or her individual experience is kept at the forefront. Chapter Five then presents the themes and process that evolved from the analysis.

**Lou**

Lou was a female resident and was 34 years of age at the time of the study. Lou was diagnosed with MS in 1999. Lou had a partner but was living separately from him due to her high care needs. Prior to moving to “Mei Domus”, Lou lived in a residential care facility for nearly two years. Prior to the decline in her health, Lou was employed in an administrative capacity for a Government organisation and she participated in a number of sporting activities. Lou reported that when her health permitted, she attended a regular pottery class outside the apartments. She also reported attending a weekly crossword activity and the movies screened weekly at the apartments. Lou used a motorised wheelchair and had been hospitalised on numerous occasions since moving to the new accommodation.

Lou spoke about “Mei Domus” as a place that had allowed her to establish a connection with other people. She had developed relationships with residents who were
close to her in age, and with some of the staff members who were involved in her care. This new environment allowed her to spend more time with other people, and she described the experience as being more “real”. She described her previous environment as uncomfortable, highlighting the large discrepancy between her age and that of the other residents with most of them very senior to her, which impacted her social connections. “In a mob of 35 people, there was only four or five that I actually spent time and talked” [Lou:II:5:150-151]. This new “home” was providing a base for Lou from which to connect to others and the technology assisted with this process.

Availability and access to technology increased her options for communicating with others. “Then I’ve got the trusty old Internet as well, so if I get really stuck for making contact with anyone I can just jump on line, send emails and all that sort of stuff” [Lou:II:1:19-21]. She was able to access a landline telephone when she required, which was in contrast to her previous accommodation where she would have to “push” staff to assist her to access the telephone or choose the expensive option of using her mobile phone. She believed that staff at “Mei Domus” were willing to assist her when needed.

The amount of space afforded to Lou allowed her to set up an office within her apartment, which she spoke of proudly. This space and privacy allowed her to be “set up”, she had the things she needed, not just the things other people determined that she needed. She felt comfortable leaving things out in her apartment, and had a greater sense of security and privacy compared to her previous accommodation. This space had made a significant difference to her as it had increased her independence and her ability to manage her own affairs (e.g., paying bills). She was now able to be self-directed and could adopt strategies to compensate for her memory deficits (e.g., printing out information to remind her about her bills and appointments).
She had increased opportunities to engage in self-directed activities (e.g., making signs and certificates for her Mother). She could actively participate in celebrating others achievements and creating things for her family. This access to technology also afforded her a new level of connection with others through sites such as Facebook. She had contact with lots of other people online and enjoyed this interaction. This type of connection minimised the need for her to be outside the apartment which was often not possible, and may have reduced the restrictions created by her disability.

Lou had many roles and relationships that she liked to maintain (partner, daughter, sister, aunt), and she managed this mainly through the use of the telephone. She spoke to her partner several times a day, and with her sister daily. Her partner visited every weekend and her sister and niece visited weekly too. When Lou’s partner visited, she had the sense that he was comfortable there. She spoke fondly of how he, “just comes in and takes over”, and commented that the time they spent together was longer than at her previous accommodation. Lou’s mother moved into the local nursing home, which allowed Lou to visit her more frequently. She now plays an important role in her family again, acting as a link between her mother and father.

“Mum and Dad, well they don’t visit much but it’s changed a little bit recently because my mother has been put into the nursing home just up the road from here and I go and visit her every day, and if my Dad is here visiting her he will sometimes pop in here. But he is not physically too capable of doing stairs and all that sort of stuff, so it makes it awkward. But again, on the phone every day with my Dad, updating him with what’s going on with Mum and all that sort of stuff” [Lou:11:11-15].

Lou also had the opportunity to have her niece come and stay with her for extended periods of time. She had control over the length of stay rather than visits being determined by the organisation. Previously, time with her niece was restricted to a few hours when another adult was present. This restriction was a cause of frustration for her, as she had always played a significant role in looking after her niece prior to
needing care herself. Staff at her previous accommodation questioned her capability of looking after her niece and removed that role. Through her new increased freedom and autonomy, Lou was able to re-establish her role as part-time guardian of her niece. Allowing Lou to choose when she received visitors and for how long, as well as regaining her role of part-time guardian for her niece had assisted Lou in re-engaging with who she was and what was important to her in life. Without the need to seek permission for people to come and visit, she had a greater sense of autonomy, control and an ability to be spontaneous.

At “Mei Domus” Lou had the opportunity to meet new people. She described a comfort in being able to be herself now, although there was an underlying uncertainty that maybe she was not as connected to other residents as she would like to be. She had developed a strong friendship with one of the other residents which appeared to be based on some common interests. Lou had also developed a strong friendship with a resident who subsequently died. She spoke about her overwhelming grief, that this had “hit her beyond speaking”. Both herself and her niece had developed a connection to the resident and her family and now that connection was gone. She spoke about how this affected her niece, highlighting that what happened to the residents at “Mei Domus” did not happen in isolation.

Lou talked about some of the friendships she had developed at her previous accommodation, and the importance of building and maintaining these friendships. She missed those friendships, which was perhaps highlighted by the limited number of friendships she had made at “Mei Domus”. She commented “what are you doing remembering me?” when a staff member from her previous accommodation acknowledged her, emphasising her sense of being isolated and forgotten where she had previously lived.
Lou talked about communicating with others and the sense of community at “Mei Domus”, but she did not seem connected to the people there. She described residents cooperating with and accommodating each other, and looking after one another. She described how they “band together” when people from outside come in. She made a distinction between the outside world and the inside world, with many residents having things to do in the outside world that are somehow separate from “Mei Domus”, as well as a number of residents who were “unit bound” and unable to participate in the ‘outside world’.

“So many of us have things to do on the outside world, but also quite a few of them, including [name], are very room, unit-bound, they don’t leave their unit very often. So you’ve got people such as [names], they don’t very often come out of their rooms unless they have to” [Lou:115:172-175].

She talked about the communal area as being an important social area.

“When we are all in the dining room and everything we all seem to communicate and talk quite well. Yeah, I think we are all on pretty much common ground and we are all a lot younger than the people over at [previous accommodation]” [Lou:11:5:175-6:178].

When talking about her previous accommodation, Lou mentioned she had no real control over what happened in the communal area and that if you wanted to interact with someone else you had to go to visit them in their room. Although this appeared to be the same at “Mei Domus”, she spoke about it as if it was somehow different. Lou reflected on her previous accommodation as a type of stop gap for people, a place with no permanence. Everyone around her was older which she found depressing.

“I was living at [previous accommodation] which is run by [organisation name] and I was the youngest one there and I was there for just under two years and all of the people around me were much more older. At least 10 years if not more. So I guess that was almost a nursing home sort of environment, aged care. It wasn’t meant to be. It was just supposed to be there for MS sufferers but it’s just the way the cookies crumbled and a lot of the people were actually there waiting for a nursing home” [Lou:12:1:4-11].
Lou described how social occasions and outings were determined by other people in the past, “I was able to go out when they were going out places like movies and things like that [Lou:12:3:85-86]”, whereas now she had her own schedule, access to taxi vouchers and a companion card, all of which increased her opportunities to go out, without having to rely on staff to accommodate her.

“We’ve got transport available to us for things. But priority is medical appointments. If you want to go to a movie and somebody has already got the car out for going to a hospital appointment or even just a doctor’s appointment, sorry you can’t go to the movie and that’s fair enough. If you want to go to the movie that bad, get a cab. You know because we have taxi discounts and stuff as well. We’ve just recently been given our companion cards and that’s really good so we can take someone out with us and they can get in for free or discounted” [Lou:12:3:86-91].

Lou described how prior to going into “care” you have a life, and then when you move into “care” you no longer have that life. Lou believed that MS takes over your life and you have to move into a “home”, and whether that is aged care, “Mei Domus” or somewhere else, they are all versions of the same thing. Although at “Mei Domus”, she believed she had a life again. She noted that people’s perceptions of residential care created a barrier to them visiting her.

As time went on, Lou often became bed bound at “Mei Domus” and had a number of hospital stays. These circumstances increased her isolation and the friendships she had developed with staff became increasingly important. However, there appeared to be an inequity in her relationship with staff in that the staff knew about her life, and she believed it would be nice for her to know more about them. Some of the staff members were friends with her on Facebook. She had the sense that some staff relationships were reciprocal whereas others were not. Some staff were just doing their job and she felt obliged to appreciate them for doing so. She had the experience of there being caring and uncaring staff. However, when staff appeared to be uncaring, she attributed blame to herself.
Lou wanted to be listened to and when staff made decisions about her without her approval, she tried to assert herself and take control. She talked about being “annoyed” when staff did not consult her and sounded angry when discussing it. Although she was thankful that it did not happen often, she believed it should not happen at all. When staff treated her this way, she felt hurt, angry, dehumanised, and as though she did not matter. She described it as feeling like a zombie.

Cut backs in staffing led to longer waiting times and the delay in response time emphasised Lou’s reliance on the staff. She pressed her buzzer and then had no control, she just had to wait. On one occasion, she experienced an incident of choking followed by an inadequate staff response, which was very distressing for her. Since the incident, Lou had taken some control of the situation and had made her own arrangements for emergency situations. Her partner had organised a Care Alert alarm that Lou wore day and night. This assurance made a big difference to her level of comfort, but increased communication from staff would ease some of her discomfort.

Lou was reluctant to speak negatively about staff at “Mei Domus”. She acknowledged there were some problems associated with insufficient staff levels, but “can’t really say”. She also briefly mentioned personality conflicts with staff, but then said she had “nothing negative to say”. At her previous accommodation, she had not wanted to complain for fear of negative consequences. She still believed that if you did not comply, then you would miss out.

“Over at [previous accommodation], it was very regimented, you had to do it the way they wanted you to do it. You didn’t want to say, ‘Oh no, I wouldn’t like to have lunch now, I’ll have it later’. If you don’t have it now you don’t get it” [Lou:11:8-263-265].

This previous experience may have influenced Lou’s level of comfort about communicating openly at “Mei Domus”. She thought she had to be grateful, as she stated she had been “given my life back”. Since moving to “Mei Domus”, Lou had
rediscovered hopefulness and sense of vitality that she was now living her life rather than just existing within a care facility. Lou spoke frequently about celebrating life and having her life back. She seemed to have gone through several distinct phases, including: her pre-illness self; a period of time when she had been diagnosed but was not experiencing debilitating symptoms; a time when she felt MS took control of her life; then a time when the staff and environment of her previous care facility were controlling her life, followed by her transition to “Mei Domus”, where she had regained some control. She talked about “Mei Domus” as being life changing. Life had been on hold and then it had started again. She expressed gratitude to the people and place who made this possible. The space and the opportunity for her to invite people to socialise and celebrate with her gave her hope for the future and increased her future-oriented planning. Despite her ill health, she believed that life was good. For her, the positives outweighed the negatives.

As time progressed, Lou becomes more bed bound, although the equipment in her apartment, the layout of the environment and access to technology allowed her to retain some choice and control, and a level of independence she might not otherwise have had. Lou talked a lot about having to be in and out of hospital. She described how the “Mei Domus” staff brought her back from the brink of “absolute” death following one hospital visit. Her use of the term “absolute” contrasted this type of death to the metaphorical death Lou experienced prior to living at “Mei Domus.

The different stages of her disease impacted her life differently. She spoke of the job she previously had and how she missed that part of her life. When talking about her job, she sounded sadder than at any other time, with the exception of when speaking about her partner. In her previous job, she had assisted people with disabilities to find housing and settle into a home, implying that the concept of home was important for
Lou. She knew the importance of environments that accommodated disability but now she had experienced this at a personal level. The stability of a home was important to her. She believed home provided safety, love, security, and a sense of ownership. It was a place for family and friends. A place you could organise just as you want it, so you could have your life the way you need your life to be. Being at home felt wonderful, it was a feeling of love, even when you were alone. For her, home was also an indescribable feeling that you needed to experience. The presence or absence of her partner impacted significantly on Lou’s feeling of home. They had been together more than 14 years and lived together for most of that time. She missed starting and finishing the day with him. Without him “Mei Domus” was not really home.

**Ivan**

Ivan was a male resident and was 57 years of age at the time of the study. Ivan was diagnosed with MS in 1998. Ivan was married and his wife also had MS, they lived together at “Mei Domus”. He had three adult children and one grandchild. Prior to moving to the new accommodation, Ivan and his wife lived in their own home that they had built with specific modifications for their disabilities. Prior to the decline in his health, Ivan was employed as a skilled tradesman and regularly participated in a number of sporting activities. Post-diagnosis, he had significant involvement in a MS support group; however, he no longer participated in this group due to the deterioration in his health. Ivan rarely went outside of the apartments, although he did occasionally stay at the home of a friend who also had MS. Ivan regularly socialised with other residents in the communal areas of the accommodation and participated in the themed events that were held at the apartments. Ivan used a motorised scooter, as well as occasionally a walker or a cane to assist with mobility. Ivan had been hospitalised twice since moving to the new accommodation.
When Ivan reflected on his experience of living at “Mei Domus”, he spoke a lot about the staff, his perception of their attitude, and the impact this has on him and his wife, “That’s really what it’s all about. If you’re comfortable with staff, with nurses here, it’s no worries” [Ivan:11:6:138-139]. People who go beyond just doing their job are “good” people. He talked about how the “Mei Domus” staff and residents grew together from the start, building firm relationships. They talked, laughed and had a joke, which he likened to being out somewhere with a group of friends. The staff assisted in creating a relaxed atmosphere. He thought everyone [residents] at “Mei Domus” was treated as individuals. Staff took the time to get to know the residents and their individual needs. Staff who genuinely cared and took the time to talk and listen to him made a big difference. Knowing they were there and available to him was a source of comfort for Ivan. This experience at “Mei Domus” showed him that staff could respond promptly during emergencies, which made him feel relaxed; knowing that if anything happened to him or his wife, help was available.

“It’s just easier here. You know that, if something happens – like I’ve been down in the community room a couple of times and someone’s taken a turn. Like [resident name], she had a seizure and someone else too. There were no nurses or staff in there. I said do you think they’d mind if I call someone. They said no. So I just screamed out help, emergency, emergency. They [staff] come running from everywhere. Everything’s – and it’s that kind of thing. Seeing that something is done straightaway just makes me feel so much easier and relaxed, knowing that, if anything happens ... So that’s why I got no worries here” [Ivan:12:13:432-442].

Ivan described his own life as being three quarters over, that he had done the things he needed to do and was resigned to life being nearly finished. This attitude followed some recent health crises, including cardiac bypass surgery. He described one time he needed to go to hospital, and staff stayed with him for two to three hours whilst they waited for the ambulance to come and pick him up. He stated that they did not need to stay, but they cared. He was reassured by staff that he did not need to worry
about his wife whilst he was away. The level of communication provided by staff was important to Ivan and relieved his burden. Another time he was away from “Mei Domus” for 11 days and was comforted in knowing that his wife was well looked after.

“I was in hospital – I had cellulitis in my leg. I have to give myself a needle every two days for my MS. I didn’t use one of those sterile wipes, and it [infection] got through to my leg. My leg was about that size [gesturing with hands]. I was really out of my tree. I was in hospital for 11 days, and when I came back I said to Susie did you miss me? She said not really... [Laughter]... That’s what I mean; she was so comfortable here when I wasn’t here. That’s kind of what takes a load off my shoulders. If I have to go away or if anything happened to me I know she’d be taken care of” [Ivan:11:9:241-248].

Ivan’s experiences of having survived a major heart attack and heart bypass surgery appeared to influence his concern about the well-being of his wife. The well-being of his wife appeared to be paramount to Ivan. He stated “If she’s happy, I’m happy. I’m happy here, she’s happy here. So that’s really all that counts” [Ivan:12:9:283-284]. This sense of security had been augmented by staff reassurance. He described an occasion when he was admitted to hospital and a staff member visited to let him know his wife was fine.

Ivan acknowledged that, due to his own deteriorating health, he was no longer able to take care of his wife. His MS had impacted significantly on his ability to maintain this role, so access to 24 hour care and reassurance from staff allowed him to take care of his own increasing needs, both physical and social. However, losing his caregiving role appeared to have some negative psychological impact on his sense of identity as a husband.

Ivan’s ability to connect with staff using humour was very important to him. If he felt comfortable with the staff, then he felt happy and had “no worries”. Unfortunately, however, his relationships with the staff were often disrupted by staff turnover. He continually used the term “Bang they’re gone”, to describe how their leaving felt sudden and shocking. Continuity of care was important to Ivan, and staff
turnover could be very disruptive. It is possible that high rates of staff turnover created a transient feeling that impacted on his sense of permanence at “Mei Domus”. Ivan talked frequently about “good” staff, which implied the existence of “bad” staff, although there was no mention of them. Ivan talks about the fact that 95 per cent of staff were “good”, but did not seem to want to talk about the small percentage of staff who did not fit into that category. He seemed to experience discomfort when talking about problems that might be present at “Mei Domus”.

The value of “Mei Domus” to Ivan appeared to be embedded in the people, interacting socially and making use of the communal area to connect with other residents and staff. Ivan was one of the oldest residents and, although he acknowledged that he was aging, he differentiated aging and being old.

There were opportunities at “Mei Domus” for Ivan and his wife to go out, but they did not access these opportunities. Ivan and his wife spent most of their time within “Mei Domus” due to his wife’s stage of illness. He appeared happy to be at home with his wife and socialised with the other residents. He enjoyed the surroundings he was in and was happy to “park out under a tree”. He acknowledged there were opportunities available to them but felt under no obligation to participate in social outings. Prior to moving to “Mei Domus”, they were more isolated, being home all day while most of their neighbours and friends were out at work. The close proximity to other residents allowed more opportunities for social interaction. Ivan believed that other opportunities to make friends were limited so took the opportunity to socialise with his fellow residents. Maintaining relationships with family and friends was easy as a result of their access to the telephone and technology within their apartment. The lack of restriction on visitors meant it was easy to organise a visit.
They had access to an extra adjoining room, which they had permission to treat as their own. They were very comfortable in their apartment, which he humorously referred to as “Smokers Hollow”, a place where some other residents came for a smoke and a talk. The door to their apartment separated them from the other areas of the building and gave him the sense that he controlled who came in. However, nursing staff walked into the apartment when they liked. Ivan stated that he had given staff permission to come in without having to knock, which may have allowed him to maintain his sense of having control.

“I don’t know. I can’t speak for anyone else here. But I think that they feel the same way. This is their home. When they’re in their unit, it’s private. The only time someone comes in is when you either call them or there’s something you’ve forgotten or you’ve accidentally pressed a button, which has happened a few times. No. It’s just so easy here.

Interviewer: It’s almost like its still home, it’s just not private.


Ivan spoke about the time it took for “Mei Domus” to feel like home. Initially, he compared “Mei Domus” to home but with the passage of time he spoke about “Mei Domus” as home. Ivan described feeling unsure about how they would fit in at “Mei Domus”. He felt comfortable at “Mei Domus”, although, for the first six months he felt restricted. He said he no longer cared about that, but clarified that he did care on a personal level. He no longer felt restricted. If he wanted to do something, he did it. He described that “Mei Domus” becoming home was in part connected to them being able to personalise the unit to suit them.

Feeling comfortable with the people at “Mei Domus” also assisted in the process of becoming home. For him, “Mei Domus” was now easy “... easier”, implying that there was still some level of difficulty associated with living at “Mei Domus”. He
acknowledged that “Mei Domus” was actually nicer than he expected it to be and access
to help and support previously took much longer to arrive, so having it close made a big
difference to his sense of safety.

Ivan had a sense of being lazy at “Mei Domus” as people were there to help him out. However, he also talked about being able to be himself at “Mei Domus”, feeling relaxed like he had when he was at home. He stated that all they [he and his wife] wanted was a house, somewhere they could suit themselves, a place they could do what they want. He thought they could do this at “Mei Domus”, which gave him the sense of home again. The feeling of home for Ivan was about having choice, control and freedom to do what he wanted, a place where he did not have restrictions placed upon him. He acknowledged that he could not do whatever he wanted at “Mei Domus”, but “more or less”. There was a time though when “Mei Domus” did not feel like home to Ivan, this was when he spent time in the communal areas, although he saw this aspect of living there as important, it created a sense of not-home.

Ivan had a sense of ownership of their unit, and this had been reinforced for him by the organisation “it’s yours, alright. We’ve been told that, ‘til the day we drop, it’s ours, we know” [Ivan:I2:11:349-350]. He compared how restricted it might be if he were having to live in a nursing home and stated that at first it was great at “Mei Domus”, getting up when you want, eating when you want, but over time he developed self-imposed restrictions due to not wanting to inconvenience people.

During the second interview, Ivan talked about a timeframe of two years before it really felt easy and relaxed at “Mei Domus”, indicating that the sense of home evolved over time and was a comparative concept. There was a distinction between this feeling being about a sense of home or being more connected to adapting to the changes in his health. He stated that it took him a long time to realise that he did not have to
worry about everything. He acknowledged that he did still worry but not like he used to. Perhaps living such chronic health concerns means he will always experience worry. However, his relationship with, and the attitude of staff appeared to minimise this for him.

“Once you know that the people aren’t just here for a job, but they care, that to me is one of the biggest things that this place has got. The people here care, the staff here care” [Ivan:11:11:304-305].

Emma

Emma was a female resident and was 47 years of age at the time of study. Emma was married, but lived at “Mei Domus” separately from her husband and adult stepson due to her high care needs. In 1998, Emma was diagnosed with MS, in 2006, it was discovered that she had a lesion in her brain stem that affected her breathing, swallowing and balance. She required 24 hour care and used a motorised wheelchair. When the lesion was initially diagnosed, Emma stayed in hospital for 13 weeks due to the lack of accommodation available at the time. Following her release from hospital, she moved to a residential care facility situated in an old building where she had her own (very small) bedroom and shared all other facilities including the bathroom. There was a strict daily routine at the facility and very limited privacy. Prior to the decline in her health, Emma had been employed in a professional capacity and was studying at University. She had an active personal life, including bush walking, hiking, swimming, gardening, writing, cooking and regularly attending church.

At “Mei Domus”, Emma had a weekly four hour outing when she choose how she spent her time (e.g., visiting libraries, art galleries or museums). She also attended plays with her girlfriends, and a weekly pottery class. She participated in a card-making class at the apartments and spent time sewing and cooking. Emma was writing a novel. She also held a weekly bible study class at her apartment and engaged in social
networking via the internet. Emma had been hospitalised twice since moving to the new accommodation.

“Mei Domus” provided Emma with the space and privacy to feel comfortable and connect with loved ones and friends. It provided choice in terms of how she used space, which was important to Emma as she had a preference for more intimate gatherings. Emma spoke a lot about intimacy and the importance of having privacy when spending time with visitors. She welcomed friends into her apartment and had options regarding where they wanted to spend their time. She had her own barbeque on her balcony which allowed her to stay within her apartment, but also had access to the communal outdoor barbeque. Emma had daily phone contact with her husband, Jack, and twice weekly contact with her family. She maintained contact with friends via email, whereas at her previous accommodation she encountered difficulties maintaining contact as she did not have a telephone line in her room, did not have a mobile phone signal and had to sit in the main corridor to make calls.

Emma had regular weekly visits from her family. She did not experience any restrictions around these visits which increased her feeling of independence. Having friends stay enabled her to “natter, as best friends do”, which allowed her to have deeper and more meaningful relationships. It also increased the regularity of visits from friends and other residents. This experience contrasts to her previous accommodation where she felt restricted and experienced a lack of privacy because the visitor area was also being used as a staff storage space. Her room at the time was not large enough to entertain visitors and the building was locked at 5pm which prevented her from spending time outside with visitors.

“Mei Domus” was a place where everyone was welcome. Emma described it as inclusive rather than exclusive and believed that social functions were more age
appropriate. She was aware that the environment could be similar to a nursing home. She described how someone had once donated crocheted lap rugs for the residents, which Emma immediately refused because of the connotations of a nursing home.

There was a distinct difference for Emma between being inside her apartment and outside in the communal areas. Home was her retreat, her haven. Outside felt different, at times she felt “battered”; she experienced a feeling of being unwelcome when downstairs. Emma described some of the residents as “obviously quite chummy” and a little exclusive, which she stated she found hard to understand. It is likely, however, that within external neighbourhoods this type of relationship formation would develop too. Emma’s relationship with the staff was different from her previous accommodation, she talked about being able to connect more with the staff and develop relationships and friendships, some of which were then maintained after the staff no longer worked there. Friendships with staff were seen as easier to develop at “Mei Domus” as they spent more one on one time together talking, and they were closer in age. Staff leaving did not appear to be as problematic for Emma as for some of the other residents (e.g. Ivan).

At her previous accommodation, if staff were seen to become too close to the residents they would be removed from their care plan case. Emma was unaware of any regulations regarding friendships with staff at “Mei Domus”. However, she did speak of an unspoken protocol between staff and residents, although this did not seem to impact her ability to form friendships with the staff. She had a sense that the staff respected her and her need for privacy (e.g. shower times). Emma felt cared for by staff, which was impacted by the way in which staff asked her directly about her needs and wants, and their attitude towards her and certain behaviours (e.g. making cup of tea, bringing in fresh eggs). Previously Emma felt controlled by the organisation, even for
simple activities like having a cup of tea. As she spoke about this control she laughed, although the laughter was not due to her finding this funny but her realisation that this was perhaps not as it should have been, her statement “I find that pretty strange” reflected this.

Emma described the environment at “Mei Domus” as “easier”, compared to the rigid nature, restrictions and lack of privacy she encountered at her previous accommodation. This new accommodation, however, was not without difficulties for Emma. The design and layout of the communal area caused discomfort for her and she found it “intimidating”. Emma’s preference was for smaller tables and more intimate evenings with other residents. She also had difficulties during social gatherings due to the layout of the room and her sense of how the staff and residents interacted. There were certain staff behaviours that left Emma feeling “excluded and forgotten” (e.g. not told about social gatherings when they started). These incidents impacted negatively on her ability to feel comfortable around other people. Emma also felt embarrassed at times when together with other residents in the communal area. For example, during organised activities such as crosswords Emma saw herself as more cognitively able than the other residents and this caused her discomfort. She found herself under-stimulated intellectually and saw her interests as quite distinct from many of the other residents.

“They have a crossword meeting on a Thursday morning and I don’t go to that. I don’t go to that for the most selfish reasons, and that is because I find it extraordinarily boring. And I’m not trying to make myself out to be better than anybody else, but often I’ll be sitting there; I’ll just catch a moment or two of it. They’ll be asked for the answer to a clue, and it will be something blatantly obvious for me, but the rest of them are sitting there unable to answer it. And I feel embarrassed about the fact that I do know all these answers, that for me it’s not difficult to access that information” [Emma:11:5:142-147].

“I still find it really difficult. I don’t know what it is. A lot of women think that an outing is going to the shopping mall, whereas I think that an outing is going to an art gallery or the library or the botanic gardens. This Thursday my outing is cooking a meal because I’m going to a play on Thursday night with my girlfriends” [Emma:11:5:163-166].
Emma described “Mei Domus” as a place where you were part of the world. The world was invited in rather than kept out, different in comparison to her previous accommodation where she felt that she was barred from the world. She described window without curtains, so outside cannot be shut out. She described “Mei Domus” as full of life, a place where everyone is welcome. Moving to “Mei Domus” for Emma meant that “life is no longer just a concept”. Since moving out of her family home, Emma had been dependent on a carer when going out. At her previous accommodation, she expressed interest in activities such as visiting the library, however outings were dictated by the on-site entertainment officer and mainly consisted of visiting shopping malls, an activity that Emma described as “hating”. Emma felt she had more choice and control at “Mei Domus” in relation to her intellectual stimulation and being able to engage in activities that interested her. She was still restricted by her illness and needed to be accompanied by a carer; however, she dictated where she went and what she chose to do. This was however restricted to a four hour time slot on a Thursday.

“I felt really odd, because when they asked me what sort of outings I wanted to do, I said I’d like to try and get to the library once a month if possible. They said oh yeah, we can do that. And the whole time I was there, I got to the library once. Because for them they thought going to the local mall was way more important. And because I need somebody to be with me to do anything like that, I can’t just go off alone, it’s kind of difficult. You’ve got an entertainment officer who thinks the best thing to do is go and visit [local] mall because you never get there normally. No it’s not.

Interviewer: That was at [previous accommodation]?

Emma: Yeah.

Interviewer: So how are things here in terms of going out and doing that?

Emma: It’s different here because I have a Thursday outing that’s mine, and I get to dictate where I’m going. Last week we went to GoMA. The week before we went to the library. This week were going to do a bit of shopping and make dinner for my friends. That sort of thing.
Interviewer: And what about other times, if it’s not a Thursday and you wanted to do something?

Emma: I go to the patchwork shop, or I go to places where I want to go. If I want to go to the supermarket I just send my husband across the road. I hate supermarkets. I hate malls. I really hate malls. I go there and I’m just like everybody else; you buy things from the mall because that’s what you do”

[Emma:11:8:235-251].

Although Emma’s health impacted on her choices, such as needing to rest in the afternoons due to limited energy, she felt she was in control of her life. She also needed assistance with some food preparation but again she had some control over the times she had her meals.

“Okay, today I get up at six because I’m an early riser. I get up at six, I have a shower and then I have breakfast.

Interviewer: Do you make the choice of when you get up?

Emma: Yes, oh yeah, absolutely. I choose to get up. On the weekends, I don’t get up that early. I might go to pottery after that which I do on Tuesday, every Tuesday I go to pottery. Back at the [organisation name] and they take me there and I go with my husband so he can stay there with me then I come home and I don’t really have much option but to go to bed for a nap, so I do that. If I don’t go to pottery, I’ll hang around here like I did yesterday. I hang around here and what else do I do?... Oh if I hang around here, everything. I’m writing a novel...I’m sewing an outfit right now. What else am I doing? I’m making Christmas cards which I’ve just about finished and I’m making a series of blank cards that I’ll have ready for all occasions that happen around here and yeah, so I do lots to keep me busy and crochet, I sew, yeah. I’m always busy... I generally just get up, watch TV and go to bed. I’m not very good after. I don’t have that sort of energy level anymore.

Interviewer: So what about things like your meals? You said you sometimes go down a couple of times a week otherwise where would you have lunch and dinner?

Emma: I’ll have lunch up here and I have dinner up here and I have breakfast up here, so yeah.

Interviewer: So do you do that yourself or do you need assistance with that?

Emma: I need assistance if I’m cooking something but generally as a rule, I have [granola] or something like that for lunch, for breakfast I should say and I might have a sandwich or something for lunch, so it’s not too hard for a carer to come up and just do those initial sorts of cuts and things like that.
Interviewer: Who would make the decision on what time you would have those meals?

Emma: Me. Definitely me” [Emma:12:7:201-8:235].

Emma also had the opportunity to start some part-time work to assist with her income, which increased her sense of independence. There were minimal restrictions to this for her, except the need to organise a staff member to assist her one hour per fortnight to enable her to go out to the local nursing home and sell her products. The source of income for Emma was not large, however, it seemed to give her a sense of independence, and she could use the income to assist with some of her medical expenses, such as purchasing a hearing aid.

Emma described her initial move to “Mei Domus” as “fantastic”, “just heaven” and that she felt very lucky to be allocated an apartment. Following her move, Emma experienced a decline in her health and acknowledged it impacted her mood, as well as how she interacted with other residents. She advised that the medications she required affected how she felt and she kept that information private from other residents which she realised may have influenced her relationships with other residents.

“When I first came here, this was fantastic, it was just heaven and I couldn’t believe I’d been so lucky as to get an apartment here. Then I had an exacerbation and I lost a lot of use of my legs and things like that and I’ve recovered from that but while I was recovering from that, I had a bit of a blip right and things really got me down over that period and I’ve recovered from it but I’m still not altogether right from that blip and...

Interviewer: Do you mean in terms of health or mood, or both?

Emma: In mood, in terms of mood, I see a therapist regularly, I see a psychiatrist regularly, every six weeks I see him. I’m on medication for mood, to alter my moods, so yeah and because of that blip, my initial experience was great because I was able to be more optimistic and freer with what I was saying and freer with what I was doing and things like that and then when I had that blip, after that blip happened, I just sort of curled up and I started suffering a lot of pain and that started altering my moods. But I’m now on meds for the pain and I’m just not altogether there yet and I think for that reason there are times
when I still feel a little apart from what’s going on around me and because nobody else in these apartments know that about me, they can’t accommodate that and I don’t want them to know. They’re not my best friends or anything like that so I don’t want them to know. So yeah, in that sense it has changed, yeah but then that’s more because I’ve had a change in my physical life as well which changed my emotional life” [Emma:12:5:145-6:163].

Emma had not built strong connections with other residents at “Mei Domus”, although she spoke of a connection with another resident who had communication difficulties. They shared a common humour and were able to negotiate the communication barrier, which Emma found interesting and engaging. She also had regular contact with one of the other residents.

“[Name], just simply because I knew him in [previous accommodation] and he’s got a wicked sense of humour. And although he can’t communicate very well he’s got a wicked sense of humour. We seem to communicate really well in a sort of non-verbal way. Do you know what I mean? He’ll say things to me, and it might be one or two words, but I will sort of extrapolate from there. So we communicate in a very non-verbal way, which I find very interesting. I think [name], it’s more because she’s just my next door neighbour, and when she moved here she knew no one. She’s moved from [suburb name] to here, so she’s moved a really long way from her family. I guess I felt that distance for her. I thought it’s horrible. She comes to my little study group on a Tuesday night” [Emma:11:4:123-131].

Emma spoke about having no desire to build relationships with other residents as she had concerns that she would adopt the negative attitude that she perceived others had.

“I mean some of the other residents; I find some of their ways of looking on life a little bit depressing. Whereas I’m always looking for what I can do; some people are always looking at what they can’t do. And yeah, I’ve got to be careful I don’t get hooked into that again” [Emma:11:4:117-120].

However, throughout the interview there appeared to be a conflict between her wanting to develop friendships and her discomfort with the layout of the physical environment. She acknowledged that she did not spend a lot of time with other residents, in order to develop any friendships. She stated that it was not because she did not like the other residents, but rather she felt false in a large group setting and found it
too superficial. Her sense of belonging was not strong and it would seem that she had difficulties connecting with the other residents, in part due to her own temperament, and in part due to the setup of the environment. Although she had her own unit within the complex, her aversion to the large group environment prevented her from initially developing friendships in a more intimate setting, prior to being comfortable to invite them into her “haven” (with the exception of her friendship with Justine).

“I’d like to do that here. I’d like to form relationships with people here, but I just don’t know. I guess in [previous accommodation], [name] and [name], because we had that opportunity to get to know each other at a dinner table that was more intimate, that sort of thing” [Emma:I1:6:184-186].

Emma talked about how she had thought that all the other residents got on really well together, until she spoke to a resident that had been unit-bound due to illness. Emma was surprised to learn that no residents had been to visit this resident. She stated that the residents downstairs talked about “Mei Domus” being one big happy family and that everyone looked after one another, but this has not been Emma’s experience. She wondered who was included in the big happy family. Emma stated that if she felt she was part of a big happy family then she would be able to express herself better. This for her is perhaps a reminder of the reality that she is not at home with family.

“I saw another resident yesterday to say hello because she’s been sick and I don’t particularly get along with this other resident but I thought that lots of other people in the facility did because she’s always talking to various people and she told me that no one had been to see her and I was like oh, do you know what I mean? I was really shocked and one of the reasons I hadn’t been to see her before then was because I just made the assumption that other people were going, but nobody had been. That was a real shock to me so it’s like they talk, the residents downstairs talk about this being one big happy family and how we all look after each other and how we all care for each other and all that sort of thing. Sometimes I wonder who’s included in the we, you know so yeah” [Emma:I2:4:122-5:133].

“I sometimes feel very apart from the residents. I sometimes feel really separated from the group, you know like a couple of them talk about the place being one big happy family and I certainly don’t feel like I’m a member of the big happy family, you know and not that that really bothers me, that doesn’t
really bother me. It’s just that if I was part of one big happy family then I’d be able to probably express myself better, I’m not sure but I don’t and I really honestly don’t think I want to join their happy family because I’m not altogether sure I like some of the people that are in, yeah do you know what I mean?“ [Emma:i2:6:171-178].

Emma maintained friendships with people she had met at her previous accommodation, she felt these friendships had been easier to establish due to the more intimate design of the communal dining areas. Time was also significant for Emma, in terms of forming friendships. She repeatedly talked about a desire to form friendships but found the lack of intimacy to be a barrier to this.

Emma stated that “Mei Domus” was the best place for her to receive the care she needed. However, this seemed to be influenced by the fact that she did not have access to any other adequate services within the community and that the burden of care would be too great for her husband if she were to live with him. She believed that being at “Mei Domus” had allowed her to manage her health complications more adequately.

“Because I get the care I need, I get the assistance I need, but I also have those carers on 24 hour alert if I end up, when I stop breathing. It doesn’t happen that much anymore but it’s like I’ve got to be in a situation where if I stop breathing, I need instant help. I have no way of moving away from a care facility because if I was in the community, there’s no way that I could find someone that would give me the kind of care I needed 24/7. I mean people need breaks and my husband just couldn’t do it because he’s got a job and he’s painting and he comes in here and paints and things like that but he couldn’t do that anywhere else. Hang on, what am I trying to say? The carers are here. Even though he’s here, there’s still carers here so he doesn’t have to be. If we were at home alone, any time that he spent alone with me would be fraught with that and he still does it anyway with the constant are you alright? Are you breathing? Do you know what I mean and that kind of drives me mad after a while” [Emma:i2:9:245-257].

She described her previous accommodation as “hideous”, that it was like living in a fridge, it was forbidding, a place where people did not want to visit and when they did come they would want to leave, and a place with an unpleasant feeling. A place that was exclusive rather than inclusive.
“Oh, where I was living previously was hideous. It was absolutely hideous and I’m glad that what happened to my blip and my MS happened when I got here because if it had happened back in [previous accommodation], I’m not so sure I would have survived as well as I have here.

Interviewer: What do you think it is about here that’s helped you to deal with that better?

Emma: So I don’t think it’s any comparison at all. Do you know what I mean? I couldn’t go back there and it’s cold, it was like living inside a fridge and it’s forbidding and people don’t want to visit there, you can feel it when they walk in the door, they’re like itching to go again because it’s an unpleasant feeling and I think there was no outdoor areas where you could find privacy that was covered or no outdoor places where you could sit with friends, do you know what I mean? It was very exclusive rather than inclusive and yeah, all that stuff”

Home for Emma was a place where there was security, but it was more than just the security of having locked doors, it was a personal feeling of being safe. This feeling of being safe had not developed overnight; it had been a gradual process for this new accommodation to become the place she wanted to live. Home was her retreat, her door separated her from the outside, where she could feel more vulnerable, she did not feel “altogether safe” outside her apartment. It was about having her own space, a place that was welcoming, comfortable and where there was happiness. For her, it was a place that when you walked in you instantly felt welcome, not unwelcome. A place where no matter what you did it was right, there was no wrong at home, perhaps because she was the one who determined what was right and wrong, not someone else dictating how and when she must do things.

It was about having her pictures and belongings around her, but more than that it was about the people and the feelings that she associated with home. Home, for Emma, was a place where angry words, if spoken, were quickly forgotten. She stated that most importantly it was about privacy and being accepted as who you were and what you liked. Emma did not feel like she was being checked up on as the staff give her privacy
and respect, she did not feel like she was being a “nuisance” when she chose to stay upstairs rather than socialise downstairs.

Home was a place Emma was with her husband, Jack. Emma had experienced changes in her relationship with her husband since having to move from their family home. The restrictive nature and atmosphere of the previous environment created an emotional distance between her and Jack. He visited every day but was restricted to a 5pm meal time and then would leave shortly after. Since moving to “Mei Domus”, Emma and Jack had the opportunity to stay together overnight and whilst their time together was less frequent, there was an increased quality and deepening of the relationship. Her husband came on a Friday and stayed til Sunday night then returned Monday nights and stayed to take her to pottery on Tuesdays. Their relationship was more normalised, she spoke of a day when she woke up with her husband and had a “tiff” and a day of “snapping at each other”, then they sat and discussed it like adults. Emma emphasised the importance of this change in her relationship with Jack throughout her interview. She thought it was “wonderful” and that they were “who they were again”. They had rediscovered themselves together.

Justine

Justine was a female resident who was 43 years of age at the time of the study. She had two teenage children. Justine was diagnosed with MS in 1992. Following her diagnosis and the subsequent decline in her health, Justine’s marriage ended and she was divorced. Prior to moving to “Mei Domus”, Justine lived for three and a half years in an aged care facility close to her family home. Prior to the decline in her health, Justine was employed as a secretary. She also regularly enjoyed playing the piano, but due to the inability to use her hands, she could no longer play. Despite this inability to play, she had her piano moved into her apartment, indicating the importance of
symbolic belongings. Justine reported that she attended church weekly and participated in the themed events that were held at the apartments. She was fully dependent on other people in most areas of her life (i.e., assistance in and out of bed, movement of her wheelchair around the apartment and building, feeding and drinking, showering). Justine used a voice-activated computer program as she was no longer able to use a keyboard. She also used a mobile telephone with Bluetooth which enabled her to answer her own phone calls. Justine has been hospitalised once since moving to the new accommodation.

When Justine spoke of moving to “Mei Domus”, she described a new beginning, she focused on choices that became available to her since moving. Her children were part of the process of choosing her apartment, rather than it being merely allocated to her. She described this process as being like the normal process of finding and moving into a new place. Her children viewed the apartment as their home too, with room being made available for them and their belongings. Although travel to the new accommodation involved a one and a half hour train journey for her children, they spent more time with Justine. This time together made a huge difference to Justine and was more meaningful for her children too. Family had access to Justine’s apartment at any time through the provision of a key, as they would if Justine were still living at her family home. Justine also had regular telephone contact with family and friends. Although she was dependent on the staff to assist her with making calls, they provided her with privacy during her calls.

“Well I can’t use my hands so I press my buzzer and someone comes and dials my phone number for me.

Interviewer: And then are you able to use the phone without somebody helping you from that point? If they’ve made the call?
Justine: As long as they put it on speaker phone and put it up on my shoulder. Sometimes I can turn it off and sometimes I can’t, so I press my buzzer and they come and turn it off.

Interviewer: So you have the opportunity for a private phone call?


The provision of personal space impacted positively on Justine. She was able to socialise more frequently with family and friends, and had the option of staying in her apartment or spending time downstairs in the communal area. “Mei Domus” provided her with choice and variety. She attempted to spend some time downstairs with the other residents daily. However due to both physical and psychological factors, this was not always achieved. Justine did spend time with her neighbour Emma, with whom she had common interests. They valued their time together and there was a sense of normalcy in connecting with neighbours. Justine spoke of a common thread that linked residents together due to their high care needs. They were connected through their illness and whilst they were similar in that sense, they were all individuals sharing a common understanding.

“There are some [residents] that are down at the dining room every meal and there are others that are there sometimes and not, and I’ve got to put myself in that latter category. Because I try to go down lunch and tea every day but it doesn’t always happen. But yeah, there are some down there that I’d see every meal that I’m there. I spend a bit of time with Emma next door. As any situation, you gravitate to some people more than others. But that’s the same; it doesn’t matter where you are.

Interviewer: So what is it about the people or the relationships that you have with them that you call them friends?

Justine: They’ve all got a disability. Some of them are in the same bucket as me for MS. No two people here with MS are the same. Everyone’s got different aspects of it that are causing more problems than others. But it’s just nice to be around young people who understand what I’m going through.

Interviewer: Yeah. You mentioned before that you try to get down to meals lunch and tea every day, but that doesn’t always happen. What would be some of the reasons why you wouldn’t get down there?
Justine:  

Physio. I’m too wasted after my physio treatments so I just stay here and try and sleep. Sometimes I’m just not emotionally in the mood to socialise” [Justine:11:2:51-3:65].

Justine spoke of being at ease with other people who have a disability, and stated that it was somehow easier than being at home with able-bodied people, because of their common experience of disability. There was a freedom in knowing she could go downstairs and connect with others, enjoy their company and have a laugh.

“I sit outside for a while. I’ll come back in and I’ll either listen to some music or watch the TV. Then I’ll go down for lunch to the lunch area and sit and chat to the other residents. It helps just to mix with different people. There are some people, residents, down there that are very quiet and there are some you’ve really got to concentrate to understand them because they’re having trouble talking. But there are others down there that joke around so much you can’t help but laugh and that’s always good. I suppose you just know if you’re having a down day and you go down and you sit somewhere near Ivan you’re bound to come back laughing at something or the topic of our conversation is good. He’s a new grandfather. That’s always nice to hear him talk about it but on the other hand there are people who are in the same situation as me. There are 10 people here with MS but none of us have the same symptoms but all of us have similar symptoms. So that’s nice; we’ll sit and whinge. Not that you want to whinge all the time but every now and then it’s just nice to get something off your chest.

Interviewer:  So that social connection’s important to you?

Justine:  Yeah. Everyone’s always concerned when you go to hospital and it’s almost like a homecoming when you come back.

Interviewer:  So what does that feel like?

Justine:  You’re wanted; not needed as such ‘cause I can’t do anything so I can’t be needed by other people. But it just – it’s a home environment. There are 16 of us here and we’re all here for our own reason, different reasons, but similar reasons but we can’t look after ourselves at home any more. There’s other people in your situation and that makes a big difference to being at home with three other people that are very capable of doing everything they want and then at times you’re a burden to them ‘cause they have to do everything for you. Different environments. It’s different and it changes people’s perceptions of enjoyment of life” [Justine:12:6:166-7:184].

Justine spoke of her sense of spontaneity, choice, and of “fitting in”, concepts that were not available to her in her previous living accommodation. Previously she felt
“stuck”, restricted, and disconnected from others. Her attempts to connect and develop friendships with previous staff were prohibited, which impacted negatively on Justine as she felt these were the only people close to her age to with whom she could relate. She was surrounded by older people and struggled to connect with them or understand their activities and music.

“Yeah, because where I was I stayed in my room and I didn’t really talk to anyone. A couple of people that walked my door regularly I got to know. But here they’re my own age. And that’s, I suppose, the beauty of this place...Here I think I’m about the middle of the road age-wise. Whereas where I was I was the only one. I was the youngest by 30 years...It was really quite depressing actually. If someone didn’t come and see me I didn’t talk to anyone except staff. And I was very limited there because if management saw that I was becoming good friends with any particular staff they’d move them to a different section. So I wasn’t allowed to become friends with anyone. Which was really very depressing” [Justine:11:3:73-86].

“Like I said before, I wasn’t allowed to become friends with anyone that came. Because once management saw me getting close to someone, a staff member, they’d shift them to another department because that just wasn’t the done thing where I was. Which to me was really sad” [Justine:11:4:110-112].

Many of the residents passed away during her time at her previous accommodation, which may have impacted on her desire to connect and form friendships with other residents at “Mei Domus”. Age appeared to be very significant to Justine, not just the age of the people around her, but also the availability and access to age appropriate things, such as technology. She was limited by her disability and spent a lot of time watching television. Having access to [pay-for-service television] allowed her more variety and choice. Although she could not play the [video gaming equipment] herself, she derived much pleasure from watching her children play and spending time having fun with them. Access to a computer assisted Justine to keep her mind alert.
The space Justine was previously living in was cramped with no room for visitors. To her it was just a temporary room. She described “Mei Domus” as more than a room with a bed and television. It was somewhere she had her belongings around her, which helped her to feel part of the world. These belongings signified her history, memories and reminders of her loved ones. They reminded her in a positive way of her pre-illness life, but maybe also of the loss she had experienced. Justine’s piano was in her unit, and whilst she could no longer play herself, its presence assisted her to maintain the importance and pleasure she derived from her music. One of the staff members came to her apartment to play the piano, which Justine recalled with fondness and described how relaxing it was. There was a mutual enjoyment and sharing of experiences between her and this particular staff member.

Her apartment was also where she had ownership of the space. The staff attitudes were important in this respect, as their attitudes and behaviours assisted Justine to maintain her sense of belonging and ownership. They always “buzzed” to announce themselves before entering, Justine spoke light-heartedly when she acknowledged that she always knew who it was due to the familiarity that she had been able to form with the staff. They showed her respect when inside her apartment and deferred to her before engaging in tasks or moving anything within the apartment.

Justine’s family home was built to meet her individual needs; however, as her needs changed it became apparent that she could no longer live there. Her experience of living in aged care was of having a room, whereas now she felt she had a home again where her children could visit. Home for Justine was a place where there was space for others, with family around. At “Mei Domus” she could make choices for herself, and the attitudes of the staff assisted her in this process. Although her disability required her to be dependent on staff, she had a sense of control and choice. She talked about
sitting outside on her balcony, feeling the air and looking at the sky, a simple activity that many people take for granted.

“When the sun’s out which is most of the time, after I shower, dress, breakfast I do like to sit out on the balcony for three-quarters of an hour to get my Vitamin D for the day. But it’s nice just sitting outside... No, but I sat out there this morning. Even though there was no sun it was just nice to sit out and breathe in the fresh air” [Justine:I2:5:139-145].

On some occasions, Justine went down the street, which for her was enough even though she was reliant on staff to achieve this. An activity many of us would not even stop to think about. When outings or events were organised at “Mei Domus”, Justine enjoyed stepping out of her normal routine.

Justine spoke about the loss of having to move away from her family. This loss was difficult for her to articulate. The progression of her illness took her away from them and the restrictions of the environment in to which she had moved kept them distant. Moving away from her children was very painful for her and left a void in Justine’s life which she needed to fill by connecting with other people. However, the restrictive nature of her previous accommodation, particularly in terms of connecting with staff was very difficult for Justine. She felt infuriated and had a sense of lack of control. She felt as though her only remaining possibility of connecting with someone had been taken from her.

“Very restricted and I also found while I was there that if management noticed that I was getting close to some of the staff, they’d get moved to a different department. I wasn’t allowed to make friends as such with the staff because they just didn’t think that that was a good idea... It was really annoying because the staff were my age group. I mean there were some older, but the majority were my age group and that was the only contact I had a lot of time with anyone and wasn’t allowed to make friends with them. It was really infuriating” [Justine:I2:4:111-117].
This experience emphasised the importance of Justine’s connections with the staff at “Mei Domus”. The staff at “Mei Domus” took time to sit and listen to her, and as such, Justine did not feel like just a name or number, but a person with significance and meaning. She did not feel rushed, she felt loved and special. She believed that the staff made an effort to improve her quality of life. Justine saw herself as having nothing to offer, so felt wanted but not needed. The ability to connect with the staff at “Mei Domus” helped her to feel that she still meant something to someone. She believed that the people there cared and that she mattered.

**Barbie**

Barbie was a female resident and was 37 years of age at the time of the study. Barbie was diagnosed with MS in 1993 and her health deteriorated progressively over time. She was legally separated from her husband and had one child aged 11 years. Her child stayed with her on alternate weekends and during the school holidays. Prior to moving to “Mei Domus”, Barbie lived at home with her child. Travel time for her family to visit the new accommodation was approximately one hour. Prior to the decline in her health, Barbie was employed in an administrative capacity for a large private organisation. She spent her leisure time bike riding, sewing, quilting and spending time with her child at the movies and amusement parks. Barbie reported that she spent time outside the apartments going shopping with staff or her child, having coffee, and watching movies. She also reported attending the weekly crossword activity, trivia and the karaoke nights held at the apartments. Barbie used a motorised wheelchair and had been a hospital outpatient once since moving to the new accommodation.

The location of the apartments impacted on the regularity of visits from Barbie’s parents. She still had regular telephone contact with them and their relationship had
improved from when they were caring for her at home. She still had regular contact and overnight visits with her child. However, the nature of these visits had also changed as her child had now made friends with the children of other residents, which had impacted on the time spent with Barbie. Barbie spent time with other children at the apartments, her “adopted” children as named by other residents and staff. Barbie enjoys this contact and speaks positively about it. When living at her family home, her and her child used to spend a lot of time going shopping and to the movies, whereas at “Mei Domus” there were restrictions due to staff assistance with outings.

“It’s quite some distance away. It’s an hour’s drive for Mum and Dad and it’s about an hour and a half each way to go and see my son, pick him up for the weekends, or for my husband to come and pick him up. But most of the time he will pick [son] up on his way home from work of a morning, so whether that’s Sunday morning or Monday morning after he’s worked a night shift at the airport. So that’s a lot closer then... Where I was living before I still saw [son] the same amount. I probably saw Mum and Dad a lot more frequently because one of them used to help me into bed every night, so one would always make sure that they were there to help me every night to get into bed and make sure I was in bed. As for [son], it was probably easier because school holidays he used to spend a lot of time with me at home. Now with school holidays... Oh yes, Christmas time was good because the majority of the time I had [son], because my husband went interstate with his new partner for a wedding, so [son] stayed here over Christmas and the whole Christmas school holidays. But still most the school holidays I will get him the majority of the time, rather than... Well, it’s still the same, it still stays the same, that I still get [son] the majority of the time because it’s easier for Dad to work, to do his own recreational thing and easier knowing that [son]’s here with Mum, so he doesn’t have to worry.

Interviewer: In terms of [son] being able to visit. You were at home before you came to “Mei Domus”, weren’t you? So do you find it easier or more difficult for him to be visiting now you are here?

Barbie: Only because, only distance-wise that would be more difficult but I don’t really see any change. He loves coming here because he’s made new friends here through staff’s children and it’s, I get told that I have adopted children, I may have got rid of [son] over a period of time but then I’ve adopted other staff’s children who come back here and say ‘Can I play the X-Box? [Son]’s X-Box?’, ‘Yes, you know where it is’. So I’ve been told that I’ve lost one boy for the day but then I’ve adopted two more children as well, and that’s a good thing because I also have interaction with other kids as well and they feel comfortable to come here and talk to me as well. So yeah, things that they can’t
see downstairs because the Wii room might be occupied, they can at least come up here and have a watch of Foxtel cartoons or whatever, so yeah” [Barbie:II:1:8:2:37].

Since moving to the apartments Barbie’s social engagements appeared to have increased, and although she missed her son, it seemed that she was now more able to engage in activities that met her needs as an adult. She had the opportunity to engage in activities with other residents. Some activities based on more intimate sharing of common interests and some designed to accommodate many of the residents, such as crosswords, trivia and Friday night “junk food” nights. Barbie continued some of her previous activities, as well as engaging in new ones. She was integrating her previous and present lives to establish a new way of living within her new environment.

“I have [similar interests to other residents], but it’s harder for me because those interests I can’t, one big interest I did have was sewing and there is another resident here that loves to do that but she has actually got a machine that is all push buttons, so she doesn’t have to use a foot pedal, and I sort of think gee, I wish I could do that. When I asked her how much did it cost her, it cost her about $6000 to get that machine and that eats the budget a bit. But yeah, other than that yes, I do have card making which I love to do with one of the other residents here and we have a lady that comes out and sees us at least once a month and she does card making with us. Crosswords, every Thursday we all go downstairs interests. There’s a whole heap of different interests that I’ve not only found here, but that I’ve brought with me, so yeah, and we continue to do them” [Barbie:II:4:121-130].

This blending of past and present also applied to her relationships. Barbie built friendships with previous support workers and maintained contact with them. She felt a sense of love and affection from them, although it was unclear whether she was included in their lives in the same way.

“We still, now I still get along with all of them and now they are not actually support people to help me, they are more friends and everything and we all celebrated my birthday together, went out for my birthday for drinks and lunch and whatever, and when I go up there my partner actually says to me, says to the girls ‘How come I don’t get a kiss like that? I don’t get a kiss on the cheek’
and they say ‘Because you don’t deserve it. We haven’t seen Barbie [actually uses nickname] for that long. She deserves all the kisses we can give her’. So before I never used to get any of them, but I get big kisses and cuddles.

A couple of friends have come to visit me here, a couple of my support workers have come to visit me here, and I will always hear from them on the telephone or on the computer and they will still come and visit me. I will socialize with them when I go back to my Mum and Dad’s. They will come and visit me at Mum and Dad’s or we will go to functions and I will meet up with them there. So they are not just the old support team of workers, but they are now my friends as well and they see it that way” [II:6:197-7:208].

Barbie also had a sense of friendship with the “Mei Domus” staff. She spent time with them both during working hours and outside of their rostered hours. She believed that the staff made an effort to connect with her and were not just there doing a job. She felt connected to the people who worked with her and did not see them as “just” workers. She invited one staff member to accompany her and her son on a long weekend away, which addressed her care needs and retained a sense of autonomy and independence as well as friendships. Although her relationships with the “Mei Domus” staff were similar to those with her previous support workers, the system within which these relationships operated appeared to be very different. Previously, she was reliant on the system which dictated her routine with limited consideration for her basic needs (e.g. left for hours unable to toilet, etc).

“When I was living at home I used to only have help twice a day, they actually changed it. I lost my help twice a day at one stage because I had people that came to do sleepovers with me and when they, DSQ, introduced the sleepover I lost my afternoon shift with people from 3 to 5 and I just told them I can’t do this. I can’t sit from 9 o’clock in the morning until 8 o’clock at night without going to the bathroom, getting myself tidied up, my showers and whatever and after a lot of struggling and my team of support workers putting their words in, that ‘How on earth can you let her go 11 hours without being able to go to the bathroom, you can’t do that to her’, DSQ decided okay we will give her back those two hours from 3 o’clock to 5 o’clock, but they still had my people come in at night time twice a week, which is on a Monday night as well as a Friday night” [Barbie:II:6:187-195].
At times, Barbie became emotionally overwhelmed and having access to staff she believed cared about her gave her the opportunity to share her feelings with someone. This process assisted in taking care of her mental health. Her life could feel monotonous and depressing, but the attitude of staff and the connection she felt with them was important in breaking this cycle. There was some tension for staff about being friendly with residents, but Barbie believed they were not just routinely doing their jobs and they did want to spend time with her. When staff were more spontaneous with Barbie, her sense of being cared for increased. Barbie felt respected by the staff and believed that they treated her the same as themselves. However, by virtue of the personal tasks involved (e.g. showering, toileting), this was not really the case.

There appeared to be some conflict for Barbie regarding her new accommodation. On the one hand, she “can’t stand it [living in a different part of town]” [II:4:133] but conversely stated, “and the one good thing is that I’m happy that I’m here ” [II:8:242-243]. She appeared to have a lack of connection to the wider community outside of “Mei Domus”, whereas she felt connected to her local area when in her family home. She described a recent situation where she was touched by the kindness of a stranger, which helped her to feel connected.

“Here it’s sort of like a different community, but I have actually found that one of the nicest things was when I was at the shops one day by myself and I actually asked for some food and I couldn’t lean over the counter because the counter was so high up, and a lady actually came up to me and said ‘Would you like me to get change for you?’ and I said ‘I just can’t reach up there’ and she said ‘No worries, I’ll hand the lady the money, just give it to me, I will hand it to her, I’ll collect your change as well’ and she did that, which I thought wow, this complete stranger just offered to help me and I thought that was really really nice of her and that was something that you don’t really see, people just don’t go out of their way to help you and I thought that was so much of this lady to do that” [Barbie:II:4:151-158].
She did have a sense of community within “Mei Domus” which seemed to extend to the nursing home next door. She derived pleasure from her connection with the older people, which may be linked to the decreased regularity of visits from her own parents. Barbie spent less time in the wider community, than she did prior to moving to “Mei Domus”. Although she had the ability and opportunities to go out independently, having increased opportunities to connect with others and participate in activities in her new home environment may have compensated for this need. The proximity of others made it easy for her to spend time with friends without needing to rely on others or access the external community.

“Mei Domus” provided a place for her where she did not feel isolated. She viewed “Mei Domus” as home and stated that her son also viewed it as home, which helped her to feel at home. It was a comfortable place for both of them. She was comfortable with the other residents and there were opportunities for her to connect with others and have a laugh, whilst still being aware of others boundaries.

It was the balance between people and privacy that made it home. She was not alone at “Mei Domus” as there was always someone to talk to. Having spaces where she could get together with others or choose to spend time alone was important, it normalised her experience. Knowing that she had some choice and independence helped her to feel relaxed, but also knowing that she had access to assistance if needed. Prior to moving into “Mei Domus”, she spent a lot of time on her own. If she needed assistance, she would telephone for outside help and then be dependent on when they were able to come to her house. At “Mei Domus” she felt safe because staff were there to assist. Although she was still dependent on their response to her call for assistance, the proximity of staff gave her comfort.
Barbie spoke about the decrease in staffing levels at “Mei Domus” since she moved in and the impact this had on her in terms of staff response times. She believed this situation created needless suffering for her and the other residents. Increased periods of time spent waiting for assistance heightened her awareness of her dependence on others. When staffing levels changed, she felt “disturbed” and was unable to establish a regular routine. It also meant that staff no longer came by just to see how she was. If she did not call for them, she felt forgotten, as though other people become more important than her. Barbie’s disability and dependence on others was highlighted by the fact that she could not reach the overhead cupboards in the kitchen. Thus, all tasks required assistance from staff, which depleted Barbie’s feeling of independence and created a sense of guilt about her need to be dependent on others. Barbie was aware that her need to engage staff in these basic tasks also impacted on other residents who then could not have access to staff.

Choices have been made for Barbie, which she appeared to accept without question. After moving to “Mei Domus”, she was changed from a manual to an electric wheelchair. Previously, she would complete her household chores at home (e.g., clothes washing) and made regular use of her hands. However, since using her electric wheelchair, she had noticed a decline in her ability to use her hands which had increased her dependence on staff. All her household chores were completed by staff members, removing an important role.

The most significant event for Barbie came when another resident was moved into her apartment. Prior to this time, Barbie had been living in one of the two bedroom apartments by herself. This brought up both practical and emotional issues for Barbie. It became apparent that the design of the apartment was not suited to two people living
separately (i.e., not a couple) due to lack of separate storage space and privacy. It also highlighted the inadequacy of some design features for people with disabilities.

Barbie’s experience of the new resident moving into her apartment was a disruptive one. The staff did not involve her in the process, including conversations about the situation and the day when the new resident was shown around the apartment. Barbie waited to be invited to participate in this process and when this did not happen, she did not assert herself and stayed downstairs away from her own apartment during the process. The attitude and behaviour of staff during this time left Barbie feeling unsure of what was happening. She felt she had no control over the situation and felt like a number for the first time since moving to “Mei Domus”. Barbie waited for permission to enter her own apartment during this event which suggests that the sense of home she reported earlier was tenuous and fragile. She had no voice in what was happening and felt like her home was being taken from her. The event reinforced that she had no control and that other people ultimately have control over what happens to her. She referred to herself as “just part of the furniture”.

This sense of disruption was visibly distressing for Barbie and highlighted how a single event can dramatically disrupt a resident’s life. She had a sense that her home was being taken away from her, which was another loss on top of everything else she felt she had lost. A second event that impacted negatively on Barbie involved her pet guinea pigs. Initially, she was told by management that this was her home and she could make decisions about having her pets with her. However, following a change of management, these rules changed. There was a sense of unfairness for her as she saw different decisions being made about other residents (i.e., another resident is allowed to keep pets). Her pets formed part of her daily routine and were also a source of companionship for her, but this had been lost.
“I was told by management to get rid of them. I was actually advised by [manager’s name], when he was the boss here, that the guinea pigs there’s no problem, so I was able to have them and when my son was here we used to take them downstairs and put them on the grass every day, cover them up and leave them to eat the grass and they used to love it. Then I just got told one day by management, the new management, that they have to go. I thought to myself okay, well things that were said to me – well it was in the beginning, but it was shortly after the beginning – that this was my home and basically because they’re only guinea pigs I can have them. So I brought them back here and we went and picked them up from [fire alarm test interrupted]... They said to get rid of them, they had to go... The reasoning for that, I don’t know. The silly thing was one of the other residents was told – they got rid of all the birds that were outside, we had cockatiels outside and one of the residents said I would buy the cage and amongst other residents here we disagreed with that because the birds were the last to come, and it was actually written down in a newsletter for our friends – residents and friends funding, which is to raise money for our own purposes – that she was supposed to get rid of the birds. She hasn’t got rid of the birds, instead – it was supposed to be done on the weekend – and instead her children came a brought her another cage. To this day she still has her birds.

Interviewer: So what’s your understanding of why you can’t have your guinea pigs?

Barbie: They were saying that at night-time it was too smelly, because basically every night I would bring them in, every night, and I would put them against the wall there in their cage. The only reason it got smelly, the guinea pigs were not smelly, it was their faeces. It would be every morning it would be changed and every night it would be changed and they’d get fresh paper after their feed, because it was usually after they ate that they would urinate or their faeces would come out. Before they went to bed they always got changed and they had fresh paper and I think it was specifically one particular staff member complained about it because she used to work for the RSPCA and it was because of that person that I had to get rid of the guinea pigs. I actually mentioned it to management that it was a bit unfair that I had get rid of my pets, and that this particular person was told to get rid of hers and she still is able to keep them on her back patio. But the funny thing is she will call my son to go and feed her birds and give them water because she can’t do it herself. When I told management that, management said I didn’t know that, but to this day her birds are still there.

Interviewer: How important was it for you to have pets?

Barbie: Very important, that was part of my life. Because I used to – and other residents – used to come in here and talk and chat to my girls and they’d talk back and they knew when it was feed time, they’d all start singing and dancing and making their noises. That’s one thing I really miss, because some of them I’d had since they were babies and when they were living with my husband and my son, my son just rang me up one week and said to me, mum this one’s gone and I thought don’t tell me that. Then a week later he told me that this one’s gone and I thought this is an absolute joke. So I’m left with two, and I
said no. So that’s when I spoke to management and they said yes, they’re only guinea pigs you can bring them so I went and picked them up, brought them back here, I’ve got a brand new cage for them and everything. Every once or twice a week they would go downstairs, eat their grass, be transferred into a cage on the grass and then at the end of the day they’d be put back in their cage, have a bit of food, at night-time their paper would be changed and whenever their paper was changed it never used to smell. Then the next morning, of course it would smell, until the paper got changed again” [Barbie:12:13:404-14:450].

Time spent socialising with the other residents who she had “grown to love” still felt good to Barbie. However, following the two events there had been a shift in the way she felt about the apartment and her sense of it being her home. She talked about moving away from “Mei Domus” to be closer to her parents. This rupture in her sense of home brought up a lot of memories of loss and grief for Barbie surrounding other versions of home. She still saw “Mei Domus” as the best alternative for her, but it no longer felt like home, she felt trapped. If she were to go to live with her parents she felt she would be treated as a child, whereas she saw herself as the mother of a child. There was also a sense of the unacceptable burden she would place on her parents. She talked about her dignity and how this had been damaged by the experience of her family seeing her so vulnerable. She felt equally exposed during the course of being cared for by staff, but felt this was her best option.

“I do know mum and dad wanted me to move back home with them, but I felt like if I was to move back home with them, I would be treated like a child all over again even though I’m a grown adult and I’ve got a child of my own and that child happens to be their grandchild. I just think well no, I cannot do that to my parents; my parents are in their sixties. Mum’s turning 60, my dad just turned 60 too, in May, and I can’t go back to that. That’s like when I go home for a weekend, dad will say to me, your mum can give you a shower, I’ve seen you as a baby, I don’t need to see you as a grown adult. So yes, so it will always be mum that takes me to go and have my showers, same as when I go to the toilet, dad will help me to go to the toilet, but they always make sure I’m covered up so that – as he said, I’ve seen you as a baby, I don’t need to see you as a grown adult. So that’s just dad for you” [12:11:327-336].
Barbie perceived she has some choice about her daily routine (e.g., when to get out of bed) but she was still dependent on the staff responding to her call. Barbie chose her routine in terms of what suited the staff. For example, she had her shower in the afternoon as she knew staff were busy with other residents during the morning. Initially, residents chose what time they wanted their meals, whereas meal times had later been designated for all residents. Barbie saw this change as a natural evolution, because residents all began congregating in the dining area at certain times. However, for participants like Barbie who valued privacy and choice; congregate meals at set times were not her preference.

“It’s basically, it’s a choice that’s been made between management and staff, for staff to be able to have their own breaks. It was more suitable for us to have an earlier lunch rather than lunch at 12 o’clock, 12:30.

Interviewer: More suitable for you or more suitable for staff?

Barbie: Staff.

Interviewer: So how is that decided?

Barbie: Through management, and we just briefly got explained by management at the residents and staff meeting. Just briefly got told, now we need to allow for our staff to have their breaks, because there are people that are starting at six o’clock in the morning and having no breaks until they go home in the afternoon, which is understandable. Because they can’t function without having their own breaks as well, so that’s understandable and we all understand that. The funny thing is some people will come up to me and the first thing I would say to them, have you had your break yet? If they say no, I’ll say go away, I don’t want you, I’ll get somebody else. Because it’s more important for them to be able to function by having their own breaks and I find that if – I can’t function by having a break myself, well how are they going to deal with this” [Barbie:12:9:293-10:306].

Memorabilia of Barbie’s family, especially her son, gave her the sense that family were with her whenever she looked around. It was important for her to feel connected to them. She missed living with her son; although they both had a sense of comfort that she was living at “Mei Domus” and not on her own.
“Well here is my home now, and my son, I remember one day, when I went and picked him up from school even last year he said to me, mummy can we go home? I said to him, well we can’t go home because I’ve moved out of home and you know that. No, I don’t mean our old home mummy, I want to go to your home. I said well where’s my home, and he said “Mei Domus”, and so that’s a good feeling for me to know that my own son thinks that this is home. That’s a lot better atmosphere for him because he feels comfortable here and so do I, we both feel very comfortable and we know that this is mummy’s place, this is where mummy lives and he knows all the people that are here as well and some of them he gets along with really well” [Barbie:12:2:41-47].

She missed being close to her family and she described a sense of watching as she was slowly pushed out of the life of her child. Life seems to be “falling down” around her. She had no sense of control and feels like she does not matter.

“Then he [son] started to discuss with me about him only coming once every three weeks, and I was like this is great, your dad’s getting exactly what he wanted in the first place, which was to have no contact with mum. I just felt like everything around me was falling down around me [cries] and I was really depressed last night from it and I had to hang up on him and I said look, I can’t talk about any of this tonight, I’ll speak to you when I come and pick you up tomorrow, I’ll be there to pick you up in the afternoon. He said okay, but apparently one of the decisions that was made for him to come once every three weeks was what he suggested to his father, and I just thought to myself yes, okay well that’s great because dad gets exactly what he wanted and he actually threatened me before I left home that I would never see him again [cries]. I’d never see my son again and that it was my responsibility to come and pick him up and to bring him home every weekend.

I thought that’s exactly what you want, you want me out of our son’s life and he said I would never do that, but the funny thing is when we moved – I moved here, he helped me move in. Now he is very distant and cold to me, especially since he’s got another partner and he actually rings up and says okay, I’ll come and pick him up at this time and he’ll always turn up half an hour earlier. I will say to my son, you know what your dad’s like, you know he’ll turn up half an hour earlier like he always does [and my son just thinks] I’ve got that mum. It’s just like everything around me is caving in after what happened last night, I just thought I can’t deal with this, I don’t need the added stress of it. I don’t need my little boy taken away from me [cries], and my husband has already gone, he chose to leave” [Barbie:12:11:355-12:371].
Freda

Freda was a female resident who was 52 years of age at the time of the study. At the time of her aneurysm in 2002, she was married with three children aged between 17 and 23 years. Following her brain injury, her marriage ended and she was divorced. At the time of her injury, Freda was responsible for home duties, led a busy and active life and was involved in competitive sport. Following her release from hospital she lived with her mother and then moved to a residential aged care facility where she lived for two years prior to moving to “Mei Domus”.

Since moving to “Mei Domus”, Freda received regular weekly visits from her mother and semi-regular (three weekly) visits from her children. She had frequent telephone and email contact with family and friends. The availability and accessibility to communication technology within her apartment allowed Freda to stay in contact with family and friends. Previously, she did not have access to a private telephone so had to make calls in the public area of the residential facility.

There was the option at “Mei Domus” for family or friends to stay overnight, and whilst this had not yet happened for Freda, she often talked about her plans for friends to come and stay, something that was not an option for her at her previous place of residence.

Freda had made several connections with other residents at “Mei Domus”, and she spent time reading to one particular resident. Freda saw herself as being more able than this resident and appeared to enjoy providing some assistance to her.

“I’ve made a lovely friend called Justine. I go and read to her. She’s blind so at the moment I’m reading to her. I’m going Friday night actually” [Freda:II:2:38-40].

Freda reported that “Mei Domus” was friendly, open and welcoming. She found the other residents to be generally interesting and nice people. Freda saw herself
as being someone who made friends easily and had developed friendships at her previous accommodation. She took interest in other people and tried to find others who shared some common interests such as cooking. However, she had not yet found anyone with similar interests. Although she talked about enjoying cooking, she had not engaged in any cooking since being at “Mei Domus”. The provision of meals by the staff inhibited her cooking for herself. She described herself on a couple of occasions as being “lazy” in this regard and talked about no longer needing to cook as the staff do that for her. She justified her lack of cooking by stating that if she were to cook as well as eating the meals prepared by the staff, she would “get fat and put on too much weight [Freda:11:3:71]”. As someone who had been very active, her inactivity impacted on the way she felt about herself.

Freda described the staff at “Mei Domus” as being caring, “lovely” and commented on the fact that she “hasn’t met a crabby nurse yet [Freda:11:4:86]”. This was unlike her previous residence where she described some of the staff as being “awful, they were horrible, they didn’t offer to do anything for you [Freda:11:5:103-104]”. She described how the staff at “Mei Domus” would regularly do small things for her like clean her glasses before giving them to her and, if she needed personal assistance, they were ready to offer help (for example, wiping her bottom if she had difficulty on the toilet). Freda saw this as very caring behaviour. She believed that she was liked by the staff, which she attributed to her own good manners and behaviours.

“They make little comments to me about, they’ll often say to me, you’re very easy to look after Freda. We all like looking after you because you’re easy to do, you’re very – congratulating of staff, because I thank them and I use my manners. They tell me that, so it’s nice” [Freda:11:4:92-94].

When Freda reflected on her previous accommodation, she described it in very negative terms.
“It was dreadful, I was just stuck in my room all day, I had no interaction with anybody. If I wanted a nurse I had to call for one. I wasn’t given any physio[therapy], well, there was a physiotherapist there but he only came in if he wanted to work all day, so that was very rarely. So I was just stuck in a room all day. I didn’t even…. I think I had….., my mum bought me a small TV in the end so I could watch a bit of TV. I was just stuck in the room all day, nobody to talk to because everybody there was very old, half of them couldn’t talk. So I was just stuck in the room all day and that was it” [Freda:12:1:9-15].

“Terrible, absolutely terrible. I did nothing all day. The kids did come and see me every now and again but not very often. They didn’t like it there either. I was stuck in a room in a nursing home. I just had a room and that was it. I didn’t have any of my things about. There was nowhere to put anything you wanted. Just one room and that was it” [Freda:12:6:154-158].

“It was horrible, very, very – you felt ostracized, you felt like an outcast. It was horrible” [Freda:12:7:160-161].

In contrast, she described “Mei Domus” as “great terrific, yeah terrific” [Freda:12:6:151]. “Mei Domus” provided her with room to move, and space to put her things around her “I can see all my things about and it’s making me feel like myself again” [Freda:12:7:163-164]. It allowed her a level of independence, choice and autonomy that was previously lacking. She experienced choice and flexibility in regard to the structure of her day at “Mei Domus” together with a sense of routine including regular physiotherapy appointments. There appeared to be some imposed structure around meal times, however, she still had choice regarding where she had her meals.

“Well, dinner is approximately about 12 or 12.15-ish. You can go at 12.30 if you like, but around that time you go down for your dinner. Same thing at night-time, dinner’s around five, 5.15, 5.30-ish. If you go down then you should get your meal” [Freda:12:7:179-181].

“You can have your meal in your room if you wish. Sometimes I’ve had my meal in my room, I’ve been watching – sometimes in the afternoon I watch a bit of tennis on TV and it was a really good tennis game so I bought my meal back to my room so I could finish watching my tennis game. Yeah, you can have your meal in your room if you wish or you can have it in the dining room with everybody else. Do as you wish” [Freda:12:8:187-192].
Freda had the sense that she could do as she wished, and there was a sense for her of being spoiled which she attributed to being lucky. Freda mentioned on a couple of occasions being spoiled, as though her experience at “Mei Domus” was above her expectations.

“The meals are tremendous, we’re very spoilt. We have a very good cook and she gives us a wonderful selection of meals. We’re very lucky” [Freda:12:7:183-184].

Interviewer: “What’s that like, being able to have those choices?
Freda: It’s wonderful. It’s very good, we’re very spoilt” [Freda:12:8:194].

“Oh, we’re very lucky. Yeah, we’re very lucky to be able to choose where we wish to eat” [Freda:12:8:196-197].

Although “Mei Domus” exceeded expectations for Freda, it still did not constitute “home”. According to Freda, “there is no place like home” [Freda:12:8:212]. For her home was a wonderful place, a place where her favourite meals were cooked by Mum. It was a place where she was with family, somewhere family could “pop in” with no restrictions, where she had her own things around her. Freda believed you can never replace home. Having her own things around her at “Mei Domus” was important to her and gave her a link to her past, her memories, providing her with history and identity.

However, it was not enough just to have her things around her. Her family was missing which made it “not-home”. “My family aren’t here all the time. Although my family do come to visit me and they come quite regularly, they’re not here all the time” [Freda:12:3:73-74]. She missed the familiar experiences (for example, the cooking smells) that were associated with home. Even though the food was excellent at “Mei Domus”, this did not equate to home for her. There were even things for her
that highlighted the fact that “Mei Domus” was not home, the large television in her apartment, which she enjoyed, somehow reminded her that if she were at home she would not have such a large television.

Freda: “At home I don’t have such a good TV as here. No, I’ve only a little one. Here is fantastic, huge screen TV. Oh, it’s like going to the movies just to watch television. It’s very good. So you get very spoilt having a huge TV like we have here. Oh, yeah, look at the size of it.

Interviewer: So does that make it feel like home or less like home?

Freda: Less like home because I wouldn’t have one like that at home. No, I’ve only got a little TV at home” [Freda:i2:3:78-4:88].

Freda understood that she required a high level care and was not in a position to live with family. “Mei Domus” appeared to be a good substitute for home; a place where she received the care and direction she needed. Freda reported her experience of living at “Mei Domus” as positive.

“Very enjoyable, yeah very enjoyable... Just the air, just the whole place is so nice. You have your own things, you’ve got good meals, you’ve got good people, you’ve got good therapies. Everything is good” [Freda:i2:9:226-229].

“Oh, I love it here, it’s fantastic. It’s very, very nice. Lovely having your own space and having your own things about. It feels good, I like it, I love it. You’ve got the space to be yourself to start getting back to the old you. You’ve got room to be yourself again” [Freda:i2:5:123-129].

Thus, in some ways, “Mei Domus” provided the space for Freda to be herself again, to rebuild her post-injury self, which she differentiate from her pre-injury self. She previously saw herself as a wife and mother, but she was no longer a wife and her role as a mother had changed dramatically. Some of this role change was a natural transition due to the age of her children; however, some of this change had been triggered by her need to change residence. The time spent in her previous residence
created a distance between her and her children due to the restrictions imposed upon them.

Freda experienced “Mei Domus” as open and bright, a place where she could wander around and choose to spend time indoors or outside, she experienced the place as being “beautiful”. Despite the benefits of this environment, she would choose to return to her family home if she could access the services she required. Home remained a place for Freda to go back to in future.

**Therese**

Therese was a female resident who was 52 years of age and had been married for 29 years. In 2002, Therese had an aneurysm which left her in a wheelchair. Prior to her aneurysm, Therese was a full-time mother to three children now aged between 17 and 20 years, a role from which she derived great pleasure. Following her aneurysm, Therese stayed in a hospital for two years and went home for the weekends. Therese’s accommodation at the hospital was located with patients who had dementia.

When Therese initially moved to “Mei Domus”, she saw her family regularly. Her husband visited during the week with a friend of Therese’s and again at the weekend with their children. They used to visit more frequently when Therese was in hospital; however she advised that the time there was very stressful and pressured. She described “Mei Domus” as being calm and relaxed, a place where “they make you feel wanted, so you really don’t have any worries about that” [Therese:11:1:12]. In contrast, when her family visited at “Mei Domus”, there was a sense of pressure created by her family’s presence. Therese did, however, miss her family and felt shut away from them. Access to her own telephone allowed her to maintain regular contact with family and friends. Her sister also contacted her from overseas weekly and was planning to come and stay with Therese. The option for people to stay at “Mei Domus”
assisted the process of maintaining contact with others. Therese described feeling relaxed and having more freedom since moving to “Mei Domus” and this was not only positive for her but also impacted the people in her life.

“My best friend from Sydney, she came over last year and stayed with me in the spare room. We had a ball. We went to [local shops] and we did shopping and everything together” [Therese:11:2:41-43].

For Therese, being at “Mei Domus” normalised her disability, she had a sense of being accepted and welcomed there, a sense of belonging that she no longer felt she had within the community or even at her family home. Over time, the frequency of Therese’s contact with her children reduced. Therese formed relationships with other residents at “Mei Domus” and through these connections; she had the opportunity to spend time with another resident’s child, which appeared to fulfil a “mother” role for her. The strongest relationships she appeared to have made were with the staff at “Mei Domus”, and due to the relatively young age of the staff, her interactions with them provide further opportunities for “mother-like” experiences.

“With the carers and nurses here, the friendship I’ve built up with them is so good. I really miss them when they are on holidays and stuff like that” [Therese:11:3:81-83].

This experience contrasted sharply to her experience of staff when staying at the hospital.

“That’s what I wrote in a letter to [hospital]. I told the clinical nurse, I said you should take a few classes off the clinical nurse here [at Mei Domus] and see how well the staff act to the residents. You will die of a shock if you come here and see the way they treat people, they have patience and everything. There was one MS patient in [hospital]; I remember how these nurses used to treat her like dirt. My bedroom was in the corner and I could hear all the nurses grouping together and discussing the patients. Here, I never, ever hear them bitch on anything….You never hear them discussing patients. Which is really good” [Therese:11:4:98-104].
Therese had established some structure and routine for her days with assistance from the staff at “Mei Domus” who also encouraged her to be as independent as possible. This encouragement gave Therese a sense of pride, achievement and independence.

Therese stated that she preferred now to think of “Mei Domus” as home, yet there appeared to be some conflict in her mind. On the one hand, she referred to “Mei Domus” as her home and had no desire to leave, but this seemed to be related to not wanting to be a burden to her family. To some extent, her decision was also based on her desire to take care of her own needs in this process. “Mei Domus” provided a place where she felt wanted, relaxed and safe. She had access to the therapies she needed, and she was comforted by knowing that there were staff to assist her when she required. She acknowledged that this level of care would not be available if she moved back to her family home. However, she maintained the belief that, at some unspecified stage in the future, she would return home, albeit when she was ready.

“To me this is home. This will always be home. This is my home. I love this place. I love the people. I love the way it’s set up” [Therese:12:6:160-162].

Yes. It’s really good. See, at home I can’t have that. I feel very, very safe here... It’s one thing I feel very safe and I know everyone, the carers are here to help me. They’ll do everything possible, their best to help me. Still, till I’m one hundred per cent sure that I’m fine to go home, I won’t go home. I have to be a hundred percent sure that I’m okay, then I’ll go. But I will lose my, I’ll miss all my friends here and that’s going to be really, really hard” [Therese:12:13:367-373].

Although Therese had a definite sense of home at “Mei Domus” there was no real sense of permanence to this home. Staff members appeared to provide some of the characteristics of family, but there was a deep sense of loss in relation to her children.
Conclusion

This chapter has provided an overview of the participants’ experiences at “Mei Domus”. The examination of the individual stories gives a sense of who the participants are, highlighting the individual nature of each person’s experience. This has also allowed comparison between participants, highlighting the similarities of many of their experiences, as well as the differences within those stories. The following chapter will further examine the data to assist in understanding the process of how the participants experienced home and what influenced their sense of home.
Chapter Five: Results – Understanding the Experience of Home

The purpose of this chapter is to build a theory about how the participants experienced home at “Mei Domus” and what influenced their sense of home. In summary, two core themes emerged from the data, namely Perceived Qualities of Place and Identity. Perceived Qualities of Place explores the perceptions and experiences participants had of the new environment they were living in, both positive and negative. The Identity theme looks at how the participant’s identity is influenced not only by the environment they are in but also the interactions with the people around them. These themes seemed to be inextricably interlinked with each other, and to the extent that they overlapped, a sense of Home was created. The theme of Home outlines the participants’ sense of what home meant to them as individuals, whether a strong sense of home was developed, as well as factors that created a sense of not-home. These two core themes were influenced by a core process that took place for this group of participants, namely, Deconstruction and Reconstruction of the sense of home. This process is explored and the factors that influence the deconstruction and reconstruction process are highlighted.

The core process was influenced by the theme of Connections, which was constructed from three sub-themes: Interactions with the physical environment, Relationships with family and friends, and Relationships with staff. The impact of these connections were evident for all participants and is presented including the positives, challenges and complexities of these interactions. Each of the core themes and processes will be described below, using excerpts from participants’ interviews. Although the themes overlap and do not operate in isolation, they will be described separately for the purpose of clear presentation. Each theme is evidenced by multiple quotes from across the participants. All quotes used are taken verbatim from the
transcripts with changes only to the names of people and organisations to ensure anonymity. These quotes were selected in order to give voice to all participants, where possible, and also to demonstrate either convergence or divergence of their experiences.

For a visual representation of this theory see Figure 1 below.

Figure 1: Experience of home for young people with disabilities living in long-term residential care at “Mei Domus”
Home

Home is a latent multidimensional construct (i.e., constructed from other concepts). It is comparative and based on an individual’s own memories and experiences (i.e., identity). Home is defined in relation to previous experiences and in terms of how well it meets particular requirements to satisfy an individual’s sense of comfort and belonging (i.e., perceived qualities of place). For most of the participants, especially those who lived in inappropriate accommodation prior to “Mei Domus” (i.e., Lou, Emma, Justine and Therese), their sense of home at “Mei Domus” was strong.

Emma describes the essence of home as a combination of people, objects and feelings.

Emma: “Has pictures on the wall, my pictures on the wall. Has magnets on the fridge. Has my photo boards and all that sort of thing. It’s not so much about things as it is about people and feelings, do you know what I mean? I mean it’s all those things, the pictures, it’s being able to watch the channel you want to watch on TV without having somebody go that’s not what I want to watch, therefore without any negotiation. It’s a place where angry words if they’re spoken, they’re forgotten quickly, yeah those sort of things. Do you know what I mean?

Interviewer: What do you think are the things in this environment that feel like home to you?

Emma: The most important is the fact that I can stay upstairs here in my room and just do my thing all day long without having somebody knock on my door going are you alright, do you know what I mean? It’s just accepted that I like being alone and doing my thing.

Interviewer: So what does that mean to you, not having that happen? People not knocking on the door and checking on you?

Emma: Oh, it means everything to me because it means that these people aren’t spying on me I guess or checking up on me every half hour. Making me feel like a nuisance if I don’t go downstairs at least once a day or making me feel like I’m just yeah, just all those things” [Emma:12:4:95-112].

For Barbie, having a sense of community with those around you assisted in her sense of home. Knowing that there were other people around to engage with allowed
Barbie to feel less isolated and part of a community, which assisted in her reconstruction of her sense of home.

“The people that are around us, I think makes it home. The community, being able to get out and about in the community and not feeling isolated, because that’s a key factor. If you’re feeling isolated, you’re feeling withdrawn from everything around you, and that’s one thing we don’t have here. We’re able to basically – being home, what I classify as home, we live in our own community, we have a community of our own. We don’t feel like we’re on our own, we’ve got other people to talk to as well. Whereas when I was at home on my own, most of the time, and only saw my son on the weekends or school holidays, it was still home and even though I had carers there, sometimes what would you do when you didn’t have the care that you needed at all times. Because sometimes things would happen and I would have to ring up some of my staff and say look can you come, this has happened, I need help, can you please come now. They would have to drop everything and be here, whereas now we’re on basically a call system where if something does happen we can just buzz and within a certain amount of time some people will be here to assist you” [Barbie:12:2:50-61].

Home was spoken about as a “feeling”, something that had to be experienced and could adequately be described. Emma described home as a place where, when you walk in, you instantly feel welcome, a place where there is no wrong, a haven.

“A place when you walk into it, you instantly feel welcome, not unwelcome. A place where I feel safe and comfortable, not just – it’s more than secure, it’s a safe feeling. It’s like security is lock sort of thing but safety is more about a personal feeling that when my door opens in the middle of the night, it’s a carer coming in to empty my night bag, not some stranger coming in to do the same job. Do you know what I mean? Like it will be somebody I recognise. A place where no matter what you do, it’s right you know, there’s no wrong in that place. Yeah, all those things” [Emma:12:3:82-89].

Lou described home as a place connected to family and friends and that being at home gave a feeling of love, even when you were alone.

Lou: “So I just think a home is somewhere that you can have family, you can have friends and can you have your life the way you need your life to be, so yeah.

Interviewer: What do you think it feels like to be at home?
Lou: Wonderful. [pause] I think it's wonderful. The love that you get when you're at home whether you're with someone or not with someone is just – I can’t really describe it. You feel safe and secure. Well that's how I feel.” [Lou:I2:4:132-137].

Yet despite this description, Lou stated that it felt like not-home when she was alone without her partner.

“There’s no Steve, because Steve and I have lived together for too many years [laughter]. We’ve been together 14½ year, been living together for about 12 at least, if not more. So home is where we met up at the end of each day after work and we wake up together in the mornings. I miss that. I don’t miss his snoring but I do miss not having him every day when I wake up and every night when I go to sleep.” [Lou:I2:4:149-152].

For Therese, home was where she felt relaxed; it provided her with a sense of freedom and she felt accepted for who she was.

“I have more freedom here. I can talk to people, about the way I feel and everything. For a fact, my girlfriend came the other day, because I had a seizure at church and I couldn't make it to her place that night for dinner. She was worried and she came to see me. She was really happy to see I was so relaxed here. Then we went and had a cup of coffee downstairs. It’s just like being at home. Everything is so relaxed” [Therese:I1:2:31-34].

“That’s one thing I hate, whenever I go, even when I go to church, I feel people are watching, looking at me all the time. Because I’ve got so used to this place here, because when I walk or do anything, no one bothers. We’re just part of it; we’re just another piece of furniture. It’s great” [Therese:I1:3:61-63].

The sense of home was temporal. Although participants were not asked how long it took them to feel at home at “Mei Domus”, three participants spoke explicitly about this and their experiences were different. For Lou, home had always been an important concept, realised through her work in public housing.

Lou: “I miss not being able to work for public rental housing. I’ve had other jobs as well but mostly in my working life it was public housing and I really miss that, being able to assign houses to people and give them bond loans and all things like that that helps their lives. So, yeah, I miss that.

Interviewer: What was it about being involved in housing?
Lou: Well, as I just said, being able to allocate people homes, people that have been waiting on waiting lists because there’s a huge waiting list in public housing and I was able to ring them and say ‘I’ve found you a house, come and have a look’ and with bond loans being able to give them money so they can get a new apartment or whatever they needed the bond for.

Interviewer: You mentioned that you would find homes for people. What do you think it is about a home that is important to people?

Lou: Stability and especially if there’s children involved. I mean there are people on the waiting list that - you know, it’s not just one lady by herself. It’s normally one lady with two or three children or it could be a couple with two or three children and they have tried their best to make ends meet in the public rental sector, meaning real estate agents and stuff, but it’s just not affordable. So when you can give them an affordable place to live and have their children safe and stable, I think that’s important. I was also involved in [pause] properties for disabled people. I was sort of the secretary to the OT, occupational therapist, at one stage. Being able to ring people and say we’ve got a house for you that is completely disability modified, that was ... Wow, that was amazing. Because they need it more than anybody else and I know that now as someone who is disabled” [Lou:I2:3:109-4:128].

When Lou relocated to “Mei Domus”, the sense of home felt immediate. Lou had been living in accommodation where she felt her life was on hold and the deconstruction process for her was considerable. In moving to “Mei Domus”, Lou experienced having her life back and was able to immediately regain the losses that had triggered the deconstruction process (i.e., her loss of privacy, loss of guardian role, space to organise her office, and time with her partner), as described in the connections theme later in the chapter.

“The first thing I did when I arrived last March was thanked [name], I said ‘Hey, thank you so much for doing this’ because I’ve got my life back. Well and truly got my life back. I’ve had other people who have visited here, friends and that. I had a housewarming – housewarming – I had a unit-warming party last May, it was a few months after I got here and quite a few people came along. I’m having another party next month, like to celebrate my birthday as well as one year anniversary of being here and also just a, hopefully an annual get together of friends. So I am hoping that people will come to that. I’ve got a few people that have responded already and said, ‘Yeah, I’ll be there. I’ll be there. Keep me away’, sort of thing. So that’s looking promising” [Lou:I1:3:98-4:106].
“I have my life back. It’s all I can say to people when they say ‘How do you feel about living at “Mei Domus”? ’ ‘I have a life’. ... it’s my life. My life. I do it when I want, how I want. Of course, as I said, keeping it in mind that the staff have other things that they have to do” [Lou:11:8:268-271].

Emma expressed how long it took for “Mei Domus” to become a place where she felt safe and wanted to be (i.e., reconstruction). It became somewhere she wanted to be and was happy to be, however, this sense of home had to develop over time for her.

“I mean I think that you get the idea that I really like it and it’s my haven and all that sort of thing and I mean it didn’t happen overnight, right? It didn’t feel safe overnight but it just gradually became this place where I want to live, you know and where – yeah, you know it’s where I want to live and where I’m happy living” [Emma:12:9:260-264].

In contrast to this, Ivan and his wife moved to “Mei Domus” together from a home they had modified for themselves. He described a feeling of restriction for the first six months. He also believed it took at least twelve months for “Mei Domus” to feel like home and two years for him to really feel settled, although his sense of feeling unsettled appeared to be linked to his health and his concern for his wife if he were not there. This, however, impacted on his sense of home.

“It’s taken us 12 months to feel comfortable here” [Ivan:11:7:176].

“I suppose – oh, at home, you could say it was more personalised, but it’s not really. Because we’ve been here two years and we now – I now feel that what we’ve got here is personalised. Susie – it takes her – she needs a bit more attention. But she always thinks of it as home, you know, because well it is our home. There’s nothing – there’s no other way to describe it. It’s just – that’s the way it is” [Ivan:12:3:78-81].

“Now, it feels comfortable. When we first came in, we were a bit dubious about how things were going to go, because it was all new. Well, it was new to Susie and I. It was totally new to us... I was a bit dubious about how we were going to – not mix, not fit in, but just how we were going to handle being in this kind of a situation. It’s probably for the first six months, I felt tied down or restricted. But now I don’t. I don’t care anymore. No, that’s not right. It’s not that I don’t care anymore. It’s just that I don’t – yeah, I don’t care anymore. That’s right. That’s about right. I do care personally. But if I want to do something, I’ll do it. If I want to go somewhere, I get someone to take us somewhere. If I want to see
something, I can get someone to take us there. I don’t know if you’ve heard of them. There’s a new thing out now. We just got ours last week. It’s called an aid companion card. Like say we wanted to go to a play, right. We get one of the staff members here to come with us. They get in for half price. So you can take a companion with you wherever you want to go. I got a card. Susie got a card. Oh, everyone’s got a card in here. But that’s why it’s just so much easier”

[Ivan:I2:8:238-252].

For Ivan, moving to “Mei Domus” initially took away some of the aspects of the physical environment that for him were home and included aspects of his identity, therefore, he needed time to reconstruct his identity and sense of home within the environment of “Mei Domus”.

“Like Susie and I, we used to spend a lot of time just being at home. That was all we wanted, you know. We both wanted a house. We built the house. We decorated the house. We changed the house around to whatever we wanted. You can do that here. You can change the room around to whatever you want. You can move things. You can do things, there are no restrictions. Oh, there is, you have to be sensible with what you want to do, but you know, it’s just easy”

[Ivan:I2:6:175-179].

The exception to this was Freda, who believed that there is no place like home and that home is a place with family. Although “Mei Domus” provided her with accommodation where she could have her physical needs met, it did not represent home for her.

“If I could get physios to come to my home to see me I would go home and have a physio come to me but we just can’t get a physio to come to our house. I still need a bit of physio care, or physio direction. So here, I guess, is the best place for me because I’ve got them on hand here” [Freda:I2:8:201-204].

Although the model fitted for Freda in terms of the inter-related connections impacting on her perceived qualities of place and her sense of identity, her identity appeared to be firmly entrenched in her previous home as a healthy woman to which she believed she would return, therefore she was unable to create a sense of home at “Mei Domus”. It seemed that she had a strong core belief that home was with family and that
she was welcome by family. This contrasted with Therese, the other participant with ABI, whose family relationships were not strong and staff relationships were positive, assisting her in creating a new identity located within “Mei Domus” as home.

**Perceived Qualities of Place**

A major contributor to sense of home was perceived qualities of place. All participants talk about home as a place where they can have their things around them but also a place where they can move things around to suit themselves. It was seen as a place of comfort where they were able to be themselves. Being home meant they could have a place in which to connect with others. It was a place where they belonged and where they could have a sense of well-being. Home was not experienced in a vacuum; it was linked to many things and other people. What happened at “Mei Domus” did not just happen to the participants; it also impacted those around them.

There were some common features across the participants that defined the qualities of the place, such as: a place where you feel welcome, safe, secure, and comfortable; and where you have choice about what you do; space to have your own things; the ability to manipulate the environment to suit your own needs; and space and opportunity for family and friends to spend time and develop and/or maintain deeper relationships. Having access to technology and a private telephone assisted these participants in maintaining contact with significant others. There was no need to rely on staff if they wished to speak to loved ones and arrange visits (except in the case of Justine due to her physical limitations). This sense of freedom and choice allowed them to maintain a sense of independence and feel relaxed within their environment. This not only impacted the participants but also on family and friends who had to adjust to their loved ones living in residential care.
For Ivan, a sense of the place being personal and relaxed was of importance to him in creating a sense of home. Knowing that other people are around to assist if needed was also a comfort for him, adding to his sense of relaxation.

Ivan: “It’s personal. It’s just – it’s good. It’s good. Yeah. I thought it would be harder to get used to, but it’s not. It really is. Plus, I suppose, being a bit lazy here, I know that, if something needs to be done in the unit or with Susie, that I can get someone to help. Whereas before, at home, sure, I could get someone to help, but it might take two or three or four hours ‘til someone gets there to help with Susie, you know. That was the main thing, you know” [Ivan:12:3:92-97].

Ivan: “It’s just more relaxed here. It’s very relaxed here. It’s like being at home, at home when you’re very relaxed” [Ivan:12:6:173-174].

There were also times when Ivan’s perceived qualities of place led to a sense of “not-home” at “Mei Domus”. There was a distinction between his apartment and the communal areas. Although he still used the term home to describe the communal space, he did not see it as a personal space. Time spent in the communal areas changed the nature of connections with others, and impacted choice making, although he does acknowledge that he has the choice not to engage with others in those areas if he does not want to. The role of these connections became stronger (e.g., having to consider the impact of his behaviours on others) and had an impact on the deconstruction of his sense of home.

Ivan: “I think the only time that I don’t regard this as a home is because – is when – say of a night-time, if we’re all down having tea in the community room. We haven’t got to have it in the community room. See, that’s another thing. We can have meals in our own room if we want to. But if we’re all down in the community room together, that’s about the only time I don’t regard it as a home.

Interviewer: So what do you think of it as then?

Ivan: It’s more of a – it’s more of a complex. Like it’s a – well, I don’t know what you’d call it. I just [pauses] – it’s hard to think of a word. You feel like more or less – oh, I guess, at times, you don’t think of it as your personal home. I think of it as home, if you can understand what I mean by that. I think of it as a place where we live, where we do what we want, more or less when we want, you know. But then again, you’ve got to look on the other side of it. You say,
The space provided opportunity to spend time with friends and family which was important for residents and assisted in increasing their perceived qualities of place and enhanced a positive identity, influencing a strong sense of home. Emma had the opportunity to start entertaining with her husband and friends, something she was prohibited in doing at her previous accommodation. She had choice in the different areas she could entertain and this allowed for a variety of social events for her, ranging from a fairly large gathering of friends for a barbeque to a more intimate evening with her husband and another couple. Emma also appreciated the atmosphere of functions arranged by “Mei Domus” staff, as they were in contrast to the functions aimed at elderly people at her previous accommodation and more age appropriate for her.

Emma：“Here in January I had a barbeque for about 14 people, 16 including myself and John. And that started at six o’clock. It wasn’t lockdown or anything like that; we weren’t told they were going to lock all the doors on us or anything like that. There was none of that. So that was really good. I used the barbeque area outside, it was very private. There were a couple of people on the inside watching TV and they said they heard nothing. It was completely soundproof. So it was good. I didn’t feel uncomfortable; it was great. On Saturday night just gone I had – there was myself and my husband and another couple, [names]. They came and we had a barbeque here. This time it was just in my apartment, the four of us. There’s space for four people, even six people up here. And that was really intimate, it was really lovely. And because I’ve got a barbeque on my balcony, I don’t have to use the large communal barbeque if I don’t want to, for small, intimate occasions. Yet it is still nice to be downstairs in the big outdoors, if you like, as well. So we’ve got that option” [Emma:11:1:22-33].

Emma: “I don’t know, it’s just that whole thing about when we have functions here, friends and family are just as welcome as members, as residents and staff and because it’s like the carers come from a young generation of people as well, it’s like when we have a function, it’s not geared for the 40s or the 30s or whatever and it’s not restrictive, like it’s not exclusive, it’s inclusive, yeah and we’re not exclusive either. I mean there’s all those words stuck in there but we’re not encouraged to dislocate ourselves from the world” [Emma:12:3:68-74].
Identity

When the participants’ disabilities were highlighted, either by disease or connections with others, their perceptions of the place changed, as did their sense of identity, all of which impacted on their sense of home. Conversely, a positive shift in their identity (e.g., an increase in feelings of competence) resulted in a reconstruction of their sense of home. Participants discussed how changes in their daily activities and declines in their ability to participate in tasks impacted on how they felt about themselves. For Ivan, there was a shift in his role as carer to his wife, which appeared to have a negative impact on his identity as a man and “good” husband.

“They get up me all the time. Like if I try and slide Susie in a chair, I’ll stand up on this, on my scooter and do it. They come and get up me and say get out, leave her alone. They’ll do it, you know. But things like that. There’s just – it’s just – but that’s just normal. Being a man, I guess, that’s sexist, I just love to do things myself for Susie, as my wife, you know. I find there’s things I can’t do because I just haven’t got the strength” [Ivan:12:12:416-420].

Having said this, his comfort with the provision of service at “Mei Domus” assisted him to feel at home, knowing his wife was adequately cared for by others. This experience matched his value of being a loving and caring husband and allowed Ivan to recreate an identity as a part-time carer. It also afforded him the opportunity to focus on his own needs.

“Not freedom, but it just gives me relaxation. Yeah, I can seem to relax more. Even though I still do a lot for Susie, right, because, um – [staff member] told me. She said Ivan, once that door closes, you are Susie’s carer. I said yeah, yeah, but it’s not the same. It’s not like it used to be. I used to have to do everything for Susie. I’m not – I didn’t mind doing it for Susie, you know. I wouldn’t have married her if I thought that that would have worried me. But the point is that I just know now that Susie would be taken care of. That’s basically that’s where it stops. I know. Not I think or that she might be taken care of, I know she will be. That’s what this place is all about. It’s just so relaxing, as I said, to know that – like I got a mate of mine, he’s also got MS. He just sold his unit and he’s just moved into another one. He wants me to go up and stay with him for a couple of days, you know. If we were at home, I wouldn’t have done that. Even though I knew that somebody might be in or whenever they come in. Whereas here, I know that, if I go up and stay with [mate’s name] for a couple
of days, that no worries. [staff member] even told me to go on a holiday. Get lost, take a hike, for a week or 10 days. She said you know – you know that everything will be done for Susie. So that’s the idea. That’s it. It’s just easy – easier, yeah [Ivan:12:4:127-5:140].

Barbie’s experience of no longer carrying out everyday tasks, such as laundry, had an impact on her sense of competence and she spoke of regret about changing her equipment from a manual wheelchair to electric because she had lost the opportunity to be more independent. This decision was made for her following an assessment by her physiotherapist and a mobility subsidy scheme organisation. Barbie had accepted the recommendation without question, however, following the change believed it was the “worst thing” she had done. This experience highlighted her reluctance to be assertive regarding her own needs, which appeared to be a pattern for her. Her decreased participation in everyday household tasks shifted Barbie’s identity from one of homemaker to one of dependent disabled woman. When she compared her current life to her previous life in her family home, this shift created a deconstruction in her sense of home at “Mei Domus”.

“I was in a manual wheelchair and the worst thing I ever did was come into the electric wheelchair, because I lost my upper body strength in my arms and it basically took me away from doing things that I used to be able to do on my own at home, like putting my facial cream on and things which I can’t do now. So staff have to assist me and do that ...... Yes, but the whole time while I was at home, my home was basically equipped, there was no cupboard anywhere except in the lounge room, we had a rug in the lounge room, and basically the floor was all wooden floors and tiles, so I could move myself around. I could do everything on my own when it came to doing the laundry, I used to do all the washing on my own, I used to be able to wheel it out the back door and because the clothesline was basically on the back deck – it wasn’t a clothes line, it was a system that was set up by my husband – I was able to go and hang the washing. I was able to go back outside in the afternoon to unpick it, fold it up and put the washing away. Being in an electric wheelchair now, I can’t do any of that stuff. Our washing is basically done for us and I’ve actually found that my mobility skills with my hands have deteriorated greatly since I’ve been here” [Barbie:12:9:264-284].
Freda, who was once an athletic woman, now saw herself as lazy as she no longer engaged in household tasks within “Mei Domus”. This perception was a stark contrast to the sense of herself as an athletic woman that she previous held.

Freda: “Playing sport. I used to play netball twice, when my aneurism I was playing netball twice a week” [Freda:11:3:57].

Freda: “No, I haven’t done cooking here. I’m a bit lazy. I could do, but I haven’t.”

Interviewer: Is there anything in particular that’s stopped you?

Freda: Only I’m lazy. I get such good meals provided, I don’t need to cook” [Freda:11:3:63-67].

In contrast, participants all spoke about activities they were now able to do again after moving out of inappropriate accommodation and into “Mei Domus”. These opportunities to regain roles and develop a positive sense of identity assisted participants to reconstruct a sense of home within “Mei Domus”. For example, Lou re-established the role of paying her own bills. She organised an office space within her apartment which assisted her to feel independent, whilst still being connected to family. She also had the opportunity to regain her role as guardian for her niece which had a positive impact on her identity, giving her a greater sense of choice and control. The ability to have her niece stay with her at “Mei Domus” contributed to her sense that this was home.

“As far as my niece goes, ... I can now have her here whenever I want, for however long I want. I just need to let the staff know that she is here. Whereas where I was living at the [previous accommodation] I couldn’t have her there for more than a few hours and never overnight and even towards the end of my time with them they started to say I couldn’t have her there without a guardian, a parent or guardian, and they didn’t understand that me babysitting her for my sister when she was working, I was the guardian, so they made it really difficult” [Lou:11:1:23-28].
Therese’s opportunities to water her plants and re-learn tasks, such as washing up, assisted her in rebuilding her identity as a competent woman. She regained a sense of comfort with who she was, which assisted in her reconstruction of a sense of home.

Therese: “Even yesterday [staff] got me to get a watering can. I felt so proud of myself and I went and filled the watering can full to the top from the bathroom and I was able to lift. I kept it on the carpet and dragged it, dragged, dragged right to the end and it was able to go and fill up, water my plants. Admittedly I had to do it four times whereas standing, if I could have stood up, I could have walked with it. This was on the wheelchair. I did it four times. It was hard, hard work

Interviewer: How did you feel about yourself after you’d done that?

Therese: It was such a challenge and [staff] said, “you did it Therese, you did it. That’s good, you can do it. If you did it once, you can do it again.

Interviewer: What was that like for you to hear that?

Therese: Fantastic. That means I can do it every day” [Therese:12:6:172-7:182].

Ivan was known as the “joker” at “Mei Domus” and he seemed to accept this identity with a sense of joy and comfort, as having a laugh and getting along with others was of great importance to Ivan. Although Ivan described a less personal feeling about his interactions when in the communal areas, his connection with others was of great importance to him and being with others and having a laugh was integral to his sense of identity. The reinforcement of this identity among other residents at “Mei Domus” increased his perceived qualities of place and assisted in Ivan reconstructing his sense of home.

“We have a few drinks here too, which is really good. That to me is good because everyone gets down in the community room and you get a laugh. That to me is a big thing. When I used to work I was taught right at the start, the first week or two I was an apprentice – the bloke said to me Ivan, you’ve got to learn to laugh. If you don’t laugh every day it’s not worthwhile, and I make a point of – I’ll make a joke about things. There are a couple of younger people down here that need that kind of attention. So I’ll make a point – I’m not blowing smoke up
my own chimney but I just feel – no we’re very friendly with them”
[Ivan:I1:7:165-171].

Emma had the opportunity to start a part-time job which allowed her to engage
in a meaningful activity that also brought her into contact with other people in the
community, and allowed her to financially manage some of her own health needs. This
opportunity added to her sense of independence, despite her need for a carer to
accompany her.

“We are encouraged to go out into the community and do things in the
community. I’ve just become an Avon rep[resentative] and I asked the
supervisor because I need a carer with me all the time wherever I go. I asked
her if I could go up for one hour a fortnight and spend one hour a fortnight up in
[local nursing home] sitting outside their shop selling the Avon and she said yes,
do you know what I mean? So she’s allowing me – I mean I won’t make a lot of
money out of it but what I do make out of it will go towards giving me a pair of
hearing aids which I need” [Emma:I2:2:59-3:65].

The sense participants had of who they were within the “Mei Domus”
environment had a profound and inseparable impact of their sense of being at home.
The nature of their experiences within that place determined whether that sense of home
was being deconstructed or reconstructed.

**Process of Deconstruction and Reconstruction**

The deconstruction process started with the onset of the individual’s illness,
which instantly impacted on their identity and dismantled their sense of home. For
participants who were forced to move to alternative accommodation (other than “Mei
Domus”) due to their illness, this process further deconstructed their sense of home due
to the inappropriateness of this accommodation, which was always the case.
Participants who were able to stay within their own homes for longer still experienced
this process due to the introduction of medical equipment, and the decreased ability to
manage independently within that environment.
For example, Lou experienced the progression of MS pervading through her life and her need to utilise a wheelchair for mobility. This decline in health impacted Lou’s identity and her ability to engage in her surroundings, which deconstructed her sense of home.

“Prior to being hospitalised and care provided wise and all that, I had a pretty good life at home. I didn’t need to want for anything. I was still working. Even though I’ve had the MS for 10 years, it’s only in the last four or five that I’ve got to the stage of needing a wheelchair and hoist and all that sort of stuff. So I was able to hold down a job full time and I miss it” [Lou:12:3:106-109].

Freda’s aneurysm also changed her identity as a mother and homemaker, which impacted on her identity and deconstructed her sense of home. However, her sense of identity still appeared to be connected to her family, and as a result, although “Mei Domus” was seen as being more appropriate than her previous accommodation, and a place in which she felt comfortable, because her family were not there, she did not construct a sense of home.

“Well, what I was before I had my accident. I was a mother at home with three children to look after. I had a husband to consider. I don’t have that here. I’m on my own here. Whereas when I was at home, I had three children and a husband to consider. I don’t have them anymore…. I miss my children, I miss them greatly. When I had my accident, my aneurysm, my daughter was only 10 years old, she was only a baby, so I miss having the children about. The two boys were a little bit older but they weren’t much older. I’ve missed a lot of things with the kids” [Freda:12:6:134-142].

Ivan lost his strength and was no longer able to do the things for his wife that he could do previously, resulting in a need to give up the home they had built together and relocate to “Mei Domus”. This resulted in a period of deconstruction of Ivan’s sense of home, which was only reconstructed once he and his wife moved to “Mei Domus”.

“Well when we were living at home you felt easier because they were coming to your home. It’s hard for us – we only just now call this home, even though it’s taken 12 months. Well this is our home” [Ivan:11:6:143-144].
Therese had to relearn basic activities following her aneurysm, which highlighted her disability and how she interacted within the environment, resulting in a sense of being a burden to her family and incapable of conducting her previous activities. This created a change in her identity and a shift in the perceived qualities of place; resulting in a deconstruction of her sense of home.

This deconstruction process was also influenced by the environment when individuals were forced to move into inappropriate accommodation or they lost roles they had previously valued. For example, Lou lost her role as guardian for her niece, whereas for Barbie, Justine and Therese their everyday role as mother was dramatically changed. Ivan needed to give up their family home and move into an environment where his wife’s needs are catered for more appropriately and his role as her carer was diminished. Emma had no alternative but to move into alternative accommodation away from her husband and this impacted their roles as husband and wife. These roles were part of their identity at home. Home is the place where they acted out these roles and when those roles were removed, their identity was impacted which then triggered the deconstruction of their sense of home. The restrictions imposed on participants, their family and friends within certain environments, their decrease in autonomy and independence, and the distance from their original homes further added to the deconstruction process and impacted on the individuals’ identity and sense of home.

There seemed to be a transient sense of home and if there is a rupture within that environment, either due to the physical environment or relationships with that environment, some residents regressed to a previous version of home, which could trigger both positive and negative memories. It seemed that the concept of home was tenuous for all participants, but more vulnerable for some. This vulnerability appeared to be influenced by a number of factors, such as previous life experiences, past
experiences of loss, level of perceived support, and the residents’ personality and their willingness to assert themselves when required. It seemed that deconstruction happened quicker than reconstruction. For example, when staff ignored Lou during their interactions with her she quickly felt dehumanised, and when staff left “Mei Domus”, Ivan reported this as a sudden impact “Bang, then they’re gone” implying a quick deconstruction process. Although Lou appeared to reconstruct her sense of home quickly during the interaction with staff and was able to assert herself and her needs, Ivan described having to get used to new staff members which ultimately took time.

The reconstruction of the participants’ sense of home was also impacted by their illness, the environment they were now in, their own previous experience, as well as the support they had from others, including loved ones and staff. The extent to which the environment could be modified to suit each individual also impacted on their sense of independence, choice and control, further impacting on their identity, their sense of how they fitted within the new environment and their sense of home. For example, when staff encouraged and assisted Therese to regain independence this allowed her to reconstruct her identity and her sense of home in a positive way. Justine regained a sense of belonging and feeling special and wanted when staff provided comfort and caring to her and spent time with her talking and making her laugh, which influenced the reconstruction of her sense of home. Ivan experienced a reconstruction of his identity and sense of home assisted by staff communication and behaviours that allowed him to let go of some of the burden of being his wife’s carer and focus again on his own needs. Freda regained a sense of her “old self” through the availability in the physical environment of her belongings, which acted as reminders of her family and her own history, assisting with creating a sense of home, albeit a tenuous one. For Justine, Emma and Lou, the provision of private space and the limited restrictions on residents
and visitors allowed relationships to be rebuilt and strengthened, which influenced the reconstruction of their sense of home.

**Table 5**

**Examples of events that defined deconstruction and reconstruction**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Deconstruction</th>
<th>Reconstruction</th>
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<tbody>
<tr>
<td>Lou</td>
<td>Initial diagnosis of MS, loss of job, moving into inappropriate accommodation</td>
<td>Moving to “Mei Domus”, ability to manipulate environment to suit her needs, including setting up her “office”</td>
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<td></td>
<td>Loss of living with partner</td>
<td>Provision of private space and non-restrictive environment allowed more time with partner</td>
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<td>Loss of guardian role to niece</td>
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<td>Choking incident, inadequate staff response</td>
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<td>Ivan</td>
<td>Initial diagnosis of MS, progression of illness, inability to continue full-time carer role for wife</td>
<td>Opportunity to manipulate environment to suit their needs</td>
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<td></td>
<td>Initial move to “Mei Domus”, resulting in loss of home they had built</td>
<td>Connection with residents and staff</td>
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<td></td>
<td>Loss of staff from “Mei Domus”</td>
<td>Establishing new relationships with staff</td>
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<td>Shift in carer role</td>
<td>Relief from burden of care giving opportunity to focus on own needs</td>
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<td>Deterioration in own health</td>
<td>Assurance from staff that wife will be looked after if he was not there</td>
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<td>Emma</td>
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<td>Move to “Mei Domus” with opportunity to reconnect with friends and family, regained privacy</td>
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<td></td>
<td>Loss of role as wife</td>
<td>Opportunity to manipulate environment to suit her needs</td>
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<td>Regimented restrictive environment at previous accommodation</td>
<td>Re-establishing relationship with husband</td>
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<td>More choice and control at “Mei Domus”</td>
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<td></td>
<td></td>
<td>Opportunity to start part-time job</td>
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<tr>
<td>Name</td>
<td>Initial diagnosis and progression of illness, moving into inappropriate accommodation</td>
<td>Move to “Mei Domus”</td>
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<tr>
<td>Justine</td>
<td>Change in role of mother</td>
<td>Space and non-restrictive environment provided opportunities for children to spend more time</td>
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<td></td>
<td>Isolated from others, disconnected from staff</td>
<td>Developed relationships with staff, felt cared for and special.</td>
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<td></td>
<td>Move to “Mei Domus”</td>
<td>Opportunity to connect with other residents</td>
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<tr>
<td>Barbie</td>
<td>Initial diagnosis and progression of illness</td>
<td>Opportunity to establish relationships with residents and staff.</td>
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<td>Isolation at family home due to illness</td>
<td>Availability of staff when needed</td>
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<td>Awareness of limitations to physical environment, increased dependence on staff</td>
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<td>Loss of pet guinea pigs</td>
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<td>Freda</td>
<td>ABI, increase in identity as disabled</td>
<td>Move to “Mei Domus”, opportunity to connect with residents and staff</td>
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<td></td>
<td>Move to inappropriate accommodation, restrictive and isolated</td>
<td>Increased opportunities for family to visit (however, still not there all the time)</td>
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<td></td>
<td>Change in role as wife and mother</td>
<td>Having belongings and memorabilia in apartment</td>
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<td></td>
<td>Absence of family, except weekly visits</td>
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<tr>
<td>Therese</td>
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<td>Move to “Mei Domus”, ability to manipulate environment to suit her needs, developed positive relationships with staff</td>
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<td></td>
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<td>Sense of acceptance from staff and residents at “Mei Domus”, sense of belonging</td>
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<td>Increase in identity as more competent resulting from staff encouragement and non-restrictive nature of physical environment at “Mei Domus”</td>
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<td></td>
<td>Family home environment restrictive, increasing identity as disabled</td>
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Interactions with Physical Environment

Participants also operated in relationship to the environment they now found themselves in. If the relationships with the environment were facilitative rather than prohibitive, it appeared to increase or reconstruct their sense of home. However, if not then this appeared to contribute to deconstruction. The importance of privacy and space and the opportunity to change and decorate their environment to suit themselves was highlighted by all participants.

Justine: “No. When I moved in the first thing [daughter] said, ‘oh mum, it’s going to be so nice to be able to get a meal in a kitchen and not on two chairs’ ‘cause that was the only space I had at [previous accommodation]. You could put two chairs beside my bed. Someone could have the space to walk past, get their legs past the chair and that was it."

Interviewer: So they can come here and prepare stuff in the kitchen and sit at the table?

Justine: Yes and they love it and I suppose really that is the most important thing to me for living here is my kids are happy to come and see me” [Justine:12:7:198-8:216].

Justine: "Probably two to three times a week. Mum comes over every three days. And my kids come down probably once, sometimes twice a week.

Interviewer: And how easy or difficult is that for people to do here?

Justine: Very simple because they were given cards to get in the front door if it was after hours and had been locked. And they can also get into my room if the chock is not in the door” [Justine:11:1:4-8] “.

Justine: “Well there’s a Wii Playstation downstairs. That one I’ve never participated in but I’ve certainly got a lot of enjoyment watching my kids play it and a few friends have gone down there as well. This facility was set with a lot of donations and there is a TV in every room and downstairs in the dining room. Foxtel have donated all the TVs and Foxtel programs. There’s things here, and between that and my computer, to keep your mind alert and with that and the programs outside as in the crosswords and the singing and the activities they organise” [Justine:12:4:96-100].

Emma: “At [previous accommodation] we had set meal times. There was nowhere that was really private that you could have visitors. There was one
room you could use for visitors, but it was often being used by staff as a storage area so you would often be interrupted by the staff, with visitors. You couldn’t sit in the outdoor area at night because that area was locked. You were locked in; it was like lockdown at five o’clock. I mean that sounds horrible, but it was because of security and all the rest of it. You couldn’t use the outdoor area comfortably after five. It was all those sort of things. I couldn’t entertain in my own room because it was too small. Once you have two or more people in there it was crowded” [Emma:11:1:12-19].

This sense of privacy and the opportunity to manipulate their environment to suit their own requirements, and to add personal touches and memorabilia, gave participants a sense of belonging and a way of putting their own identity onto the space in which they were living, resulting in a greater sense of home.

Justine: “You can have your own things around. [Pause] It’s mine. I’m not living in a little room with a bed and a TV. Yeah sure, here I’ve got a bed and a TV but I’ve got other things. There’s a balcony out there with table and chairs and I’ve got some plants out there and I can sit out and get my little bit of sunlight in the mornings. This place is mine and the staff make it feel like it’s your apartment, your space, this is your area.

Interviewer: What is it that the staff do that help you to feel like that, do you think?

Justine: They don’t come inside, in the door, unless they – they always press the buzzer, the doorbell, first and some of them tell me who’s coming in. I don’t need them to say that ’cause as soon as they say hello I know by voice who it is. They won’t touch anything unless they ask. First they won’t move things unless they ask first. They usually clean up my kitchen. Would that answer it?

Interviewer: You mention that the staff help for this to feel like home and having your children come and having the space for them to be able to stay also helps it to feel like home, makes it feel like home. What are some other things in this environment that make it feel like home to you?

Justine: I’ve got my piano here and I know people that come and play it. That’s nice...There is one staff member that plays. When she’s got time she’ll come. Her family don’t live close by so she doesn’t have a piano as such to play so she’s left her music here in my piano stool. That is nice. It’s just relaxing for me to listen to someone playing my piano and I have a couple of friends that come over and play it for me... I’ve got all my photos up on the wall. It’s nice reminders. Days gone by. People that love me. It’s good” [Justine:12:2:61-3:79].
Barbie: “To be at home having my own things, decorated the way I like it, having my own memorabilia of my family, especially my son. That just makes me feel more comfortable that I can turn around and I can see him whenever I want to. To be able to get on the phone and chat to him and say I miss you and him saying yes, I love you and I miss you heaps, and we just have competitions like no, I miss you even more. It’s just like a big battle, it’s like no, we’re not fighting, we’re just going to say we miss being with one another. So it just makes us both feel comfortable because he feels like I’m in a safe place and I know I’m in a safe place” [Barbie:12:3:93-98].

Freda: “They’re [belongings] part of your past, part of your memories, part of your past, you remember things, who gave them to you, when they gave them to you. They’re just part of your past or part of you” [Freda:12:3:66-68].

Freda: “Just having your own room to move about, your own kitchen to put things into and make a cup of tea if you want one. You can hop into bed as you wish afterwards, go the toilet when you wish, just doing little things for yourself” [Freda:12:6:145-147].

The access to telephones and technology within the apartments, and the non-restrictive atmosphere assisted participants in connecting with others. This was often in contrast to the participants experience to their previous accommodation, where access to telephones and privacy was an issue.

Freda: “I didn’t have a phone in my room at [previous accommodation]. I had to go out to the public area and try and get a phone there. I have a phone in my room here, it’s easy” [Freda:11:2:26-27].

Lou’s experience was similar to Freda’s in terms of previously having a lack of appropriate access to technology. Since moving to “Mei Domus”, Lou had set up an office space within her apartment, complete with computer and internet access. This allowed her to regain some independence and stay connected with important people in her life without the need to rely on staff. This ability to reorganise the physical environment to suit herself had a positive impact on Lou’s identity, assisting in the reconstruction of her sense of home.
Lou: “I didn’t have an actual phone in my room or anything over there, and you really had to push to ask them for an actual phone to make a phone call. So I was constantly reliant on my mobile phone, so it was quite expensive” [Lou:11:2:45-47].

Lou: “You can do it because every unit has phones, most people have mobile phones, but if I didn’t have a phone or a mobile I don’t think that there would be a problem if I asked [staff name] or [staff name] or someone to make a phone call for me, so that wouldn’t be an issue” [Lou:11:1:17-19].

Lou: “I wasn’t as set up as I am here with the computer. I wasn’t on broadband, whereas here they’ve arranged broadband for us and it’s of no cost to us. I was only using a laptop over at the Lodge, and it wasn’t always working for me and stuff, having to use a modem card thing didn’t always connect properly and stuff and I always had the problem where I had to get the laptop locked away after I’d finished with it because of possible theft or removal, there was quite a few theft issues over at [previous accommodation] where people were taking money and all that sort of stuff. Whereas here, at Christmas time I was able to get myself an actual PC, I got rid of the laptop and I’ve got a printer and all of that now and I am a fully qualified office and I have no concerns that someone is going to come in and steal my computer.

Lou: Huge difference. A huge difference. Because I can now get on line and pay my own rent and pay my own phone bills and all of that. Whereas when I was restricted with the laptop I couldn’t get on line and do all that, whereas here I can and now I’ve got a printer I can print what I’ve paid off so I remember to pay that bill” [Lou:11:3:67-81].

Lou: “Well I’ve been able to like make signs and stuff, like at Christmas time my mother had been smoke free for six months and that’s a big thing for my mother to not have smoking, so Alana and I sat down one day and just did a certificate and gave it to her at Christmas time, just to say ‘Proud of you, Mum. Knew you could beat the fags’, something like that we wrote. So, yeah, I was able to do that on my computer, so again it was something I wouldn’t have been able to do” [Lou:11:3:86-90].

Emma also previously had difficulty staying connected with people. At “Mei Domus” she was able to easily connect with others and utilised numerous forms of communication (e.g., phone, email, Skype). Emma did not establish many friendships within “Mei Domus. The availability and access to technology, and the privacy afforded by her own space was important to Emma in meeting her needs to connect to
her family and friends outside “Mei Domus”. This also assisted in the reconstruction of
her sense of home.

Emma: “I speak with my husband every day. I speak with my parents about
twice a week. Those are my only family members that I have. I speak with
friends - I’ve got a couple of really close friends, and I don’t so much speak to
them but I email them. I’m in email contact with them.

Interviewer: And you can do that from your apartment?

Emma: I can do that. And I also have Skype contact, so I can use that as
well... I find it really easy. I find remaining in contact with my friends and family
really easy. It wasn’t so easy in [previous accommodation] because the phone
there would cut out in my room. So I didn’t have my own line into my room. If I
was on the phone to a friend or family member I would have to sit in the main
corridor. And it’s very difficult to have a private conversation when you’re
sitting in a main corridor, because the phone won’t work in your room .... I
would either have to use a mobile phone or sit in the main corridor on the land
line, yeah” [Emma:11:2:35-47].

When residents experienced difficulty in accessing aspects of the physical
environment, whether this was reaching items from cupboards or discomfort in
socialising within the communal areas due to the layout, there was an impact on how
they perceived themselves as operating within “Mei Domus”. Their level of disability
was highlighted and their dependence on staff increased, or they became more isolated
from other residents and staff. These outcomes, in turn, impacted on whether “Mei
Domus” felt like home to the residents.

Barbie: “It is a big change, yes. After living on my own for so long and then
having to divide everything back up into two, it’s like where am I going to put
these things now and that’s the same as staff was going through my pantry stuff
and they just thought this is ridiculous, and they showed management yesterday
and said this is what we’ve got, we’ve got three cupboards and two draws left
for another resident, where are we going to store our veggies and pantry stuff.
We’ve got nowhere to store it. Other people have pantries in their room, we
don’t have a pantry. One cupboard is actually absolutely wasted because of the
table in the corner and even the management actually said now this is the
handle on the bench there, they said this is actually useless because I can
imagine bashing into that every time. So I think they just saw things in a
different aspect as well, and it was like now this facility has been built for
disabled people who are all in wheelchairs, just about everybody cannot stand,
how on earth are they supposed to access the things like in the top of cupboards, because we can’t access them. I think that was a real eye opener for them as well. Well they didn’t design this very well because it’s not within reachable use for people in wheelchairs.

Interviewer:  What does that mean for you?

Barbie: Well for me, it means that I’d probably have to get more staff involvement to get things out of the cupboard because they’re being put way up the top of the cupboard. So I can’t get access to them so I’d have to call for a staff member to get off the floor, and that means that’s one staff down to just get simple things for me... I guess it’s a bit of independence taken away from me, because I shouldn’t have to call people to go and grab – just to get something out of the top of the cupboard because I can’t reach it. I shouldn’t be taking staff away from having their own breaks or helping other people. So it’s more of a guilt trip for me as well.

Interviewer: So that would make you feel guilty if you do that?

Barbie: It would make me feel guilty if I do have to do that, yes, because I’m not only taking them away from their own breaks, I’m also taking them away from other residents who need their assistance for more important things and that’s only a minor thing. But then I can sit here all day and I can think well, I want that but I can’t grab it, what am I going to do about that. The good thing about it is, when I do see my son, at least he’d be able to get a chair and grab the things that – like things have been put up the top there, I can’t grab them. Management looked at them and said that shelf is completely useless if you’ve got pantry stuff that had been stored up there, how are you supposed to access it, well I can’t access it, that’s why I would have to call staff to access it for me. That’s just simple things like every morning I have a herbal tea, I go downstairs with my herbal tea, I can’t grab it, where it is, because it’s way up the top I just cannot grab it. So it makes it a little bit more difficult for me, and it makes it a bit more difficult for staff, even though they’re here to do that, but they’re not here to run around and do 50 million chores for all of us” [Barbie:12:7:206-8:240].

This experience for Barbie highlighted the importance of the layout of the physical environment and its impact on her connection with others. Emma also experienced difficulties with the layout of the physical environment. For example, she found the communal areas overwhelming and the lack of intimate space available outside of her apartment prevented her from engaging easily with others residents. This in turn impacted her perception of how she fitted in with other people at “Mei Domus” and influenced her sense of home.
Emma: “I find it really hard to deal with a group of more or less strangers at a meal table or something like that, and keep that flow of superficial banter going. Do you know what I mean? I’m more of a one on one person I guess. And because we meet in a situation where it’s a group situation rather than one on one, yeah” [Emma:11:5:138-141].

Emma: “I think the way they’ve got the tables set up for meals, I find that very intimidating. I’d rather that there were smaller, intimate tables. Because the way it is, if you want to speak to somebody at the other end of the table, you have to shout over everybody else, that sort of thing. And I believe that we should have more group barbeques and things like that. The last one we had, it was just the group around one big table, and there again I think it should be set up more so that it’s more intimate. I don’t really like that big group thing. I do find it intimidating” [Emma:11:5:154-159].

For Therese, the restrictive nature of the environment at her family home highlighted the benefits of “Mei Domus” in terms of the physical environment. Rather than being a restrictive environment, “Mei Domus” allowed Therese to move around more easily and engage in tasks that she might otherwise be unable to participate in. “Mei Domus” gave her sense of safety that assisted in the reconstruction of her sense of home.

Therese: “It’s just got room enough that the wheelchair can wheel around, you’re not knocking things, it’s easy to get through. That’s what’s easy, whereas if I went home, to get through corners, half the time I was knocking through doors. It was a real pain. Here there’s ample room to get out” [Therese:12:6:168-171].

Therese: “If I need help or assistance I can press the buzzer. If I know if I’m getting a seizure I know exactly where to go and plus I’ve got a buzzer. I press Emergency [buzzer] and that goes straight to all the carers and they know exactly what to do. They come running with the oxygen bottle. Then if I hit the Emergency button they have to come with the oxygen. That’s why I feel safe here because when I get a seizure that is so scary, because I feel helpless, it’s terrible” [Therese:12:12:348-353].

“Mei Domus” is located in the grounds of an age care facility which was experienced differently by different participants. The issue of age appeared to be more significant if a participant had spent time living in a nursing home or similar
environment “Depressing. Generally filled up with older people than myself”

[Lou:12:1:3]. It was as though some participants distanced themselves from older people in order to re-create (or reconstruct) their own identity, which in turn influenced their sense of home.

Emma: “Granny squares, crocheted granny squares lap runs and they – somebody, some organisation crocheted us some lap rugs and we were asked if we wanted one and I immediately said no because it was that sort of connotation associated with it... So and I just couldn’t do it, you know? I have a lap rug but it’s not a crocheted square thing you know. I think that’s because I associated it with the nursing home, yeah” [Emma:12:1:25-2:34].

In some ways Ivan separates himself from the other residents at “Mei Domus” stating that he is old, however he sees himself as old but not elderly.

“You know, I’m no chicken myself. But you know what I mean? Old people, you know, 80, 85. It’s just company. There wouldn’t be – there would be company, but it wouldn’t be people that you can have a joke, have a laugh” [Ivan:12:2:28-30].

For Barbie, however, being in close proximity to older people seemed to bring a certain comfort.

“The wonderful thing is the old people from the aged people’s home come past and I think they enjoy actually seeing people younger than them who also have other problems as well and one of them went past me the other day and beeped his horn at me and he had a horn that sounded like a clown, a circus clown with a big toot toot horn type thing. I said to him, I said ‘Gee, that is wonderful, my boy would love that’, he said ‘I love it too’, but it was really nice to actually be able to communicate with other people as well who may be older but who can appreciate your humour and you can appreciate their sense of humour as well” [Barbie:11:5:139-145].

This presence of older people provided a substitute for the absence of her parents. Being close to older people and interacting with them seemed to contribute to a sense of home for Barbie and provided an opportunity for the reconstruction of her own
sense of home. Although associated with the physical environment, this finding highlights the importance of social connections.

**Relationships with Family and Friends (including Residents)**

Participants had existing relationships with loved ones and they brought their experiences to the new environment and had the opportunity to reconstruct, rebuild, and strengthen some of these relationships. Furthermore they had the opportunity to form new friendships with other residents at “Mei Domus”. Barbie not only reconnected with old friends after her move to “Mei Domus”, but also made friends with other residents and believed her social life had increased since she moved there, as previously her social life was mainly time spent with her young son.

Barbie:  “I’ve actually been in contact with a friend who I lost contact with years ago and she has actually made a couple of visits out here to come and see me and we’ve gone shopping together, and that sort of thing, and I’ve been best friends with her ever since we were in high school, so it’s wonderful to be able to catch up with people like that. So anybody that lives on the south side that I didn’t have contact with before I now have contact with, which is even better.

Interviewer:  Do you regard any of the people who live here as your friends?

Barbie:  Yes, all of them. Too many.

Interviewer:  Why do you consider them to be friends?

Barbie:  Because we all get along, we get along, we crack jokes together. We all have our own little, I guess, celebrations for certain occasions. Friday nights is what we call our junk food night, so the cook doesn’t have to cook for us and that’s a night where we go and get takeaway food of some sort and we have drinks. We will always toast to Irene [deceased resident] every Friday night, to remind us that she should be here with us but she’s not, she’s not. So yeah, it just brings back things like that. But it’s good to be able to go downstairs and actually not worry about your own problems but talk to others and have a good laugh, which is really good... Well, usually Fridays there are certain ones of us that will sit down and drink and party together.... I think I’ve probably got more of a social life here now. Whereas before I used to find, I used to do a lot of things with [name], my son, and our big hangout was the shopping centre out where we used to live and I saw that the other day on my birthday and I said to my partner, I said to him, ‘and this used to be [son], our hang-out over the weekends to go and see the movies or go and play in the video games arcade and whatever’ and that’s one thing that I do miss, but we can still
get to go and see movies here, it just means that staff usually have to take us to either Indooroopilly or to Southbank to go and do that” [Barbie:II:3:65-99].

Following her move to “Mei Domus”, Lou was able to form new friendships with some of the other residents; factors that contributed to this were their similar age, common interests and their similar diagnosis. She was also able to spend more time with family members, as “Mei Domus” provided the space and privacy for these relationships to develop and for visitors to feel more comfortable compared to Lou’s previous accommodation.

Lou: “I like Barbie. Barbie and I get along really really well. We are around the same age group. She’s got a 10 year old son and I’ve got a 10 year old niece, so they sometimes play together” [Lou:II:3:92-93].

“We’re around the same age, we’ve got the children in common. Barbie can talk as well as I can. We don’t have any barriers of, you know, she can’t talk very well, blah, blah blah. We are both articulate. We are both intelligent. We are both computer freaks, do what we can with the computers. I don’t know, I think her and I just jelled straight away. I guess the fact that we’ve got the common MS, that’s always a good thing to have in common, I guess. You’ve got to have something in common” [Lou:II:5:140-145].

Lou: “Steve, my partner, he is here at least every Sunday but if he has time during the week he pops in and visits as well. With my sister, she is in a different situation now. She tries to see me at least once a week. If my niece comes over to visit she [sister] generally drops her off, stops for a little while and then she picks her up two days later and they socialize a little bit. But mostly it’s just on the phone. With Steve every single day, at least once, maybe 10 times we are on the phone to each other. My sister and I are pretty commonly on the phone most days” [Lou:II:1:4-9].

Lou: When he [Steve] comes here he can sit on the lounge and watch big TV and all that, and he does, especially the cricket. I hate cricket.

Interviewer: So would you say that he feels more comfortable coming and visiting?

Lou: Yes, most definitely. He honestly just comes in and takes over, so that’s how I know that he is quite happy to be here and to visit. He will stay for up to five or six hours if he wants to.... I think the maximum visiting I had with him over at [previous accommodation] was about an hour, depended on the weather” [Lou:II:2:37-41].
For participants who spent most of their time at “Mei Domus”, the opportunities for establishing new friendships were limited to the other residents. Ivan joked about making the most of the opportunities he had in regards to making friends and felt that other residents were friendly and he and his wife had made connections with others at “Mei Domus”.

Ivan: Well really, there’s nowhere else that you can kind of make friends so you do with what you’ve got. [Laughs] No, we’ve made friends with quite a few of them here, a couple we hadn’t. Not that we – most of the people here are friendly. But see there’s about three or four of them here that can’t speak at all. We’re still friendly with them. I’d just like to think we’ve made friends with everyone here [I1:3:51-55].

Ivan: We have contact with quite a few of the people here. They regard this as smoker hollow. They come in here for a smoke and a talk. [Laughs] No, we’re pretty good friends with everyone here [I1:3:46-47].

The age group of the residents had a positive impact on participants being able to connect with other residents. Comparisons were made to a nursing home environment and the restrictions that would have been evident within that environment. “Mei Domus” was perceived by most participants as a friendly place, where people had respect for other people’s boundaries.

Barbie: “Mei Domus”, well since being here I’ve been very happy because it’s more of an environment with younger people around my age and maybe a little bit older. But the good thing about it is that we can all sit around, we can all joke with one another and nobody takes it seriously as though it’s offensive to anybody, we don’t find anything really offensive. We all know what each other’s boundaries are, and I think in a nursing home, you wouldn’t be able to do that. You wouldn’t have that freedom to communicate with other people on the same level as you and be able to joke with other people because you may feel like you’re offending others. But here we don’t seem to offend anybody. We all carry on and it’s just like we know it’s all a joke, so we don’t take it seriously and to heart” [Barbie:I2:1:23-30].

For some people, however, the residential care environment holds negative connotations and is thought of in the same way as aged care. This belief regarding
residential care had an impact on some people visiting Lou; however, this appeared to reinforce her own belief regarding the positive nature of “Mei Domus”, which likely prevented a deconstruction of her sense of home.

Lou: “One of my friends or my sister’s friends when I was doing respite at the [previous accommodation] before I moved in as a resident, he didn’t want to come and visit me with her and she asked why not. He said ‘nah, nursing homes they all stink, they all stink stink’ and he was referring to mostly urine and some faeces. She said ‘it’s not like that. It’s [previous accommodation], it’s not a nursing home’. But, no, didn’t want to see a bar of it. I’ve been here since March 2008 and he still doesn’t want to come here which is – well it’s a completely different environment. ‘No no no, I don’t want to go and see your sister in a care facility, whether it’s aged or not’. But I mean a lot of people do have that sort of idea about nursing homes and places. They’ve got no idea about “Mei Domus” and how wonderful it is and how much it's changed my life having the ability to come here” [Lou:I2:1:14-22].

The lack of restrictions at “Mei Domus” allowed Emma to connect easily with family and friends and to have a sense of independence that was previously lacking for her. The opportunity to spend unlimited time with friends and the space for friends and family to stay in her apartment allowed the reconstruction of a sense of home for Emma.

Emma: “Very easy [for family to come and visit]. I don’t have to make times; do you know what I mean? They don’t have to be here by a certain time and out by a certain time. Lunch or dinner or any of the meals can always be put on hold, or they can share those meals with me, all that stuff. The independence of being able to have members here whenever, it doesn’t matter what time” [Emma:I1:1:7-10].

Emma: “And over Christmas I had one of my very best friends from New Zealand come and stay for six days here with her granddaughter. Because they’ve got this spare room, [name] and [name and [name’s] friend could stay here. In the end we had the two girls in the spare room and [name] had a foldout bed in the lounge here. I could never have done that at [previous accommodation]. They would have had to stay in a hotel. That would just not have been anywhere near as convenient as it was. It meant that [name] and I, because she was here in the room with me, at night we could do what girls do best, natter until midnight. Just catch up like best friends do” [Emma:I1:3:64-72].
Similar to Emma, the space, privacy and lack of restrictions allowed Justine to spend more time with her children. It provided space for their belongings, creating a more welcoming place where they were happy to come and stay. This opportunity made a huge difference to Justine and influenced her sense of home at “Mei Domus”.

Justine: “I was seeing my kids once a week for an hour and a half if I was lucky. Now they’re more than happy to sit on the train for an hour and a half to get here. And they come in here and it’s like their own house. There’s a kitchen, lounge area, there’s beds here. There’s room for them to hang their clothes up, keep toiletries and things here. So it’s just like moving to a new house. Everything’s so - they’re more than happy to come and stay.

Interviewer: And how long would they stay here compared to where you were before?

Justine: Where I was, they’d spend maybe an hour and a half on a Tuesday night if I was lucky and that was it. Now they usually stay a couple of days during the week or over the weekend. And one of them is at school still and he comes down after school and Mum picks him up at 6.30 in the morning and he goes back to school. So it’s nice.

Interviewer: So what difference has that made to you?

Justine: Huge. I get to see them and spend time with them and that has made an enormous difference” [Justine:II:1:11-22].

Therese’s friendship with Barbie provided her with not only companionship, but also further opportunities for “pseudo-mother” experiences.

Therese: “Like Barbie, she’s my best friend.

Interviewer: Why do you consider her a friend?

Therese: At night-time, she comes into this unit and we just have a little chat at night. If I make a special meal, and she’ll come and help me and then we have dinner together sometimes here. It’s really good... Even her little kid is really sweet. He chose this lounge as his bed. He comes, jumps on the lounge, puts the TV on and watches TV, because Barbie is busy doing her thing there, he treats this like his home... It’s lovely. He’s like my kid, a big kid, a boy, a noisy boy” [Therese:II:3:65-73].
The opportunity to engage in these relationships allowed participants to reconstruct their sense of identity in relation to their different roles (e.g. guardian, wife, carer to non-carer). Emma’s relationship with her husband benefited from her move to “Mei Domus” and allowed her to rebuild her identity as a wife and changed her perception of her living environment, assisting in reconstructing her sense of home.

Emma: “I believe that my relationship with my husband, my significant other, has improved since I’ve been here, because he stays overnight; he doesn’t just visit, he stays. He comes on a Friday night and he stays til Sunday night. He leaves on Sunday night, goes home for a night, comes back on Monday after work, stays Monday night and takes me to pottery and whatever I have to do on a Tuesday. So my relationship with my husband has improved. We’re now behaving like a proper little couple.

Yesterday he woke up, he wasn’t well. I woke up and I was out of sorts; I had my period. Too much information I guess, but I was out of sorts. And we had a little bit of a tiff, I guess. We don’t shout at each other or anything like that, but we just didn’t see eye to eye the whole day, and in the end we sat down and discussed it like two adult people would. It came out alright, nothing was broken or anything like that. But just like at home, if we were at home in a normal, everyday relationship. We had a tiff; we had a day of snapping at each other. And every relationship has that… and that is what makes a relationship real, is not having that unreal sort of Mr and Mrs Nice Guys all the time.

Interviewer: So how would that have been different when you were at [previous accommodation]?

Emma: Well firstly when we were at [previous accommodation] we never saw each other long enough to have a tiff. Jack would come after work – it seemed like I saw him more often because he lived just down the road from there. So he would come after work every night and have a quick meal with me in the kitchen together, but he would have to be there at five o’clock to have a meal. So we’d have a quick meal together then he’d leave. That was it. And the relationship – we were losing depth. We were not so much in contact with each other.

When you’re in a relationship to a certain extent you can pre-empt what your partner’s going to do in a week, because it’s just a routine. But when you’re living like that you can’t do that pre-empting anymore. It’s almost as if you need a diary to – and you do anyway, as couples. But it was like – do you know what I mean? It was separate to me, totally separate.

Interviewer: Sounds like the frequency of contact was there but the quality of contact wasn’t there.
Emma: Yeah, that’s right. Frequency but not quality. Whereas this way I’ve got – perhaps not the frequency but I’ve got better quality.

Interviewer: And how do you feel about that?

Emma: I think it’s wonderful, it’s truly wonderful. Jack and I are who we are again, you know? Not some sort of pretend couple, if you like. We’re real again. And I feel really good about that, I like that” [Emma:11:3:76-4:106].

Ivan took a long period of time to reconstruct his identity from carer to non-carer and this then allowed him to feel more relaxed and comfortable, qualities that represented home for him.

“Yeah, 22 months, yeah. It’s taken me all that time to realise that – Hey Ivan, settle down. There’s no reason for me to worry. I still worry, but not like the worry I used to there [previous home]” [Ivan:12:13:445-446].

Participants’ sense of identity in relation to others, together with their sense of identity regarding themselves combined to influence their sense of home. It appeared that participants who did not have a strong sense of family, could have a strong sense of home at “Mei Domus” based on the comparative nature of how they felt they were accepted by family. Therese appeared to have conflict between feeling under pressure when family were with her at “Mei Domus” and missing spending time with her family.

“When they do come and visit me, I feel pressured sometimes, in the way, because I’m used to how it’s so relaxed here. When they’re here, you feel they’re prying into everything, which I don’t like. I’ve just got used to it. It’s my little unit, it’s my little den, I just like it here” [Therese:11:1:16-18].

“I phone my family every day and every night and speak to my husband. Because I miss the girls a lot, I miss the twins, a lot. They’re very precious to me….. I spent almost all my time before I had my aneurysm, morning, noon and night with them, taking them to school and bringing them home, going to all their other activities with them. After this happened, I just felt I was shut away” [Therese:11:1:20-25].
For Therese, her perception that family would not welcome her as she was with her disability impacted her identity, which then influenced the reconstruction process that reinforced her sense of belonging and sense of home at “Mei Domus”.

“To me, I prefer this as home -- prefer to be here because if I go home I won’t be welcome home. I’m a lot happier here. I know there’s no restrictions here, I know I can press the bell, I don’t feel bad to ask anyone, whereas if I go home there’d be things I need to ask for help and I’d feel restricted, because the kids are going to school and they say, oh Mum, we’re busy, we’ve got no time. I don’t think it’s fair, that’s why I prefer to be here. I think I’m being fair by them by staying in here” [Therese:12:3:72-78].

“I’m happy. The thing is I lived my life, I’ve worked all my life and I think I owe it to myself [to be happy]. It was not my choice to have [an aneurysm] and I resent being like this” [Therese:12:3:80-81].

It would seem that when participants had significant others, such as partners and children, to whom they felt close, when those people were not around they experienced a feeling of not home, resulting in a deconstruction of their sense of home. This particular experience did not happen for Ivan as he had the opportunity to continue living with his wife, whereas for other residents they had opportunities for significant others to come and stay at “Mei Domus”, albeit for a limited duration.

**Relationships with Staff**

Participants developed relationships with the staff at “Mei Domus”. These relationships differed amongst participants in the quality and quantity of time spent with staff. Some participants had greater need for staff attention due to their physical and medical needs and others had a greater need for closeness with the staff, often due to the lack of time available with their loved ones. The relationships developed with staff, also impacted on the relationships with their loved ones. If participants and their visitors felt “Mei Domus” was welcoming, private and non-restrictive, this seemed to impact the frequency and duration of visits from family and friends. If the relationships
with staff were positive it appeared to increase the sense of home. If not, then this appeared to decrease the sense of home.

For instance, Ivan’s relationship with others and his sense of being comfortable with people impacted greatly on his sense of home and, therefore, any disruption to these relationships also disrupted his sense of home.

“Whereas here, everyone’s treated differently. Because the carers are totally different. I’ve met a few of the carers up in the nursing home up here. I’m not saying that they aren’t – I wouldn’t want them caring for us, but the point is that here, we’ve just grown up – well grown up – we’ve grown as this place has grown. The carers have grown too, you know. There’s just – you’re just – the relationships with carers and nurses, the nursing staff, and also the main staff in the big staff. It’s just totally comfortable. Whereas even just the odd ... person I’ve spoken to in nursing homes, you don’t – it’s as if, oh, they’re always in a hurry to do something. Whereas here, you speak to someone, they’ll stop and they’ll talk to you and they’ll laugh and they’ll joke with you. It’s just like being out somewhere. It’s just with a whole lot of friends. That’s all” [Ivan:I2:2:36-44].

“It’s totally – you used a good word, individual. It’s – everyone’s treated and they know everyone and they know everyone’s foibles and they know what people are like, you know. Like I can comment on that, but my wife, Susie, she’s totally – she gets a fright very easy. So she’ll – like she’ll get – she’ll scream or things like that. Not because she’s hurt or because she’s scared, but just because – it’s just unusual, different for that to happen. She’s – but they, all the staff here, are used to that. They know her. They know what she’s like. They’ll joke with her about it. But she’s always smiling. So that’s all there is to it. It’s just we feel very comfortable here. You are treated as a kind of an individual. Well with us, an individual couple. That’s – it’s good though” [Ivan:I2:2:48-55].

Although Ivan expressed a need to consider staff within the environment, his perception of “Mei Domus” was of a relaxed environment where he could do what he liked. It appeared that the self-imposed nature of his restrictions makes it more acceptable at “Mei Domus”

“In a nursing home, they have getting up times, lunch times, tea times at a certain time, blah-blah-blah, bed times and that. Here, you more or less get up when you want. You eat when you want. Which after – which at first was great, but then you have to restrict it to yourself. You know, you have to be reasonable. You can’t say, oh, I might have lunch at two or three o’clock today. You can’t do
that, you know. Because you would be putting people out if you did that. But no, a typical day here is just a totally relaxed feeling for the whole day. We can do whatever we want” [Ivan:12:9:299-305].

High turnover of staff could be disruptive, and this appeared to affect some residents more than others. For example, when Ivan experienced staff leaving, it influenced the deconstruction process and he experienced discomfort within the environment until he was able to establish relationships with the new staff.

Ivan: “Yeah. It’s sad in a way because you get friendly with someone and then bang, they leave. See most of them here are nurses training. You get on well with them to start with and then their time is up, and they get transferred away or things like that. Not just us, but quite a few of the residents here are in the same boat. They get friendly with someone and then bang, they’re gone. One of the nurses that just finished her time applied to come back here, so she’s here now full time and it’s really good. She’s only a young girl; I suppose she’d be about 25. But she was happy working here so that’s what she did.

Interviewer: So what difference does that make for you as a resident here, when the staff leave?

Ivan: Well it’s hard, mainly for Susie, because – how can I say this? Susie needs more – as you probably can see – attention than me. And she gets comfortable with certain people, then after 12 months – there are a couple still here that have been here for 12 months. I really can’t say it enough; the staff here are really good. The only time it’s hard is when they get some agency people in to fill in. That’s hard because Susie doesn’t mind being showered and that if it’s a couple male nurses, but she’s not really keen on it. She’s one of the only ones here doesn’t mind that. And three of the male staff here are really good, really really good. You just feel comfortable with them, that’s the main thing. If you’re comfortable you’re happy” [Ivan:11:5:118-6:134].

Emma, on the other hand, did not appear concerned when staff left, and if she had developed a relationship with them, she made choices about whether she wanted to remain in contact. Emma’s experience of relationships with staff at “Mei Domus” was more positive than her previous accommodation, where she found it very restrictive. Although she believed there was an unspoken protocol at “Mei Domus” regarding
friendships between staff and residents, this did not impact her ability to form relationships with staff.

Emma: “Because you deal with them [staff] on a one on one basis, and because we just get on really well in general, and we talk. One of them has left, and I’ve still got her phone number and all that sort of thing anyway. You know what I mean? It’s not quite the same. Another of the staff members – and I shouldn’t say this cause it’s going to go in your report, but another of the staff members here I feel particularly close to as well, for other reasons. We talk with each other. It’s not just a client professional relationship, it’s deeper than that.

Interviewer: Is that different to when you were at [previous accommodation]?

Emma: At [previous accommodation] they disapproved of people making friends with the residents. And one carer, we were making a connection, so the management said they would have to take her off my care plan case because we were getting too close to each other. A little bit hard, but anyway, that’s the way the cookie crumbles sometimes…. I don’t think there’s any regulation here, I don’t know, I could be quite wrong, that staff are not allowed to form friendships with residents. I don’t think there’s that rule here. I also think that because of the age group we are, it’s very difficult not to form a bond with a resident or a staff member… The age because I would meet a staff member that’s my age group, so that instantly means you’ve got something in common, do you know what I mean?

Interviewer: So you find a lot of the staff are similar in age to you?

Emma: Yeah, so that makes it easier to make friends with them.

Interviewer: Is there anything that perhaps would make it difficult?

Emma: Well I guess the fact that they are staff and we are residents. There is a sort of protocol involved, and all that, but I wouldn’t say there was anything that would make it difficult” [Emma:11:9:262-285].

Lou also appeared to experience staff leaving in a similar way to Emma, and took the opportunity to stay in touch via social media and email.

“I got along with quite a few of the staff over there [previous accommodation], mainly one of the supervisors, [name], very close to her. I didn’t want to leave because of her being there, but that’s just because she is what you see is what you get and she doesn’t pull any punches. She even remembered me at Christmas time just gone. She sent me a present and a card, and so I am like ‘Hang on. I haven’t been there for the last nine months, what are you doing remembering me’. She is hoping to come to the party next month. Yeah, there
was another staff member that was there and her and I got very close, she ended up having to leave, but she is one that I am definitely in touch with now through [social media], through email, through text messaging and she is actually trying to organize a fund raiser for “Mei Domus” with her biking group, they’ve got motor bikes, and they want to go on a long distance thing and they get sponsors to do that, so she is organizing that at the moment”[Lou:11:7:215-224].

For Lou and Emma, staff disruption did not create deconstruction of their sense of home, because the physical environment allowed them to access the technology that facilitated the maintenance of important relationships. However, when staff numbers were reduced due to budget constraints, this did appear to have a negative impact on the sense of home for most of the residents. For instance, Lou described a situation where she felt unsafe due to the increased waiting times for staff assistance. This event, described below, reduced her perceived qualities of place and increased her identity as disabled. It also highlighted the importance of her partner to her sense of safety, as he was able to organise a Care Alert system. This incident impacted Lou’s sense of identity and also highlighted for her that her partner was not always around. Together these influences deconstructed Lou’s sense of home.

“I know that here they’ve had to cut back on staff and we’re all sort of feeling the bite from that because less staff, longer buzzer times. In “Mei Domus” we don’t have emergency buzzers in any of the rooms. So once you press your buzzer it’s a matter of just waiting til someone comes which, for me personally, has been a big issue for me in the fact that I sometimes have problems with drinking water or eating food and I choke. A month or so ago I had some dinner and I had a drink of my ice coffee that I have to drink and for some reason it went down the wrong tube and I started choking, pressed my buzzer. Thankfully I was able to pretty much sort myself out and got myself breathing again. Then a carer came to answer my buzzer, 20 minutes after I had buzzed, and looked at me and said ‘What’s wrong with you, you’re all flushed, what have you been doing?’; ‘oh just you know just had to get myself back from a choking incident’, ‘a what?’ and he sort of understood then that - oops. The carers need to be able to answer the buzzers a lot sooner. Even if it’s just a case of them coming and saying ‘we know you buzzed, is it urgent? If it's not, we’ll be back shortly’. That’s easy…. It was very scary for me and thankfully my beloved partner decided to take the problem into his hands and has gone out and spent a lot of money and brought me a Care Alert. So if anything urgent happens again I can press the Care Alert, it will ring the mobile phone of the nurse downstairs and if
it's not responded to by her the next call will go to him and so on and so forth. Thankfully I haven’t had to use it recently. I’ve only had it for about three weeks. But I have got it and I wear it every day. All day every day and all night every night. So it makes a big difference” [Lou:12:2:52-69].

Barbie also described feeling “disturbed” by the reduction in staffing, although she did not appear concerned by individual staff losses.

Barbie: “At the moment we still have to wait, like yesterday I was waiting from three o’clock until nearly five o’clock just to have my shower. I’ve opted to help the staff by not – everybody has their showers in the morning and I’ve opted to ease the load off them here, that I’ll go back to having my showers in the afternoon, which is what I used to do at home. When carers came in I’d go for a shower and they’d go around the house and do what they had to do around the house. Now I think, well okay I can press my buzzer and if nobody comes there’s a reason why, even though they’ve downgraded the staff, I think a lot of us are suffering from that, with the staff being downgraded, but we’re trying to have to work around what we can.

Interviewer: When you say downgraded the staff, what do you mean by that?

Barbie: Well basically they’ve been told that they have to reduce the budget.

Interviewer: So there’s less staff?

Barbie: Which means less staff as there was when I first moved in here. There is less staff in the morning and there’s less staff in the afternoon and early evening. So there’s a lot less staff, so that’s like yesterday when I buzzed to go and have my shower, there are two people on the floor and that was it. Instead of there normally being four or five people on the floor, there were only two people that were available. It was like one person having to say I’ve got to go and find somebody and they disappeared, and by the time they came back, well they didn’t come back, somebody else came and said I thought you were in the shower, well no I’m waiting for somebody to come and get me into the shower, out of bed and into the shower. So that’s a bit hard in that aspect.

Interviewer: So what’s that like for you?

Barbie: Well for me, sometimes it’s a bit disturbing, but you have to deal with it.

Interviewer: When you say disturbing, what do you mean?

Barbie: By disturbing, it’s like I can’t get into a regular routine because if it was happening on a regular basis, where staff would come up and say okay you’re ready to go and have your shower now? Yes, no worries. But now,
because of the staff shortages and the cutbacks, I don’t get that flexibility of being able to – people come into to see me, okay we’ve got time to do it now, can we do it now, yes, that’s fine with me. Now, unless I buzz, they just don’t come at all, because they’re run off their feet assisting to all other people. That was one dilemma we had yesterday, which was not a good thing” [Barbie:I2:2:64-3:90].

Like Lou, increases in waiting times highlighted Barbie’s level of disability, which in turn reduced her sense of control and detracted from her identity as an independent woman, which in turn deconstructed her sense of home. The impact of staff attitude and behaviour could be both positive and negative. It provided a source of comfort, especially when staff were perceived as going over and above what they needed to do.

Ivan: “A couple of them will go out of their way to help you. If I need a hand to do something or Susie needs a hand, I can normally tell if they do it not because they have to do it, but if they want to do it or not. And if ever I find that they – I can normally tell if they want to help. I don’t know about you but you can tell by someone’s attitude. That’s what I mean. Most of them here are good like that. I’d say all of them, all the staff that are here permanently. But the agency staff takes a lot of getting used to” [Ivan:I1:8:191-196].

Ivan: “When I was crook, when I had this trouble with my leg, I was really out of my tree. Two of them came down here before they called the ambulance, and they sat there for about two or three hours. They wouldn’t leave the room until the ambulance came. They care. I suppose that’s my way of telling if someone cares. When the crunch came, they didn’t have to stay with me but they just sat in there next to the bed. When they ambulance came they were right” [Ivan:I1:10:282-11:286].

Ivan: “You know, it’s this – I had to go to a hospital about two months, three months ago. I was a bit dubious about going because I was concerned about Susie being here by herself, worrying about her and that. [Staff name], the person in charge here, she said to me – I can’t say what she said, but she swore. She doesn’t normally swear. She said get lost, Ivan, just go. I said but – she said no buts. She said I can see you’re concerned about Susie. She said there’s no need to be. Someone will be here all the time for her, whenever she wants them” [Ivan:I2:4:107-112].

Ivan: “One of the carers even came up to the hospital, because I was in the [hospital]. Not so much seeing me per se; they came up to tell me don’t worry, everything’s okay, Susie’s fine. And once I knew that, I was fine. It just takes a
load off your shoulders. That’s what it’s all about. As long as you’re comfortable and happy, which we are” [Ivan:II:11:289-292].

Seemingly small gestures by staff could give participants a sense of being cared for and being special to someone, which assisted in the reconstruction of their sense of home. The personal interaction and friendly approach of staff assisted Therese to feel wanted at “Mei Domus”, which contrasted with how she felt around her family, and was also different to how she had experienced rehabilitation at her previous accommodation.

Therese: “They don’t force you to do anything and it’s just, it’s the way they tell you to do things. It’s just a very nice way of rehabilitation. They’ve got a nice way of doing rehabilitation here. It’s a beautiful way they do it. They make you feel you’re wanted” [Therese:I2:1:26-29].

Therese: “Oh yes. The staff are excellent.....When they come to me and say Hi Therese, how are you today. If I ask them to do anything, it’s not a big chore for them to do. They do it with a smile. It’s not something, it’s not a big effort for them to do, they just help out. They’re ever ready to do anything you ask them to do” [Therese:I1:4:94-96]

Therese: “That’s one main thing I love here. They show a lot of caring and they’re very, very patient. Every night, when they knock the lights off and say, see you Therese. I said thank you for your patience and your caring, because they’re so patient. It takes such a lot of time to put people to bed. It’s nothing for them, changing clothes. The time and effort. As much as we’re tired, they’re tired too” [Therese:I1:4:106-109]

Therese: “The smile on their face. It’s just the way they greet you. Like when they’re changing me, they say would you like to take your top off please? They’ll help me with my left hand and right hand. Even going to the toilet, they say would you like to go to the toilet? Sometimes, half the time, I don’t need help. It’s just them asking, it’s so sweet. You don’t find many people doing that” [Therese:I1:5:112-115].

Barbie also had times where her experience of the staff assisted her to manage her emotional state and re-engage downstairs with other residents. Staff being playful and joking with her also assisted Barbie to feel more “normal” and accepted as she was, thereby impacting positively on her identity and assisting with reconstructing a sense of home.
Barbie: “That is like the other day I, every now and then you’ve got to have your big outbreak of tears and whatever and that’s like last week that happened to me and one of the staff actually came up and said ‘We haven’t seen you all morning’ and I said ‘Because I can’t go down the street’ and she said ‘Why?’ and I said ‘Because the day has started off wrong and I just can’t bear to see anybody at the moment. I’m too upset’ and I just cried with her. She came up and gave me a cuddle and she said, ‘Do you want to talk about it?’ and I said, ‘Yeah, I will now. Okay.’ So I said what was wrong and she said ‘Okay’ she said ‘Now are you happy that you’ve got that off your chest?’ and I said ‘Actually, I am’. That night I did go downstairs for dinner and I did actually talk to all the people, all the other residents and everything, which was good. It sort of broke the monotony and I didn’t have to sit here and be depressed all day, which was good…. Affection, taking you out, unexpectedly just saying ‘Oh, can we go out and do this?’ which is good. The same as socializing with you privately, so when they are not rostered on, having our own little parties and drinks and outings together. Just in small ways they will show it. But they don’t want to show it too much in front of other staff members that are here, and especially with the staff as well I think one of the ways that they can show that they care is to communicate with you, not treat you any differently. Like, we’ve all got disabilities to some degree here. They don’t treat you any differently. They treat you on the same level and they will crack jokes with you and make you laugh and make you laugh until you cry tears and then things like when you’re having a shower I will say to them ‘Are you trying to drown me?’ ‘No, that’s okay, don’t breathe through your nose’ and they’ll block my nose and just play silly games and it is just like, okay, I see you enjoy all that, sort of, monotony, of getting away from them not only being support people that come and have to do their job for you, but they’re also happy to communicate to you, with you on a normal level and not treat you any differently from anybody else” [Barbie:11:7:213-236].

These staff relationships seemed to provide a substitute for the absent family who often represented home for the participants. Due to her disability and the distance from her family, Justine was more dependent on staff and more isolated than other residents and therefore the relationships she developed with staff were highly significant to her. The less physically able the participant was, the more important the connection with others appeared to be. It becomes a dependency on others for basic needs and survival. Staff assisted Justine with a sense of belonging and influenced her reconstruction of a sense of home.
Justine: “I’ve been taken away from my family, my kids, basically and that has made a huge hole in my life so to speak. Sure they still come but they’re not around all the time like they would be if I lived at home. And I need someone to fill that void. If there are some staff that you get on really well with, then they’ve got the time to sit and chat to you. It’s good. It just gives you a feeling of well, I still mean something to someone” [Justine:I2:5:123-126].

Justine: “It just makes you feel like you’ve got some control of your life. Generally speaking, being stuck in a wheelchair and you can’t do anything ‘cause I can’t use my hands, your life is controlled by everyone because everyone does everything for you and that happens when they want to do it. Whereas here they will get me up when I want to get up and they’ll give me a meal when I want to eat. All this comes into variations and considerations” [Justine:I2:6:159-162]

Justine: “They’re happy to listen and talk to me. That’s probably the - they are willing to talk to me. Yeah... [staff] Quite happy to chat to me while I’m in the shower or getting dressed or - excuse me - yeah, they’re not here to do a job. I’m not a number. They take their time, they don’t rush through as fast as they possibly can. I had one nurse this morning say, well I asked him, am I a hard person to look after? And he said, no. You’re not hard, it’s time consuming with you, whereas some other people, it’s hard physical yakka but they get through things fairly rapidly. So everyone’s different here. But they are more than willing to help me out and laugh. There are some staff, when I know that those staff are on, I’m going to have an awful lot of laughing. That’s just how it is.

Interviewer: And what sort of difference does that make to you when people are like that with you?

Justine: Makes me feel loved. It just makes me feel like I am important to someone. Even though I can’t do anything. That they want to spend time with me... I was having a bit of a hard time a couple of weeks ago and two gentlemen [staff members] decided I needed cheering up. So they dressed up in operating gowns and they made halos for their head out of cardboard and wire and got my hymn book and stood at the end of my bed and sang hymns to me.. Two staff members. Well at the end of the day I was told, well you probably don’t need your depression medication tonight Justine. I said, probably not, I’ve laughed myself silly. And it’s probably going to take me a long time to go to sleep now tonight. It was just a laugh and they went and did that to a few other residents that night as well. I suppose it’s that aspect of this place where the staff are more than willing to go the extra mile to make you feel happy.

Interviewer: And what does that mean for you?

Justine: Just made me feel really special. Really special” [Justine:I1:4:117-5:146].
Therese’s limited time with her own children appeared to influence the depth of relationships she had with staff. Therese experienced a decrease in the frequency of contact with her children and appeared to gain a “pseudo-mother” experience through her interactions with the younger staff members at “Mei Domus”, providing a substitute for her absent children. This helped recreate the sense of who she previously was at home, thereby influencing the reconstruction of her sense of home at “Mei Domus”.

Therese: “Even on the weekend they [children] don’t come to see me. They used to come and see me every Sunday; they don’t come and see me anymore. School holidays, see there’s room, there’s an extra room there. They have all the opportunities to come and stay in that room there. They won’t. From the time I’ve been here they’ve never been once here to spend a school holiday, spend it with me. Sometimes I feel they’re ashamed of me because I’m in a wheelchair. That’s one good thing about [“Mei Domus”]. I don’t feel, I know the carers are not ashamed of me. Even when I went to [Musical], even going to the movies they take me in the wheelchair, they’re not ashamed of me” [Therese:12:8:228-236].

Therese: “[name], she’s an RN [Registered Nurse]. She had her wisdom teeth out ..... I felt so sorry for her and I made some chocolate mousse for her to take home, because I knew she couldn’t eat, the poor thing. I kept asking to find out how she was, because I was really worried about her. They’re like my children, they’re so young. They’re good kids, they’re really good people” [Therese:11:4:87-90].

Emma acknowledged that staff at “Mei Domus” were paid to do their jobs. However, she also acknowledged the extra things that staff did for her that showed they cared and assisted her to feel independent. This was highlighted for her by the comparison to her previous accommodation. The attitudes and behaviours of “Mei Domus” staff impacted on Emma’s identity, and assisted the reconstruction of her sense of home.

Emma: “I know they’re being paid to do this, but in the way they make you a cup of tea, you know? And when they’re here they’ll say is there anything else I can do. Do you know what I mean? When we’re showered in the mornings I can
wash myself, so they leave me alone in the shower to do that. They let me have that intimate time. It’s all those little things. I think yeah, they do.

Interviewer: Is that different to when you were living at [previous accommodation]?

Emma: Oh yeah. The rule was that the staff were not allowed to get close to you. Also I think the place was understaffed, so you didn’t have that – each resident had a set amount of time they had to be showered and dressed in. You had your meals – breakfast was this time, morning tea break was at this time, lunch was this time, afternoon tea break this time, dinner this time, after dinner break at a certain time. And if you wanted a cup of tea or anything like that, that’s when you’d get it.

Interviewer: So if you wanted a cup of tea at two o’clock and it wasn’t afternoon tea time...


Emma: I don’t know. [Staff member] brings in eggs from her hens to me; I get fresh eggs from the hens. I was looking for buttons one morning and she said she’d bring in some buttons for me. It’s just those little things. Nobody objects to any of that; it’s not something that you have to hide that you’re doing. They took me shopping and helped me choose something really nice to wear one night when I was going out, that sort of thing. That’s what makes it so different” [Emma:11:9:289-10:307].

In contrast, Emma also had experiences with staff that impacted negatively on her sense of belonging at “Mei Domus”. Emma’s perception of how she was treated by staff influenced her engagement with others outside her apartment.

Emma: “And whenever we’ve had – like they had a Melbourne Cup day last year, and things like that. I found that really intimidating because we were told Melbourne Cup day was going to be at 10:00 or 10:30. So I waited up here until 10:30 and went down there, and everybody had obviously been there for at least half an hour. It had got going half an hour earlier. And because of the setup of the tables down there where you’re all in one line, it was like when I got to the door there was nowhere to go. So I was sitting at the door, and I had to leave because I found that situation overwhelming. Do you know what I mean? I really felt excluded and I really felt a lot like I’d been forgotten, in a sense.

It had started earlier, and I was told afterwards it had only started earlier because residents arrived a lot earlier than they were supposed to. But I sort of think well that’s okay for them, but what do you do for – do you know what I mean? You can’t just sort of leave another person – do you know what I mean?
If everybody else gets down there half an hour early you’ve got to go and let the other people know. But anyway, that’s not how it works apparently”

[Emma:II:7:201-214].

The attitude and behaviour of the staff could “dehumanise” the participants by interacting with them in a way that underestimated their competency and abilities. When staff ignored the needs of participants it created a sense of anger and frustration. This impacted negatively on their sense of self, and, in turn, their sense of home.

Lou: “There is a couple [staff members] that don’t really show much caring, it’s like ‘I have to do this’ kind of thing, but that could just be me with a personality clash kind of situation. I mean, I’m not perfect and I shouldn’t expect other people to be perfect….but when it comes to work I do find a couple of them are very much, ‘I’m just doing this because I’m here because I need to, because I’m getting paid’, but not too many of them.

Interviewer: So in what are the people that you think are caring towards you, in what ways are they?

Lou: Just the fact that they listen when I am talking. I mean, I had an incident just last week with an agency staff. Something happened that I could have been spoken to about, but she just went to another staff member and said ‘What can I do with this? What should I do with this?’ and when she came back I said, ‘Why did you go to her? You could have asked me’ and she just looked at me and went ‘Well, I needed to know what to do with it.’ I said, ‘Well, once again, you could have asked me. I know what’s going on’....

Interviewer: So is this around your care?

Lou: Yeah.

Interviewer: And she went and asked somebody else how you needed to be cared for?

Lou: Pretty much. So it just annoys me that some of the staff, primarily I guess agency, which we have to have, they just from time to time they treat me as though I am one of the residents that can’t speak and I am one of the residents that can’t think. You know what I mean? I’m very articulated. I can talk. I can think. I can make decisions for myself…. Sometimes when they treat me as though I can’t, it just really grates on me. I mean, fortunately that doesn’t happen a great deal but it does happen from time to time.

Interviewer: So when that does happen how does it make you feel?
Lou:  *It makes me feel like I am an absolute zombie. I mean, you just imagine if you were for example at the hairdresser and you told the hairdresser what colour you want and what style you want, and then all of a sudden the hairdresser goes over and says to the other hairdresser, ‘She wants this colour and this style, I don’t think it will match. What do you think?’ Not talking to you about it. You’re there, but talking about you to someone else as if you’re not there and you don’t matter, and that really hurts and, to me, angry. It gets me angry. Thankfully it doesn’t happen too often” [Lou:11:7:226-8:254].

Participants made a distinction between regular “Mei Domus” and temporary agency staff. More familiar staff assisted in creating a sense of home, whereas the introduction of agency staff who have not had the opportunity to get to know residents’ resulted in treatment that highlighted their disability, impacting on their identity and ultimately their sense of home.

One of the most revealing events was Barbie’s experience of another resident moving into her apartment. During this process, staff failed to communicate adequately with Barbie, even to the point of excluding her from any introduction to the new residents, or asking her to be involved in the new resident’s visit to view the apartment prior to her moving in. The way in which this event was managed by staff had a considerable impact on Barbie’s sense of belonging at “Mei Domus”. It created an immediate deconstruction of her sense of home. The following extract illustrates this process in full.

Barbie: *“The only thing that would impact is being a shared apartment, because you’ve got to share with somebody else and you don’t know – especially, I’ve only met the new person once and it makes it really hard. Like yesterday, I found that I wasn’t included, seeing that it was this apartment that was being inspected, I felt like I wasn’t included, I wasn’t part of the discussion. So I didn’t know what was going on and then when the lady actually did finally come downstairs, and they were introducing people, I was never introduced to this lady that you’re going to be sharing with. I had to actually step forward and say my name is Barbie and I’m the lady that you’ll be sharing with, and it was never – they knew they were coming into a shared environment, but I was never announced as the person who you were going to be sharing with. I sort of thought, hang on something’s not right here, and then for this person to be*
coming up to the apartment without me being there or being able to answer any questions was really hard for me to get used to.

Interviewer: So what was that like, knowing that somebody was having a look around the apartment and you weren’t a part of that? How did that feel for you?

Barbie: It felt really strange, because it felt like no, it’s not my home. I just felt like I wasn’t being included, like okay I’m part of the furniture and that’s all there is to it and that’s how I felt yesterday.

Interviewer: So you’d gone from very much feeling like this is your home now, to then this isn’t my home.

Barbie: Exactly.

Interviewer: What do you think – what was it about that that made you feel well, it’s not my home? Do you know?

Barbie: I think because I wasn’t included in the discussions that were going on in my rooms, so I have no idea what went on, what was discussed. I do know management did come up in the morning with another staff member who actually helped to clean my room, and the other staff member said look, this is ridiculous for a shared apartment, we don’t have this, we don’t have that, we don’t have storage space, nothing. It was just like well, I don’t know what was discussed.

Interviewer: So when the management and staff come up in the morning, had they approached you to let you know they were doing that?

Barbie: No, they didn’t even approach me. I asked what time is this person coming, I was told 11, this person didn’t come until quarter to 12, and straight away as soon as she came in the door they came straight up to the room and I just thought, well hang on, aren’t I part of this, shouldn’t I be involved in going up there as well. Yet, nobody invited me to go up. So I felt like okay, well I’ve got my room, but this person needs to know that okay this is stuff that I’ve gone you’re free to use this stuff, and this stuff is basically what was here beforehand, but this stuff is my stuff you are free to use it, but if something does happen you have to understand that it will be going with me, and just things like that. I just felt like I didn’t have a say, which is not right. I didn’t think that was fair at all that I didn’t really have a say in what was going on.

Interviewer: So then you said that you ended up introducing yourself to this lady, and how was that?

Barbie: It was fine, at the time. I didn’t feel as comfortable as I should have. If I had of met her from the first moment, but it was left until she came downstairs and it was a meeting to meet all the residents and it was just like I was another number. Like I’m resident number 15, you’re resident number 16. So it was just – I felt like it was a very cold approach to the situation, so I didn’t
feel comfortable in the way that it was approached, but I thought it could have been handled a bit more better with a bit more involvement. They keep saying to me now, you can say to this person what you think needs to be changed, you’ve been living here for so long. Now this person’s coming into the area, so you need to be able to say what you feel, what needs to be changed, what they think needs to be changed, but we didn’t get to discuss any of that. On the visit that we had yesterday, we still didn’t get to discuss any of that, so I won’t get to discuss any of that until this person comes to live here which could possibly be as early as next week.

Interviewer: Okay, so I’m just wondering you’ve gone from feeling like this was home, to feeling like it’s not home and you describe yourself as I’m just resident 15, how are you feeling about this place as your home today?

Barbie: Today, well being able to have breakfast for breast cancer with all the other people here that I know and I’ve got to love, that was really good. I don’t know, it’s still really hard to say because you don’t know – I don’t know enough about this other person that’s coming, all I know is her age and that she has a child of her own that doesn’t live with her or her husband and that she’s never here on weekends, but it’s just like what do I need to know for when this person is here. Don’t I have a right to know – it’s really hard to say. I just feel like because I wasn’t included in yesterday’s discussion and it was only management that was included, I felt like I was the third wheel. So I felt like, hang on, this has been my home for the last 14 months and now all of a sudden it’s turned around and it’s just like, hang on do I need to go somewhere else.

That’s one thing that’s been worrying me and especially after I spoke to my son last time and I just thought to myself maybe I maybe need to move closer to my mum and dad and my family and be near by them, because they’ve got their own medical problems that they’re going through. I know one thing I can move just around the corner from them, but maybe it’s waiting list as well, that’s a waiting game, to be able to move there. At the moment, I just feel like everything is up in the air, that’s how I feel.

Interviewer: It sounds like that’s had a really big impact?

Barbie: Yes [cries], sorry.

Interviewer: No, no need to apologise at all, Barbie. You talked before about this sense of I’m just resident 15, I’m just wondering what that’s like for you? Have you always felt like resident 15 here?

Barbie: No, I was actually resident 14 when I moved in here, and then somebody else moved in about two or three weeks after me. But no, I haven’t felt like a number, I haven’t felt like a number until yesterday. I just thought well, hang on, shouldn’t I be involved in discussions that are going on up here and I was never invited. So while this person was going around up here and they spent more than an hour up here, I thought well that’s really nice, you can at least introduce me to the person, you could at least ask me to go upstairs so that this person could ask me any questions they needed to ask. But I just felt like
no, all of a sudden, no I don’t count, that’s what I just felt like and I thought while it’s been my home for the past 14 months, it just feels like all of it’s been taken away from me. I just felt like a number yesterday, so that was a bit of a bad experience for me yesterday. I’ve never felt that way before. [cries] Sorry” [Barbie:12:5:133-7:204].

Conclusion

In this chapter, I have identified the themes that have emerged across all the interviews and have illustrated these with direct quotes from the residents who participated in the study. From the analysis of the interview data, the overarching category of Home emerged from two core themes Perceived Qualities of Place and Identity, a core process Deconstruction and Reconstruction, and the theme of Connections, which consisted of three sub-themes: Interactions with the physical environment, Relationships with family and friends (including residents), and Relationships with staff.

Fundamental to the perceived quality of place were concepts such as safety, security, comfort and a sense of belonging. Home was defined by participants as a place where they could house their belongings and special reminders of family or their own personal history. It was also a place where they could move things around to suit their requirements, giving them an opportunity and ability to manipulate their environment. Home was somewhere they could be themselves – “Home is where I am myself, this is where I belong”. Participants’ perception of the qualities of “Mei Domus” seemed to be intimately linked to their sense of self and how they believed they fitted into the environment. Conversely, their perceived sense of place and whether they felt at home at “Mei Domus” influenced how they felt about themselves within that environment. The more interlinked these two themes were, the greater the sense of home.
In all cases, participants’ illnesses initiated a deconstruction process which impacted negatively on their sense of home. Specifically, their illnesses challenged their sense of identity and altered the perceived qualities of the place in which they lived, thus depleting their sense of home. Their illnesses ultimately resulted in a need to move away from their home and families into alternative accommodation in order to manage their situation. Unfortunately, for some people, their accommodations were not appropriate to meet their needs, which created further deconstruction by not allowing a sense of home to develop. For participants who were temporarily able to remain in their family home, deconstruction still occurred as their illness progressed and their ability to manage independently within that environment was diminished. Irrespective of their current living arrangements, the opportunity to move to “Mei Domus” usually occurred at a point of intense deconstruction. Following their move to “Mei Domus”, the perceived qualities in the new environment enabled a positive shift in identity and a reconstruction of their sense of home. Any changes in the perceived qualities of place or identity (e.g., deterioration in health) could easily alter the equilibrium between deconstruction and reconstruction, indicating the tenuous nature of home.

The three inter-related connection sub-themes were important for all residents throughout the deconstruction and reconstruction process irrespective of where they lived. Interactions with the physical environment included the participants’ ability to access items in their home, manoeuvre themselves around their space, and the availability of spaces that facilitated positive time spent with family and friends. If these interactions with the physical environment were prohibitive (i.e., the environment restricted participants in some way), then there was an increase in their dependence on the relationships they had with staff (and on some occasions with family and friends), which in turn highlighted their increasing level of disability and impacted negatively on
their identity and their perceived quality of the place. These changes appeared to be automatically and immediately reflected in their sense of whether or not the current accommodation could be considered home (i.e., deconstruction of home). Conversely, the choice and opportunities made available by the physical environment at “Mei Domus” impacted positively on the time they could spend with family, friends and residents who lived in the same environment. The nature of the relationships participants had with staff and other residents also influenced their interactions with the physical environment in a cyclical way. These interactions contributed to a positive identity and a sense that the qualities of place were positive, leading to a greater sense of home (i.e., reconstruction).

Participants who did not have positive family relationships tended to form stronger relationships with staff, which in many cases seemed to act like a substitute for absent family. However, where family relationships were positive and strong, this substitution did not seem to occur. Although all participants formed relationships of some kind with the staff, the intensity and familiarity of these substitute relationships was obvious. This finding also confirmed the interdependency of the *Connection* sub-themes.

If any combination of the three *connection* sub-themes were experienced negatively, the process of deconstruction was exacerbated and reconstruction was ruptured. For example, if the physical environment was not accessible (e.g., inability to reach cups in cupboards to make a cup of tea), participants immediately became more dependent on staff, which in turn reinforced their identity as being more disabled, and triggered a decrease in the perceived qualities of place. If these relationships with staff were perceived as being negative, this further damaged the way in which participants viewed themselves and their experience within the environment, detracting from their
sense of home. In its extreme form, this negative cycle created a sense of dehumanisation and/or a lack of belonging in the residence (i.e., complete deconstruction of sense of home).

If these connection sub themes were experienced in a positive way, the reconstruction process was enhanced, which had a positive influence on the participants’ sense of identity and the perceived quality of the place. In cases where this occurred, participants shifted from thinking such things as they “had put everything on hold” [Lou:12:1:23] to feeling as though they had started living again (e.g., “I have my life back” [Lou:11:8:268]). Reconstruction resulted in being able to establish routines and having a sense of choice and control over their lives, despite the restrictions imposed on them by their illness, which in the case of participants with MS was deteriorating. The core process of deconstruction and reconstruction was best described as a continuum along which participants progressed in a fluid and responsive way. Participants oscillated regularly between the two extremes, demonstrating the transient nature of home. The process was extremely vulnerable to events in the environment, with negative events resulting in a rapid reversal towards deconstruction. It appeared that deconstruction occurred much more rapidly than reconstruction, highlighting the importance of maintaining positive trajectories.

In summary, perceived qualities of place and identity overlapped to create or construct a sense of home. Deconstruction and reconstruction were heavily influenced by the three interlinked connection sub-themes, interactions with the physical environment, relationships with family and friends (including residents), relationships with staff. The perceived qualities of place and identity, in turn, influenced how and why the three sub-themes influenced the deconstruction and reconstruction process, demonstrating the interdependent and cyclical nature of the theory and the complex
nature of the participants’ experiences. The study has provided a theory to assist in understanding the process these participants undertake to achieve a sense of home when their illness has required them to relocate to alternative residential accommodation. The following chapter will examine this theory in the context of existing knowledge about home and it will explore the practical implications of the theory and its limitations.
Chapter Six: Discussion

The current research explored the experience of home for young people with disabilities who were living in a long-term residential care environment. Although a large body of research exists regarding the meaning of home, overwhelmingly this research is conducted with non-disabled individuals, the elderly or individuals with intellectual disabilities. There is little known about how the population of interest in this study experience their care environments as home. This chapter will review the findings of the current study and discuss how these findings add to what is already known about the experience of home in general, and specifically in regard to young people with disabilities. Implications for practice and theory will be discussed, limitations of the study will be outlined and suggestions for future research will be proposed.

The aim of the current study was to examine multiple domains of home as they were experienced over time through a series of semi-structured personal interviews conducted with residents at their apartments. The purpose of the interviews was to understand the residents’ ‘lived experience’ within the residential apartments, and specifically to answer the following questions:

1) How do residents experience home within a residential care setting? and;

2) What influences their sense of home?

Review of Findings

The comparison of the stories presented in this thesis demonstrates the different ways people experience new environments and the impact this has on their lives. Four major findings have emerged from this research.
First, the importance of connections for participants appeared to be paramount in their development of a sense of home. Previous research has found social relationships develop between residents and care providers and can be beneficial to an individual’s well-being (Bitzan & Kruzich, 1990; Bowers et al., 2001; Li, 2004; McGilton & Boscart, 2007; Morse et al., 1992; Nussbaum, 1991). Street’s (2007) research highlighted the importance, in terms of their sense of well-being, of residents’ perceptions of their relationships with other residents and staff within a care environment. Although previous research has linked the importance of social relationships to general well-being and quality of life, the current study found that these perceptions of relationships were also important in terms of how they impacted on the participants’ sense of home. Positive relationships, particularly with staff, created a sense of belonging and comfort that assisted in the reconstruction of their sense of home.

Street’s (2007) research also revealed that contact with family and friends had no significant impact on residents’ life satisfaction. The current study, whilst not measuring life satisfaction, found that interactions between participants and family were critical to the participants’ sense of home. For Ivan, his unique situation of the presence of his wife at “Mei Domus” assisted his sense of home in a way that other residents were unable to experience. For Barbie, her son’s comfort in her new accommodation and the opportunity to have him stay with her assisted her to construct a sense of home. For Justine, the opportunity for her children to participate in the selection of her apartment, and to stay overnight, impacted on her sense of home. For Therese, the presence of her family decreased her sense of home because of the negative nature of these relationships. However, to compensate she had formed strong relationships with staff at “Mei Domus”. Given the young age of the staff, these relationships appeared to
provide a substitute for Therese’s family, allowing her to enact her highly desired “mothering-experiences”.

Freda’s experience of home was diminished by the absence of her family. For her, home was the place where family were always present. To compensate for the absence of her children, however, she compared “Mei Domus” to her childhood home with her own mother. This “regression” to her childhood experiences was defined by familiar cooking smells and favourite meals. Like Therese, Freda also perceived the staff as being friendly and caring. However, she did not seem to experience the same depth of relationship with staff. Freda’s experience of relationships with staff is in line with research that demonstrates how resident-staff relationships tend to exist out of necessity but lack emotional attachment (Iwasiw et al., 2003; Pietrukowicz & Johnson, 1991; Robbins et al., 1992). Staff did not appear to provide her with a substitute for family. For Freda, the longing to be with family remained strong and although she had regular visits from family, it was not enough to create a sense of home for Freda. Instead, Freda sought comfort from the familiar memories and reminders of her “real” home (i.e., with her mother). For Emma and Lou, the absence of their partners led to a feeling of not-home, but being able to spend time at “Mei Domus” in a relaxed and non-restrictive environment contributed to a sense of home. Thus, it seemed that the predominant driver of a sense of home may be identity. Although connections and perceived qualities of place can contribute to a sense of home, its presence is only fully constructed if identity is congruent with a sense of belonging.

The attitude and behaviour of staff impacted on participants’ sense of home in both a positive and negative way. Justine had an increased sense of home influenced by the caring nature of the staff, and the privacy afforded to her by them. Ivan also experienced an increased sense of home when he felt connected to staff and was able to
have a laugh with them. His sense of home was assisted by the caring attitude of the staff towards his wife and the level of communication he experienced with them in relation to her care. The way Therese was treated by staff influenced the reconstruction of her sense of home. At “Mei Domus”, Therese felt encouraged by staff to increase her independence, for example, she had the opportunity and encouragement from staff to water her plants daily and do her washing up. She experienced them as patient and accepting of her disability, which contrasted with the experience of her own family, with whom she felt like a burden and believed they were ashamed of her disability. These experiences of resident-staff relationships lend support to Clark and Bowling’s (1990) suggestion that facilitative relationships within care environments can assist with enhancing self-esteem and autonomy. These positive experiences impacted on the participants’ sense of identity, indirectly influencing the reconstruction of their sense of home. In contrast, Freda felt liked by the staff and welcome at “Mei Domus”, but her level of independence was negatively impacted by the intervention of staff in everyday tasks, such as cooking. This intervention detracted from her sense of home and her identity as a competent woman.

McGilton and Boscart (2007) highlighted the barriers to connectedness created by inadequate staffing levels and workload, which was found to be problematic in the current study following staff reductions due to budget cuts at “Mei Domus”. These changes impacted on all participants and the level of connectedness that was possible. Research conducted by De Veer and Kerkstra (2001) suggested that it is the quality rather than the quantity of the interactions that is important. When social interactions are negative there can be a detrimental impact on home and identity. Lou’s and Barbie’s experiences at “Mei Domus” highlighted this finding. There was a clear association between expressions of home and expressions of positive interactions with
staff. Conversely, expressions of dehumanisation were associated with descriptions of negative staff interactions.

The experience and meaning of home is likely to change for people over the course of their life. For individuals who are living with chronic illness and disability, the home environment may become the main place they conduct their lives, therefore the impact of this place increases in significance. Ivan discussed the limited opportunities to meet other people, highlighting the importance of the relationships within “Mei Domus” and it is important for service providers to understand the nature of these relationships in order to ensure that negative impacts are minimised for residents.

The second main finding of this study was that the nature of home emerged as an important concept that was comparative, temporal, tenuous and vulnerable to deconstruction. Deconstruction appeared to take place more rapidly and easily than reconstruction. Home was found to be tenuous in nature. It was a vulnerable construct that could quite easily be destroyed through negative interactions with the physical environment and/or interactions with others. This vulnerability to the construct of home appeared to be influenced by the individual’s sense of identity, as well as their perception of the quality of the environment in terms of how it met their needs. It has been found that the provision of care services within an environment can disrupt a person’s privacy, impact their identity and challenge their meaning of home (Dyck et al., 2005). Barbie’s experience, outlined earlier, supported this finding and demonstrated the importance of staff interactions. The need for residents’ privacy and sense of control to be considered when working within residential care environments is essential if we are to ensure minimal disruption to an individual’s identity and allow them to develop and maintain a strong sense of home.
The current study found that home was comparative and the process of reconstruction was developed through actually living at “Mei Domus” and comparing the new environment to the previous environment. Prior to moving to “Mei Domus”, all participants were living in environments that were not appropriate for their ongoing needs. For Ivan and Barbie, this meant moving from their family home, whereas for the other participants an opportunity arose to move out of inappropriate accommodation. The decision to move from one home to another is influenced by the meaning placed on that home, and as such creates a situation where the individual initiates a process of reconstructing meaning in the new environment (Rowles & Ravdal, 2001; Rowles & Watkins, 2003).

Home was subjective, private and dependent on multiple factors, which added to its vulnerability. Home was an individual construct based on participants’ private memories and experiences. The current home was experienced in relation to previous experiences of homes and the extent to which the new setting met particular and unique requirements for building a sense of comfort and belonging. These memories and experiences influenced the participants’ identity and their perceptions of the new environment, leading to the development of a sense of home. There were common qualities of home that participants shared, such as a place where they felt welcome, safe, comfortable, and had choices. Home was described as a space in which to have your own things, the ability to manipulate the environment to suit your own needs, with space and opportunity to develop and/or maintain deeper relationships with family and friends. These qualities of home are consistent with previous findings by several researchers (e.g., Despres, 1991; Sixsmith, 1986; Smith, 1994) regarding the meaning of home. Common features of the physical place, such as access to technology and a private telephone, assisted them to maintain contact with significant others. The ability
to speak to loved ones and arrange visits without relying on staff to assist gave them a sense of relaxation, freedom and choice, and allowed them to maintain an identity of independence.

The physical environment also impacted on the participants' sense of comfort and belonging. The space and layout of the environment allowed ease of movement, and choice about where and with whom they spent their time. This all contributed to the reconstruction process. In line with De Veer and Kerkstra’s (2001) research, the opportunity for participants to personalise their own space and the provision of privacy that enabled them to spend time alone assisted participants to feel more comfortable. For example, Ivan appreciated the opportunity to organise their apartment, deepening his sense of home. Lou’s ability to create her own office space within her apartment allowed her to connect more with family and gain a sense of independence, as well as making the environment more comfortable for her partner, resulting in him spending more time with her. All of this contributed to her sense of home. Therese compared “Mei Domus” to her experience at her family home where she had difficulty manoeuvring around the space, constantly bumping into walls and doorways. The absence of these barriers at “Mei Domus”, and her perceived qualities of her new environment created a more relaxed space for her in which she could reconstruct her sense of home. Finally, the ability to make choices and develop a level of independence combined with these other features to create a sense of belonging and a connection to a place which could then be thought of as home.

Little attention has been paid to the impact that a person's change in level of competence has on the meaning of home. Rather it has looked at whether home is usable and accessible (Steinfeld & Danford, 1999). Although considerations of accessibility and usability are important, it is also necessary for us to understand the
impact on identity and sense of home that occurs when interactions with the physical environment are negative. When aspects of the environment created difficulties for the participants (e.g., spaces prevent them from managing small tasks themselves, such as making a cup of tea, and/or discomfort with physical layout of communal areas), or tasks were routinely carried out by staff, their reliance on staff was increased, highlighting their disability and impacting negatively on their sense of independence, choice and identity. This finding demonstrated an interaction between the participant, the environment and the staff which influenced the deconstruction process, impacting on participants’ identity and sense of home. For example, Barbie experienced inaccessibility within the apartment which, in combination with behaviour of staff resulted in the deconstruction of her sense of home. Emma frequently experienced difficulties interacting within the communal areas due to the lack of intimacy in those spaces. This impacted on the amount of time she spent with other residents outside her apartment and influenced the deconstruction of her sense of home. For Ivan, a sense of home was experienced within his apartment, but not within the communal areas of “Mei Domus”. However, these spaces were still indirectly important to his identity and sense of home in terms of connecting with others and having a laugh.

Thus, place, people and personal expectations interacted to create a sense of home for participants. Robertson et al’s (2001) study drew attention to the relevance of the physical environment in terms of the impact it may have on an individual’s social networks. This connection should not be underestimated. The perception of the place extended beyond the people living within “Mei Domus”. At times, the perceptions of “Mei Domus” could have a negative impact on friends’ desire to visit, as they assumed it would be the same as a nursing home. Lou’s experience of a friend not wanting to visit did not, however, appear to directly impact on her sense of home. However, if the
perception of visitors continued to prevent them from connecting with residents, it may have an indirect impact on sense of home. Findings from Robinson’s (1986, as cited in Thompson et al., 1990) study indicated that people make quick impressions of the physical features of a home and their behaviour can be indirectly influenced by the symbolic effect of certain physical features. However, it would seem that the subjective experience of place (as opposed to external perceptions) remain distinct but could impact indirectly in the long-term.

The construct of home is tenuous because it is dependent of multiple factors, a case in point is the comparison of the two residents with ABI. A noticeable difference between residents with MS and ABI is that the two residents with ABI talked about “going home”, whereas the residents with MS did not. One exception to this was Barbie who talked about the possibility of moving back to her parents’ home. However, this occurred during a period of acute deconstruction following another resident being moved into her apartment without her involvement. For the two participants with ABI, there was a temporary nature to home, however this appeared to be for different reasons. For Therese, although she had developed a strong sense of home at “Mei Domus”, there appeared to be conflict between wanting to view “Mei Domus” as her home (as opposed to the alternatives) and striving to be “ready” to return to her “real” home. Therese appeared to be working towards “getting better” in order to return home to family no longer as a burden. In the meantime she was able to satisfy her need for connection to others through new relationships she has established at “Mei Domus”.

For Freda, home was constructed from many things, including favourite meals, familiar feelings, autonomy, choice, and a place to have your belongings and memories. Although she had these things at “Mei Domus”, they were not enough to constitute home for Freda. Home for her was where her family resided and “Mei Domus” could
only provide an inadequate substitute. It allowed her to access the necessary medical and rehabilitation services that she would not be able to access if she returned home. Freda had a longing for family which was not satisfied by alternative relationships within the apartments and if it were possible to access the services she required she would chose to move home to be with family.

Third, as noted, the current study found a strong link between the participants’ identity and their sense of home. This was influenced by their perception of the environment, as well as their interactions within that environment. Previous research has demonstrated that this is an important link. ‘Who we are’ has often been intimately related to questions of ‘where we are’, and the importance of place for constructing and maintaining a sense of self has been established throughout the literature (Dixon & Durrheim, 2000). Knez (2005) concluded that identity and place-related attachment evolve similarly over time and are influenced by complex interwoven and interrelated sociological and psychological factors. For a long time it has been believed that it is not only the social roles we hold that impact on the development of identity, but also the positive and negative cognitions we hold regarding a particular place that assists in defining who we are and the value we see in ourselves and how we believe others may see us (Proshansky et al., 1983). Lou’s experience of negative interactions with staff led to her feeling more disabled and ultimately dehumanised, as a result of how she believed she was perceived by staff. Conversely she had experiences that increased her sense of competence and responsibility, for example, the ability to re-establish her guardian role for her niece. These differing experiences impacted her sense of identity and influenced the deconstruction or reconstruction of her sense of home. Despite these previous findings regarding identity and place, we do not tend to use this information in
relation to the design of environments and the provision of long-term care for young people with chronic and complex health needs.

Research exists on the reconstruction of identity following brain injury and the importance of clinical interventions to assist with the reconstruction of identity (Hoogerdijk, Runge, & Haugboelle, 2011; Muenchberger, Kendall, & Neal, 2008; Ylvisaker & Feeney, 2000). Although the existing research assists us to understand the process that individual’s go through following injury and deconstruction of their sense of self, it has not been applied to the meaning of home for this population. Although we have access to some research in relation to identity and ABI, this change in identity is created by an obvious sudden change in functioning and capacity of an individual. People with MS experience a gradual decline in health and functioning with a palliative trajectory which is not necessarily taken into account. The current study suggests this illness trajectory needs to be considered more in terms of the impact of these degenerative conditions on an individual’s identity. Whilst there are some differences to the experiences of home for people with ABI compared to people with MS, there are also many similarities, which hints at a universal experience of home. The current study serves to bridge this gap between the two areas of literature and provides a starting point from which to further explore the interaction between these two important concepts.

Finally, the current theory is important in relation to Despres (1991) proposed four theoretical models which could be used to explain home. First, the Territorial Model was extrapolated from animal studies to explain why people mark out their space and stipulate the permitted behaviours within that space as a sign of their control. Second, the Psychological Model included two major perspectives: a psychoanalytic perspective, which viewed the home as a subconscious expression of the self, and a
Maslowian perspective, which was based on the well-known hierarchy of needs developed by Maslow (1943). From the Maslowian perspective, home is seen as the mechanism that enables a person’s psychological well-being to be achieved by first meeting physiological and safety needs, providing an environment that fulfills love and security needs, and allowing the expression of self-esteem and social respect. Finally, the home provides a way of meeting a person’s need for achievement and growth.

Third, the Socio-Psychological Model suggested that the home shapes an individual’s personal and social identity, as it can personify and express “messages about the resident” to the larger community (Annison, 2000, p. 257). Finally, the Phenomenological and Developmental Model proposed that home is influenced by the events in an individual’s life and changes over time, creating a dynamic process. This perspective suggests that home serves as a connection between a person’s past, present and future.

The current study shows the links between these four models and highlights that they do not operate in isolation. In the current study, participants did mark out their space (territorial model), by displaying familiar objects and memorabilia, and deciding on boundaries and permitted behaviours, which is in itself a subconscious expression of the self. Home also provided fulfilment through the satisfaction of needs for safety, security, expression, and growth (psychological model). These activities and the satisfaction of needs influenced the participant’s sense of identity, which in turn impacted the reconstruction of their sense of home. The opportunity to have control over their own environment, welcome people into their apartments and develop an identity of competence (socio-psychological model) influenced the reconstruction of home. An environment that connected participants’ past, present and future
(phenomenological and developmental model) by allowing artefacts, engagement, and planning also encouraged a sense of home.

The current study found Despres’ (1991) general categories of home to be relevant with a couple of exceptions. Home was not seen as an indicator of personal status. Despres’ understanding of this was related to the economic status represented by a person’s home. As residents did not own their apartments it would not be expected that this would apply. Further, Despres highlighted home as “a place to own”. Despres described this ownership as being associated with significant economic investment, freedom, privacy and permanency. Residents at ‘Mei Domus’ did not have economic ownership of their apartments. However, the connotations of freedom, privacy and permanency did apply within the current study. The residents appeared to have a sense of ownership without the economic investment that Despres describes.

The majority of Sixsmith’s (1986) categories relating to home were also found within the current study. In line with the “Physical Home”, some residents (e.g., Lou and Barbie) created a “work environment” within their apartments that enhanced the meaning of home for them. The “extent of services” described by Sixsmith were also important aspects of home for the residents. In relation to the “Social Home”, the “type of relationship and personal choice” were facilitated by the private and communal spaces which allowed residents choice over who and where to spend time with. The aspects of “Personal Home” were also evident in the current study with a few noticeable differences. The “responsibility” that Sixsmith describes was not evident in the current study due to the fact that residents did not own the properties nor were they responsible for any ongoing maintenance. For some residents the sense of “permanence” was relevant, however, for others (e.g., Freda, Therese and Barbie) this did not always apply.
Furthermore, there was certainly a level of privacy within the residents’ apartments, however, it was not always at a level that was desired by each individual.

Smith’s contributors to a sense of home and non-home were also reflected within the current study, again with the exception of “ownership”. A lack of ownership did not appear to contribute to a sense of non-home, whereas other factors such as dissatisfaction with internal social relationships, poor physical environment, lack of permanence did appeared to be strong indicators of a sense of non-home. The factors contributing to a sense of home found by Smith were also strong indicators within the current study. Added to this was a sense of belonging, as suggested by Sixsmith (1986).

It is clear that when understanding the concept of home, it is not sufficient to examine only the physical, social or psychological features, but to view all three elements as interrelated (Somerville, 1992, 1997). This study has highlighted the interrelated nature of home, and provided a way to assist understanding the experience of home for young people with disabilities living in long-term residential care.

As Annison (2000) suggested, many features combine to create the sense of home, however when one feature is absent this can create a feeling of “not-home”. When this is family, it is imperative that staff members understand the relationship each resident has with family members, the meaning of that experience and the link between home and family, in order to provide each individual with the optimum experience of home.

Stedman (2002) highlighted that meaning is ascribed to a place that meets a range of basic needs, including services, sociability and physical characteristics, and that these meanings are important in terms of attachment, satisfaction and behaviours. Freda’s experience at “Mei Domus” demonstrates that whilst a place can meet basic needs and can provide satisfaction, if their attachment is connected to another place,
then these provisions are not enough to ensure a sense of attachment to the new dwelling. This is consistent with Mesch and Manor’s (1998) belief that whilst one can be satisfied with a place, this does not immediately lead to an attachment to that place.

The findings from the participants’ experiences at “Mei Domus” lend support to Annison’s research regarding how home can contribute to quality of life. “Mei Domus” met fundamental needs such as provision of shelter, it also accommodated intermediate needs, such as participants having a sense of belonging, privacy, safety and they mainly experienced an emotionally supportive environment. This highlights the events that Barbie and Lou experienced which were not emotionally supportive and deconstructed their sense of home. Finally, individual growth needs were supported through the ability to manipulate the environment, opportunities for self-expression, such as photos and memorabilia displayed in the apartments, participants choice of structure and routine for their daily living (with the exception of the introduction of set meal times in the communal area), and for some participants there was the opportunity to manage daily tasks. For participants where this was not possible, this influenced the deconstruction process and impacted their sense of home. The current study has, however, refined Annison’s conclusion by highlighting the specific importance of identity irrespective of the positive impact of connections and perceived qualities of the environment.

**Implications and Recommendations for Practice**

As disability increases, dependence on staff relationships increases making the relationships with staff more significant. It is therefore important for staff to be aware of the process of deconstruction and reconstruction in terms of how it relates to residents identity and sense of home. This will assist in preventing the creation of episodes of deconstruction. It is paramount that engagement with residents takes into
account their individual needs for privacy, engagement with family and other residents, assistance in household tasks, and desired level of autonomy and control. Service provision ought to be conducted in a manner that maintains residents’ sense of control and minimises any disruption to their identity. Behaviours and attitudes that dehumanise residents need to be understood and avoided. There is a need for staff to be aware of, and understand the factors that decrease residents’ sense of competence, in order to prevent this happening. If staff are unaware of the deconstruction process, they can inadvertently create numerous episodes of deconstruction which can take a long time to reconstruct, particularly if nothing is done to assist this reconstruction process.

Provision of education to staff and family members may assist in their understanding of how residents experience their new living environments and allow for communication regarding specific needs, in order for residents to develop and maintain a strong sense of home. There is a need for increased awareness, on behalf of front line staff and organisational management, of the importance of home for the residents. It is also necessary for them to understand the impact, both positive and negative, of the physical environment and resident-staff interactions. Sufficient time should be made available, where possible, to assist residents to manage their own household tasks. Allowing residents to participate in managing their own daily activities will assist in fostering their sense of independence and autonomy.

There is an overwhelming need for more of these alternative accommodations for young people with disabilities. However, it is important when constructing these new accommodations that consideration is made to the accessibility of the physical environment. The negative impact on residents’ identity and sense of home when they cannot adequately access their environment could be avoided if the design of the accommodation took into consideration factors such as: wheelchair access, limited
strength of residents and inability to reach out of the way areas. Beyond these basic physical design issues, the place needs to support positive identity development and connections.

**Limitations**

The current study investigated the experience of young people with disabilities living within a new long-term residential care environment designed specifically for individuals with chronic and complex healthcare needs (i.e., MS and ABI). The approach used to investigate this phenomenon allowed for a meaningful exploration of home for these participants. However, there were a number of limitations that could potentially be addressed in future research.

It is acknowledged that whilst the participant sample used for this study was small, it did represent almost half of the population of residents, including residents with both MS and ABI. It also included female and male residents (albeit only one male) who had moved from both their family homes and alternative accommodation, a range of age groups, parents and non-parents, and married and single residents. It is also acknowledged that “Mei Domus” is a very unique and contained environment and therefore it would not be possible to generalise these findings to other residential settings. However, the findings do provide a point from which to extend this research and test the theory to explore whether it adequately explains the experience of home for residents in other settings (e.g., young people still residing in aged care, older aged care residents). Ideally a larger sample of a similar population would be beneficial, however, until such services increase for this population this is likely to be difficult to achieve.

Ideally, from an IPA perspective, the sample should be as homogenous as possible in order to illuminate the psychological variability within participants (Smith et al., 2009). This contrasts with the purposive heterogeneity that is often sought in other
forms of qualitative research. There was homogeneity in the sample in that they were all residents living in the same accommodation, all were living with the impact of a disability, and they had all experienced separation from their family (with the exception of Ivan). However, the age range was varied. It may be that the experience of participants differs in relation to their age, some participants were in their thirties, some in their forties and one resident was in his late fifties. Another difference among participants was the age of their children, a factor that may influence participant experience as the natural parenting role with younger children would be different and the loss of this role could potentially be more profound. It may also be of benefit to extend the research in regard to the pathway to residential care for the residents given the comparative nature of home (i.e., whether residents have moved from their family home, or an inappropriate alternative accommodation).

Another consideration is the exclusive inclusion of residents with adequate verbal abilities. Although this was necessary for the method used, it may be that the experience of residents with verbal and cognitive difficulties would be very different and therefore require different service provision. However, this is challenging to overcome in research, as the main alternative to interviewing individuals with communication difficulties is the use of proxies which in itself is not the opinion of the individual. In this situation, families who have relinquished care of their disabled relative will have a unique set of views that may influence the findings.

**Suggestions for Future Research**

It is hoped that these findings will provide a basis for future research in larger settings where more participants would be available. Further investigation of the relationship between sense of home and a variety of psychological outcomes (e.g.,
depression, anxiety, and quality of life) would be of benefit to assist service providers in optimal service delivery.

Further research may investigate the potentially reciprocal nature of the relationship among the themes. For example, when residents are in a deconstruction process, does this have a detrimental influence on their interactions with others compounding the experience of home? Conversely, if they are in a process of reconstruction does this have a positive influence on their interactions? This cyclical nature of the theory could not emerge in this short term study.

It would be of interest to test this theory within an aged care setting, where there may be the opportunity to include both young and elderly residents and compare the experience of home for these different age groups. This may also serve to highlight the need for separate services for differing age groups and assist in influencing government policy regarding funding for younger people with disabilities who find themselves in need of long-term residential care.

It would be of benefit to investigate the types of interventions that may assist in the reconstruction of residents’ sense of home or prevent deconstruction. Is it possible that a psychological intervention would be of benefit and would this be delivered in an individual or group format? Alternatively, would there be more benefit from a staff education intervention? It could be possible to compare a staff education intervention targeting connections to a more individualised psychological intervention targeting the residents’ own perceptions of life within the environment, focusing on their sense of identity and perceived qualities of place. However, this would require a multi-site design which is not currently available in Australia.

Families and significant others are often neglected in service provision, and therefore it may be of interest to investigate the experience for family members and
significant others. What influences them in terms of their connection with their loved ones? Are there barriers within these new environments that could be easily overcome?

**Conclusion**

This study has provided an empirical contribution to the knowledge about home through the qualitative analysis of the participants’ interviews. It also offers a theoretical contribution to the literature, expanding on the understanding of the meaning of home, in relation to a specific population of young people with disabilities. Together with existing knowledge regarding the construct of home, the developed theoretical framework offers a way to understand the experience of home for young people with disabilities living in residential care environments. To my knowledge, there is no comparable model within the literature pertaining to disabilities. Finally, this research has practical implications for the development of policy and the provision of services to individuals living with disabilities in long-term residential care environments.


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Appendix A

Overview of Multiple Sclerosis and Acquired Brain Injury

Definition, Prevalence and Symptoms of Multiple Sclerosis

Multiple Sclerosis (MS) is a complex disease with the overall cause still unknown. It does, however, appear to be influenced by the immune system, environmental factors, viral factors and genetics (National Multiple Sclerosis Society, 2011). MS is a degenerative disease that affects a person’s central nervous system white matter, and causes various clinical signs and symptoms by creating inflammation, local edema, and demyelination in the brain, spinal cord and optic nerves (Miller, 2006). The term sclerosis is Greek and means ‘hardened tissue or scars. Multiple sclerosis involves many hardened tissue or scars within the central nervous system that can, to varying degrees, create problems with the transmission of nerve impulses throughout the brain, optic nerves and spinal cord (MS Australia, 2005).

MS is a disease that affects people worldwide, although considerable epidemiological variation has been found in incidence and prevalence rates. According to MS Research Australia, each year 1,000 new diagnoses of MS are made, and MS affects 20,000 Australians and 2.5 million people globally. MS affects women more often than men, with ratios varying from 3:2 to 2:1 (Miller, 2006). Whilst the disease may manifest at any age, it most frequently develops in young adulthood (Miller, 2006). The manifestation of MS is highly variable and there is no one symptom that signifies the presence of the disease. There are many symptoms that regularly occur in MS. These include: fatigue, including normal fatigue that is found in persons without MS, neuromuscular fatigue, and lassitude or MS specific fatigue; spasticity as a result of upper motor neuron dysfunction; weakness, usually as a result of demyelination, but can
result from deconditioning; urinary dysfunction; bowel dysfunction; sexual dysfunction; pain either due to joint, back or orthopaedic problems, or a burning, irritative pain known as dysesthesia; tremor; visual dysfunction; paroxysmal spasm, repeated episodes of sensory disturbance or spasm; pathological laughing or crying; and depression (Schapiro, 2006).

Predicting the course of MS is very difficult due to the great variation among individuals. Some individuals experience minimal symptoms while others rapidly progress to total disability, with the majority of people somewhere between these two extremes (MS Australia, 2011). While there is such variation among individuals, there are a number of typical patterns that describe the clinical course of MS, each of which can be experienced as mild, moderate or severe. Relapsing-Remitting MS (RRMS) is the most common form of MS. MS will initially begin as RRMS for 70-75% of people. It involves unpredictable relapses that involve new symptoms or the worsening of existing symptoms, followed by partial or total remission. These relapses can last for days or months, and the disease can then be inactive for months or years (NMSS, 2011). RRMS may later become steadily progressive, and relapses and partial recoveries may increase. This is known as Secondary Progressive MS (SPMS). Of the 70-75% of people who initially have RRMS, more than 50% will go on to develop SPMS within a 10 year period; and 90% within 25 years (NMSS, 2011).

Primary Progressive MS (PPMS) is characterised by an absence of distinct attacks. It has a slow onset with symptoms worsening steadily, and symptoms do not tend to remit. Approximately 15% of people with an MS diagnosis will be diagnosed with PPMS. Relapsing Progressive MS (RPMS) is quite rare. At diagnosis of MS, approximately 6-10% of people appear to have RPMS. This form is characterised at
onset of the disease by a gradual progression of disability accompanied by one or more acute attacks (NMSS, 2011).

**Definition, Prevalence and Symptoms of Acquired Brain Injury**

In 1999, it was estimated that 338,700 Australians (1.9% of the total population) had a disability that was related to an acquired brain injury (ABI). A large number of those people (160,200) were profoundly or severely affected by ABI and required daily support.

ABI may result from various cases, including disruption to the oxygen supply to the brain, stroke, degenerative neurological diseases, infection (e.g., meningitis), tumours, infection and trauma. The nature of the damage and the location of the brain affected can vary depending on the cause. Strokes tend to cause localised damage to the brain, whereas trauma resulting from motor vehicle accidents can in some cases cause widespread and diffuse damage (Jennet et al., 1981 as cited in AIHW; Fortune & Wen, 1999). Stroke is the leading cause of ABI, a stroke occurs when the blood supply to the brain is stopped by either bleeding or a clot. Physical disabilities often result from a stroke, as well as alterations in their emotions and thinking. It is estimated that around 60,000 new strokes occur per annum. Normally something that happens to people in the older age bracket, however, one in every five strokes occur in people under 55 years of age (Brain Injury Australia).

It is not only the nature and severity of the damage to the brain that influence the resulting disability. Social, personal and medical factors need to be taken into account in relation to the nature and severity of the disability. The brain plays a central role in all aspects of cognitive, physical, sensory, behavioural and social functioning. If only one type of impairment (e.g., physical or mental) develops then it is likely that the person will be able to develop compensatory adaptations, however, where multiple
impairments develop this is less likely to happen, resulting in an increased need for support (Jennett & Bond, 1975 as cited in AIHW; Fortune & Wen, 1999). Due to the broad range of types of disability that can develop from ABI, people with ABI can have very diverse support needs.

Many of the social and emotional difficulties, including depression, mood swings, disinhibition and aggression, resulting from ABI can be particularly challenging for individuals and their families. These changes in behaviour and personality can affect close relationships. Often to ultimate goal for a person with ABI is to be accepted as a valued and participating member of their family and the community. Support is required to assist individuals with ABI to build relationships, establish social networks, access community services and resources, develop skills, achieve independence and autonomy, and build confidence and self esteem (AIHW; Fortune & Wen, 1999).

Research has found that people with ABI often had inadequate access to necessary services, due to the absence of appropriate services, lack of funding and resources, inaccessibility due to physical factors or communication difficulties, lack of awareness of appropriate services, and the lack of understanding by service staff of the needs of people with ABI (Ramsey & Hilton, 1995 as cited in AIHW; Fortune & Wen, 1999).
Appendix B

Interview Protocols

Social Environment Interview

Thank you for participating in this interview. Before we start the interview I will need to ask your permission by signing this consent form. I would also like to tape record this session, as it is difficult for me to remember everything we might talk about. Is that OK?

I am going to ask you some questions about your social relationships. These questions will be split into two categories. The first part will ask questions about the relationships you have with people who live outside of the “Mei Domus” apartments. The second part will ask questions about the relationships you have with people who live or work within the “Mei Domus” apartments. This is a fairly informal interview and we are particularly interested in how you experience your social relationships now you are living here at “Mei Domus”.

1a. How often does a family member visit you?
   b. How easy or difficult is that here? Example?
   c. How has this changed since you moved to “Mei Domus”? Example?

2a. How often do you speak on the phone with family?
   b. How easy or difficult is that here? Example?
   c. How has this changed since you moved to “Mei Domus”? Example?

3a. Do you have regular contact with friends that do not live here?
   b. How easy or difficult is that here? Example?
   c. How has this changed since you moved to “Mei Domus”? Example?

4a. Do you regard any of the people who live here as your friends? Why?
   b. Is that different from where you were living before?
5a. Have you met residents here with similar interests to yours?

b. Is that different to where you lived before?

6a. Do you feel like a member of the community here? Why?

b. Is that different to where you lived before?

7a. Do you feel that you have friends among the staff? Why?

b. Is that different to where you lived before?

8a. Do you feel that the staff shows affection and caring for you? In what way?

b. Is that different to where you lived before?

Is there anything else you want to add about your social relationships that we have not talked about today?

Thank you [NAME] for your time today. Your experiences are extremely valuable to us and will help us understand what really works and doesn’t work for residents and how to build places like this in future. If you have any other thoughts about the interview today, please do not hesitate to contact me. Here is my number [give resident business card, or contact card].
Resident’s Meaning Interview

Thank you for participating in this interview. Before we start the interview I will need to ask your permission by signing this consent form. I would also like to tape record this session, as it is difficult for me to remember everything we might talk about. Is that OK?

I am going to ask you some questions about your thoughts on different places. I’m also going to ask you some questions about your experience of living here at “Mei Domus”. This is a fairly informal interview and we are interested in your thoughts and experiences and what is important to you.

1. I’d like you to think about a nursing home for a moment and then I'd like you to tell me what you think a nursing home is like.
   Prompt: When you think about a nursing home what do you think about?
   Prompt: Sights, smells, colour, etc

2. Now I’d like you to think about “Mei Domus” for a moment and then I’d like you to tell me what you think “Mei Domus” is like.
   Prompt: When you think about “Mei Domus” what do you think about?
   Prompt: Sights, smells, colour, etc

3. Now I’d like you to think about home for a moment and then I’d like you to tell me what you think home is like.
   Prompt: When you think about home what do you think about?
   Prompt: Sights, smells, colour, etc

4. What makes somewhere home?
   Prompt: What does it look like?
   Prompt: What does it feel like to be at home?

5. What are the things in this environment that feel like home to you?
6. If you were trying to explain to somebody why this wasn’t a home what would you say?

7. People can feel different things in different places. I’d like you to tell me what it has been like for you living here over the past [number of] months

Prompt: How do you feel living here?

8. How does this compare to where you were living before?

9. Describe for me what a typical day would look like for you here?

Prompt: Who would make that choice?

Prompt: How is that decided?

10. You are in a position where you know you need a certain level of care. Where do you think is the best place for you to receive the care that you need? Prompt: Why?

Thank you [NAME] for your time today. Your experiences are extremely valuable to us and will help us understand what really works and doesn’t work for residents and how to build places like this in future. If you have any other thoughts about the interview today, please do not hesitate to contact me. Here is my number [give resident business card, or contact card].
Appendix C

Information Sheet and Consent Form

Information Sheet

Evaluation of an accommodation option for younger people with continual care needs

Researchers: Ms Hayley Quinn (h.quinn@griffith.edu.au), Professor Elizabeth Kendall (e.kendall@griffith.edu.au), Dr Heidi Muenchberger (h.muenchberger@griffith.edu.au)

BACKGROUND

This information sheet (2 pages) tells you about a research study we are conducting at Griffith University into the experiences of younger people who were living in, or were at risk of living in, residential aged care, who have ongoing high care needs. "Mei Domus" has forwarded this information and consent form to you on behalf of Griffith University.

- If you identify as resident in the “Mei Domus” apartments, requiring continual care, we would be interested in your participation in this project.

In 2006, the Federal government established an advisory group to better determine the needs of younger people living in nursing homes. One area that has been identified by community and advocacy groups is the need for alternative accommodation options for younger people with chronic conditions and who require continual care. Indeed, it has been recognised that there is a need to explore other long-term care accommodation options for younger adults with chronic and disabling conditions.

A number of recent initiatives have emerged that aim to provide community-based supported accommodation options for this population. These new initiatives, such as “Mei Domus”, aim to provide continuous care for younger people while addressing their psychological, physical, and social needs. The opinion of younger people regarding their ‘experiences, perspectives and expectations’ in accommodation facilities has been lacking in the research literature. This study aims to improve this lack of knowledge by interviewing consumers (or residents) about their experiences with usual care services, and a new accommodation option, the “Mei Domus” apartments.

Results from this study will assist health care organisations and health professionals to understand what younger residents with continual care needs experience in relation to their usual care, and a different type of accommodation option, the “Mei Domus” apartments. The study will potentially help residents with continual care requirements identify their health and psychosocial needs (met and unmet) over time and inspire them to reflect on their valuable life stories.
What do I need to do?

For Consumers:

A. PLEASE NOTE: Participation in this study is voluntary and you may withdraw at any time. Your participation or withdrawal will not affect your health care or service program with “Mei Domus” or Disability Services, and you will remain eligible for all government and non-government services regardless of your involvement.

B. We would invite residents to participate in an interview with an experienced interviewer at the accommodation units on two occasions. The interview will ask you about your experiences of living at “Mei Domus”. All interviews will be tape-recorded and transcribed for accurate translation. Any identifying information will be excluded from the transcript, or substituted for a pseudo-term or general reference. A separate consent form will be provided if information you supply is to be published in any other form other than general research findings.

C. Any information provided by you will remain anonymous and your name or any identifying information will not appear on published information. Information from the study will be reported using fictitious names, and all personal information will be removed from the research publication.

D. Participation in this study is voluntary and you may withdraw at any time without penalty, or questions asked.

E. If you agree to participate in this study, Griffith University researchers will not be in a position to advise you or otherwise have input regarding your health care program with “Mei Domus”. Any queries or concerns regarding your program should be directed to your health worker or case manager.

F. Ethical clearance: This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. Any concerns about the conduct of this research project should be directed to the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (ph 07 3735 5585 or research-ethics@griffith.edu.au).

Please turn to the consent form if you wish to participate in this research.

Thank you for your interest.
Consent Form

Evaluation of an accommodation option for younger people with continual care needs

Researchers: Ms Hayley Quinn (h.quinn@griffith.edu.au), Professor Elizabeth Kendall (e.kendall@griffith.edu.au), Dr Heidi Muenchberger (h.muenchberger@griffith.edu.au),

Your participation or withdrawal will not affect your health care or service program with “Mei Domus” or Disability Services, and you will remain eligible for all government and non-government services regardless.

Yes, I have read the attached Information Sheet and understand that:

- This research is to investigate my experiences living at the “Mei Domus” units.
- I am being asked to complete two interviews about my experiences and current life situation.
- The interviews may be conducted over several occasions, for up to one hour on the first occasion, and up to 40 minutes on subsequent occasions.
- My participation is voluntary and I may discontinue my participation at any time without penalty or questions asked.
- Information will not be published in any form without my expressed consent, regardless of prior copyright agreements.
- Any reports or publications from this study will be reported in general terms and will not involve identifying features without my consent.
- The data will be kept confidential at all times and in a locked filing cabinet in the chief investigator’s office for a period of 5 years before being destroyed.
- A summary about the study findings will be made available to me. I can contact the researchers at any time at Griffith University, Queensland, on Telephone: 07 3735 3313 or email: h.quinn@griffith.edu.au
- I am free to withdraw from the study at any time. If I do not wish to be a participant in this study there will be no disadvantage or penalty to me in any way.
I have read the consent form. I agree to participate in this study and give my consent freely. I understand that the study will be carried out as described in the information statement, a copy of which I have retained. I realise that whether or not I decide to participate is my decision. I also realise that I can withdraw from the study at any time and that I do not have to give any reasons for withdrawing. Withdrawing from the study will not impact on any services I receive from “Mei Domus” or the Government. I have had all questions answered to my satisfaction. Any concerns about the conduct of this research project should be directed to the Manager, Research Ethics, Office for Research, Bray Centre, Nathan Campus, Griffith University (ph 07 3735 5585 or research-ethics@griffith.edu.au).

……………………………………………………………………………………….  …………..  …………………
YOUR NAME AND SIGNATURE DATE TELEPHONE

(print name)

INVESTIGATOR NAME …………………………………………………………………………………
Appendix D

Samples of Audit Trail

Project Title: Meaning for Residents
Interviewer (I): Hayley Quinn
Respondent (R): R0011 Therese
Audio Length: 49 minutes
Transcriber (T): Pacific Solutions

154 R: Yes, get like an oval table, something like that.
155 I: What difference would that make to you?
156 R: It's just when I have people that table's not big enough. I have to get the table from there and put them together. If I had a longer table it's easier.
158 I: __________, if you were trying to explain to somebody why this wasn't a home, what would you say to them?
159 R: To me this is home. This will always be home. This is my home. I love this place.
160 I: What do you love about it?
161 R: I love the people. I love the way it's set up. The only thing I wish we had was a full length mirror in my bedroom so when you're getting dressed you can see yourself. Somewhere there's a full length mirror.
165 I: When you say you love the way it's set up -- what do you mean by that?
166 R: The kitchen, the way it's -- the cupboards and the way it's built. It's got the fridge, the water cooler -- the way they position everything. The dishwasher, and they put the lounge there. It's just got room enough that the wheelchair can wheel around. You're not knocking things. It's easy to get through. That's what's easy. Whereas if I went home -- to get through corners, half the time I was knocking through doors. It was a real pain. Here there's ample room to get out. It was difficult.
172 Even yesterday I got me to get a watering can. I felt so proud of myself and I went and filled the watering can full to the top from the bathroom and I was able to lift. I kept it on the carpet and dragged it, dragged, dragged right to the end and I was able to go and fill up, water my plants. Admittedly I had to do it four times whereas standing, if I could have stood up, I could have walked with it. This was on the wheelchair. I did it four times. It was hard, hard work.
178 I: How did you feel about yourself after you'd done that?
179 R: It was such a challenge and T said, you did it, you did it. That's good, you can do it. If you did it once, you can do it again.
181 I: What was that like for you to hear that?
Social bonds

Superordinate themes and sub-themes

Connection with others (staff and residents)

Page Line

Regular visit from family

1,2-6

Every week, yeah. Easy because they won’t be full time so they need to come on...weekends. It’s no worries to them.

4,24

Easy access to accommodation

1,2-6

Very simple, just go and see them.

2,37

Run out of food

1,2-6

We have contact with quite a few of the people here. They regard this as an annual holiday. They come in here for a moose and talk.

[Laughs] Hi, we’re pretty good friends with everyone here.

1,46-47

Place to connect to others and socialise

1,2-6

Well really, mainly because she knows that you can sort of make friends as you do with what you’ve got. [laughs]

1,51-52

That’s about it. It’s just that you can make

3,51

Barriers to communication

3,12-54

Nice, we’ve made friends with quite a few of them here, a couple we haven’t. Not that we — most of the people here are friendly. But one

3,02-03 4,89-90

that Suvi can make friends. We’re normally down there and a group of us get down the end of the table and laugh and joke. No, it’s fine, it’s great. That’s what it’s all about.

Close proximity to others provides opportunities to socialise

4,92-93

See the point is here they take you anywhere you want to go. Whenever, all you’ve got to do is tell them, say tomorrow I’ll be back, they’ll come to get you and so on. Yeah, Bang. See, they take you to the movies and everything here. Not that we’ve been out that way, to the movies... Since we’ve been here Suvi’s been down to the cinema, to a show down there.

Opportunities available to go out

3,07-09 4,90-93

One day she’d just put this to bed and we set out in the kitchen. I don’t normally speak about religion because that and politics are the

2,11-217

Access is easy to maintain here, because all you’ve got to do is pop up the phone, or they pick up the phone and call. And there’s no worries.

Net exclusion

2,37

We’re normally down there and a group of us get down the end of the table and laugh and joke.

2,40-03

This is one of the only apartments that’s got a little hall that goes right around. They can hold you in the chair, into bed, out of bed, into the shower, anything.

Equipment increases independence

10,279-274

The person I’m concerned about is Suvi. But Suvi — like Friday night I’m going out with a couple of the boys, like did two weeks ago.

3,277-249

as an example, it must be a细则 place where we had a corner that used to come to Suvi out in the hallway. When we moved out here, she walked out for lunch, would you come out to [lady name]? I’d never seen the place. And she said, yeah, yeah. Cause she lives down at

3,277-274

Shorncliffe. It’s a fair hike. So, here we down and saw (lady’s name) and said we’ve got a car that’s interested in coming. This is

2,11-217

Only in with about five minutes, Bang.

Continuity of care

5,109-114

Now she had to go back to New Zealand, she had breast cancer. She went back and, I’ve got two letters from her as far as

5,277-249

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5,119 7,186-188

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Impact of staff leaving (Bang - keeps repeating) Loss of support

5,119 7,186-188

It’s odd in a way because you get friendly with someone and then bang, they leave. So one part of them here are nurses training. You get on

218
And three of the male staff here are really good, really really good. You just feel comfortable with them, that's the main thing. I don't know about you, but I can always tell by someone's tone of voice whether I like them or whether they like us or not. I'd say 50 per cent more than that. I'd say all the staff here now are really good. There was one young girl who left the other day - she was honest - she was really good. It's not that they show affection, it's just that they have to care. A course of them will go out of their way to help you. If you need a hand to do something or Sue feels a bit, she can normally tell if they do it because they have to do it, but if they want to do it or not. And if you find that - I can normally tell if they want to help, I don't know about you but you can tell by someone's attitude. That's what I mean. Most of them here are good like that, I'd say all of them, all the staff that are here permanently. But the agency staff takes a bit of getting used to. There was an agency guy here, a male nurse, and I still calls us. He doesn't work here anymore, he's at a hospital now too. But he calls us on the phone to say 'hey, we would come out and see us at short notice and talk for half an hour or an hour, even when she didn't have to.' Like a job's been, they're gone. But he makes a point of coming out and telling. We just feel comfortable here, I don't think I'd like her, I thought she was going to be a bit rough and tumble here. But after she'd been out about two times, she just fitted in so much, not her only, but she's the kind of staff member that really makes it worthwhile. Because you can be tough, you can be joke. That's what I mean by all. It's the same thing. Will it work, mainly for Sue, because - how can I say this? Sue needs more - more attention than me. And she gets comfortable with certain people, then after 12 months - there are a couple still here that have been here for 12 months. You've just got to start all over again.

The only time it's hard is when you get some agency people in to fill in. That's hard because Sue doesn't mind being showered and that it's a couple make nurses, but she's not really keen on it, that's one of the only ones here doesn't mind that. If you're comfortable you're happy.

They're okay. What's it all about? If you're comfortable with your nurses how you're okay. If I've got a problem - like the other one comes out at night with Sue. There's normally two, sometimes three. And when they're going into Sue's ward, it is to say you can talk about something, they'll say 'no' and sit down and listen to what you're saying. If they can help you in any way they will. That's just what it's about, you know?

I think everyone's the same; they've got the same interests. Everyone is here in the same sort that everyone's got MS in here. Because, to get honest, there's not a lot you can do when you've got MS, so you're restricted to what you can do. If you're restricted to what you can do. I regard myself as the baby one here, because I can still get around a bit.

I think the whole idea of why we moved out here to found for Sue, who is going downhill. But no, it's fine, it's good.

This might sound dumb but as long as she's happy, I'm happy.

This sounds dumb. My first three quarters over, right? I'm at an age where I've done whatever I have to do.

It's hard for us - we only just now call this home, even though it's taken 12 months. Well this is our home, it's taken us 12 months to feel comfortable here. We don't really care anymore.

That's not the whole difference really, but when you're at home and here now, you're comfortable with certain people you just make it a lot easier.

I guess you could say you just feel comfortable. You feel - not that you can do whatever you like, it's taking it out of context. But you more of less, you do what you like here, to a degree, which is nice. There are no restrictions on you here. Well if there is, you don't notice them. Like at home, you have to have your breakfast at a certain time, lunch at a certain time, tea at a certain time. Well I don't have breakfast here, to a degree. I might have a cup of coffee, a bit of toast. But I can go down there at two, three, four o'clock and say 'I'm hungry.' Cause if you don't eat, they'll keep it for you.

We get to know everyone, they get to know us. They get to know your needs, what you want, what you want it, how you want it. No, it's a piece of cake.
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<tr>
<th>Social Roles</th>
<th>Page/Line</th>
<th>Key words</th>
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<tbody>
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<td>Communication with others</td>
<td>1.4</td>
<td>here at least every Sunday; pops in (flexibility/freedom)</td>
</tr>
<tr>
<td>Family visits</td>
<td>1.6</td>
<td>stops for a little while</td>
</tr>
<tr>
<td>Social contact</td>
<td>1.9</td>
<td>common on the phone most days</td>
</tr>
<tr>
<td>Communication equipment</td>
<td>3.17</td>
<td>every unit has phones, most people have mobiles</td>
</tr>
<tr>
<td>Availability and access to technology/equipment</td>
<td>3.38</td>
<td>someone to make a phone call for me, so that wouldn't be an issue</td>
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<td>Belief that staff are willing to help</td>
<td>4.124-4126</td>
<td>get to know her mum, dad...her girlfriend organized a high tea...invited me</td>
</tr>
<tr>
<td>Connection with friends and others</td>
<td>5.064</td>
<td>staff over there...been to my party...hopeful coming to next one</td>
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<tr>
<td>Maintaining friendships</td>
<td>5.143-141</td>
<td>licence can talk as well as I can. We don't have any turners</td>
</tr>
<tr>
<td>Communication barriers</td>
<td>4.119-121</td>
<td>only people she saw were staff or friends from outside...so other tenants had visited...speed a lot of time in her room</td>
</tr>
<tr>
<td>Isolation</td>
<td>4.126</td>
<td>I was the only one she invited from here</td>
</tr>
<tr>
<td>Acceptance from others</td>
<td>6.187-188</td>
<td>altogether in one room...communicate quite well</td>
</tr>
<tr>
<td>Community as communication</td>
<td>7.241-243</td>
<td>it just annoys me that some staff...treat me as though I can't speak...dine...</td>
</tr>
<tr>
<td>Staff as problematics</td>
<td>7.222</td>
<td>she is actually trying to organise a fundraiser for 'new compass'</td>
</tr>
<tr>
<td>Staff as supporters</td>
<td>6.156-199</td>
<td>staff here...add them to facebook; she even remembered me at Christmas</td>
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<tr>
<td>Boundaries</td>
<td>2.62-7.217</td>
<td>gives me a bit more insight into their lives...they've got 100% into mine</td>
</tr>
<tr>
<td>Pseudo-friendship/mentorship in relationships with staff</td>
<td>1.55-199</td>
<td>staff here...add them to facebook; she even remembered me at Christmas</td>
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<tr>
<td>Technology</td>
<td>3.78</td>
<td>huge difference now get on line</td>
</tr>
<tr>
<td>Difference in independence</td>
<td>3.81-3.83</td>
<td>we've made contact through the internet...I've been able to add them to Facebook</td>
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<tr>
<td>Increased communication with outside world &amp; others</td>
<td>3.221-222</td>
<td>I am definitely in touch now through Facebook, through email, through</td>
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<tr>
<td>Link between friends</td>
<td>5.67</td>
<td>wasn't as set up as I am here</td>
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<td>Establishing self</td>
<td>2.57-58</td>
<td>he's got to go back to NZ;</td>
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<tr>
<td>Loss and Grief</td>
<td>4.131</td>
<td>really hit (need) when we lost, it hit me beyond speaking</td>
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<td>Celebrating Life</td>
<td>8.268-269</td>
<td>I have my life back; I have a life...</td>
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<td>Life as good</td>
<td>9.283</td>
<td>life is good, yeah life is good</td>
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<tr>
<td>Hope for the future</td>
<td>4.103-104</td>
<td>hopefully, an annual get together of friends</td>
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<td>Gratitude</td>
<td>3.39</td>
<td>thank you so much for doing this because I've got my life back</td>
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<td>Importance of space/environment</td>
<td>2.56</td>
<td>just tests and lets me know...coming over today...test him back and say go for it</td>
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<td>Freedom - not restrictive</td>
<td>2.38</td>
<td>He will stay for up to five or six hours</td>
</tr>
<tr>
<td>Length of visits</td>
<td>3.35</td>
<td>he sat in the lounge and watched the big t</td>
</tr>
<tr>
<td>Comfort in the environment</td>
<td>5.175-176</td>
<td>he honestly just comes in and takes over, so that's how I know he is quite happy to be here and to visit</td>
</tr>
<tr>
<td>&quot;Normalising&quot;</td>
<td>6.189-190</td>
<td>all band together...make sure we all have enough room and all that sort of stuff</td>
</tr>
<tr>
<td>Social space</td>
<td>8.274</td>
<td>a bummer that the buses don't come here very often from certain places</td>
</tr>
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<td>Community spirit</td>
<td>5.277-279</td>
<td>thought would be direct route...don't do from here...it's a bit of a busker</td>
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<td>Location as restrictive</td>
<td>5.32-5.34</td>
<td>he didn't like coming; wasn't a very comfortable place to visit someone</td>
</tr>
<tr>
<td>Access difficulties</td>
<td>3.71</td>
<td>there were quite a few fett issues over at...</td>
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<td>Security</td>
<td>1.33</td>
<td>was primarily older people; I was the youngest one there</td>
</tr>
<tr>
<td>Relevance of space/environment</td>
<td>5.16-5.177</td>
<td>we're around the same age; we are all a lot younger than the people at GL</td>
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<tr>
<td>Choice and control</td>
<td>5.23-24</td>
<td>whenever I want; for however long I want</td>
</tr>
<tr>
<td>Choice and control over time</td>
<td>5.23-24</td>
<td>whenever I want; for however long I want</td>
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Roles and responsibilities

Abilility to define role as guardian to receive

Organising own routines
Previous routines
Legal issues

Outside vs inside world

Self (maybe and identity (e roles)

Sense of self - pride
Managing self
Compensation strategies - self directed
Creativity
Engagement in activities
Self worth
View of self as problematic
Self doubt about friendships
Different to others - level of ability
Same as others - similar diagnosis
Sense that she does not matter
Being heard
Being ignored
Non-human

5.16  was on resident's committee (previously)
1.21-26  couldn't have her there, didn't understand that she was the guardian
8.208  Here I can have breakfast whenever I want, wherever I want
8.259  I can do what I want at my time
8.263  It was very regimented, you had to do it the way they wanted you to do it
1.5  It's also my enduring power of attorney

5.172  SO MANY OF US HAVE THINGS TO DO ON THE OUTSIDE WORLD

3.74  I am a fully qualified office
3.78-79  Get on line... Pay own bills
8.10-81  Print what I've paid so I remember
3.86  Been able to make signs and stuff
5.88  Just did a certificate... Gave it to her
7.210  What are you doing remembering me?
7.217-228  Could just be me with a personality clash... I'm not perfect
3.95  Get along all right with everybody, though, I think I do anyway
7.243-244  I'm very articulate, I can talk, I can think, I can make decisions for myself
5.161-144  We've got the kid in common, that always a good thing to have in common, I guess
8.233  Talking about you to someone else as if you're not there and you don't matter
6.201 1.333  Reviewed when I talked; just the fact they listen when I'm talking
7.214-237  She just want to another staff... you could have asked me... well I needed to know what to do...
8.249  It makes me feel like an absolute zombie
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<td>Restrictive vs non-restrictive</td>
<td></td>
<td></td>
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<tr>
<td>Choice</td>
<td>2.71; 3.70</td>
<td>I can have visitors whenever</td>
</tr>
<tr>
<td>Autonomy</td>
<td>3.89</td>
<td>If you want to go to a movie that</td>
</tr>
<tr>
<td>Not exhaustive</td>
<td>2.75; 2.77; 4.239-140</td>
<td>she can stay a week; she can visit when</td>
</tr>
<tr>
<td>Dependence on others</td>
<td>2.55; 2.54; 3.85</td>
<td>less staff, longer wait; you press your</td>
</tr>
<tr>
<td>Changes as painful</td>
<td>2.52</td>
<td>I was able to get out when they</td>
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<tr>
<td>Given control</td>
<td>3.79-80</td>
<td>they set me up... as</td>
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<tr>
<td>Taking control</td>
<td>2.64-65</td>
<td>decided to take the problem</td>
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<tr>
<td>Impact of disease (MS)</td>
<td>5.158</td>
<td>other than hospital stays</td>
</tr>
<tr>
<td>Temporal: life before</td>
<td>3.64</td>
<td>you find out that they used to</td>
</tr>
<tr>
<td>MS as controller of life</td>
<td>2.47</td>
<td>and then all of a sudden it's</td>
</tr>
<tr>
<td>Hospital cycle interfering with life</td>
<td>3.94</td>
<td>in and out and in and out of hospital</td>
</tr>
<tr>
<td>Stages of disease &amp; impact on life</td>
<td>3.109-109</td>
<td>had the MS for 10 years, only in last 4 or 5 stage of needing wheelchair</td>
</tr>
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<td>Grieving the loss of previous life</td>
<td>3.139</td>
<td>I was able to hold down a job full time and I miss it</td>
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<tr>
<td>Bed bound</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>2.62</td>
<td>them coming and saying</td>
</tr>
<tr>
<td>Fear</td>
<td>2.64</td>
<td></td>
</tr>
<tr>
<td>Minimal level of risk</td>
<td>2.65-66</td>
<td>just had to get myself back from a choking incident... oops</td>
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<tr>
<td>Place/Space</td>
<td>1.7-8</td>
<td>supposed to be there for MS suffers... actually there waiting for a nursing home</td>
</tr>
<tr>
<td>Transient</td>
<td>1.15-17</td>
<td>he didn't want to come and visit me... they</td>
</tr>
<tr>
<td>Barriers to visiting</td>
<td>1.18-18</td>
<td>he still doesn't want to come here, it's a totally different environment...</td>
</tr>
<tr>
<td>Still a &quot;care facility&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place of living changing</td>
<td>1.21</td>
<td>I don't want to ask your sister in a care facility</td>
</tr>
<tr>
<td>Mar Domus different venues of same thing</td>
<td>2.48</td>
<td>how wonderful it is... how much it's changed my life</td>
</tr>
<tr>
<td>Environment as accommodate</td>
<td>3.79</td>
<td>even though I'm bed bound</td>
</tr>
<tr>
<td>Environment provides control</td>
<td>6.187</td>
<td>we've got the hots, I can actually drive myself around from the bed to my chair - visual reminder of illness</td>
</tr>
<tr>
<td>Home as &quot;experience&quot;</td>
<td>4.137</td>
<td>I can't really describe it</td>
</tr>
<tr>
<td>Home as place for family &amp; friends</td>
<td>4.133</td>
<td>somewhere that you can have family, you can have friends</td>
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<tr>
<td>Availability of space</td>
<td>6.188</td>
<td>I've got a whole unit</td>
</tr>
<tr>
<td>Home is my unit</td>
<td>5.106</td>
<td>I think of this unit because it's my home</td>
</tr>
<tr>
<td>Home as organizing life</td>
<td>4.155-154</td>
<td>you can have your life the way you need it to be</td>
</tr>
<tr>
<td>Home as coming together</td>
<td>4.155-152</td>
<td>home is where we met up at the end of the day... wake up... go to sleep</td>
</tr>
<tr>
<td>Identity</td>
<td></td>
<td></td>
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<tr>
<td>Self as burden</td>
<td>6.200-6.625</td>
<td>my sister was my carer but it was too much for her on her own; it was taking too much time from her daughter</td>
</tr>
<tr>
<td>From burden to carer</td>
<td>6.200</td>
<td>sister was my carer - from last interview</td>
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<tr>
<td>Perception of people (within environment)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grieving the loss of previous life (job)</td>
<td>1.68</td>
<td>I have got it and I wear it every day. All day every day and all night every night - reminder of vulnerability</td>
</tr>
<tr>
<td>Category</td>
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<td>Text</td>
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<tr>
<td>Age</td>
<td>1.3-6</td>
<td>filled up with older people, I was the youngest ... people around me much older. At least 10 years if not more</td>
</tr>
<tr>
<td>Life</td>
<td>1.23</td>
<td>here my life started again. I put everything on hold when I was at GL</td>
</tr>
<tr>
<td>Life starting</td>
<td>2.74, 1.158-159</td>
<td>when I got a room here in March last year it started my life again; life started when I moved in...just keeps going</td>
</tr>
<tr>
<td>Life</td>
<td>3.68</td>
<td>Oh it's life, ... it's life</td>
</tr>
<tr>
<td>No life vs absolute death</td>
<td>3.100-101</td>
<td>brought me back from the brink of absolute death</td>
</tr>
<tr>
<td>Others</td>
<td>2.64; 1.57; 2.75-7</td>
<td>thankfully my beloved partner...the next call will go to him;</td>
</tr>
<tr>
<td>Importance of loved ones</td>
<td>1.33-44; 4.141</td>
<td>including my niece...can stay a week...get to see her...she gets to see me</td>
</tr>
<tr>
<td>Friendships – building &amp; maintaining</td>
<td>6.197</td>
<td>these are friendships I've built up...I will go over there; when I'm not bed bound I go downstairs and talk</td>
</tr>
<tr>
<td>Need for family</td>
<td>4.136</td>
<td>not so much for me, but for the people at home</td>
</tr>
<tr>
<td>Home as Protector</td>
<td>4.132</td>
<td>the love that you get when you're at home...I can't really describe it</td>
</tr>
<tr>
<td>Stability</td>
<td>4.33</td>
<td>stability and especially if there's children involved</td>
</tr>
<tr>
<td>Safety</td>
<td>6.124</td>
<td>knowing it's your home and no-one can take it from you</td>
</tr>
<tr>
<td>Not Home</td>
<td>4.149</td>
<td>have their children safe and stable</td>
</tr>
<tr>
<td>Reluctance to speak/complain</td>
<td>3.53-92; 3.532</td>
<td>I can't really say anything negative...staffing problem is a problem for all of us</td>
</tr>
<tr>
<td></td>
<td></td>
<td>nothing negative to say about staff...everybody has conflicts with personality</td>
</tr>
</tbody>
</table>
Ivan.

It's all about being friendly and having a laugh. Need to laugh every day to make it worthwhile.

The "perceived" attitude of staff is very important. People who go above and beyond what the job is object "good people." Staff who appear to genuinely care it takes time to talk and listen make a big difference.

Well-being is paramount. He's happy if she's happy. "Good" staff relieve some of the burden of him caring for her. He feels secure knowing she'll be taken care of if he is not there.

Emphasizes the "good" staff doesn't talk about "bad" staff.

Repeats frequently about "they're good, get to know them, care, they're gone." What is the consideration for residents when staff leave, how is this managed? Is he feeling isolated, abandoned?

Large focus on staff, connecting with people, having a laugh, being comfortable.

Takes 12 months to feel like home, then it became easy - implies prior to that it was hard. Staff turnover is very disruptive, creates some difficulties when having to get to know new staff. Is there any underlying feeling that they will soon leave too?

Comment re Nicole - You never really get that close - is there due to the turnover of staff and deterioration, health of some residents?