STILL ME: BEING OLD AND IN CARE

The role of social and communicative interactions in maintaining sense of self and well-being in residents in aged care

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ABSTRACT

This ethnographic nursing home study explores the meaning which residents make of being old and in care. Its primary focus is on the role of social and communicative interactions in maintaining residents’ sense of self. Throughout the thesis I argue that the self is socially constructed, narratively communicated and is continuous throughout the life span. This narrative, relational self is diminished in old age by bereavement and the loss of social networks, and threatened by the loneliness and isolation of the institutional environment. Nonetheless, despite the stripping of relational layers entailed in the loss of the people with whom the younger self was constructed, there is a continuing core of self which, while bending, does not break. I argue that the nursing home can be a site of recovery for this vulnerable, diminished self, offering support and the opportunity to take on new roles and form new relationships, and through these relationships, new layers of self.

Staff are key players in the healing process, and staff-resident relationships important new sources of meaning for the relational self. The ageing, marginalised self is strengthened through empathetic communication which recognises the individual person and the importance of that individual’s life, acknowledges residents’ adult status, and enhances self-esteem by enhancing personal control. For residents, telling their stories and remembering their past lives provides a means of making sense of where and who they are in the present, and of envisaging a future. Consequently, it is vital that residents have opportunities to speak and be heard, and to be recognised and spoken to. These opportunities are sometimes adequately provided by families, friends, church and other visitors and volunteers, but frequently they are not. Staff then become the main source of resident support.

The capacity of individual staff to meet residents’ communication needs is dependent on many factors including the legislative framework and funding of the aged care system, the philosophy of the individual provider organisation (translated into work routines, staffing practices, and the training, mentoring and support available to staff) and the individual personalities and communication skills of staff themselves. Continuity of staffing is a vital factor, with “Know your resident” identified by staff in this study as the most important element in understanding and recognising the needs of residents with cognitive and communicative impairment, and in building relationships which support residents and enhance their autonomy.
DECLARATION

This is to certify that

(i) the thesis comprises only my original work towards the PhD
(ii) due acknowledgement has been made in the text to all other material used
(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Signature ..........................

Date .............
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Chapter 1 – Introduction

Dorothy’s story

In 1999, then aged 86, my mother Dorothy reluctantly decided that she could no longer cope with living alone, and accepted the alternative of residential aged care. She had managed for 18 months, for nine of them distraught with anxiety following the sudden collapse of my previously hale and hearty father. He had suffered a severe cerebral haemorrhage entailing sudden loss of cognitive competence, and spent the last months of his life in hospital and a nursing home. For the nine months following his death, Dorothy’s grief and loneliness were exacerbated by her decreasing mobility and forced dependence on family and friends and local support services (District Nursing Service, Meals on Wheels, Council Home Help). She expressed a sense of being worthless, spoke often of death (but never of suicide), and of the ‘burden’ that she was to her family. She resisted all suggestions that she should live with one of her six children, and finally decided, reluctantly but fully autonomously, to enter the local aged care residential hostel (in rural Victoria). Although the decision was hers, and she was proud of that, she was very unhappy about the added loss of independence, privacy, home, garden and possessions. She finally made the move with family support, but great apprehension.

Her experiences over the next few months, tempering the difficulties of adjusting to communal life, effected a marked improvement in her general well-being, including her attitude to herself. A key was her renewed sense of usefulness, derived largely from her role as a ‘helper’¹ to fellow residents and staff. In addition she had real recognition from and social interaction with staff, and particular thoughtfulness and support over the death of a table companion for whom she had become a watchful ‘carer’. Attentive nursing care after a wrist fracture made her reconciled to the fact that she was safer in care, and emotionally she benefited also from physical

¹ As described by Savishinsky (1991).
demonstrations of affection from several members of staff who made touch part of the bed-time or end-of-shift leave taking.

Moving into residential aged care was good for Dorothy, certainly much better than she or any of her family had imagined. We had all subscribed to the prevailing belief in the negative imbalance, the giving up of independence and privacy in return for a probably depersonalising institutionalisation, a loss of personal autonomy with the risk of loss of self belief and confidence. It did not happen that way, which raised a number of important questions for me. Were the myths about the inevitably negative experience of living in care simply myths? What made Dorothy’s experience different? Was she an isolated case? To what extent did other people benefit from social interactions in residential aged care? Were staff often able and willing to form relationships with residents? What strengthened or weakened residents’ sense of self and personal control? Were resident-resident friendships frequent and sustaining? In summary, how did residents find and maintain ‘horizons of meaning’ (Gubrium, 1993) in aged care?

These questions prompted me to look more closely at the experience of ageing, and in particular to try to determine how old people made sense of their lives in institutional care. Starting with the view that social interactions played a significant part in sustaining the ageing self, I set out to explore the role of communication in the nursing home and in particular that of resident-staff relationships. This thesis is therefore centred on the lives and relationships of residents in aged care, explored and documented through an ethnographic study. It has been a profoundly meaningful personal journey, with an impact on my understanding and acceptance of my own ageing as well as on my respect and admiration for the intrepid pioneers who showed me the way. I hope that in writing about the lives of the residents I came to know that I can offer to them some of the thanks that I owe them.
Background to the study

My background in teaching and testing language and communication skills and a long-term interest in communication in the health professions led me to do a small nursing home study in 1996. I used the title *Perceptions of communicative interaction between English language native-speaker nursing home residents and non-native speaker nursing staff*, and presented it as a minor thesis for a Masters in Applied Linguistics.

Initially, I had expected to study communication between doctors and patients in the context of medical interviews, and had no thoughts of exploring long-term care and the relationships which evolve there. It was more by chance than design that I finally approached a nursing home for permission to conduct my study, but the experience of entering that world, and of meeting and interviewing the very old and the carers who worked with them, led me to a new awareness and appreciation of the importance of aged care and of those who live and work in aged care institutions. I was also surprised by my findings. I had anticipated that language would play the most important part in communicative interactions, and when I found that not to be the case, I became interested in the other things which might matter, if not more than, at least as well as language. I broadened my scope to include the full range of linguistic and paralinguistic components of communication including tone, intonation, facial and body gestures, touch and the use of silence.

Both residents and staff in the earlier study had told me that the single most important staff-resident interaction was the shower experience. The way that was managed, especially the first time, determined whether or not the relationship would be successful. This appeared to involve a delicate balance of social and communication skills: respect, sensitivity to privacy and dignity, and a use of language appropriate for building trust and defusing any threats involved in the extreme intimacy of the task (Grainger, 2002); skilled and gentle touch in personal body care; and awareness of the extent of each resident’s physical and cognitive capacity. In addition, carer attitude was an important factor. The carer had to be committed and attentive to the task (and by implication, to the whole person); one resident said he had been dropped, or
allowed to fall, by a carer he felt to be negligent. This negligence was experienced by
his embodied self, and went deeper than the bruises caused by the fall.

My mother’s experience of care, while mainly very positive, included an incident
where a staff member’s use of authoritarian and patronising language had proved
humiliating and demoralising. The intention had probably been benign, as a number of
studies suggest is often the case (Caporael, 1981; Caporael et al., 1983; Nay, 1993;
O'Brien, 1989), but the words, “You naughty girl. I should put you over my knee and
spank you”, had caused my mother to weep in the recounting. Her response, “I felt so
stupid, so helpless”, led me to begin a literature search into the areas of patronising
and infantilising language. That in turn led further into questions of negative
stereotypes of ageing and of the elderly; intergenerational communication (particularly
in aged care); and the effects of negative expectations on communicative performance
and confidence in the elderly. I also had an interest in barriers to communication,
especially deafness, which related directly to my own experience of communicating
with the elderly.

**Rationale for the study**

I am deeply disquieted by the common stereotypes of ageing which paint it as a time
of decline and decrepitude, of physical unattractiveness, with frequent representation
of the aged as other than the rest of society. To too many of us, old age is seen as an
illness, and ageism and denial of ageing is common to all age groups, including the
elderly themselves. This marginalisation extends through all levels of society.
However, I argue that political attitudes have the most significance for the well-being
of current and future old people, that is ourselves. There is an apparent lack of will on
the part of Australian governments, both state and federal, to see aged care as a
priority in budget allocations, and those who elect these governments do not hold them
to account. Aged care studies, parliamentary committees of enquiry and current media
coverage suggest that inadequate funding often leads to poor staffing practices, high
workloads, and the use of an increasing proportion of inexperienced or casual staff.
This frequently results in high staff turnover and low staff morale. The public assumption (in many cases well-founded) is that residents receive less than optimal care, and this reinforces the negative stereotypes not only of old age but of aged care and of those providing it.

In spite of these negative perceptions, there are many aged care providers who are struggling to provide the highest quality care they can, and they need the evidence and support of academic studies to help raise community and government awareness at all levels. How residents experience care under these circumstances, how they make meaning out of being old, and how well they retain their personal control and sense of self are areas which require further exploration, and these questions lead inevitably to the subject of holistic care. To what extent does failure, for whatever reason, to build and maintain a socially supportive care environment impinge on residents’ physical as well as emotional well-being?

This area of research has been identified as a priority by developmental psychologists, sociolinguists and social gerontologists because of the lack of research results at present available. Nussbaum, for example, calls for further confirmation that “communication, then, not only creates relationships, it also affects our feelings about life” (2000: 52). The few previous studies with a discourse focus have suggested that the communicative goals of the elderly in residential care remain largely unmet, particularly their need for social contact, personal validation and relationship-building conversation. Grainger (1995) draws attention to the importance of discourse analysis in determining the quality of staff-resident relationships, and the need for further exploration of this area. The significance of staff-resident relationships is potentially magnified in the institutional environment. In the case of residents without regular communication with family and other visitors, carers are the main avenue for social exchange. The goals of carers are generally determined by institutional caregiving priorities, and staffing levels and time imperatives frequently limit staff opportunities to enter into other types of communicative exchange. In addition, differences between the communicative style and subject choices of the elderly and their younger carers, or negative expectations on the part of the latter, can contribute to misunderstanding and
mismatching of conversation goals and outcomes. Communication barriers such as hearing loss and speech difficulties are frequently assumed to indicate a loss of cognitive capacity, and speech partners may overcompensate for perceived lack of competency, or not enter into exchanges which they expect to be unrewarding.

Unrecognised social needs and lack of opportunities for meaningful communication are likely to affect mental health and confidence, with a risk that low expectations of elderly communicative competence are largely self-fulfilling. Previous research suggests that the self-doubt in the elderly engendered by demonstrations of low expectations of their cognitive and communicative ability, and the isolation resulting from restricted opportunities for communication, contribute to increased dependency in the care-giving context.

There is also a need for further exploration of the construction and reconstruction of the ageing self in the nursing home context, and in particular the role of narrative in this process. A number of recent Australian PhD studies raise issues of resident and carer relationships and the meaning of the nursing home experience for both staff and residents. They are principally geared to making sense of the experience of the gerontic nurse, although one study explores the sources and nature of meaning experienced by both residents and staff. Of significance to this thesis is the conclusion of that study that residents ‘experience a sense of meaning when they are able to maintain a sense of connection with an enduring sense of self’ (Kingsley, 1998). I propose to explore that finding from an anthropological and sociolinguistic perspective, with particular interest in social and communicative interactions, and the narrative construction and projection of the self.

**Thesis aims**

The thesis aims include an exploration of staff-resident relationships, but more than that, of all of the social interactions and relationships which make the social world of residents in aged care, and of how these affect the well-being of residents. How rich or poor is the residential communication environment? The study examines the patterns of interaction, identifying who interacts with whom, why, when and how, and the
apparent effects of these interactions. In particular it seeks to establish whether or not these interactions enhance or diminish resident well-being and sense of self, and to identify the factors which facilitate or impede social interaction. It includes a discussion of institutional barriers (both social and physical) to communication and how these affect residents’ capacity to interact socially.

An additional question is the extent to which social and communicative interaction appears to play a part in establishing and maintaining power relationships within the institution, and the study aims to determine how resident independence and the quality of care delivery might be affected by these. It considers whether or not institutional goals appear to take precedence over individual resident interests and goals, and if so, what the effects on resident independence might be. It examines the extent to which daily routines are regulated by rules, timetables and a strictly medical care bias on the part of staff, and the discourse factors in communication exchanges which can also have a regulatory effect on both behaviour and communication exchanges of residents.

**Shaping the research pathway**

The following two statements about gaps in the research into aged care attracted my initial attention in that, viewed together, they link my two main research interests, the points of view of old people themselves, and nursing home resident-staff relationships.

Most lacking in research on old age and aging are the points of view of the diverse individuals who are aging or old (Keith, 1994: 105).

The resident-staff relationship has not received much attention from researchers interested in social interaction within nursing homes (Nussbaum, 1990: 160, cited in Grainger, 1995).

I believed that the social and communicative climate of the nursing home would have an important role to play in maintaining general well-being and a sense of self in the residents. As I have already explained, this belief was stimulated by my mother’s experience in care. It was partly confirmed by my extensive reading on the topic of ageing, communication and health, theories of the self, and a wide range of
ethnographic and other nursing home research, but further confirmation would only be 
found by going into the field to conduct my own study. This meant spending extensive 
periods of time in at least one nursing home in order to monitor all public social 
interactions. As a second stage, I planned to record and analyse individual staff-
resident communicative exchanges, and conduct individual in-depth interviews with 
cognitively and communicatively able residents. This was with a view to collecting 
their narratives, with an emphasis on the linkages between their past lives and the 
present, following Gubrium (1993, 1995), and keeping in view Kaufman’s reminder 
that:

Identity in old age – the ageless self – is founded on the present significance of past experience, 
the current rendering of meaningful symbols and events of a life (1986: 26).

I wanted to understand how residents saw themselves and their lives, how it was to be 
their age, in their state of health and dependence, in this particular situation – in other 
words, to find out how they perceived themselves at this time of their lives, in this 
context.

**Thesis argument**

The central argument of this thesis is that the self is ageless, relational and narrative – 
created and projected through social relationships and maintained through 
communication. It is continuous throughout the life span, in that it has an essential 
core which gains layers of experience. It is not transformed by age or tribulation into a 
new self (Goffman, 1962), or even selves as suggested by Gergen (1991). It can be 
weakened through loss and isolation, but it has the capacity to endure and surmount 
the stresses even of ageing and institutionalisation. It bends but does not break (see 
Newton, 1979).

Human social needs are universal, not lessened by the ageing process but increased by 
isolation and social disempowerment. The losses of ageing, particularly the loss of

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2 This includes residents, families and other visitors, and staff.
roles and relationships, threaten the integrity of the relational self. It is diminished by the shrinking of its social circle, and is in need of new sources of support. The needs of the elderly in residential care are greater than those of most people in the community because institutional routines, resident dependence and the built environment often restrict opportunities for social contact. A fundamental plank of my thesis argument is the role of communication in the maintenance of the self. I maintain that social and communicative interaction enhances resident well-being, sense of self, and the capacity to make meaning of ageing and the care experience. Residents seek new relationships, often with staff, and there is a demonstrated link between strong staff-resident relationships and respect for resident independence and personal control which further enhances well-being and sense of self. Care which recognises the fully embodied nature of the frail elderly, no matter how sick, dependent or cognitively or communicatively impaired, and which endeavours to meet more than physical needs, demonstrates awareness of the relational self. Conversely, when residents’ communication needs are unmet, their sense of self, quality of life, and psychological and physical health are at risk. I extend this argument to include all residents, no matter how cognitively impaired. Even in apparently non-responsive residents with dementia, neglect and the absence of social interaction (and just a greeting is not adequate) is often associated with residents slumping into a negative zone (one of ‘ill-being’) or becoming agitated. For well-being they need to be recognised and stimulated by some positive attention, whether from family, staff or others (Kitwood & Bredin, 1992a; 1992b; Kitwood, 1997).

Stereotyping of the elderly, a form of negligent ageism, can lead to false assumptions about their social and communicative needs and capacities. Both families and professional care-givers run the risk of underestimating the self-fulfilling nature of negative expectations. Failure to recognise social needs and overcome communication barriers has harmful effects on residents’ well-being and on the quality of the care they receive. On the other hand, the nursing home has the potential to be a site of recovery for the self which has suffered through the loss of personal networks. This diminished self is reinvigorated by supportive new relationships and positive and respectful styles
of communication which recognise the individual person, acknowledge the adult status of residents, and foster a sense of personal control.

The research question

The question informing the research combines all of these interests: How do communicative and social interactions in residential aged care affect resident personal control, well-being and sense of self? Further questions relate to how elderly residents make sense of their lives, how they connect their present circumstances with the past, the embodied experience of ageing and dependence, in short, what it means to be old and in care. Additionally, there are questions about the nature of the self and the ways in which it is developed throughout the life span, and about notions of dependence and autonomy in aged care.

Key definitions

From the beginning of this chapter I have referred to both ‘social’ and ‘communicative’ interactions. The terms are frequently used interchangeably, with a stronger preference in sociology for the umbrella term ‘social interaction’, and a tendency for sociolinguists to use ‘communicative interaction’. For the purposes of this thesis I include the following definitions.

Communicative interaction: Any exchange between people which indicates the recognition by one person of another, and a desire to communicate words, thoughts or emotions. This might be through speech, non-verbal sounds, facial expressions, gestures, or touch. That is, it encompasses both linguistic and paralinguistic signals, both the semantic content of speech and attitudinal signals such as vocal pitch, intonation, volume, rate of speech and the use of silence. As well, paralinguistic signals include kinesics (body language), proxemics (use of space, distance) and haptics (the science of touch). Paralinguistic signals convey important signs of
acceptance or non-acceptance of the humanity of the interactional partner, of the reality of the ‘presence’ of the person sending the signals.\(^3\)

**Social interaction**: Any sharing of space and activities with others, either with awareness and involvement, active or passive, in the responses of others, or with non-involvement (either through deliberate choice, physical incapacity or cognitive impairment).

**The study**

**Choice of methodology**

My choice of methodology was determined by my research question, and the need to find the most appropriate ways of addressing the research focus on meanings and interpretations. Qualitative methods (Ezzy, 2002: 3) offered a way to “uncover the thoughts, perceptions and feelings experienced by informants” (Minichiello, 1995: 10). The research question did not require me to quantify experiences or test hypotheses and therefore did not indicate the need for quantitative methods. My goal was to understand and interpret the nursing home environment through becoming, as far as possible, part of it. This indicated the need for research methods which would permit close and extended contact with residents, staff, families and other visitors. Ethnography with participant-observation offered me a number of key advantages: the possibility of immersion for long enough to learn about the new culture, its beliefs and practices, and its patterns of interaction (LeCompte & Schensul, 1999; Rice & Ezzy, 1999); the means of exploring “meaning and perspective of participants in the context” (Keith, 1994); tools for data analysis and interpretation; and a descriptive writing approach.

\(^3\) “Actions may not necessarily signify presence, but presence can be revealed unmistakably in a glance, touch or tone of voice” (McKee, 1991, cited in Hudson, 2000).
The role of participant-observer allows the researcher to become close to both residents and staff, to become an ‘insider’, but with the flexibility to be the observer, the ‘outsider’ as well. The insider-outsider spectrum offers a range of roles, from non-participative through to completely participative (Gold, 1958; Spradley, 1980). With less emphasis on the visual aspects of observation and more on involvement, Adler and Adler (1994, cited in Savage, 2000) offer the categories of complete, active or peripheral member researcher I planned to take an active role, and from that vantage point I would aim to “produce an account of a social setting that is faithful to the perspectives of the participants” (Green & Thorogood, 2004:135; Lipson, 1994). Kleinman offers another dimension, one partly determined by the tension of the ethnographer’s insider/outsider role, defining ethnography as “a method of knowledge production by which the ethnographer enters into the ordinary, everyday space of moral processes in a local world” (1999: 77).

I combine ethnographic methods of data-gathering and analysis with a grounded theory approach (Glaser & Strauss, 1973; Minichiello, 1995; Strauss & Corbin, 1990). This approach allows the researcher to gather and review data in an on-going way, to develop theory from the data, then to return to the field to gather more data which in turn serves to test that theory and develop new ones. In this way, new understandings and theories are developed during the research process (Rice & Ezzy, 1999). I frame the whole research project within a phenomenological paradigm, one which emphasises “the individual’s construction of a ‘life-world’” (ibid: 15) and in particular the taken-for-grantedness of that life-world. Phenomenology looks at “the everyday world from the viewpoint of the experiencing person” (Becker, 1992: 7). Thus it offers me a means of understanding and interpreting the experience of these old people within the context of their daily lives (Benner, 1994; Leonard, 1994).

**Disciplinary approach**

This multi-disciplinary project owes its main direction to sociolinguistics and anthropology, although it draws on other fields. Again, this choice is determined by
the research question. Sociolinguistics offers the means of exploring the nature, range and the quality of communicative interactions - both the content and the underlying pragmatics – the intention and the effect of interactions. Through this lens I explore how the relationships between residents, staff and visitors are established and maintained and how residents are affected by, and integrated into, the narrow social world of the nursing home. Ultimately, I aim to determine which exchanges appear to sustain sense of self and well-being in the institutionalised elderly, and which appear to be implicated in issues of institutional power and control, with the potential for strengthening or undermining resident personal control.

Anthropology provides a means for examining how constructions of the self within the objectifying environment of an institution are maintained despite dependence, loss and bereavement. From this viewpoint I collect and analyse residents’ own stories to discover the ways in which they make sense of being old, and how they continue to adapt and respond to the challenge involved of maintaining their own agency in an institutional environment. Questions of the embodied self are also fundamental, especially concerning denial and the ‘mask of ageing’ (Featherstone & Hepworth, 1989; Hepworth, 1995). Do residents whose bodies are the site of pain and disability, as well as vulnerable public territory, feel this to be an area of betrayal? How do they reconcile the ageing self with all of the nuances of dependence? In comparison, I reflect on my mother’s responses to her pain and disability. When threatened by new evidence of dependence her complaint is “I’m sick of me”, but it is followed by the valiant claim “I’m still here, and I’ve a lot to be thankful for”.

From other disciplines, I narrow my selection to my specific areas of interest. I refer to psychological studies for aspects of my discussion of ageism and constructions of old age; for approaches to theorising ageing; for description of life stages and ageing and development; and for discussion of language and communication changes throughout the life course. In addition to sociolinguistics, I draw on sociology and social gerontology for language, communication and discourse theories; semantics and pragmatics; language and symbolic power; and ageing, communication and health. My
research question asks what it means to be old and in care, and my interest in narratives is in response to this: there is an identified need for further exploration of the role of narrative in the construction and reconstruction of the ageing self. For discussion of narrative and reminiscence as tools of maintenance of the self I draw further support from sociology and social gerontology, psychology and narrative gerontology.

Frequently the sources I draw on are themselves drawn from a number of disciplines, pre-determined by the interests and experience of the researchers. The unifying theme influencing my own research is the belief that communication, ageing and health are inextricably linked. Some examples of such researchers are Jon Nussbaum, Peter Coleman, and Justine and Nik Coupland although there are many others. I owe much to the anthropological and sociological research of Sharon Kaufman, Jaber Gubrium and Joel Savishinsky on ageing, the self in old age, narrative, quality of life, relationships and the many meanings of life and work in a nursing home. They all contributed greatly to my exploration of sources of meaning for the ageing self.¹

I find appropriate research paradigms, theories and methods in qualitative research in health care, and more specifically, in ageing and aged care settings. This inevitably raises ethical considerations, both those involved in qualitative research in general, and more specifically around the ethics of conducting ethnographic research, particularly in the areas of health and ageing (Green & Thorogood, 2004; Gubrium & Sankar, 1994; LeCompte & Schensul, 1999; Lipson, 1994; Rice & Ezzy, 1999). I consider the ethical challenges of conducting research into the lives of the institutionalised elderly and, by extension, the people who work in aged care settings, more extensively in Chapter Four.

¹ These three writers strongly influenced my research direction from the initial research questions to the choice of ethnography as the research methodology.
Theoretical frameworks

The themes of the thesis are interweaving and encompass aspects of each other, and I draw on a wide range of theoretical frameworks which reflect this. I begin with the view that old age is socially and culturally constructed, but that experiences of the constraints of ageing are also a consequence of physical and biological change (Wainwright & Turner, 2004). These physical and biological changes contribute to the negative stereotypes of ageing which lead to social marginalisation and other forms of ageist discrimination.

Theories of ageing

Empirical evidence shows that many elderly people withdraw progressively from engagement in social activity as they age, and this is variously described in terms as far apart as a disengagement by choice because of the need for time to prepare for death (Disengagement Theory), or an inevitable loss of social opportunities through loss of social networks and declining health and mobility. I draw elements from a number of these theories, finding Social Environment Theory (Hendricks & Hendricks, 1986) best suited to describe the ageing of the communicative, relational self. This theory takes into account both internal and external factors, the variability in people’s ability and desire to engage socially, the agency which allows the individual to make choices about levels of involvement, and the environmental restrictions which determine the possibility of pursuing these choices (Nussbaum, Pecchioni, Robinson et al., 2000).

Theories of the self

The self I describe is a fully embodied resourceful relational self, one which adapts to change, can suffer loss but which has the capacity for renewal. I draw on Cohen’s (1994) vigorous agentic self, one which adds accretions throughout its experience of life, but which retains an essential core. This matches Kaufman’s ‘ageless self’ (1986) one which also undergoes a process of cumulative identity and, despite change and loss, demonstrates the continuity of the core self. Gubrium (1993, 1995, 2001), along
with Kaufman and others, describes the self which reconstitutes itself through narrative, and finds ‘horizons of meaning’ in ageing and institutionalisation through linkages between past and present.

The self I describe is also embodied (Csordas, 1994; 2002; Turner, 1991; 1992; 1995; Wainwright & Turner, 2004), but made increasingly conscious of the limitations of the body by age, illness and disability. These challenge the natural acceptance of the thoughtless embodied state (Leder, 1990), the ‘absent’ body. In old age and disability the dislocation between mind and body becomes increasingly marked, especially in cases of paralysis, and challenges the notion that the self needs a body to maintain identity. Identity is clearly maintainable through mind and senses, and although the body may not be denied, it is not an equal partner in the projection of the self. It is still part of the presentation of the self - the clothes, the makeup and jewellery which make part of the public bodily self are still on display - but the body becomes a passive partner in the social life of the paralysed person.

**Communication and ageing**

I am indebted to many different theorists for my discussion of theories of communication, intergenerational communication, and the communication challenges of ageing. These include Coupland and Coupland (1990), Coupland, Nussbaum et al. (1991), and Giles et al. (1994). Their analysis highlights the discourse factors of ageism and the communication of ageist attitudes towards the elderly. They also discuss the changes in older people’s voices and communication style which communicate ‘age’ to conversation partners, and identify the individual speech characteristics of older people which are generally considered inferior to younger people’s. From Coupland and Coupland (1990) I borrow the terms ‘diachrony’ (the perspective on change over time) and ‘decrement’ (progressive decline in health or competence) to describe the prevailing belief about older people’s declining communicative capacity, though this decline in competence is not supported by evidence (see Williams & Nussbaum, 2001; Ryan, Kwong See, Meneer, & Trovato, 1994). I draw on Ryan et al. for the *Communication Predicament of Ageing* (1986), in
which discrepancies occur between the communicative competence of elderly people and the negative perceptions held about them by others. The constraining effect of ageist communication and denial of opportunities for the patronised older person to communicate in a fully adult and meaningful way is harmful to both self-esteem and performance. The loss of confidence in the person believed to be incompetent can lead to loss of actual competence. For this discussion, and for the links between life-span communication and health, I draw on many sources (Coupland & Giles, 1988; Coupland & Coupland, 1995; Giles, Wiemann, & Coupland, 1990; Hummert, 1994; Nussbaum & Coupland, 1995; Ryan et al., 1994; Ryan, Hummert, & Boich, 1995; Williams & Giles, 1988; Williams & Nussbaum, 2001). Among the many others who contribute to my discussion of ageist and patronising communication with the elderly are Caporael (1981); Caporael et al. (1983); Grainger (1995); and Hockey and James (1993). In my discussion of theories of social ageing, communication and the environment (including institutional barriers to communication) I find myself in agreement with Nussbaum et al. (2000). With them, I argue that communication is central to successful adaptation to biological ageing.

Institutional barriers to communication

I maintain that amongst the many institutional barriers to communication, loss of hearing is one of the greatest. It is, however, an area in which it is relatively easy for nursing home staff to make a difference. My own observation and experience confirms that Gravell’s (1988) advice on ways of communicating more effectively with the hearing impaired, if followed, would reduce much of the frustration and loss of confidence in those who fail to hear, blame themselves, and reduce their social participation to avoid further failure (see also Coleman, 1995; Wiemann, Gravell, & Wiemann, 1990). Many nursing home staff do not have adequate training in communication skills, in the manipulation, maintenance and fitting of hearing aids, and do not have the time (or perhaps the understanding), to make this a priority.
Ageism

I discuss ageism and the formation of ageist stereotypes (Cuddy & Fiske, 2002; Hummert, 1990; 1997); and the role they play in undermining the successful ageing of the marginalised ‘out-group’. I also include the cultural representations of ageing (Bytheway, 1995; Bytheway & Johnson, 1998; Featherstone & Hepworth, 1989; Hepworth, 1995; Hockey & James, 1993) which contribute to society’s retention of many of these negative stereotypes of old age and old people even when there is undeniable evidence that they do not stand up to scrutiny.

Narrative and the embodied self

I argue, with Williams and Nussbaum (2001: 152), that the communication environment is a key factor in the way in which the elderly self is created and maintained and enabled in its interactions with others. Savishinsky (1991) also takes up the theme of communication and narrative – the need the institutionalised elderly feel for their stories to be heard. This need to communicate, and above all to be listened to underlies my argument throughout this thesis. The self needs to tell it-self in order to remember, to feel pride, and believe in the past as well as link it positively to the future (Gubrium, 1993; 2001). I draw additional support for this argument from Coupland, Nussbaum et al. (1991) who highlight the positive effects on self-esteem and well-being of locating the self in the past, linking it to the present and future and communicating it to a willing listener. I define well-being as a state of health which goes beyond the physical body to encompass social and emotional factors. Social and emotional health enhances and is enhanced by physical health, but is not dependent on it. In aged care settings well-being is enhanced by the delivery of care which respects the whole person, and by social interactions which strengthen self-esteem and a sense of personal control. Finally, still on the theme of narrative, I find a parallel to stories of the ageing self in Frank’s ‘wounded story-teller’ (1991). His narratives are of illness, but are applicable to the illness, pain and disablement of old age which also needs a voice, and a means for the embodied self to communicate with other embodied selves.
Dependence and autonomy

I began this thesis believing that a key goal of aged care should be enhanced autonomy for residents, defining autonomy as the right of cognitively competent individuals to make decisions about the conduct of their own lives and to carry out these decisions. I still believe that care goals should include enhanced autonomy, but do not believe that it is possible for dependent residents in aged care to achieve autonomy in the full sense of the term. It is a problematic concept, given that residents in High Care frequently do not have the capacity to carry out their own decisions and are dependent on the assistance of staff. I accept Agich’s (2003) argument that there is a need for a new framework for autonomy in aged care, one which encapsulates the full range of caregiving tasks and reflects the relationships of the nursing home, but I cannot call this new concept ‘autonomy’. The difference between being able to know one’s own mind and make decisions, and the capacity to carry them out, is too great. Consequently I argue that aiming at enhanced autonomy for residents should be the goal, but that what is realistically achievable is respectful consideration of residents’ choices and decisions and assistance to carry them out wherever possible (limiting factors will always include staff understandings of their Duty of Care). I argue that instead of autonomy in the traditional liberal sense, it is more important to aim for enhanced personal control in a climate of respect for the individual person and for individual decision-making. This enhanced personal control hinges on the maintenance of attentive communication and supportive relationships which enable staff to know the wishes of residents, to carry them out where possible, and to present any denial of these wishes in a respectful manner.

Combining the theoretical frameworks

I bring these theoretical frameworks together in an interweaving pattern of themes which emerge repeatedly throughout my thesis. All of them play a part in my exploration of the meaning of being old and in care and the role of communication in maintaining the self. Communication underpins the whole thesis: I argue that the self

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Agich, following Collopy (1988) argues that the two should be considered separately. He distinguishes between decisional and executional autonomy.
is narratively constructed and projected, and is sustained through communicative and social interaction. Equally, it is through empathetic, relational communication that the weakened, institutionalised self is assisted in its regeneration. Respectful communication is the key element in recognising the worth of the individual and enhancing autonomy. Conversely, patronising and unsympathetic communication, often the product of ageist attitudes, is destructive of resident self esteem and well-being. Institutional barriers to communication determine how readily residents have access to social activity and support, and to exercising personal control which in turn enhances the sense of self. Ageist attitudes at the wider social and political level determine levels of funding and regulation of aged care facilities, thereby influencing the kind of care deliverable at the institutional level. Institutional priorities, routines, and staffing practices affect staff capacity to communicate with residents: to allow their narratives to be heard; to communicate respect for the embodied self; and to support independent decision-making and personal control.

**Thesis outline**

The interweaving themes and theoretical frameworks are presented in the following thesis outline. The thesis consists of nine chapters and is divided into three parts: an introductory section which includes theoretical discussion and a methodology chapter; a discussion which incorporates findings from participant-observation and interviews and explores the story of the ageing self in care; and a concluding section which explores key issues of communication and respect within the institutional environment, and reflects on the themes and arguments of the whole thesis.

**Part One: Setting the scene (Chapters 1 – 4)**

Chapter One – Introduction

The current chapter introduces the study, outlining the background and rationale, the research interest, the theoretical underpinnings and the main themes of the thesis.
Chapter Two – “Old People as People”

In this chapter I open my investigation of what it means to be old and in care. I concentrate initially on the concept of ‘old’ and social understandings of old age. I explore theories of ageing (physical, biological and social) and of ageism and argue that our society, like other comparable Western societies, thoughtlessly marginalises old people. I discuss common myths and stereotypes of ageing, and the negligence rather than cruelty which makes it possible for people to accept and perpetuate these ageist stereotypes in the face of evidence that refutes them. I maintain that human social needs are universal, that old people are simply themselves grown older, not a different or ‘other’ kind of human being with different or other needs.

This chapter, like the whole thesis, is also about communication. It opens the discussion of communication by, with and about old people, including the communication of frailty. This is connected to ageist beliefs about the communicative competence of old people, of ways in which ageism is communicated, and of the self-fulfilling nature of negative expectations of communicative competence in old people. In the context of theories of ageing, I discuss the role played by the environment in facilitating or impeding social interaction, and the implications for the provision of aged care which meets the social and communication needs of residents and supports them in finding meaning in their old age.

Chapter 3 – “A Place Like This”: the nursing home environment

The second part of my thesis title – what it means to be in care – becomes salient in this chapter, although the argument about the pivotal role of social and communicative interactions in the successful adaptation to ageing continues to unfold. The chapter describes the Australian political and social context of aged care provision and includes reference to the limitations which accommodation to medical and managerial rather than holistic and resident-centred models of care impose on institutional practices. My discussion covers the imperatives imposed by accreditation and funding requirements, internal organisational structures, staff allocation and duties, care routines, demands of documentation and reporting for both internal and external
purposes, internal communication, and levels of staff autonomy within individual organisations. I reflect on the difficulty faced by care providers in an inadequately funded system of aged care, one which, with staff shortages and the need to do more with smaller budgets, risks privileging the physical body at the expense of the social and psychological health of residents. Again, I argue that a communication-starved environment is disempowering and harmful, whereas one which meets residents’ communication needs has positive effects on self-esteem, health and general well-being.

The chapter includes a discussion of the nature and role of nursing homes, and the experience of becoming a resident. It also describes the environmental barriers, both physical and social, to social participation in the nursing home. The social environment encompasses the facilities and opportunities for resident interaction as well as the attitudes and values of the institution and staff, and is linked inextricably to my earlier discussion of the social and political climate which determines funding and regulation of nursing homes. I acknowledge that there are individual resident barriers to social participation, only some of which can be overcome with adequate staff levels, training and commitment. The chapter concludes with a reflection on staff support of social interaction, which again brings to salience the philosophical goals of the provider organisation and the adequacy of staffing levels and staff training.

Chapter 4 – Evolution of the Study

Here I present an overview of the study. I refer to my key interest in exploring what it means to be old and in care, and my conviction that the social and communicative climate of the nursing home is a key factor in successful adaptation to ageing. I describe my choice of nursing home sites, my entry into the field, the two nursing homes and the residents, and my role and initial experiences as a participant-observer. The second section relates to the data collection and analysis, with special attention to interviewing techniques I employed for soliciting residents’ narratives. A key section of the chapter relates to my self in the project: my influence on the nursing home, the residents and staff; my part in instigating many of the social interactions which I then
observed and reported; and my self as a social participant with my own distinctive history and personality. The chapter concludes with an examination of some of the ethical issues involved in the study, above all the challenge of working with this most vulnerable of vulnerable populations.

Part Two: The story of the self (chapters 5 – 7)

Chapter 5 – The Social Self: “Still here, still me”
In this chapter I explore constructions of the ageing self. The self I describe is a vigorous, relational, embodied self, one created, maintained and communicated through social interaction. The accretions of experience and relationships make this a many-layered self with an underlying, continuous central core. I discuss the role of narrative in the creation and maintenance of the self, and argue that communicating the self is vital for constructing meaning. It forms linkages between the past and present experience; it integrates whole-of-life experience; and it enables the old to make sense of who and where they are in the present. I draw on the narratives of my cohort of elderly residents, and show how the shared experiences and values of their generation help to form concepts of a Good Life (or a Hard Life) and determine which personal characteristics they see as virtues and which as faults. Within the framework of these values they are able to take stock of their own lives, make sense of the past and the present and envisage a future in which they will play a part, however limited in scope or duration. The chapter prepares for my discussion of the challenges of old age and institutionalisation which partially strip but do not overpower the layered relational self.

Chapter 6 – The Vulnerable Self: bending but not breaking
This chapter has a melancholy leitmotif of loss and bereavement. It reflects on the processes through which the embodied self surmounts the many challenges of ageing, illness, dependence and institutionalisation, noting that there is continuity in loss, that it is a life-long continuum and that many of the losses of old age, apart from
bereavement and sudden physical incapacitation, tend to be incremental. The ageing self has practice in experiencing loss, as in the death of parents, though it will be stricken anew by loss of friends, siblings, life partners and adult children. Even physical loss can be placed on a continuum, given that ageing is a slow process, but all loss is relative, and the total loss of movement resulting from a stroke cannot be equated to the gradually stiffening joints which limit physical activity in independent middle age or even ‘young’ old age. In addition, there are the stresses of institutionalisation. The uprooted self must contend with adapting to new living space, new routines and to dependence on the care of strangers.

Here I return to the notion of the layered, cumulative self, pared back to its essential core through loss of relationships and of the former relational world. I argue in this and the following chapter that this self, rather than yielding under these pressures, evolves and finds new strengths and new means of maintaining and reconstructing itself. It bends, but does not break. It endures and adapts to living with illness, pain and the loss of physical and sensory function. Its work of self-maintenance is, to a greater or lesser degree, aided or hindered by the quality of care and support provided, and the amount of respect and dignity afforded the old person.

**Chapter 7 – Regenerating the Relational Self**

In this chapter I take a hopeful view, and argue that the nursing home also has the potential to be a site for growth or, as in a forest after drought or fire, for regeneration. It can offer an environment in which the vulnerable self is supported in adapting to its losses and can begin, albeit slowly and shakily, the process of renewal. New relationships and even new roles (for example as ‘helpers’ or ‘supporters’ for other residents, as leaders in organised social activities, as confidants for staff members) offer new possibilities for the diminished self. I describe a self which is strengthened, supported, re-enlarged by new accretions. It is not quite the old self, beyond the essential continuous core. Its new relational layers are different: there are new dimensions enveloping the core, but there is new strength.
The chapter also includes reference to the struggle for elderly residents to maintain self-esteem and a sense of purpose and the means by which they can be aided in the process. I explore the significance of the new social environment and key sources of support: the nursing home as a community; family and friends; church visitors and volunteers; and the role of the activities program. I discuss the role of these relationships in helping residents find new sources of meaning to supplement or replace those lost or diminished through their experience of ageing and institutionalisation.

Part Three: Taking stock (chapters 8 – 9)

Chapter 8 – Respecting the Ageing Self: staff-resident communication

I come full circle in this chapter, linking all of my arguments about the meaning of being old and in care and communication and relationships in the nursing home to an exploration of power, control and autonomy. I have consistently argued that empathetic communication confirms identity and reinforces self-esteem, and I now argue that the key to empowering residents lies in the word ‘respect’. If the individual person is viewed with respect, the ageing body is handled with respect, communication is respectful, respect is given to resident’s social and psychological needs, there will inevitably be respect for residents’ rights, including independent decision making. A sense of personal control is the cornerstone of resident self-esteem which in turn serves to sustain the self and give meaning to the resident’s experience. In the course of the chapter I problematise the notion of autonomy in aged care, finding it incompatible with high levels of dependence. Instead I argue that respect can deliver to residents this sense of personal control which certainly enhances but does not and can not guarantee full autonomy. My discussion also covers the notion of ‘total institutions’ and the contribution which codes of ethics can make to the delivery of resident-centred, holistic care. This holistic care implicitly recognises the whole person and the history of that person. Staff, in developing relationships and knowing
and respecting that person and that history, are empowered themselves, able to meet the goal of aged care delivered with respect and dignity.

Chapter 9 – Conclusion: Respecting Aged Care

In my final chapter I reflect on the arguments which I have maintained throughout the whole thesis, and on the future of aged care provision in this country. I have demonstrated that the nursing home can offer support for the regeneration of the self made vulnerable by the losses of ageing and institutionalisation. I have established that respectful communication is the key to delivering care which, through this respect, builds resident self-esteem which is fundamental to successful ageing. The role of social and communicative interaction in residents’ adaptation to the losses and stresses of ageing cannot be over-emphasised, but in the current political climate residents’ social needs are doomed to be neglected in favour of ‘essential’ care of the body. I argue that, now that we know what works, we know how to provide a supportive aged care environment which respects old age, but we are not in a position to adequately support the providers who are trying to provide holistic care on inadequate budgets, or to regulate those who are not.

While Australian governments (and indeed Australian society) do not make aged care a higher priority and the system continues to be under-funded, while staff recruitment, retention and training remain insoluble problems, and training priorities do not include a thorough grounding in communication skills, while staff workloads are heavy, and all staff are under the pressure of time and task rather than person-oriented routines, the well-being of nursing home residents is at risk. An additional cause of concern is the non-implementation of recommendations from government-commissioned enquiries into aged care, particularly regarding closer monitoring of facilities, and the establishment of a benchmark of care to ensure minimum staff levels and skills mix. Nursing home relationships are profoundly important in residents’ capacity to find meaning in being old and in care, but staff cannot carry the responsibility in a system which does not support them. I argue that it is essential to have continuity of staffing; appropriate mixes and levels of staffing; salary parity with nurses in the acute sector;
and adequate training and mentoring for staff in the work place. This is an appropriate investment in aged care, both for the residents who live in nursing homes now, and for those of us who may live there in the future.

**Summary**

In this chapter I have explained my personal motivation and the background to my decision to conduct an ethnographic nursing home study. I have outlined the rationale for the research direction within that study, including identified gaps in existing research, which led to the formulation of the research question and choice of disciplinary approach. The research aims are to explore the meaning of being old and in care, the role of narrative in the maintenance of the ageing self, and the effects of social and communicative interactions on resident well being and independence. The thesis argument takes up these aims with the claim that the self is communicatively constructed and projected, ageless, and resilient to the stresses of ageing and institutionalisation. When residents’ communication needs are unmet, not only their sense of self but also their health and quality of life are at risk. My choice of methodology was determined by the research question, one which called for ethnographic methods of data collection, analysis and reporting. These methods include participant-observation and in-depth interviews, and a grounded theory approach to data collection and analysis. I have also explained my choice of a phenomenological paradigm to interpret the lived experience of my informants – the residents in two nursing homes. In outlining the theoretical frameworks of the study, I highlight the complexity of the relationships between the themes which emerge in this thesis. The chapter concludes with a detailed thesis outline.

In the next chapter I take up the argument that old people are not a separate group with different social needs but simply themselves grown older. I explore approaches to understanding ageing, and to theorising ageing, arguing that societal ageism is responsible for much of the involuntary withdrawal of the elderly from social activity. My discussion of communication issues, also related to ageism, outlines the
communication predicament of ageing – that is, the self-fulfilling nature of negative expectations about the cognitive and communicative capacities and performance of older people.
Chapter 2 – “Old People as People”

Anthropologist Jennie Keith wrote *Old People as People* in answer to the question “Aren’t you saying that old people are just like everybody else?” (1982: ix). Now, more than twenty years later, I borrow her title to dispute the same negative understandings of ageing which she sought to rebut. I maintain that old people are indeed just like everyone else, and, following Keith’s advice, seek to find the meaning of ageing from the point of view of the actors – old people themselves. In arguing that the social and communicative needs of old people are as significant as such needs are for any other group, I consider possible approaches to understanding normal ‘social’ ageing, and the role which social activity plays in successful ageing.

The role of communication is inextricable from my central theme, the meaning of being old and in care. Communicative interaction both supports and undermines positive self-perceptions of older people. It supports by conveying positive evaluations of the capacity and worth of the person and it undermines by conveying negative expectations and evaluations. Communication with and about older people plays a powerful role in perpetuating myths and stereotypes of ageing which contribute to the categorisation and marginalisation of those perceived to be old, ill and incompetent. Beliefs that the elderly are child-like or incompetent carry through into some medical contexts, including aged care facilities, and have serious implications for the care and well-being of residents. Conversely, positive relational communication strengthens the embodied, social self and is a major factor in its ability to withstand the multiple challenges of ageing and institutionalisation.

**Approaches to understanding ageing**

The generally accepted ‘official” beginning of old age is based on chronological age and arbitrarily indicated by certain socially constructed markers (retirement age, pension eligibility and life insurance categories etc). Retirement age is sensitive to economic conditions (Tallis, 1993) such as unemployment or labour shortages, and
has little to do with an individual’s capacity to work. Given that each ageing individual has a unique biological and psychological profile and ages within a unique social and environmental context, it is nonsensical to attempt to describe the ‘old’ as a single category. Instead, in the discussion below I note and distinguish between different understandings of ageing: chronological, biological, psychological and social.

**Chronological ageing**

Current debates on ageing include distinctions between the young-old and the old-old, terms first introduced by gerontologist Bernice Neugarten. The young-old, aged from 65 to 74 under her definition, are distinguished from the middle-aged by their retired status, and from the old-old by their ‘continued vigor and active social involvement’ (*New York Times*, January 18, 1975: 24). The old-old are thus seen to be the group over 75 (from 75 to 100+). Communication researchers Ulatowska and colleagues have suggested a cut off date of 77+ (Ulatowska, Cannito, Hayashi, & Fleming, 1985, cited in Coupland & Coupland, 1990: 454), and others consider 80, or even 85 to be a more accurate demarcation point. Fulks bases his argument on demographic figures reflecting hospital use and relative health care costs of different age groups, with the greater proportion of both involving those 85 and older, and this is consistent with Baltes and Smith’s (2002) contention that in developed countries over the past 30 years same-aged older persons have gained approximately five “good” years of life. This suggests that old-old age is now measured from nearer 80 or even 85 than 75. The bad news for the old-old is that they will have much higher levels of illness, frailty, and loss of function, though Baltes and Smith make the point that individuals will enter this stage (commonly called the Fourth Age) at different ages, some as early as 60 and others around 90. These differing figures serve to highlight the diversity rather than the homogeneity of those aged over 65. There is evidence that older people themselves make a distinction between ageing and being old, and that being old relates

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to the experience of *feeling* old (Minichiello, Browne, & Kendig, 2000; Thompson, 1992) rather than to chronological or biological age.

**Biological ageing**

Biological ageing refers to the physical changes that take place in the body. These changes affect everybody, are in most cases subtle, and are demonstrated or felt at different ages and in different organs and body systems. The process involves changes in the functioning of cells, and represents ‘a loss of adaptive capacity, or impairment of the ability to maintain homeostasis⁸ in the face of challenge’ (Comfort, 1979, cited in Tallis, 1993). All body systems are subject to the effects of ageing: the central nervous system, the digestive, reproductive, muscular, skin, skeletal, cardiovascular, respiratory and excretory systems. Along with causing changes to molecular and cellular structures and tissues, biological ageing affects immunity to disease. The British Society for Research on Ageing describes ageing, while not a disease or even the sum of symptoms of disease, as an independent but potent risk factor for the development of many diseases, emphasising that “the relationship of the ageing process to disease is akin to that between a worn part and a broken part”⁹. The rate of biological ageing is determined by both genetic and environmental factors, and as such is highly variable.

Biological ageing is linked to social ageing in frequently invoked images of old age. The visible and audible signs of physical ageing are instant triggers for stereotypical assumptions about the physical frailty and cognitive and communicative capacities of the older person. A corollary is “the implicit loss of autonomy and mobility” (Bytheway & Johnson, 1998). These signs, reflectors of age-related changes in sensory and physical functions, include facial and physical features as well as vision, hearing and mobility aids. Changes so perceived include: the lens of the eye, causing long-sightedness; the cochlea of the ear, leading to age-related hearing loss; the vocal cords

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⁸ Homeostasis is the property of an open system, especially living organisms, to regulate its internal environment to maintain a stable, constant condition – Wikipedia definition: en.wikipedia.org/wiki/Homeostasis – accessed 1/12/2005.

and the respiratory system, affecting voice quality, pitch and loudness; and loss of muscle and bone mass which, with changes to the Central Nervous System, affects posture, balance and steadiness of gait. Other visible triggers are wrinkles and grey hair due to changes in skin texture and hair pigmentation.

**Psychological ageing**

Psychological ageing refers to changes that take place in relation to the individual’s adaptability, intelligence, memory and learning. It affects both behaviour and mental processes, and is complicated by conditions such as depression and dementia. Life span communication research indicates that the most clearly documented differences between language processing capacities of young and old people lie in comprehension and inferencing, related to the ability to understand and process new and non-explicit information quickly (Coupland & Coupland, 1990). However, these findings are cited with the warning that “the studies in question invoke a decrement continuum as their implicit rationale” (ibid: 455); there is generally no examination of other factors which might affect the performance of older adults in laboratory tests. These might include motivation, and attitude, and the context in which elderly people are considered to perform less well. There is also general acceptance that a decline in working memory capacity and processing speed affects discourse-processing abilities in older adults, and although vocabulary is maintained and even increased with ageing, especially in people who have been involved in education, word retrieval is sometimes problematic, as is memory for names (Williams & Nussbaum, 2001: 78). Although the evidence suggests that there are age-related language and processing changes, it does not support the argument that the elderly have reduced communicative competence (ibid: 81). Nonetheless, preconceptions about the communicative competence of the elderly, like those about biological ageing, are also linked with social ageing.

**Social ageing**

Social ageing refers to age-related changes in the individual or society as a whole. Implicated are both the individual’s perceptions and responses to socially imposed
forces, and the wider group’s perceptions, expectations and responses to those socially imposed conditions. The individual may accept or reject societal expectations, but continues to seek adjustment through interactions in familial or other environments as well as with the community at large. In a nursing home context the challenges include resisting negative evaluation based on beliefs that the dependent elderly are weak, frail, and cognitively and communicatively impaired. Not only does the individual older person face stereotyping and possible discrimination from others, he or she may subscribe to the same stereotypes and feel diminished by the ‘spoiled identity’ (Goffman, 1968) attributed to the frail elderly. Other challenges include the physical and biological changes and loss of home, possessions and significant others as well as loss of role, status and independence. Additionally, the experience of institutionalisation can be depersonalising and demeaning, and feelings of loneliness and loss of purpose are exacerbated if social and communication needs of residents are not adequately recognised and met.

The formulation of theories of ageing and the processes of ageing have often in the past been complicated by the ageism of theorists, for instance in gerontology where “research on aging has – itself – sometimes endorsed generally agist assumptions in ‘problematising’ the elderly” (Coupland, Nussbaum et al., 1991: 89). Hepworth reminds us that ‘geriatric’ is not a neutral term, and lists the preoccupations underlying the ‘geriatric gaze’ from the late 19th Century as immobility, incontinence and intellectual impairment (1995: 16). Levin et al. (1980), cited by Coupland, Nussbaum et al. (1991: 89), confirm that the “the literature in gerontology is shot through both with the assumption of decline with age and, partly as a result of this assumption, with the findings of physical, psychological and sociological deterioration in aging individuals”. Similarly, as reported in a number of studies (Coupland & Coupland, 1990), much of the research in language and communication has been driven by ideas of diachrony (the perspective on change over time) and decrement (progressive decline in health or competence).10 They argue that although the study of linguistic and communicative impairment is logical in gerontological linguistics, it is essential to...

build a body of language and communication research based on a population of non-impaired older people. Normal social ageing should not be viewed in the light of “the avoidance of decremental pathologies” (ibid: 4).

“Old People as People”: social needs and participation of the elderly

Kaufman, in her groundbreaking study *The Ageless Self* (1986)\(^{11}\) reported that “[t]he old Americans I studied do not perceive meaning in ageing itself; rather they perceive meaning in being themselves in old age” (ibid: 6). In being themselves they retain the personalities and tendencies of a lifetime. In the words of Keith, “[t]o understand the significance of age as a social identity in late life, it is essential to know what was its importance at other points, such as adolescence” (1982: 3). With this in mind, it becomes easier to sift through the arguments relating to what the social needs of the elderly might be and to reject the idea that they no longer have social needs comparable with younger people or indeed wish to play social roles, as is suggested in Disengagement Theory (Cumming & Henry, 1961). Human social and communication needs are both universal and infinitely variable, and thus the needs of each older person must be viewed in the light of the individual’s personality, experience and current health and social circumstances. It is also futile to categorise ‘the elderly’ as a homogeneous group. The contradictions and disparities are readily evident, with the most unacceptable being the forty-year range in chronological age calculated from the onset of ‘elderliness’ or ‘old age’ at 65. As I have argued, chronological age is not a reliable indicator of social, psychological or biological age, and even when distinctions are made between the young-old and the old-old, the variables are many. The range of factors to consider includes age and gender, health history and status, cultural background, socioeconomic status, current social involvement and support, personality and cognitive capacity, education and employment experience, residence (rural or urban) and personal experience of historical events and social evolution.

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\(^{11}\) Kaufman’s title refers to the *self* and is unrelated to the denial of ageing inherent in the stereotype of physical agelessness (see McHugh, 2003).
There is no more a separate cluster of needs or a single perspective on social activity for the ‘elderly’ than there is for any other age-selected group.

It is evident that many retired older people find their social opportunities are lessened as they lose contact with former work colleagues, are less confident about their ability to afford or cope physically with foreign travel or previously enjoyed cultural activities, or lose social support because of distance from or death of loved ones and former friends. It is equally true that many older people have great financial resources, enormous energy and confidence, and that they form a powerful consumer group to be wooed by politicians and advertisers. In making this contrast I tread with caution, because I do not wish to further the positive stereotypes of agelessness and anti-ageism which drive much of the denial of ageing. This very denial, and exaggerated claims of ‘perfect’ or near perfect retirement and ageing, play a part in sustaining negative stereotyping and ageist discrimination. Cole calls this phenomenon bipolar ageism (Cole, 1992), a notion cited and elaborated in McHugh’s study of prevalent images of ‘Sunbelt Retirement Land’ in the United States (2003).

**Approaches to theorising ageing**

It is undeniable that many older people have, or appear to have, much less social activity than younger groups in society (or other older people). Carstensen (1987) observes that such changes are variable and that there are very active older people, even though she sees reductions in social activity as normal for older people. Perceptions that disengagement from social activity is a natural process have prompted a number of attempts to theorise ageing. Some of these claim that “withdrawal is normal and adaptive; others contend that it is solely the result of social and physical barriers and that optimal aging involves the maintenance of social activity levels into old age” (ibid: 222). For my discussion I have drawn on a number of summaries of these theories and collections of research findings (Carstensen, 1987; Nussbaum, Pecchioni, Robinson et al., 2000; Rook, 1995; Turner, 1987).
My argument is that the degree to which older adults participate in social activities is dependent on both personal and external factors. External factors include the opportunities for social activities which are available and the extent to which participants are supported in these activities, and personal factors include the extent to which participants perceive these activities to be desirable or rewarding. I consider that these conditions are best accounted for in Social Environment Theory (Hendricks & Hendricks, 1986). This theory offers a comprehensive explanation of social engagement and activity, taking into account external as well as internal factors which play a role in successful age ing. It explores the impact of the social and physical environment on social activity, and is of particular relevance in an aged care facility where building design and institutional attitudes and values can control social interaction. It incorporates the notion of culture as environment, with its responsibility in defining roles and influencing attitudes towards ageing. The theory incorporates aspects of other attempts to explain the social participation of older people, and compensates for some of what I see as their limitations.

I agree that for many, but not all people, successful ageing is linked to an active social life, but not, as argued by proponents of Activity ‘Theory’ (Havighurst, 1963), that levels of social activity need to be maintained in both quality and quantity (Lemon, Bengston, & Petersen, 1972). I do not believe that lessening activity in old age is necessarily externally imposed, though it certainly may be, particularly in the residential care environment. Such factors as “declining health, a reduction in the number of social roles, and the deaths of friends and relatives” (Carstensen, 1987: 223) are indeed important, but they present an oversimplified explanation of elderly withdrawal. They deny the possibility that in the process of adapting to age-related physical and psychological changes and changing social contexts, old people can continue to grow and evolve in directions of their own choosing.

Continuity Theory (Atchley, 1989; 1991), however, gives agency to the individual, in that it acknowledges that adaptive choices will be made, but argues that the strategies employed in making adjustments to new circumstances will be linked to old people’s past experiences of themselves and their social world. I agree with this emphasis on
people’s experience of themselves, given that I see successful ageing as an ongoing process, a continuous adaptation of a resilient core self to new circumstances, including loss and bereavement (discussed in Chapters Five and Six). Atchley argues that older people are likely to engage in whatever type and level of activity they previously enjoyed. However, the notion that old people can be as socially active as they wish to be does not deal with the problem which arises when continuity with previous social activities and networks cannot be maintained.

Socioemotional Selectivity Theory (Carstensen, 1992) offers an explanation for the apparent choices which older people make in reducing their amount of social activity, suggesting that these choices involve reducing the negative aspects of their experience and maximising the positive ones. Rather than battle with potentially negative expectations from strangers, they may prefer to spend their time with family and friends who can give them positive emotional support. The theory suggests preference for reliable, albeit narrow, networks with emotional resources devoted to closer relationships. Carstensen argues that the perception that time is limited is significant, causing a higher value to be placed on positive emotional experience than on novelty (see also Whitbourne & Sneed, 2002). I am not convinced that older people draw on their chronological and biological age to calculate how much time they might have to live, and therefore how much they have to spare, but agree that they prefer to engage in rewarding interactions. The withdrawal involved in this selection process presents older people as agents controlling their own experience. This contrasts with Disengagement Theory (Cumming & Henry, 1961) which suggests that old people should withdraw voluntarily from social activity as part of the natural process of ageing, and that this is in fact necessary and beneficial for them in that it provides time for leisure activities, contemplation and preparation for death (Carstensen, 1987). Carstensen proposes that reduced rates of interaction are the result of lifelong selection and adaptation processes – the lifespan approach to the “accumulation of rewarding relationships and the discarding of dissatisfying relationships” (1992: 331). The communication implications of this theory are that older people should enter into frequent interaction with close others and avoid that with strangers or acquaintances;
the relationships that are maintained should have a high level of closeness; the level of activity should be apparent – conversation with close others should reflect interest in community and others and conversation with those less close should be about health or personal needs (Nussbaum, Pecchioni, Robinson et al., 2000). While agreeing with Carstensen that many old people find adequate social activity in their close relationships, I disagree with her on several issues, finding her theory too prescriptive concerning old people’s, particularly nursing home residents’, willingness to engage with strangers, and their interest in a wide range of topics. She also envisages a level of agency in dependent old people which ignores the social and environmental issues which can restrict opportunities for communicative and social activity.

I find useful the linking of communication and the resilience of the self in Baltes and Baltes’ (1990) Selective Optimisation with Compensation model, which presents a series of strategies for successful ageing, seen as a lifelong adaptive process. With age we begin to lose some of our reserve capacities, but knowledge-based pragmatics and technology can help to off-set these. The key to successful adaptation to new challenges and contexts is the resilience of the self in old age, but people around can either support independence or reinforce dependent behaviour with the risk of taking control away from the older person. Communication should foster a positive view of the self by maximising the individual’s ability to retain control of his or her own life (Nussbaum, Pecchioni, Robinson et al., 2000). This statement of ideal communication does not however deal with the many barriers to communication imposed by social and environmental conditions.

I argue, with Nussbaum et al., that it is through describing and understanding the environment of elderly people that we can understand “how the environment affects their relational world, which, in turn, affects their ability to successfully adapt to the ageing process” (2000: 15). The environment plays a vital role in regulating the communication within its context, a view which I discuss more fully in the next chapter.
Myths and stereotypes of ageing

We need look no further than Disengagement Theory (Cumming & Henry, 1961) for a particularly pernicious myth, one which asserts that older people choose to be marginalised. The mutually beneficial process of disengagement liberates jobs and positions of authority for younger people. The elderly voluntarily disengage and relinquish power and position in exchange for freedom from onerous tasks and responsibilities, and have the additional benefit of the time they gain to enjoy leisure activities. The theory ignores the fact that the powerful elderly do not appear inclined to surrender authority and influence, and that those who are the least powerful and affluent before retirement are the most likely to be gradually impoverished both socially and financially by obligatory disengagement. In summary, social disengagement is more likely the result of loss of social role and financial resources than a desire to contemplate and prepare for death and “there is little evidence to suggest that social disengagement leads to a normal adjusted life for the elderly” (Turner, 1987: 117).

A second myth is that old people are lonely and depressed, have no friends or family and have a higher rate of mood disorders than younger people. Associated with this myth is the belief that old people are rigid and unable to cope with the challenges of ageing. Research shows that these myths relating to psychosocial resources and capacity are not supported by evidence (Whitbourne & Sneed, 2002). A third myth sees old people not as individuals who differ from each other as much as any other members of the community do, but as a homogenous group in which all members resemble each other and share common traits and attitudes. According to this myth, these similarities increase as people age. Again, research suggests that old people are far more likely to differ from each other than to show similarities (Thompson, Itzin, & Abendstern, 1990).

Another prevailing myth is that older people are incompetent. This breaks down into two areas: constructions of physical frailty (they are seen as sick, frail and dependent) and cognitive and psychological impairment. Constructions of frailty as well as those
of cognitive impairment have in part been reinforced by bias in gerontological research, but as with myths relating to psychosocial resources and capacity, neither of these myths is supported by research evidence (Whitbourne & Sneed, 2002). Neither frailty nor senility is inevitable, though physical, sensory and psychological changes are associated with ageing, and there are losses in attention and working memory (ibid). These do not constitute dementia, which affects a relatively minor proportion of older people. Dementia has become a salient factor in people’s expectations of ageing, both their own and that of their relatives, and while public awareness is desirable for both social and political reasons, the disproportionate fears are harmful to a balanced view of ageing.  

The myth of ‘agelessness’, referred to in an earlier section of this chapter, contributes to the view that with enough personal effort people can stave off old age. This contributes to the denial of the normal manifestations of ageing, both in the minds of younger people and in the elderly themselves.

A final important myth, one which is integral to my thesis, relates to the communication skills and style of the elderly, often perceived as inferior to those of younger people. While communication scientists tend to agree that age-related changes in working memory may slow down the processing of new information, and there is evidence that some older people have problems in word retrieval, there is also evidence to show that the accumulated experience of older conversationalists provides them with strategies to compensate for cognitive and hearing losses, at least in the absence of extreme deafness. There are also changes to voice quality, speech production and rate of speech, but overall, the changes in communication skills that do occur in healthy older people are small. There is no overall evidence to support the idea of loss of communicative capacity in normal ageing (Coupland & Coupland, 1990; Ryan et al., 1986; Williams & Nussbaum, 2001). Perceptions of older people’s

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12 The average rate of moderate to severe dementia amongst Australians is about one in fifteen aged 65+. Among people aged 80 to 84 the rate is one in nine, and among those aged 85+ it is one in four. These statistics are from the Alzheimer’s Australia site, quoting the Access Economics report, Dementia Estimates and Projections: Australian States and Territories, released in March 2005. http://www.alzheimers.org.au/content.cfm?infopageid=956.
communication styles include the belief that they are boring, and self-centred and prone to “off-target verbosity”. In fact there is an argument that generational differences, particularly in the perceived value and goals of ‘talk’ underlie these views (Giles, Coupland, & Wiemann, 1992; Ryan et al., 1994).

The communication predicament of ageing

In any examination of communication about and with the elderly it is essential to explore the language which constructs frailty and dependence (Giles et al., 1994). Obviously such constructions go beyond language, and include stereotypical interpretations of capacity and behaviour which are readily triggered by visual and acoustic cues. Older people are frequently communicated with in an ageist fashion, and many reports offer examples of harmful consequences for the elderly (Grainger, 1995; Hummert, 1994; Ryan et al., 1995; Williams & Giles, 1988). As Ryan, Giles et al. (1986) argue:

The effectiveness with which older adults communicate is dependent on attitudinal expectations and social opportunities as well as on their cognitive and linguistic competence (Ryan et al., 1986: 6).

I have already referred to the importance of social interactions for successful ageing, particularly for successful adaptation to residential aged care. In later chapters I will discuss staff-resident communication and, in particular, issues of dependence and autonomy. My discussion now refers to the general dilemma for the elderly posed by those who hold negative stereotypes of their communicative capacity. The communication predicament of ageing is defined as “the situation in which undesirable discrepancies occur between the actual communicative competence of an elderly person and the negative perceptions of his/her competence” (ibid: 6). At issue is the extent to which elderly people respond to ageist communication styles, and in so doing collaborate in communication exchanges which can undermine their confidence and their performance and reinforce their self-perceptions of inadequacy.

The self-fulfilling nature of negative expectations about language performance in old age is described by Ryan et al. (1994). If interlocutors expect poor cognition and
communication skills they may misinterpret effective communication or use inappropriately condescending language strategies. In a patient or resident considered to have cognitive deficits, legitimate comments about health and care needs may be misinterpreted or ignored, and the autonomy of the elderly considered to be incompetent is severely restricted by such expectations. Confidence levels are rapidly lowered, and emotional factors may pose a barrier, likely to increase the difficulty and reduce the effort made by the older person. This is also demonstrated by the behaviour of the hearing impaired who turn off hearing aids and avoid social contact when they fear they will not hear, or when convinced that not hearing is their sole responsibility (Gravell, 1988; Villaume et al., 1994). Ryan et al. (1994: 19) draw the conclusion that “older adults’ self-appraisals in the light of others’ negative expectations of language performance can lead to underachievement”.

In the vicious cycle described above, “the changes of aging (e.g. physical appearance, voice quality, hearing difficulties, slowness of movement, loss of role) elicit interpretations from others of diminished competence, and these inferences then lead to constraining conditions in which the older person has less opportunity to communicate effectively” (Ryan et al., 1986: 16, cited in Okazaki, 1999: 236). The stress of unmatched conversational goals impinges on both carers and care-receivers, but the effects on the latter are more serious and, I argue, entail long-term harm. In Grainger’s words: “The neglect of the social needs of the elderly cannot fail to have damaging effects on the physical and mental health of elderly recipients of long term care” (1995: 426).

Common stereotypes of old age

Negative stereotypes of ageing and the elderly persist, but there are equally unrealistic positive stereotypes such as those promising ‘perfect’ or near-perfect retirement and, by implication, ageing, often in advertisements for retirement accommodation and investment opportunities. Hummert and others (Hummert, 1990, 1997; Hummert, Shaner, Gartska & Henry, 1998) confirmed a number of the most commonly held stereotypes: *perfect grandparent, liberal matriarch/patriarch, John Wayne*
conservative, recluse, severely impaired, vulnerable, shrew/curmudgeon, despondent. Their research suggests that people may hold multiple and even contradictory views of the elderly. This ambivalence is highlighted in a review of some of the literature on stereotyping (Cuddy & Fiske, 2002) which concludes that, at least in the United States, elderly people are “stereotyped as incompetent but warm…pitied but not respected” (ibid: 17). It is worth noting that women are negatively stereotyped at a younger age than men, thus risking the double jeopardy of ageism and sexism (Whitbourne & Sneed, 2002: 249).

The fact that old people are most frequently seen as incompetent has serious implications for their independence. I will explore the themes of dependence and personal control more fully in Chapter Eight, although it is relevant now to reconsider the ways in which old age is so frequently and systematically equated with childhood, and the widespread and mostly unquestioned infantilisation of the elderly which is the direct corollary of such rationalisation. Hockey and James in Growing Up and Growing Old: Ageing and Dependency in the Life Course (1993), draw important parallels in the ways in which both children and adults are marginalised (for example excluded from the world of work and other ‘adult’ pursuits) and rendered dependent through social structures, practice and discourse which emphasise their perceived incompetence. Of particular relevance to my thesis is their specific reference to similarities in the life experiences of elderly people in residential care and those of children, in terms of the restrictions placed on them and the opinions and expectations of ‘carers’.

[E]lderly people in residential homes and children in their family homes were both subject to regimes of control which, while masked by loving care, effectively denied them much active choice or say in the direction of their own lives….both elderly people and children were made dependent through the particular strategies employed by independent adults….in their roles as carers (ibid: 2).

Cultural Representations of Ageing

The images and reproductions of old age (Bytheway; Featherstone & Wernick, 1995; Hepworth, 1995; Hockey & James, 1993) are all around us – advertisements, media
(newspapers, magazines, television) jokes, conversation, literature and artistic representation (including photography). Birthday cards in particular exhibit a variety of negative constructions of old age. These range from depictions of the ugly, angry, unattractive decrepit old person to the extreme of the senile or more particularly, childlike one. The stereotypes which allocate to the elderly the capacity, tastes and status of children are constantly repeated in everyday life. In my own recent experience, the only 90th birthday card offered in one shop had a childish design of a pink cake with candles, very suitable for a six-year-old. I said so to the young salesman, who replied “Most ninety-year olds are like six year olds.”

This process of equating old age with childhood, (as for example in birthday cards), is a factor in the ready acceptance and propagation of infantilising discourse and attitudes, and has potentially far-reaching effects on the delivery of aged care. If we consider the delivery of health care as a largely communicative act (Wiemann et al., 1990), it is logical that inadequate communication in medical interviews must lead to inadequate health care delivery. This argument extends to the sphere of residential aged care, where it is immensely difficult for residents to resist the pressure of infantilising treatment. In this inappropriate communication there are serious implications for increased resident dependence and loss of confidence as well as failure of the institution to deliver optimal health care, care which accurately responds to both physical and psychosocial needs of residents.

The social discourse of infantilisation has been discussed by a number of authors (Bytheway, 1995; Hockey & James, 1993). Hockey and James, in making clear that such metaphoric linkages are not a new phenomenon, quote from Shakespeare\textsuperscript{13} to illustrate how “old age was again seen as child-like” (ibid: 3). Beyond this metaphor, there is a vast lexicon of pejorative terms for the elderly, much of it dating back to the 18th century (Berman & Sobkowska-Ashcroft, 1986; Covey, 1988; Nuessel, 1984). In his discussion of the topic, Bytheway (1995: 59) suggests that the word ‘imbecility’ alone has a great deal to do with sustaining ageism. Slater and Gearing (1998: 29)

\textsuperscript{13} \textit{As You Like It}, II. vii.
quote Samuel Johnson (1709–84) with much relish to illustrate the point that negative stereotypes trigger negative interpretations of capacity and behaviour.

There is a wicked inclination in most people to suppose an old man decayed in his intellects. If a young or middle-aged man, when leaving a company, does not recollect where he laid his hat, it is nothing; but if the same inattention is discovered in an old man, people will shrug up their shoulders, and say, ‘His memory is going’.14

Other studies report discriminatory beliefs and practices to which the elderly are subject, for example in cases of road accident their competence and skills are likely to be called into question, whereas a younger person would be asked about speed or alcohol consumption (Carver & de la Garza, 1984; Coupland, Nussbaum et al., 1991). There is also a wide body of literature on ageist behaviour in medical settings, with health professionals frequently tending to patronise, to listen less to the patient’s views, to give less time to the interview, to order fewer diagnostic tests, and to attribute symptoms to age rather than to treatable conditions (Adelman, Greene, Charon, & Friedman, 1990; Allman, Ragan, Newsome, Scoufos, & Nussbaum, 1999; Beisecker, 1996; Greene, Adelman, Charon, & Hoffman, 1986). Mental health is a particularly neglected area, where elderly patients are referred less frequently to psychiatrists than younger patients with the same symptoms (Cuddy & Fiske, 2002).

There is no shortage of explanations of how we receive negative stereotypes (Bytheway, 1995; Cuddy & Fiske, 2002; Hockey & James, 1993; Montepare & Zebrowitz, 2002) but important concerns are how we are able to sustain them in the face of evidence which disproves their validity, and the risks entailed for our own successful ageing. It seems that it is easier to make exceptions for all of the older people who do not fit the negative stereotypes than it is to question the stereotypes themselves. Some attempts have been made to counter these stereotypes in education and practice in a number of the health professions, and it is apparent that in some cases at least, contact with older people helps to break down negative stereotypes (Cuddy & Fiske, 2002; Giles, Williams, & Coupland, 1990). Nonetheless, denial of ageing

14 Recorded in Boswell, James (1791) The Life of Samuel Johnson.
remains a widespread phenomenon, and the answer to this denial may lie less in fears of illness, death or dementia than in our current cultural obsession with youth, beauty and fitness. If we subscribe to the belief that the external appearance of the body reflects the quality of the person within, what Turner calls “the signs of one’s inner moral condition” (1995: 257) such denial is obligatory.

**Ageism**

“Ageism is about age and prejudice” (Bytheway, 1995: 3) not only towards older people, but it most frequently has negative results for the vulnerable elderly. In his unpacking of Butler’s much quoted definition, Bytheway (ibid: 115) directs our attention to the following sentence:

Ageism can be seen as a process of systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this for skin colour and gender (Butler & Lewis, 1973).

Bytheway’s argument disputes, amongst other issues, the notion of ageism as a process rather than an ideology, of Butler’s use of ‘systematic’ and ‘stereotyping’, of ‘discrimination’ only as a negative process. He concludes with the recognition that “we are all ageing, are all of an age, and are all vulnerable to ageism. In addition, however, we understand that ageism affects different groups differently” (1995: 120). Johnson and Bytheway suggest a simpler definition of ageism which more succinctly reflects issues of power and control: “the offensive exercise of power through reference to age” (1993: 205). For my discussion, the significance of ageism for residents in aged care facilities is a key issue. Bytheway (1995) is only one of many commentators (see also Bytheway & Johnson, 1998; N. Coupland & Coupland, 1999; Featherstone & Wernick, 1995; Nelson, 2002). However, in spite of the increased acknowledgement that ageism causes harm, little seems to have changed in the two decades since Keith (1982) challenged audiences with her suggestion that old people are indeed just people.
Older women: double jeopardy

Gender must be included in any discussion of ageism, given that the discrimination which older women suffer is often due to a combination of ageist and sexist attitudes. Gender counts in stereotyping, with women generally affected at an earlier stage than men. There is a wide body of literature on women’s experience of ageing, including MacDonald and Rich (1984), Woodward (1994, 1995) and Feldman (1999). All comment on the social invisibility of the older woman, with Woodward also describing her as “a missing person in psychoanalysis” (ibid: 79). Nay (1993) attributes the ‘benevolent oppression’ of elderly women in residential care to both direct and indirect effects of sexism. They suffer from ‘normal’ discrimination against older women, and receive more negative treatment from staff (principally female) which is often the result of their lowly professional status and feelings of powerlessness within the institutional framework. I will return to the discussion of power and control and staff-resident interactions and relationships in later chapters, particularly to discussion of the possibilities within relationships which do offer support to residents, both female and male, rather than the benevolent oppression referred to above.

Judging a book by its cover

In a society which is increasingly preoccupied by staying young, taking personal responsibility for maintaining health through exercise and diet, and above all maintaining physical attractiveness, it is easy to see why many find it possible to judge and categorise others largely on the grounds of appearance. The body has become the site for the construction of old age and dependence, and physical signs of ageing are culturally exploited in the dissemination of negative views of old age. Hockey and James (1993) discuss the body as a social signifier, in particular the forms of physical alteration which may be used to mask the signs of old age, in fact to “buy time”. Buying time is an avoidance of bearing the physical stigma, the signs of ageing which risk advertising decrepitude or inferiority of the person within. The association of the physical ‘cover’ with the quality of the person within has been explored by others – Hockey and James (ibid: 165) cite Barbara MacDONald (Macdonald & Rich, 1984)
whose prosaic account of the view of her own ageing body is singularly honest and dispassionate. What stirs her grief and passion is the experience of being judged, by her physical appearance alone, as perhaps not fit, or worse still, not fit to decide to walk in a protest march. “The monitor didn’t pick me out because I looked weak; she picked me out because she believes that a sixty-five-year-old woman lacks judgment about what she can do” (ibid: 33). Her capacity to make judgements, and to perform physically was assumed to be advertised by her bodily appearance.

Passing: avoiding the stigma

Other writers develop the discussion of the physical body and its implied reflection of personhood (Featherstone & Hepworth, 1989; Featherstone, Hepworth et al., 1991; Hepworth, 1995). Hepworth, in his discussion of images of old age, is emphatic in his reminder that “the answers to questions concerning the nature of aging and old age are not found on or in the body but in the meanings we give to the observations we are able to make of biological changes” (1995: 14). He also argues that the conflict between what the body represents to others and what the ageing person feels him or herself to be creates a threat to the ageing person’s self-acceptance. Bytheway and Johnson, reflecting on how we recognise age in the sight of our bodies, ask “is this me or is this an old person?” (1998: 248). Hepworth defines the concept of the Mask of Old Age, “an image that reflects the subjective experience many older people describe of being constrained by the expectations of other (often younger people) into wearing a mask or disguise of physical aging” (1995: 26). This subjective sense of distance between the inner self and “the outer or observable social self indicated by the geriatric and physiognomic bodies” may lead to a denial of the body in an effort to conserve enjoyment of the perceived separate younger self (ibid: 26). This denial of the body, or at least of the external visible changes in the body, may involve a range of strategies which enable the person to ‘pass’ as a member of the desirable category ‘adult’ rather than the stigmatised category ‘old’. Research into the social world of old women (Hockey & James, 1993; Matthews, 1979) lists a number of these strategies, which include avoiding giving one’s age, avoiding expressing personal views which might appear old-fashioned, dismissing physical changes or ailments as being the
same as any younger person’s, and denying that changes in appearance reflect ageing. To my mind, perhaps one of the most damaging for the maintenance of social involvement is “the avoidance of hectic or demanding situations which they could not manage without revealing their frailty” (Hockey & James, 1993: 165). They are curtailing their social opportunities as well as threatening their successful adaptation to ageing. In order to remain visible in society these people are repressing acceptance of the aspects of bodily change which they fear will advertise their loss of value, and in so doing are threatening their own embodied self.

**Coming to terms**

It is undeniable that the ageing body, in varying degrees, experiences changes in vision, hearing, speech, memory, strength, mobility, speed, endurance and balance (Taylor, 1994). Some of these changes may presage illness or dependence, but as well as limiting some previously enjoyed or anticipated opportunities, may present others – for example the opportunity to review and evaluate past experience, and to reflect on “personal meanings for time, self and the body” (ibid: 186). I develop the theme of the ageing self more fully in Chapter Five, but it is important now to consider the implications of the denial of the body entailed in Hepworth’s ‘mask of ageing’. ‘Passing’ as described above, and by others (Macdonald & Rich, 1984) is an act of denial, which of necessity constitutes an impediment to successful ageing, a process in which self-acceptance is an essential element. This ‘passing’ or denial should not, however, be equated with legitimate ‘conscious political’ resistance to predominant social views of what constitutes age-appropriate behaviour or to stereotypical expectations of frailty and incompetence (Fairhurst, 1998; Hockey & James, 1993). Nonetheless, such resistance should be conscious and limited if it is not to be damaging to the integrated embodied self.

It is hard to draw the line between pride in youthful appearance and outright rejection of bodily signs of ageing. In my own research I have encountered the former but not the latter – anger, frustration, depression at times, and a wish to be free of pain and disability, but not denial of ‘ownership’ of the body, more a rueful acceptance of the
undeniable. The old people I have come to know in the course of my study have never suggested that their faces and bodies are not an integral part of who they are now. They are sometimes wistful about past capacities and depressed by pain or loss of function, but they do not deny the body through which they have experienced and continue to experience this. Similarly, a Swedish study found “no decline with age in the common view that our bodies reflect who we are” (Oberg & Tornstam, 1999 cited by Bytheway et al., 2000: 3).

**Fear of ageing and death**

The predominant themes underlying popular beliefs about ageing include physical decline, dependence, childishness, passivity and marginality. Most of us must know at least some older people who are living in the community, and who are certainly not debilitated by illness or loss of function. The puzzling question is why, in spite of these readily available examples of healthy and ‘successful’ ageing, so many people so readily associate ageing and the old with totally negative traits of appearance, function and perceived value to society. The comparison with themselves is always unfavourable to the ‘other’. Ageism is unique in that, unlike other forms of discrimination such as sexism or racism, most people from the in-group will eventually become members of the out-group (Nelson, 2002). The scope of this chapter does not extend to a full examination of Social Identity Theory (Tajfel, 1978) and the implications of in and out-group behaviour, but it serves to explain why, when we make age-related judgements about others, we are making them on the basis of whether or not that person belongs or does not belong to our own age group (Kite & Wagner, 2002). According to the theory, our need to have a positive self-identity requires us to make a distinction between ourselves and others we perceive in negative terms. In contact with the very old or very sick, or even people we perceive to be so, our positive self-identity is threatened by the prospect of our personal ageing and loss of vitality and relevance. The psychological feat of distancing oneself from the elderly (Keith, 1982: 2) becomes less ‘remarkable’, and more a predictable necessity for those who fear ageing, but carries a heavy burden of risk to their own future well-being. These risks are outlined in a warning from Coupland and Coupland that “a society that
represses old age leaves us casting around, in later life, for warrantable social identities and accounts of our own place and purpose” (1999: 185). Thus the costs of ageism are multiplied, and denial of the essential humanity, rights and dignity of the elderly is only a precursor to denial of our own.

Levin and Levin coined the term *gerontophobia* in an earlier study of fear of ageing, (Levin & Levin, 1980, cited in Coupland, Nussbaum et al., 1991). Coupland et al. also report the argument that these negative feelings can affect those who work in the caring professions. Norman’s claim that “work with old people is not a prestigious occupation, and there is a vicious circle in that jobs with low prestige tend to attract unambitious and less skilled workers” (Norman, 1987: 9), is supported by much of the nursing home literature. A number of studies (Diamond, 1992; Nay, 1993; Shield, 1988), without going so far as to claim that the principal cause is fear of ageing, support this view. They blame much of the observed disrespect and casual neglect of the elderly on the lack of education and training as well as the low pay and status of the staff concerned, and this remains a source of concern to those providing residential aged care today. Fear of death may be a powerful element in the avoidance of identification with the elderly. Many studies on the management of death terror have drawn on anthropologist Ernst Becker’s (1973) theorising around the potential of such fear to create paralysing anxiety in those affected – an adaptive problem our species needs to overcome. Terror Management Theory (Greenberg, Pyszczynski, & Solomon, 1986; Greenberg, Solomon, & Pyszczynski, 1997) following Becker, argues that humans need self-esteem to manage their existential anxiety about death, and that contemplation of death increases support for in-group ideologies, with the concomitant avoidance of those in the out-group.

**The problematisation of ageing**

We are reminded that “elderly people enter our consciousness as the manifestation of a problem: ageing” (Cohen, 1994: 100). Cohen and others point out that ageing is a categorisable affliction, one that a compassionate society feels an obligation to
respond to, but one which is nonetheless distinguished by having different characteristics from unafflicted mainstream society. This discrimination may be benign in intention, as in the provision of pensions and aged care services, but it is a differentiation which is often perceived negatively by those affected, who “begin to feel that in the eyes of society they have become another species” (Blythe, 1979). Blythe goes on to claim that:

[T]he growing bureaucracy, amateur and professional, voluntary and state, for dealing with geriatrics, makes some old folk feel that they no longer quite belong to the human race any more. They want those who really knew them as fully operative human beings to speak up for them (1979: 114, cited in Cohen 1994: 100).

The unproductive old: an economic and social burden

I have already mentioned the marginalisation of the elderly in social practices, and the problematisation of ageing in the bias of many researchers both in social gerontology and in language and communication, and would argue that little has changed in the twenty-five years since Blythe’s work was published. The problem posed by an ageing population is increasingly a feature of grim economic and social predictions. Ageing and care of the aged are currently seen as major economic problems which pose serious risks to prosperity: a shrinking workforce will result in reduced productivity and economic growth, and the care needs of the growing number of old people will stretch existing health services beyond capacity and be a drain on financial resources. There is an increasing emphasis on the burden which catering for the health care needs of the current middle-aged (soon to be the unproductive old) will place on the income-generating and tax-paying sector of society. The failure to expand health and care services to meet even existing demands is regularly reported in the press, but so far fails to capture the attention of a sufficiently large and influential group in society to influence budgetary and social priorities of those responsible for policy and funding decisions.
The problem of sexuality

The expression of sexuality in the ageing is a further ‘problem’ particularly in aged care settings as described by a number of researchers (Hockey & James, 1993; Minichiello, Plummer, Waite, & Deacon, 1996; Nay, 1993; Nay & Gorman, 1999). Myths about the asexual elderly still prevail (Minichiello, Ackling, Bourne, & Plummer, 2005). Older people are consistently seen as less physically attractive and less likely to have or express sexual feelings than younger people. Those who do may be called ‘dirty old man’ or ‘dirty old woman’. We have many witnesses to the fact that people are “often repulsed by the thought of the elderly having sex” (Greenberg, Schimel et al., 2002: 41). Greenberg et al discuss the psychological threat posed by this idea, suggesting that it reminds us of our animality and therefore of our mortal nature. In Simone de Beauvoir’s anguished description of ageing they find this negative portrayal of elderly desire:

[If] old people show the same desires, the same feelings and the same requirements as the young, the world looks on them with disgust: in them love and jealousy seems revolting or absurd, sexuality repulsive and violence ludicrous (Beauvoir 1972: 2, cited in Greenberg, Schimel et al., 2002).

Once again the ageing body is the site of negative constructions of meaning, and in many cases of regulative practices (Turner, 1995: 256). It is seen as something to be controlled, something ugly or disgusting (Hepworth, 1995), something to be hidden or disguised (Hockey & James, 1993). The aged female body in particular is seen as an image of horror or mockery (Tulloch, 2002), the aged male body more the latter. It is convenient for welfare and other authorities to suggest that, with the ageing of the body there is a normal lessening of desire, but Blythe views this as part of the repression of ageing: “Old age is not an emancipation from desire for most of us: that is a large part of its tragedy” (1979: 16).

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15 Some residential sites have rooms for married couples and now look more sympathetically on intimate relationships between residents, with the provision of ‘private rooms’ in some facilities. Staff training materials are also becoming available eg The Heart has no Wrinkles, a video produced by Health Media, New South Wales Health.
This refusal to allow a view of older people as sexual bodies is one more challenge to the ageing self. If, as Blythe suggests, we tell the old that they must either conform to this negative ideal of asexuality or be viewed as ludicrous or indecent, frightening, pitiful or a nuisance (1979: 16), what sense are they to make of their experience and feelings, and what chance do they have of sustaining or building supportive intimate relationships which can enrich and aid their adaptation to old age and reinforce their sense of self? A denial of their sexuality is a further reinforcement of the notion that the old are different.

**Being old and in care**

In their communication-based discussion of theories and models of successful ageing, Nussbaum et al. (2000) raise a number of queries, not about the fact that social interactions of the elderly become fewer, but about what, if anything this means. There is little evidence about how relationships change in qualitative ways, and the degree to which the function of relationships might be changed. Of particular interest to my argument, they raise the issue of how society handles the special needs and interactional restrictions on elderly people, for example, “nursing homes that are seemingly constructed to protect the active community from elderly people” (ibid: 8).

My discussion thus far has many implications for the respectful delivery of aged care. Ageism on the part of care staff can be a factor in negative stereotyping of residents, and carries the risk that they may be spoken to and acted towards in a patronising or overly authoritative manner. Both styles of communication imply a lack of adult status and have the capacity to undermine residents’ sense of personal control, an important element in the maintenance of self-esteem (Coleman, 1995; Whitbourne & Sneed, 2002). Residents’ communicative and cognitive capacity may be underestimated, and

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16 The term successful ageing is itself ambiguous, with no single definition. Palmore (1995: 914) suggests that it involves “survival (longevity), health (lack of disability) and life satisfaction (happiness)”. I would add two more key components: successful adaptation to change, and the capacity for the elderly to find meaning in their past, present and future in order to recognise themselves in old age.
their social needs either neglected or inappropriately addressed. This neglect of appropriate psychosocial support has implications for residents’ health status, and indeed for the delivery of effective health care.

Provision of a flexible and imaginative social activity program in aged care facilities is an essential component of empathetic care. Social activity levels in residents will always be variable, and my purpose in providing the contrast between different elderly people’s capacity and motivation to participate in social activity, particularly in groups, is to argue against making any judgements about the elderly as a single social group, and to avoid equating social activity with physical activity. Social activities may indeed be physical, and in cases of loss of mobility, those who have previously enjoyed playing sport are still likely to enjoy watching and talking about it. People who enjoyed card games and gambling will wish to participate in those even when they need assistance to place bets. Equally, people who have never been interested in sport or games are unlikely to suddenly become interested, unless the social environment surrounding those activities is rewarding in other ways. Sometimes the people organising activities are dynamic and attractive enough, and the other residents attending the sessions of sufficient interest, for the social event to be more important than its designated purpose. People who did not previously like Bingo may attend sessions to meet others, to be part of an activity, to pass the time, or even to demonstrate gratitude to the staff organising the event.

Hockey and James (1993) cite valid criticism of the controlled and often inappropriate nature of social activity programs provided in centres for non-resident elderly, and the assumption that “members would attend these establishments for the simple pleasure of meeting other people” (Hazan, 1980: 33). While I am aware that many activities organised in residential aged care appear to the outsider to be patronising and futile, I have nonetheless observed that for willing participants in sensitively organised activities (even, and perhaps especially, undemanding ones) there are social and emotional benefits involved. The key words here are ‘willing participants’, and ‘sensitively organised’, and I will return to that subject in later discussion of my research findings.
I have established that the social and communicative needs of the elderly are, by and large, the same as those of any other members of society, and am grateful to the nursing home staff member who summed it up for me as follows: “The only difference between them and us is they got there first” (Staff Interview #23). I share the view of Nussbaum, Pecchioni et al. and believe “that at the core of any successful attempt to adapt to biological aging is communication” (2000: 7). Residents in aged care, isolated from many of their former social supports, have an even greater need for social activity and meaningful communication opportunities, and this has inevitable implications for staff-resident communication and relationships.

**Summary**

I have presented some of the major challenges of ageing in western society, including some of the myths which form the basis of so much of the prevailing societal negativism towards ageing and the elderly, and the means by which negative images of ageing are depicted. Many prejudiced views of ageing and old age are shared by older people themselves, often to their own psychological detriment. However, of greater risk to the health and well-being of the elderly is the fact that many health professionals, consciously or unconsciously, subscribe to the same views and treat this ‘group’ differently from younger people. Ageism at a societal level often reinforces infantilising social and institutional practices, and the belief in the incompetence of the elderly makes it possible to further disempower them through denying them rights and status equal to those accorded to normal ‘adult’ people.

In the next chapter I discuss important aspects of residential aged care in the current Australian context, including funding, accreditation and regulation. I discuss the tension between perceived health and social needs of residents in care and the pressures encountered by nursing home providers and staff. I also consider the nursing home environment with a view to identifying barriers to resident social activity and

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17 To preserve staff identity, throughout this thesis I use numbers rather than pseudonyms which might indicate gender and therefore identity.
meaningful communication. These include the physical environment and institutional structures and practices as well as residents’ individual physical and communicative capacity and degree of dependence on staff assistance to participate in social activities.
Chapter 3 – “A Place Like This”: the nursing home environment

In Australia, as in Britain and the United States, there is tension between perceived health and social needs of residents in care, with the risk that care can become task and routine-centred, privileging the body rather than the whole person. Such care can easily create a restrictive custodial environment rather than a supportive social one, with negative effects on residents’ opportunities for social activity and meaningful communication. The dilemma for Australian care providers lies in accommodating the externally imposed conditions of accreditation and funding, and in doing more with less in terms of budgets. Because of the relatively low priority accorded by governments to finding ways of adequately financing residential aged care, providers are restricted in their capacity to offer optimal holistic care, that is, care which embraces social and emotional as well as physical needs in the ‘recipients’. In this chapter I discuss important aspects of residential aged care settings. I describe the Australian political and social context of aged care provision; the nature of the aged care facilities; the ways in which aged care settings accommodate to medical and other models of care; and the limitations which this accommodation can impose on institutional practices.

I also consider the nature and role of aged care facilities, with reference to the experience of becoming a resident. I discuss the impact of environmental barriers, both physical and social, on social participation in the nursing home. It is possible for motivated and supported staff to at least partially accommodate some of the barriers to social activity and meet residents’ communication needs, but there needs to be strong commitment of management and senior staff to meeting the psychosocial needs of residents. Individual resident barriers to social participation are more problematic, but again, adequate staff levels, training and empathy can help to build confidence and lessen the isolating effects of, for example, hearing and speech impairment. My discussion of environmental factors, while informed by features of the two sites covered by my own study, also draws on relevant nursing home literature and theories.
of communication and ageing. I return to a key theme of my thesis, that of the importance of staff-resident relationships in enabling residents to make their needs and wishes known and to have these as far as possible met.

Aged care in the Australian context

Residential aged care facilities in Australia are government-subsidised institutions. They provide accommodation and health and personal care for the vulnerable dependent elderly who meet rigorous assessment criteria in order to establish eligibility for such care. Until 1997 there was a two-tier system of care provision, with different names for the two groups. Hostels theoretically catered for residents with low dependency levels, and nursing homes for those with high dependency levels. Since the implementation of the Aged Care Act 1997, there has been an amalgamation of the two types of facility into a single category – Residential Aged Care Facilities. Levels of dependency of individual residents are assessed under an eight-category Resident Classification Scale (RCS). Levels 8 to 5 on this scale reflect Low Care needs, and levels 4 – 1 High Care needs.

Ageing in Place

One of the specified objectives of the amalgamation under the Aged Care Act 1997 was the implementation of the policy of Ageing in Place. This had the laudable goal of allowing residents to stay in former low care facilities as their dependency increased, thereby avoiding the dislocation and, in many cases, trauma involved in transfer to a high care facility (AIHW: Gibson, Rowland, Braun, & Angus, 2002). The main administrative goal, however, was the recognition and normalisation of the hostels’ role in providing care to residents with high dependency. The resolution of the funding anomalies and the acknowledged goals of Ageing in Place has enabled former hostels, where buildings, equipment and staffing conditions permit, to increase the number of high dependency residents without suffering direct financial loss. It has also reduced funding in some nursing homes where residents have been classified as less dependent. The overall figure (across both nursing homes and hostels) for residents
classified as high dependency has risen from 58% in 1998 to 66% in 2004. The figure for low dependency has fallen from 42% to 34%.\(^{18}\)

**The Resident Classification Scale (RCS)**

With the amalgamation of the two types of aged care there was the simultaneous introduction of the eight-category Resident Classification Scale (RCS) which measures resident dependency and determines the amount of the government subsidy to be paid for each resident. Theoretically it ensures that all facilities are treated fairly and all residents are able to receive the levels of care which they need, but in fact it remains a highly controversial subject. Providers claim that it does not fully recognise levels of care needs, or compensate financially for the staffing levels and time allocated to meeting those needs. It has also proved to be a time-consuming burden for nursing home staff, with the onus on them to provide detailed evidence in care plans and other documentation to not only justify reclassification of residents whose needs have changed, but to ensure ongoing payment of subsidies for residents already classified. Problems with the scale and the need to relieve staff of some of the burden of paperwork have been acknowledged, and in the 2004-05 Commonwealth Budget, it was announced that the residential care funding system would be rationalised under a Reduced RCS, down from eight to three categories, with the creation of two new supplements for challenging dementia-related behaviours and complex palliative care needs. The new funding model, the draft Aged Care Funding Instrument (ACFI), is based on dependency not care-planning/delivery. It is being trialled in 2005 and due to be implemented in 2006 (Australian Government Department of Health and Ageing, [AGDHA]).

**The role of the Australian (Commonwealth) Government**

The Australian government is responsible for planning, funding and regulating aged care, and the funding thus provided is combined with resident contributions (means tested daily care fees and, in hostels, accommodation bonds which are theoretically

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ear-marked for capital works programs) to provide ‘specified care and services’, the same for all residents regardless of their level of care. Providers of residential aged care include the non-profit sector (religious, charitable, local government and community based groups), the private for-profit sector and state governments.

The naming may have changed since the amalgamation of the two forms of residential aged care, but the public still tends to associate the provision of High Care needs with the old label, and the terms ‘nursing home’ and ‘hostel’ are still in current usage. Many providers have kept their old names, even when they have adopted a mixed model of care delivery, so I continue to refer to the institutions in my study as nursing homes, and those which cater predominantly (or did before the amalgamation) for low dependency residents as hostels. In fact many hostels had residents with high levels of dependency before the amalgamation. In 1995 an estimated 20% of hostel residents had higher levels of dependency than those being cared for in nursing homes (AIHW: Gibson et al., 2002), but hostels were suffering from serious inequities in the funding system which was based on the classification of facilities rather than levels of resident dependency. A full discussion of the history and political climate behind the changes introduced in 1997, and the effects of those changes since, is beyond the scope of this thesis. My discussion will consider the aspects of the current system which most affect the global well-being of residents, currently referred to by the Australian Government as “consumers of aged care services” (Quality Assurance and Accountability document 5.4).\(^\text{19}\)

**Current situation: supply and demand**

The Australian Government is responsible for residential aged care funding, standards and accreditation. Despite recently announced increases in the number of beds to be created under new funding allocations,\(^\text{20}\) there is an acknowledged shortage of residential accommodation, with delays for many people in gaining admission to a facility. This impinges directly on the state governments who have joint responsibility

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\(^{19}\) For a full exploration of the subject of the ‘commodification’ of aged care see Diamond (1992).

\(^{20}\) 8600 new places in the 2004 funds allocation (3,495 High Care; 5,105 Low Care) Source: Australian Government Department of Health and Ageing Press release (5/3/05).
with the Commonwealth government, through a complicated funding system, for public hospitals. Many of those waiting for residential care places become long-stay hospital cases, putting stress on an already overcharged hospital system. According to a newspaper report\textsuperscript{21}, in March 2005 there were 450 people in public hospitals in Victoria who had been assessed as needing residential care, but who could not find places. Stories from other states, New South Wales in particular, are similar. According to this report, the Commonwealth government rejects Victorian claims for assistance in meeting these costs, on the grounds that the number of residential aged care beds in this state has been increased by 6,500 since 1996, and that another 3,080 places will be allocated to Victoria in the next two years.

The most recent report from the Australian Institute of Health and Welfare (2005)\textsuperscript{22} gives the figure of 156,580 places Australia wide (84.2 places per 1000 persons aged 70 years and over). Combined with the figure for Community Aged Care Packages (support for those living at home but eligible for low-care residential places) and Extended Care at Home (support at home for those eligible for high-care residential places) this represents a ratio per 1000 persons over 70 of 100.3.\textsuperscript{23} The figures vary from state to state, and in Victoria the current ratio is 99.3, which helps to explain Victorian government criticisms. This published allocation of places does not give the complete picture because of time lags between the approval and allocation of places and those places actually becoming operational. There is criticism, particularly from the states, that the time lag is too great, and that the target is not high enough to meet actual needs, and that some of the new places announced are not in fact new, but a reallocation of previously announced places. These factors all contribute to the long waiting periods experienced by many people who have been assessed as eligible for entry into residential care.

\textsuperscript{21} The Age newspaper, Melbourne, 1/3/05, page 7.
Current situation: funding issues

The most frequent complaint from providers, residents and their families, health professionals and the community, supported by the Hogan Report (2004)\(^{24}\), is that funds are insufficient for providers, especially the not-for-profit sector, to meet optimal standards of care and still remain viable. Estimates of the size of the increase needed in resident subsidies to maintain viability of the sector vary, but the figure of $10 per day per resident has been suggested. There is widespread agreement on the need for increased funding for capital works, and the Hogan Review was commissioned specifically to look at future arrangements for private and public funding, performance improvement in the industry and longer term financing. The Hogan Review raised the issue of resident bonds for nursing homes, one which was rejected by the government in 1997 because of its electoral unpopularity. A coalition of 23 aged care operators and consumer groups reached agreement in February 2004 to support the introduction of bonds, renamed as “refundable deposits”, a marked change from their previous position. However, the government is yet to make a decision on long-term capital funding. The figure commonly quoted for a necessary immediate injection of funds into the aged care system is $500 million.\(^{25}\)

Standards and accreditation: criticisms of the Aged Care Act 1997

Aside from funding, the Commonwealth government is indirectly responsible, through the Aged Care Standards and Accreditation Agency, for standards and accreditation of residential care facilities. Criticisms of the Act include the latitude allowed to individual aged care providers in the Quality of Care Principles. As Jocelyn Angus points out, these principles do not prescribe staffing numbers/resident ratios, staff qualifications or skills mix. “In an environment informed by economic rationalism, the provision of care is dependent on the goodwill of the providers” (Angus, 2002). There is a general consensus amongst other critics such as the Victorian government, the Australian Nurses’ Federation (ANF) and the Australian Labor Party (currently in

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opposition in the Commonwealth government), providers, particularly from the charitable sector, and the media that there is above all a need for more definition in minimum requirements, and greater consistency in the interpretation of the standards. This criticism was echoed in the Hogan Report (2004) which recommended essential clarification of issues associated with regulation.

One of the chief criticisms, as stated by the ANF, is that “there is no longer any Victorian or Commonwealth law requiring aged care providers to employ a minimum number of staff.”

Periodically there are publicly reported failures of aged care facilities to meet standards at inspection by the Aged Care Standards and Accreditation Agency and more rarely reports of resident neglect and abuse. In such instances of understaffed facilities and demonstrably inadequate standards of care, there is provision for providers to be warned, have sanctions imposed or have their provider status revoked. However, since the provision of aged care is largely self-regulated, inappropriate staff mixes might go unreported and unsanctioned (as is frequently claimed by media and other sources, especially releases from the ANF). The ANF Claim for Nurses and Personal Care Staff (2005: 3) includes the charge that:

reductions in skills mix seriously impact on workloads and put the remaining Registered Nurses at professional risk and result in personal care staff being expected to perform work for which they are neither educationally prepared nor financially compensated.

The Australian Government Senate Inquiry into Aged Care recommendations (released in June 2005 but awaiting a government response at time of writing) include the improvement of monitoring of standards, especially through more ‘spot checks’ of facilities, and the development of a benchmark of care which would ensure

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27 In 2002 Girrawheen Nursing Home (Victoria) failed to meet 32 of 44 accreditation standards, but was allowed to remain open after it met 43 of 44 two months later. The Age newspaper 30/1/03. www.theage.com.au/articles/2003.--accessed 23/3/2005.


29 Personal email confirmation from the Senate Community Affairs Committee Secretariat on 14/2/06 that the report is yet to be tabled in Parliament.
minimum staff levels and skills mix. Such a requirement would not in itself ensure quality, and accreditation standards should also highlight poor care outcomes regardless of the cause. Determining quality indicators and measuring outcomes is extremely complex (Saliba & Schnelle, 2002), and evidence to date suggests that quality outcomes are not directly linked simply to staffing levels.

Meanwhile there are continuing high levels of disquiet amongst those trying to provide genuinely resident-centred care on current levels of funding, and a number of former providers from the charitable sector are expressing anxiety about their capacity to remain in the field. In February 2004 the community was shocked by the Salvation Army’s decision to sell 15 of its 19 not-for-profit facilities, retaining only four in different state capital cities to cater for the most disadvantaged residents. Their decision was directly related to inadequacies of funding in the sector, and their withdrawal regretted by the Australian Medical Association (AMA) as well as the community:

The Salvation Army is certainly an iconic provider of care in the system and if they’re pulling out it must mean the system isn’t paying, isn’t viable. If the system isn’t viable then others will pull out (Mukesh Haikerwal, AMA President).

**Implications for social support of residents**

Aside from the obvious difficulties in monitoring standards of physical care, it is difficult to know how many nursing homes are failing to provide environments where residents receive supportive emotional care. Anecdotal evidence suggests that in some cases there are few or no organised social activities, and that those activities offered may be “counterfeit” rather than meaningful (see Henderson, 1995: 46). Under the largely self-regulatory principles of care it would be unsurprising if costs for lifestyle and activities programs were reduced in order to maintain the funding for essential

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care and support staff. The government standards of care, which include recognition of residents’ rights and needs beyond purely clinical and personal care, are very loosely framed, leaving such expressions as ‘a supportive environment’, as quoted below, open to the interpretation of individual providers.

Older people who enter residential care require not only personal and nursing care, but a supportive environment where they have security and peace of mind. The Accreditation Standards reflect this, covering all aspects of residents’ needs, from health and personal care and safety, to a range of lifestyle matters including independence, privacy and dignity.  

The acknowledgement in the list of basic care standards that residents should be provided with social activities is as non-specific as existing standards for staff qualifications, ratios and skills mix, and it is obvious that providers vary enormously in what they feel their obligations are. Without including psychosocial needs in the descriptors there is no way of ensuring that they are met. Angus (2002) describes how in the amalgamation process the distinction between the role of hostels (social) and the role of nursing homes (health) has been lost. She suggests that the consequent failure to distinguish between health care and accommodation funding costs “fails to address the extremely complex health care needs of residents and makes evident new gaps in the provision of aged care services” (ibid: 5). I argue that one of those major gaps is the failure to ensure that residents’ social needs are adequately recognised and catered for.

In Australia, the restricted ability of aged care providers to deliver holistic, resident-centred care quality is similar to that reported in Britain and the United States. Pasupathi et al., in their analysis of American nursing homes, claim that “most nursing homes do not have sufficient funds to employ more than the legally required staffing ratio, which usually covers only basic care needs and does not leave sufficient time for social interactions” (2002: 211). As mentioned above, the legally required staffing ratio in Australia is open to interpretation by providers, and in some cases these interpretations have grave implications for the quality of care, resident safety and well-being, and the welfare and morale of overburdened staff. Grainger, in discussing the communication needs of the institutionalised elderly in Britain, comments on the

unfairness of expecting nurses to carry the load of “implementing good communication practices, when the caring environment does not facilitate this” (Grainger, 1995: 432). Diamond (1992), an academic who completed the compulsory nursing assistant training required by the state of Illinois and then worked in a private nursing home describes the phenomenon of care tasks which can not be documented and therefore do not ‘exist’, and highlights the stress which this imposes on staff who recognise residents’ emotional needs. Comforting a terrified resident at 5.00 a.m. “was just another physically and emotionally draining moment of non-work” – non-work because the work still got done but was just not named or paid (ibid: 162). He dedicates his ethnography to those nursing assistants, the unsung heroes in a loveless ‘bureaucratic purgatory for profit’. It would not be fair or accurate to apply that label to most Australian nursing homes, but given that there have been several publicly highlighted cases of extreme resident neglect, the industry does not have an unblemished record.

**Staffing issues and the impact on quality of care**

Staffing costs are a major element in overall expenditure in nursing homes, but there is a significant anomaly in the disparity between salaries in the aged care sector and that of nurses in the acute hospital sector. Aged care nurses are paid markedly less, and in some cases the difference is as much as 20%. This is a major disincentive for nurses to remain in aged care, and for new nurses to enter the system. There are many problems in maintaining staffing, recognised by government commissioned inquiries, but to date attempts to compensate for the shortage in aged care nurses have not been effective. The government-commissioned critical review into Aged Care Nursing in 2001 found that retention and recruitment were the key issues. Among the identified barriers were: the perception that aged care does not offer the opportunity to ‘cure’

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patients and see them recover from medical problems; the need for preceptors of new nurses; staff support and management of workplace stress; stress associated with supervising unqualified staff; the low status of aged care; lack of professional recognition, including pay disparities; and workplace conditions. The main issues in need of attention in workplace conditions were identified as: the Resident Classification System, funding, nursing in the sector, accreditation, wage parity, segregation of funding for staffing and care hours, and staffing levels and skills mix.

In brief, aged care work is regarded as heavy and thankless, high in stress and low in recognition and support. This has inevitable implications for levels of care and resident well-being, as well as for staff satisfaction. Richardson (2004:33), in a major survey of the residential task force, found that, “the predominant sense of the aged care workforce is that they do not have enough time to spend with each resident…Only 13 percent of nurses and 21 per cent of Personal Carers believe they have enough time to do the job for which they are employed, to their satisfaction”. However, despite this, Richardson also reported high levels of job satisfaction. A survey conducted by the Australian Nursing Federation in August 2004 found that the most common concerns of staff, residents and families were staffing levels and inadequate standards of care, with a number of staff complaining that they had no time to interact with or support residents. One comment from a registered nurse was “I worked out that I can only spend 27 minutes with each resident during an eight hour shift. This is appalling. How can I treat people with dignity and maintain nursing standards?”

**The nursing home as a home**

The popular view of nursing homes continues to be extremely negative, with many clichés used to express the notion of hopelessness, of finality. It is the ‘end of the road’, ‘God’s waiting room’, a place where you go to die. Older people fear ‘ending


36 ANF submission to the Senate Inquiry Into Aged Care (2004: 12).
up in a place like this’, and frequently extract promises from family members that they will not be ‘dumped’. For most of us, whether through familiarity with nursing homes or because of negative cultural depictions of aged care facilities, it is a fate to be actively avoided. Fictional depictions of dreadful nursing homes such as May Sarton’s (1973) and Elizabeth Jolley’s (1983), and poems such as Auden’s Old People’s Home, sums up the concept of old people “stowed out of conscience as unpopular luggage” (cited in Blythe, 1979: 129). These literary tales simply reflect, fairly or unfairly, an era of neglect and scandal as described in the media and nursing home studies of the 1960s and 1970s, including a personal memoir of an appallingly dehumanising nursing home experience (Laird, 1979). Old people were seen by many as manifestations of a problem to be dealt with in the most efficient bureaucratic way, a way which created institutions resembling hospitals, built to cater for the physical body but with little or no capacity for meeting psychological or emotional needs in the elderly patients consigned to their care.

Gubrium’s (1975) landmark ethnographic study dispelled some of the prevailing myths of ‘decay, cruelty, and dehumanization’. Later, Bowker (1982) analysed a number of homes and made recommendations for providing more humanising conditions for the aged, but the notion of the nursing home as a hospital-style institution remained firmly fixed. Many nursing home studies, mainly from the United States, highlight the decremetal nature of the ageing process and the disempowering and depersonalising nature of residential aged care (Diamond, 1992; Kayser-Jones, 1981; Vesperi, 1983). There are, however, more optimistic studies which include relational aspects of communication and the effects on residents’ sense of self, for example Savishinsky (1991) and Gubrium (1993). In addition, several recent Australian PhD studies raise issues of resident and carer relationships and the meaning of the nursing home experience for both staff and residents (Hudson, 2000; Kanitsaki, 1999; Kingsley, 1998; Nay, 1993).

In her study, O’Brien (1989) tries to answer the question of whether a nursing home is a ‘home’ or an ‘institution’. One of Gubrium’s informants makes it clear that to the residents it is the latter, even when conditions are good: “It’s still an institution. It isn’t
my home regardless of how nice it is” (1975: 88). Shield (1988) notes that some staff see the aged care site as a home and some as a hospital, which reflects the tension between the social and health aspects of aged care, a tension which still affects the philosophy and organisation of nursing home providers and influences the attitudes and decisions of policy-makers at government level.

In Australia now there are many providers who attempt to re-create a home for residents although the notions of what constitutes a home, and how effectively this can be reproduced in an institution, are still not clear. There are luxuriously furnished private nursing homes which resemble hotels rather than the homes from which most residents would have come, and some older and poorer ones which are so limited by space and physical structures that they more closely resemble hospitals. The question here is what makes a living place a home, or an acceptable replacement for ‘home’. To varying degrees nursing homes may incorporate home-like features (design, furnishings, lighting, flowers, recreation areas and activities) to combat the traditional hospital-like environment, but there are undeniable aspects of communal living which are not home-like in the accepted sense of the word. Residential care facilities cannot offer the privacy, the individual choice, freedom of activity and flexibility of routine which are normally associated with home. As Powers summarises it:

Nursing homes are not nice places in which to live. For residents there is little privacy and personal space. One is forced to tolerate numerous annoyances, inconveniences and impositions. Opportunities for autonomy are limited. It is easy to become bored and restless. For staff, nursing homes are not always nice places to work (1995: 194).

However, Powers also reminds us that every nursing home is different in objective features, including “location, design resources, organizational make-up, policies, personnel and residential mix” (ibid: 191). The best and most imaginative of resident-centred providers will come nearer to creating physical home-like conditions, and the worst still fulfil Goffman’s criteria of ‘total institutions’ (1960), a subject which I discuss in a later chapter.
Arguably as important as the physical structures are the attitudes and values determining care routines. At either end of the spectrum these have the capacity to be totally depersonalising or deliberately supportive and affirming of resident individuality and independence. Most nursing homes, depending on the staff mix and the stresses of the day, will fall somewhere in between the two poles. The worst will contribute to the physical and mental deterioration of residents through infantilising and depersonalisation and the best will encourage resident well-being and independence by recognising adult status, treating residents with respect and dignity, and catering for social as well as physical needs (see Kayser-Jones’ 1981 comparative study of two nursing homes, one British and one American).

**Learning to be a resident: ‘making the best of it’**

People do not normally choose to live in nursing homes unless they are in need of special care. The decision usually follows the loss of personal capacity and other social support which would enable the person to remain in the community. The resident is “someone who has reached, either suddenly or gradually, a state of collapse or deterioration in human behavioural functioning which requires prolonged service from at least one other human being” (Koff, 1982: 2, cited in Nussbaum, 1990).

There is no uniform pattern of adjustment to nursing home life (Powers, 1995). Residents who make the choice to enter into care are more likely to adjust to the restricted personal space and the loss of their personal possessions more readily than those who have not made the choice themselves (see Nay, 1993; Savishinsky, 1991, citing Johnson & Grant, 1985). For those who make the choice, there is a sense of personal control, and the pre-entry period allows them to plan and choose amongst most favoured possessions (Gubrium, 1975). Nonetheless, it is frequently a highly stressful process, and the strangeness takes some time to wear off, even in the most positive of residents. There will often be lingering regrets for the house left behind, the garden, the furniture and photographs, even pets, but these losses may be insignificant compared with the loss of a loved spouse or other social support. One resident
informant, wheelchair bound after a stroke, informed me that it was nothing to him to lose his privacy and independence and personal possessions because he had already lost things which were much more important to him – his wife, his physical function, his profession (he had been a musician) and for a period, his speech.\(^{37}\)

For those who do not make the choice themselves, the adjustment is likely to be slower and much more painful. Precipitating factors may include discharge from hospital after a crisis in their own health, the sudden death or crisis in the health of a carer, diminishing but possibly unrecognised capacity to live safely in the community, even a refusal (often a reluctant one) on the part of family to take any further responsibility. There may be a strong sense of failure or betrayal, of loss and grief. Their adjustment may remain incomplete for the entire time that they live in care. It is common for such residents, especially those with increasing levels of dementia, to ask on a daily basis when they will be going home, and any contentment they feel is most likely to happen when staff have the time and capacity to deliver warm and supportive care.

The admission stage has been identified as one of the most influential in the process of learning to be a resident. Becoming a resident can create a crisis of identity and self-esteem (Grainger, 1995). Sensitive, unhurried admission procedures, and personal attention and interest in the resident are highly significant. Hudson, who fantasised about creating ‘a nursing home where older persons would receive the very best of care whilst not losing their sense of self’ (2000: 1), established procedures designed to recognise the in-coming resident as a person, a getting-to-know you process rather than a bureaucratic form-filling one.

Ultimately, successful adjustment is dependent on the perceived quality of the new life, in turn partly dependent on the type of facility which the resident has entered. The degree to which either group, the ‘voluntary’ or ‘involuntary’, might consider the new surroundings an acceptable substitute for home depends on individual personalities, their previous tastes and interests, the social networks which they are able to maintain.

and perhaps most importantly, the new ones which they are able to make in care (see Powers, 1995; Savishinsky, 1991). Many residents do not find it possible to make friends amongst other residents, and the nursing, housekeeping and allied health staff become their main sources of social support. There are many variables, but in the best of circumstances staff can be significant in creating new social networks, the ‘family’ connections which are part of most people’s experiences of home. There are many dedicated staff who do see this as an important part of their role, as I shall discuss in later chapters on the findings from my study. There are also examples of supportive staff-resident interactions (Henderson, 1995; Savishinsky, 1991), even when staff are constrained by time and routine-oriented goals.

That said, there are many reports of a widespread lack of social care. Residents suffer from “loneliness, boredom, lack of respect by care providers, and the lack of involvement in decision-making.” This is certainly a widely held view of nursing homes, and echoes reports from Australia and overseas of low levels of resident satisfaction with the quality of institutional life (Kayser-Jones, 1981; O’Brien, 1989 and others).

**Accommodating to the medical model of care**

A range of factors have contributed to a highly medicalised approach to care of the elderly. As discussed in Chapter Two, old age is commonly viewed as a period of illness and disability. A past bias in gerontological research into the ageing body highlighted the symptoms of bodily decline, thus giving rise to the ‘bio-medicalization of gerontology’ (Estes, Wallace et al., 2001; Featherstone & Wernick, 1995, citing Estes & Binney, 1991; Lynch, Estes et al., 2005). Medical science continues to make important discoveries enabling the diagnosis and treatment of an ever-widening range of conditions, and the new technologies enable the repair of body parts as well as prolongation of life (Kaufman, Shim et al., 2004). As a society we are death-denying,

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and there is a general reluctance in medical settings to abandon attempts at life-prolongation if the knowledge, technology and skills are available (Kaufman, 2001), and the expectations of families of the frail elderly may support that view. High Care nursing home residents are amongst the frailest and sickest of the elderly. They have complex care needs, ones which will increasingly involve a high level of specialised nursing skills and very frequently a high level of medication. This is echoed in the current arguments for better training of nurses, higher staff resident ratios, and better salaries for gerontic nurses. Registered nurses bear a heavy load of responsibility in their supervision of less qualified Personal Carers, and because of the increasing complexity of the physical care of the residents in their charge, they highlight the need for constant upgrading of medical skills and knowledge. Their arguments, while fully justified, give the impression that they embrace a model of care biased towards the traditional medical one. This is misleading, given that many of them subscribe emphatically to the goals of holistic care of the elderly. However, in light of prevailing economic rationalist views amongst policy makers and economists, and indeed of a large part of the electorate, there is more sympathy for the medical, scientific view of caring as cure than there is for caring as ‘being with’ (Nay, 1993: 139). As previously discussed, this has an impact on the recruitment and retention of young nurses, whose training may have instilled a higher value for curing medical problems than for managing complex chronic conditions, and who can find it very difficult and unsatisfying to look after people who cannot be cured.

Despite current government initiatives aimed at creating more places for nurses training specifically in aged care, most of the registered nurses currently working in aged care have been trained in the acute care sector. Given that the average age of nurses in the aged care sector is now 47 years\(^{39}\), for many that training was heavily influenced by the hospital model of care. They often see their role, and indeed their responsibility, as a highly interventionist one. With a primary goal of maximising residents’ health, and under immense time pressures, it is not surprising that care frequently becomes task and body-oriented rather than resident-centred and holistic.

\(^{39}\) ANF submission to the Senate Inquiry into Aged Care (2004).
Such conscientious nurses see the need to act on a physical level, sometimes at the cost of psychosocial aspects of resident care. In the words of an informant in my study: “Because we’re nurses we just have to do things to people. We can’t help ourselves, and so we’ve got to learn to step back sometimes”.  

The economic model: registered nurses as business managers

As discussed above, the role of aged care nurses carries enormous responsibility. There are no doctors in residence, and having a doctor come at short notice or out of hours is problematic. The Hogan Report (2004) acknowledged this as a concern of the Australian Medical Association, who estimated that only 16 % of general practitioners currently provide services in residential aged care facilities, citing ‘substantial disincentives and barriers’ that make it difficult for GPs and other health professionals to operate in the aged care sector.  

The impact of this absence of GP support is significant. It adds to the stress imposed by the hierarchical staff structure of nursing homes under which one person will be responsible for the medical supervision of a large number of residents. It also involves supervision of less-experienced or skilled staff, and responsibility for their mistakes and inadequacies. Often, the lack of experience of junior staff adds to the time pressures on already pressed senior staff: “A lot of the documentation falls back on us and there are a lot of people that haven’t got the documentation skills”. All documentation (care plans, incident reports, accounts and justification of care delivered to each resident etc) must be maintained at the highest of standards. This is in the interests of best practice care delivery, high quality staff communication, general accountability, and in order to meet government funding requirements, or in the words of the AGDHA “to ensure funding is spent on its designated purpose”. Inadequate documentation can result in the loss of funding, even when the care

40 Staff interview #3.
42 Quality Assurance and Accountability document 5.4
delivery is optimal for the resident and conforms to the funding classification. Time has to be found to ensure that documentation includes the necessary level of detail. A number of nurses complete their documentation after their shifts have officially ended. This is because of size and complexity of the task, and the pressure for them to be occupied in other ways while they have responsibility on the floor.

I have already referred to the effect on staff morale of this pressure which adds to the frustration of trying to meet conflicting service goals. Their training and interest is in providing optimal care, their instincts to meet psychosocial as well as physical needs of residents, but they find themselves burdened by the bureaucratic dimensions of their work. The pressure imposed by this burden of documentation has been recognised by the Hogan Review (2004) and the government response to the review. The new system for classifying resident levels of dependence is intended to lessen the paperwork burden and free nurses for what they perceive as their real job, that of direct caring for the residents. Clearly, documentation is central to ‘real’ nursing, and it is important that it be streamlined and efficient. However, for now the bureaucratic pressures remain, and staff are struggling to cope, many of them increasingly disillusioned about the constraints on their ability to meet both physical and psychosocial needs of residents.

You can have the most beautiful care plan written, looks fantastic, but if it doesn’t happen because you’re so busy writing the care plan…? It sounds great but did you do it? I mean yes, you try to do it, but a lot of the time you’re spending on care plans without actually doing the care. It all goes into some space somewhere. And it looks fantastic. But they’re going to look at that piece of paper rather than look at that happy healthy resident…They’ll look at the paper and say, “Well how did you assess this need?” And then you’ve got to go back and back and back (Staff interview #3).


There is evidence that, even when extra time is provided, nurses do not necessarily spend it on direct patient care.
When the medical model fails: old age as a diagnosis

Not all of the problems which afflict the frail elderly are easily diagnosed and treated, and for some health professionals this creates a problem. When doctors and other health professionals cannot identify an effective treatment for a symptom or find a name for a condition, they may fall back on the diagnosis of old age (Sankar, 1984). The risks of a too-ready acceptance of such a diagnosis are serious. For example, treatable pain may be dismissed as just another complaint from an attention-seeker, and the elderly person may cease to report symptoms. It is easy to miss a small injury in a resident who is immobilised by arthritis, to mistake depression for dementia, to miss other treatable mental health conditions, or to interpret confusion caused by infection-generated delirium as dementia.

The holistic model of care and resident personal control

The holistic model calls for resident-centred care, with close attention paid to both physical and social aspects of the individual. Best quality social support comes with a continuity of staffing which permits time for the development of supportive staff-resident relationships. Social support includes empathetic staff attitudes and flexibility of routines, a focus on the resident as a whole person with likes and dislikes, and a commitment to furthering independence rather than dependence. Through recognition of residents’ wishes and attempts to facilitate them, staff involved in implementing a holistic model of care work towards enhancing resident personal control.

This goal, or at least the goal of maximum independence for residents is recognised in the Standards and Guidelines Residential Aged Services Manual45, but its successful achievement is not supported by regulatory mechanisms. In recognition of this fact, in its recommendations regarding regulatory and financial arrangements for assuring quality of care, the Hogan Review (2004) states: “this aspect includes maximising the

45 Standard 3.5 (Independence). Expected Outcome: ‘Residents are assisted to achieve maximum independence, maintain friendships and participate in the life of the community within and outside the residential care service’.
opportunities for residents to achieve an optimal quality of life, maintain their self-esteem, address their physiological and social needs, and achieve security and independence”. It is also recognised that leisure interests will contribute to quality of life and may support the achievement of health goals. The relevant expected outcome (Standard 3.7) is that “Residents are encouraged and supported to participate in a wide range of interests and activities of interest to them”. Included in a list of ‘considerations’ are “activity programs for residents (for example, individual or self-organised small group activities, activities organised by staff)”. They do not include the recommendation that non-care staff be employed to implement activities programs, and indeed care staff with experience and enthusiasm conduct imaginative activities programs in many facilities. Important concerns are the number of hours allocated to such staff for this work, and the degree to which their efforts are supported. It is asking a great deal of someone who has completed a full shift on the floor to then try to organise social activities, especially if no time has been allocated to the preparation of appropriate entertainment. The risk is that contact through organised activities may become perfunctory rather than directed towards maximum resident interaction and enjoyment. It also means that activities are likely to be for groups rather than individuals, with the loss of the one-to-one specialised contact which a music therapist, for example, can provide for residents unable to interact in a group. There is a view amongst some care staff that organising activities does not count as real work, (see Savishinsky, 1991: 51) and sometimes the commitment to having residents’ personal care preparation accomplished in time for them to participate in a scheduled activity is not a primary one.

**The nursing home environment: physical and social factors**

To understand the life of a resident it is necessary to understand the nursing home environment, “the functional context of the daily lives of the elderly” (Hendricks & Hendricks, 1986: 3, cited in Nussbaum, Pecchioni, Robinson et al., 2000). As Nussbaum et al. insist, “[e]nvironment mediates, structures and even dictates the
communication within its context” (ibid: 14), and a nursing home can “control” interaction through a wide range of physical and social factors.

By physical environment I mean physical structures and layout: location, building site, land use, building design and materials, internal layout, space allocation, fittings and fixtures, floor surfaces, accessibility (doors and doorways, lifts, ramps, distance between centres of activity), activity areas, gardens and other outside space. In addition, in environmental factors I include lighting, colours (paintwork, carpets etc), smells, and above all, noise. By social environment I mean the cultural and social norms generating the organisational hierarchy and the routines of the nursing home, and the values and attitudes of the staff. As highlighted by two comparative studies (Johnson, 1993; Kayser-Jones, 1981), both physical and social environments affect the ability of residents to interact and to establish a meaningful social world, an essential element in continuing to be themselves in old age.

**Environmental barriers to social interaction**

Two of the most important physical barriers are space and noise and the two frequently interact with social factors such as time in routine and task allocation. Hugman adds another dimension, referring to the relationship between space, time, action and identity which he considers “makes the conflation of residential care settings with the total institution so durable” (1999: 197). He contends that limits on resident ‘self-control’ through the management of space and time by staff threaten identity and reinforce associations between old age and dependency. His second contention is that “managed spatial relations may affect the identity of older people as members of communities”, referring specifically to the disruption in former relationships which may be brought about by “symbolic (and sometimes tangible) barriers imposed through spatial factors in the organisation and provision of care”, citing the example of lack of space for private conversation, or limits on visiting time or on space for visitors to feel comfortable (ibid: 198).

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46 As defined by Goffman (1960).
There may be too little or too much space – too little private space, too little or too much distance between people and objects. This includes the size of dining tables, the proximity of tables to each other (is there room for wheelchairs and frames? Can ambulant residents feel safe negotiating the obstacles?), the size of lifts and rooms and bathrooms and toilets, the layout of shared rooms, the width and length of corridors, and the distance between bedrooms and exit doors and activity centres.

In the allocation of recreation space the layout and positioning of furniture may make it difficult for residents to sit facing each other, or to be close enough to each other for conversation (Grainger, 1995). A common problem is lack of space for walking frames once wheelchairs are in position, and wheelchairs may block doorways and hamper resident access, or most importantly, reduce the options for ambulant residents to leave (or residents in wheelchairs or tub-chairs to be taken out). Residents are frequently anxious that they will not be able to reach their frames and get out if they feel they have to, particularly those with anxiety about their continence (see Nettleton & Watson, 1998) and will refuse to take part in a social activity if this situation is likely to arise.

The negative effects on communication of high ambient noise levels cannot be overstated (see Grainger, 1995; 1975; Kayser-Jones, 1981; Savishinsky, 1991). If the design of a residential facility places an open kitchen with an industrial dishwasher next to the dining area, and if organisational routines call for dishes to be washed while residents are still seated, those residents are often unable to maintain conversation and disinclined to stay in the company of others.47 Other common noise sources which affect resident interactions are competing loud television sets, piped music, vacuum cleaners, leaf blowers and lawn-mowers, residents crying out, and staff calling each other. Residents with communication difficulties generally manage to communicate better in a calm and unhurried environment (Gravell, 1988), and this has implications for both the reduction of noise interference and adjustment of task priorities and staff routines. If residents are dependent on staff assistance to move

47 A hostel resident’s experience, described in personal conversation: 19/2/05.
them to their preferred activity centre or day-room, they are also dependent on staff to regulate ambient noise to the extent that this is possible.

**Barriers to social participation: individual residents**

Many of the barriers to social participation lie in the capacity and health status of individual residents. These include physical, cognitive and sensory barriers, which in many cases are worsened by the interaction with the environmental barriers discussed above.

**Physical and intellectual barriers**

High Care residents are frequently ill, in pain, debilitated, many have serious cognitive impairments, and many have no degree of autonomous physical control. They can take part in group social activities only if they are conscious and responsive, well enough to be moved, feel well enough at the time, are not too tired or in too much pain, and an appropriate social activity is available for them. Their physical problems are not invariably barriers to social participation. Many residents who cannot move autonomously can be wheeled into recreation areas, helped with games such as Bingo, and involved in quizzes. Dementia in itself is not a barrier, even if the meaning which the individual person attaches to social activities cannot be known.

**Sensory impairment**

*Hearing loss*

Hearing loss is associated with depression (Coleman, 1995), withdrawal from social activities and ‘diminished quality of life’ (Jang et al., 2003: 173). Coleman suggests that it is one of the most neglected problems associated with ageing: “Remarkably, it seems to be the one disability that is laughed at and found annoying by others”(1995: 58). The fear of not understanding the content and the importance of what is said, and consequently making inadequate or inappropriate responses, is a common occurrence in people with any kind of hearing loss. The most common form of hearing
impairment is presbyacusis (also known as presbycusis). This is normal hearing loss associated with the physical processes of ageing, affecting up to two thirds of those over 70, but causing particular difficulty in those over 80. Those affected progressively lose the ability to hear high frequency tones and there is a basic decrease in acuity and speech discrimination, “depending on the type, or types of presbyacusis, which in turn depends on the location of defects within the auditory pathway” (Gravell, 1988). Initially it is possible for the person affected to compensate through a number of strategies, most frequently lip-reading and guessing from the conversational context. As hearing loss progresses there may eventually be too few contextual cues for guessing to be accurate enough for effective communication.

An even more important loss (through the loss of discrimination of tone and other non-verbal linguistic cues such as stress, rhythm and inflection) is the ability to process the relational component of conversation. Interaction becomes a risky business, and it can be easier to withdraw (see Ryan et al., 1986; Villaume, Brown, & Darling, 1994 and others). Savishinsky describes the raised voices, unanswered questions and self-consciousness which “move in a vicious cycle that finally stops people from trying to talk to one another” (1991: 74). This is supported by my own information and observations – ultimately many deaf residents find it just too difficult and too threatening to their self-esteem to try to socialise. The expectation is that they will not hear, and that the stress of trying to do so will be too defeating (Smith & Kampfe, 1997).

The hearing impaired have their difficulties increased by noise interference (Butler & Lewis, 1982; Villaume et al., 1994), and wearers of hearing aids are particularly affected (Gravell, 1988). When unwanted noise cannot be separated from the communicative process, it is often easier to give up. “Successful acclimatization probably involves the ability to tune out unwanted stimuli of all sorts. Neglecting to turn on one’s hearing aid has this adaptive function” (Shield, 1988). However, such a strategy increases isolation in face to face situations and brings the risk of forgetting to
turn the aid on in time to allow meaningful telephone exchanges with family and friends, undermining supportive outside relationships.48

_Speech impairment_

Common conditions causing speech impairment are dysarthria and dysphasia. Dysarthria is disordered articulation of speech with unimpaired language function. Language is understood and there is no problem for the person to formulate speech and sound, but there is difficulty in articulation at the level of pharynx, mouth or lips and speech may be slurred or indistinct. It is commonly caused by stroke damage affecting lip and tongue movements, although frequently the cause may be ill-fitting or missing dentures (Myerscough & Donald, 1992). Dysphasia, or aphasia, encompasses the range of speech impairments associated with age-related neurological disease. These can present a serious communication handicap. The hardship for those affected with some types of aphasia is that their receptive function (understanding of speech) is not impaired, but because their expressive speech is, they may be considered cognitively incompetent and undesirable as social partners. Aphasics with impairment to both receptive and expressive speech may still retain the normal sounds and fluency of language. Their utterances may be meaningless, and their understanding of others’ utterances equally unsuccessful (Ryan et al., 1986). This may not be a barrier to participation in group activities which do not require meaningful language exchanges, for example some craft work, gardening, concerts and other musical entertainment. Nor does it prevent the development of affective bonds between residents and staff, but it is certainly a barrier to any meaningful language-based communication activity or relationship building. Alzheimer’s disease may cause similar loss of expressive and receptive language function. Parkinson’s disease can also affect articulation, as well as the cause the loss of non-verbal components of speech messages. ‘Flat affect’, or absence of facial expression, may convey lack of interest in, or even rejection of others’ social overtures, and this in itself is a considerable barrier to social participation (ibid).

48 Personal experience.
Vision impairment

The major consequences of limited vision are related to inability to function effectively (Jang et al., 2003). Impaired vision creates difficulty in perception of the ‘spatial environment’ and imposes dangers to physical safety by reducing ability to detect physical obstacles and maintain balance. Disorientation is frequently a problem in clinical environments, and the vision-impaired may lack confidence in their ability to move about the nursing home and enter unfamiliar rooms. They stand in as much need of help to find the scene of social activities as do the mobility-impaired, and in addition may not be able to enter into activities which involve reading, watching or interpreting actions or visual symbols. If they have a hearing impairment they are also disadvantaged in their inability to lip-read or to recognise non-linguistic visual communication cues (Gravell, 1988). As with hearing loss, loss of vision has implications for an increase in depressive symptoms and diminished quality of life (Jang et al., 2003).

Limited English language proficiency

Lack of English language resources is not in itself a barrier to participation in activities, unless they are strongly language dependent. However, the warmth of relationships with other residents and carers may only be expressed through non-linguistic behaviour, that is, through touch, gestures and facial expressions. Residents who are withdrawn and shy may find themselves very isolated if there is no-one in the facility who speaks their language, and staff may need to co-opt family members into activities to interpret and to help staff understand what can best be done to meet residents’ social needs.

Loss of body control

I include loss of body control, or fear of this, as a barrier to social participation because of its emotional strength in reducing resident confidence. “Maintaining control of the body is crucial for the presentation of self in everyday life”(Nettleton & Watson, 1998: 14). Incontinence, or fear of experiencing incontinence, frequently prevents residents from joining in a group activity which might increase their distance
from a toilet, or in some way increase the risk that they might fail to master their bodies. It can have particular effect in preventing residents from going on an outing. Their embarrassment and fear of loss of control is also a fear of social disgrace. The loss of bodily control means a possible loss of social acceptability, involving threats to adult status:

Degrees of loss impair the capacity to be counted as a competent adult. Indeed, the failure of bodily controls can point to a more general loss of self image; to be ascribed the status of a competent adult depends on the capacity to control urine and faeces (Featherstone & Hepworth, 1989: 148).

**Withdrawal: implications for resident well-being**

The social isolation which can result from withdrawal or exclusion (as in the case of those labelled as incompetent) has a profound effect on how the resident survives the nursing home experience, and indeed on the ability to make sense of this stage of life. The negative impact of such social deprivation is seen on the elderly person’s sense of self, but also has major implications for effective health care delivery. Doctors and carers who make little effort to hear or be heard are a damaging force in the social and physical health of the institutionalised elderly with hearing or speech impairment. Equally, if staff underestimate the value of social interaction or the competence of residents to be participants, or fail to support those with disability in their attempts to move about the nursing home and interact with others, they are encouraging dependence and threatening the autonomy of the residents in their charge.

**Staff support of social interaction**

I discuss in later chapters the necessity for staff to know residents well in order to be able to communicate and build relationships with those with cognitive and communicative impairment. This involves a commitment to holistic care on the part of individual staff and the organisation, and an effort on the part of the organisation to
maintain continuity of staff and establish flexible routines. Professional development programs which include strategies for communicating with the speech and hearing impaired, raise awareness of institutional noise as a barrier to communication, and give instruction on the maintenance and fitting of hearing aids can alleviate some of the communication problems outlined above (Gravell, 1988).

**Summary**

In this chapter I have described the Australian context of residential aged care, and suggested that the ideal model of care is holistic, with a commitment to maximum preservation of resident self-esteem and independence. Because of the interrelatedness of ageing, communication and health, it is of the greatest importance for institutions and staff to be aware of the contribution they can make to the mental and physical health of institutionalised elderly people (see Nussbaum, Pecchioni, Robinson et al., 2000). Social participation is an essential element in healthy ageing, an aid in the maintenance of a strong sense of self. Because continuity of staffing is such an important element in the building of staff-resident relationships, it is essential for the government to deal with the staff shortages and work overloads which encourage attrition and discourage recruitment of nurses. Only with an adequate and empowered staff will residents be socially supported and reinforced in their ‘work’ of making meaning of being old and in care.

In the next chapter I outline the methodology followed in my study. I explain and justify my choice of qualitative research methods, and emphasise the importance of reflexivity in this study. In addition, I discuss some of the challenges I encountered during fieldwork, in particular regarding moral and ethical aspects of my involvement with vulnerable residents.
Chapter 4 – Evolution of the Study

I believed that the social and communicative climate of the nursing home would have an important role to play in helping the elderly residents find meaning in their ageing, agreeing with Nussbaum et al. (2000) that communication is fundamental in successful adaptation to biological ageing. I set out to explore two aspects of this question, the opportunities which arose for resident communication with other residents, staff, families and friends, and the apparent effects of these interactions on resident sense of self and general well-being. My interest was in monitoring interactions for both social and communicative intent and for effect, and for quality as well as quantity. Because I wanted to hear from the elderly themselves, and to be able to express their voice, I needed to become as close as possible to my chosen group, and spend as much time with them “on their homeground”, as I could.  

In ethnographic methods with participant observation I found the means of becoming an insider-outsider, with a role and reason for interacting with residents and their families, staff and other participants in the nursing home world. The ethnographic approach also allowed me the time to build essential relationships with the members of the community. Through these relationships I gained an understanding of the lives of the residents, and of the institutional communication environment.

In this chapter I discuss my experience as a participant-observer in two nursing homes and the methods I used for gathering, analysing and interpreting data. I outline the ways in which I, as the research instigator, tool and reporter influenced all aspects of the study and gratefully acknowledge the influence which these inspirational old people had on me. Finally, I reflect on the ethical issues which became salient during the study.

49 Van Maanen (1988) in a footnote to page 2, points out the enormous variation in how this mandate is carried out.
The Research Project: preliminaries

Selection of the sites

My research proposal called for a minimum of two nursing home sites: this would offer a large enough population of residents with the appropriate level of cognitive and communicative competence to talk to me, and allow for the possibility of making comparisons between the sites. My selection of research sites was purposive. I knew one of the nursing homes by reputation, both from insiders and outsiders (the insider was the daughter of a resident who had passed her last years in that home), and had done some research into the goals and aspirations of this not-for-profit provider. I believed that I would only learn about the effects of social and communicative interactions in an environment where I could expect them to occur. The charitable sector has the reputation for providing more empathetic care than many of the for-profit providers. The anecdotal evidence is supported by research which indicates a “significantly lower quality of care in profit making nursing homes than in non-profit nursing homes” (Stack, 2003: 2) citing (Braithwaite, 2001: 445). While I am confident that there are excellent for-profit providers, I did not want to risk choosing one which was not seriously engaged in trying to meet residents’ psychological and communication needs. There are already studies which describe communication-starved environments or highlight the negative effects of infantilising communication (Caporael, 1981; Caporael et al., 1983; Grainger, 1993, 1995; Kayser-Jones, 1981; Nay, 1993; O’Brien, 1989; Shield, 1988). I did not want to write another expose of careless or negligent approaches to resident social health and well-being and I hoped to find better models of resident-centred care.

Negotiation of access

I approached the relevant nursing home administrator who suggested that I base myself in two of the organisation’s nursing homes, one inner and one outer suburban Melbourne. In principle agreement was given for me to become an observer-
participant, with a role as a non-carer volunteer in both facilities. We agreed that I would not observe or record in non-public areas, such as toilets and bathrooms or behind screens or curtains in residents’ rooms where their personal privacy might be at risk. My study would involve cognitively competent residents, identified with the help of Directors of Nursing and other senior staff. Staff would be notified in advance of my research role and aims. They would be advised that they could choose not to be observed, and would not be recorded without giving written informed consent. In addition I would post notices and circulate plain language statements for residents, staff and families and other visitors to give them the opportunity of declining to be observed.

I also agreed not to undertake any care tasks (for example feeding or intimate body care) which might reinforce perceptions of dependence in my informants and affect their freedom to deny consent to be observed or interviewed (I cover some of the implications of this decision in my discussion of ethical dilemmas). Access was contingent on approval from the provider’s Ethics Committee as well as the University of Melbourne Human Research Ethics Committee. With these obtained, I had meetings with each of the Directors of Nursing (DONs) to negotiate commencement of the project.

The nursing homes

Greystone is a compact ageing two-storey site with 50 High Care residents, mostly in shared rooms, with no private bathrooms and with very limited outdoor access. There is very little private space for residents, although there are large lounges and dining rooms on each floor, and corridors and foyers which provide vantage points for those wishing to monitor the coming and going of residents, staff and visitors. Staff work on either the ground floor or the first floor, in direct contact with 23 – 25 residents per shift. At the first meeting with the DON I explained my project again, and it was agreed that I would spend two days a week supporting the Activities co-

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50 I introduced myself as Jean Tinney, the name by which I am usually known. I asked all staff, residents and visitors to call me Jean, and I am identified as JT throughout this thesis.
51 To preserve confidentiality I use pseudonyms for the two nursing homes as well as for all residents and staff who are named.
ordinator. The nominated days were determined by the need for help with activities such as bocce (in this context, a kind of carpet bowls). I would get to know the facility and the residents and staff during the first few weeks, and then begin official monitoring and interviewing. I was introduced to the two unit managers as well as the Activities co-ordinator, asked to prepare an initial notice (with my photograph) to alert staff and visitors to the project, and to return the following week to attend a staff meeting. I was also asked to wear a name badge on site.

Wisteria Grove is a sprawling modern single storey facility with 45 High Care and 15 Low Care residents. Most residents have single rooms and private bathrooms, though some do share with one other resident. The whole complex is loosely separated into four inter-connecting units each with its own kitchen and dining areas and its own allocation of staff. Consequently most staff see only the 15 residents in their section, though the Registered Nurses are responsible for two of the units at each shift. There are extensive lawns and gardens around the building, but with only limited secure areas. At first meeting the DON was very interested in my project, eager to discuss other research, and proud of the facility and its innovative programs, in particular its approach to dementia care. I was shown key areas, introduced to Unit Managers and some house-keeping and Allied Health staff, and it was agreed that I would spend two days a week there helping in whatever way was appropriate and useful. Their policy excluded the wearing of name badges.

The residents

The 50 residents at Greystone were all High Care, many with multiple disabilities and a number bedridden and unresponsive. Approximately 70% were of Anglo-Saxon origin and the remainder from other European countries. I observed and interacted most frequently with around half of the residents. All except one of the residents in this group were aged over 70, and two were nearly 100. At Wisteria Grove there were fewer non-English speakers, and there was a small group of Low Care residents with generally higher communicative capacity. The age range was similar to Greystone, as
were disability and dementia levels in the High Care residents. I had frequent contact with approximately half of the 60 residents.

Of the twelve residents I interviewed, four from Greystone and eight from Wisteria Grove, eight were women (reflecting the fact that the majority of nursing home residents are female), and all except two were aged over 80. Two were over 100. Ten had been born in Australia of Anglo-Saxon parents, one migrated from England in his youth, and one from continental Europe. The two migrants had married Anglo-Saxon Australians, and the one non-native speaker had always spoken English in family and work environments. One resident had a professional background, several had trade qualifications, but most had had little or no formal training. Several had spent time in rural Australia, but most had lived in Melbourne for many years.

**Making the Strange Familiar: in at the deep end**

I approached the field with both excitement and trepidation, intellectually aware of the challenges ahead:

[N]ursing homes are among the most unique field sites because they combine the traditional challenges of cultural discovery and description with inescapable questions about the meaning of “otherness”. Anthropologists who use nursing home residents as their informants cannot work around the perplexing issues of identity, perception and experience that confront all fieldworkers (Vesperi, 1995 :8).

Vesperi points out that in a nursing home “fate and the future are dominant, unavoidable questions” (ibid: 10). The researcher is confronted by the shared inevitability of the ageing process: “Participant-observation researchers cannot avoid this confrontation; instead, must embrace it fully” (ibid).

Despite the intellectual awareness, I was not emotionally prepared for the intensity of the intimacy of nursing home life. I had previously conducted a small study in a nursing home, and had experience of my own relatives in both hostel and nursing home accommodation, but I had not been immersed in participant-observation or had
hands-on experience of strangers’ frail bodies. In my first weeks I was excessively self-conscious, hesitant in my approach to touching, fearful of intruding into personal space, and reluctant to cross the boundary into ‘care’ tasks.

Day One, Greystone

I arrived early, discussed the day’s activities with Rebecca, the Activities Coordinator, and then went with her to collect outstanding library books from residents’ rooms. The books were hard to locate, and although there were many copies of a tabloid newspaper about, at first sight I could not guess how many residents were actually reading. Unlike Shield (1988: 15), I had previous experience in nursing homes and was not unduly surprised or disconcerted by sights, sounds or smells (in fact the absence of odour was one of the first things which I noted positively). The ambient noise included sounds of residents coughing and calling out, and one CD player at a high volume, but a Unit Manager turned it down as soon as she noticed it. Otherwise, there was a sense of order and relative calm; staff were busy but not frantic, there was movement of residents but not tension, and it did not seem to be a noisy place.

I was then enlisted for a wheelchair walk. Rebecca and I helped a very frail very old woman out of bed and into a wheelchair. I buttoned her cardigan, covered her very thin knees with a rug, and took her out of the building and around the block, stopping to look at gardens but not staying too long in the sun. Back in her room, successful management of getting her back into bed safely made me feel a little less anxious. I stayed to talk and promised to return the next day to read the Bible to her.

The first group activity was bocce, and I prepared the room by putting chairs in a semi-circle, leaving enough space for wheelchairs and an oxygen tank near a power point. Staff helped with resident transfers, and when we finally had our group we handed out the plastic bocce balls. Residents dropped, threw, or rolled the balls, some

52 Except for one momentarily ‘jarring’ sight of an unusual facial cancer.
53 Later I came to realise that during the relatively rare disruptions of regular staffing, particularly if staff called in sick and agency nurses were not immediately available, the difference was obvious. When staff had to carry unexpected increases in work loads, or inexperienced agency staff were present, night linen was not cleared away as quickly and the smell of urine was more marked, residents were less prepared for the day and less calm, noise levels were higher, and staff tension was palpable.
with a very good aim and understanding of the game, some with difficulties with motor control or eye-sight. There was much hilarity and generous applause, but a keen edge of competition between the Upstairs and Downstairs teams. After eleven games we escorted residents back for the mid-day meal, in dining rooms, small lounges, or their own rooms. That left only the tidying and the administrative work, writing up each resident’s activity sheet, including how many games they had won, how they had responded and interacted, and whether they had enjoyed, or appeared to enjoy themselves. We went to take a lunch break ourselves, and I met four or five staff members. As became my practice, I introduced myself and explained my project, and answered questions about it and myself.

The mini-bus trip scheduled after lunch was another huge organisational effort. We finally took four residents, including one who stayed seated in a wheelchair which required a number of safety belts and locks. The trip was along the river to a picnic area where we opened the bus door and then poured drinks from the flasks we had brought. On return we went through the reverse procedure for unloading residents and escorting them back to their rooms or the lounges, and then recording resident’s responses to the outing on their personal activity sheets. I left, physically and emotionally depleted, but reinforced by the interest and gratitude of staff, and the realisation that I had a role which would occupy me for as long as I had the time and energy to fill it.

Day One, Wisteria Grove

After an early arrival, and an initial period of wondering what to do, I was inducted into what would become a familiar routine. This involved helping the physiotherapist and an Activities officer with the High Care strength exercise group. As the group of residents slowly gathered I began by introducing myself and interacting as best I could. There was a high general level of physical impairment, and as it was difficult to judge degrees of cognitive awareness, I fell back on small talk about myself and the
weather, and made only cautious exploratory forays into finding out about them. The circle was finally complete, with twelve participants, and I collected tea-cups and moved walking frames out of the way while the two staff members attached the residents’ leg weights. Some residents wore no weights, and some wore one only, able to exercise only one side of their bodies because of physical weakness or partial paralysis. The leg exercises were followed by hand weight work, with constant cheerful encouragement from the two staff, much laughter, joking, and affectionate teasing. The underlying strategy, obviously very successful, was to turn an exercise routine with serious therapeutic goals into an enjoyable social activity. Some residents came more for the fun than the exercise, and staff recognised this as a worthwhile outcome. At the end of the session I helped residents to their dining places and went to the staff room for lunch. I introduced myself over and over as people came and went, and each time explained why I was there and what I hoped to do. Many staff had not seen the memo about me, but were curious about my project, and open to the research goals behind it.

I then volunteered to sit with a distressed resident until it was time to escort people to the hymn singing session. The hymns were the very old and familiar ones of my childhood, and despite my lack of recent practice, I contributed as lustily as I could to the singing. At the same time I helped residents find the right page and place in the hymn-books, large-print computer pages stapled together in thin plastic covers, so not heavy to hold. The music and leadership were provided by a visiting husband and wife team, and the residents obviously found immense enjoyment in being there. I was interested to see that one with a severe speech impairment was able to sing all verses of familiar hymns even though she could only speak in monosyllables.

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54 Throughout the entire fieldwork period I avoided asking questions about diagnosis. My policy was to ask how residents felt rather than what their diagnosed problems were. Some volunteered medical information, others ignored their disabilities, and some genuinely did not know or had forgotten what their doctors thought about their condition. One resident who became a regular informant was at a loss to explain just what had precipitated her entry into care.

55 Those four staff members subsequently became regular informal informants, and, amongst others, influenced my decision to incorporate staff interviews in my research design some months later.
I left with mixed feelings. I was tired to the bone, and felt a measure of pessimism about achieving my research goals. There were unshed tears over some of the disability and pain I had seen, and indeed in response to the hymns of my childhood, and there was muted optimism that I would find a way to build a role for myself. It would take time, but I hoped I could contribute more usefully as I got to know these residents better. In my uncertainty I identified with Shield (1988), who at the beginning of her nursing home fieldwork found herself envying the nursing staff their definite roles while she, as the anthropologist, had to decide each day what to do and what questions to ask. Like her I was finding that “making the strange familiar was disconcerting and alarming – too close for comfort – but a necessary realization” (ibid: 16). I would have been less concerned if I had realised just how quickly I would become comfortable in my role, able to know what to do myself, or to be responsive to requests from others. As I discuss in more detail below, these first two days were typical of the many which followed, a mixture of group and individual interactions, of challenges, rewards and disappointments.

Data collection

Participant - observation

I maintained detailed daily fieldwork diaries of my observations, reactions and reflections, entering these directly into the computer when I reached home. During an eight month period, from November 2003 to June 2004, I established my own patterns of interaction, sometimes more observational, sometimes more participative. I encouraged recreational staff to count on my help for the set group activities, and continued to develop relationships with individual residents as the opportunities arose. I spent time with them on a one-to-one basis walking, reading, talking, simply holding hands, picking up and passing things, adjusting TV sets, and taking messages to floor

56 Two issues were the geography of the building which had no central place from which I could monitor resident-staff interactions, and the relatively few possible interviewees amongst the residents I had met.
staff. Activities staff were happy to use me for much of the individual attention, and gradually floor staff started to ask me to pay special attention to residents they felt needed it. This had the effect of building rapport with staff as well as residents, and offered some of my most deeply moving and rewarding personal experiences. I spent several periods sitting with dying residents, in one case simply reading the Bible to a woman who had previously told me that she loved the Psalms best, glad to see her calmed by my choice and my voice. Another, who had given me one of my most generous and valuable interviews, became more and more in need of company, often silent, and dependent on physical touch as she grew weaker.\(^{57}\) I spent long periods crouched over her chair to be near enough to hold her hands.\(^{58}\) Her sight was poor, and where previously she had always recognised me by my voice, towards the end she knew me by my ‘soft skin’. She was very much looking forward to her death, but punctuated the periods of silence by wistful pleas for reassurance. Her religious faith and belief in the after life were very strong, so each time she said “I wish I could see my mother”, or “When will He take me?” I felt comfortable in assuring her that it would be soon.

Other activities I participated in, or observed after I had escorted residents to the meeting place, included special holiday celebrations, musical concerts, religious services, excursions (once with the art therapist and a group of five residents to a major city art gallery), fortnightly lunches at a nearby pub, wheelchair aerobics, sing-a-longs, quizzes, newspaper reading groups, Bocce, Bingo and Happy Hour. Some of my biggest ethical challenges revolved around these social activities, as I discuss later.

I also regularly helped at the mid-day meal in the Low Care unit, carefully not crossing the boundary into the area of spoon-feeding. I escorted residents to the table, pushed their chairs in as they sat (I was very grateful to the physiotherapist who showed me how to do that without straining my own back), passed meals, fixed

\(^{57}\) Savishinsky (1991: 136) comments on society’s lack of awareness of the importance of both silence and touch, noting “how acceptable silence can be when it is made socially meaningful” and how “[f]or older persons with few other means of communication the importance of touch can be particularly pronounced”. From Sarton’s moving novel Savishinsky quotes Caro Spencer: “the body remembers for the mind”, and “memory is “kept alive through the senses” (1973: 55-60).

napkins in place, found salt shakers, and caught up on the mainstream gossip. Again, staff were glad of the help, and it was a way of seeing residents interacting and of giving some attention to those who were otherwise hard to contact.

Resident interviews

I audio-recorded in-depth interviews with twelve residents, making my requests after several weeks of interaction and conversation. My method reflected Kaufman’s (1994) comments on the importance of building trust and rapport before commencing interviews. I used the recursive model of interviewing, as described by Minichiello (1995), and returned to speak to interviewees on many occasions. Sampling was based on Fetterman’s ‘big net’ approach, “mingling and mixing with everyone” (1998: 32), getting to know as many residents as possible and then narrowing the field according to my increasing knowledge and experience. Suitability was ultimately determined by residents’ cognitive and communicative capacity, their health status, and their interest and willingness to talk to me. After the first few weeks of participant-observation I asked the DONs and senior staff for suggestions regarding appropriate interviewees and was given a list of names at both sites. Only two of those I asked were unwilling, and in both cases their suspicion of the process and fear of other agencies gaining access to information about them was an eliminating factor in itself. One regularly welcomed me and talked at length about herself, but would not hear of being recorded, even of consenting under a pseudonym. The other changed his mind constantly, often saying, “Ask me tomorrow”. I decided that it would be inappropriate to persist in either case, but continued to drop in for visits.

Several of the residents suggested by staff did not meet my own criteria of adequate cognitive and communicative capacity. I was not sure that they had a clear understanding of what was behind my request, and some had memory problems and were not able to sustain the kind of conversation I was looking for. One resident alarmed me by a delusional outburst, though until then I had believed him to be
capable and coherent\textsuperscript{59}. Several cognitively able residents had speech impairments, and could not talk about themselves without my first framing the thoughts for them. I use some of the data gained through observation and conversation with them in other parts of my discussion, but could not record their life stories in their own words. Timing of requests and sudden changes in resident health status were other factors. One man who was keen to do an interview suffered a sudden bereavement, so out of respect I deferred the interview, and then he had a health crisis which led quickly to his own death. Two other residents died before interviews could be arranged, one after a fall which precipitated the sudden decline in her health.

Soliciting the narrative

Holstein and Gubrium (2000) note that social science interviewers are usually cautioned against asking leading questions, but argue that the interview which seeks to elicit a life story demands the active participation of the interviewer. They justify this co-participation in the construction of a story because of the need to maintain topical continuity, to follow the rules of conversational interaction, and to encourage the story teller. Significantly, the story which emerges is often in a question-answer sequence, not in any single utterance. This is an important point for analysis of my own interviews, which in a number of cases, elicited short answers which demanded more questions, and failed to produce sustained, unprompted chunks of narrative. I found such residents more responsive when I offered my thoughts or information about myself first.

Sounding a cautionary note, Holstein and Gubrium point out that collaboration, that is, “complicity in actions that ‘keep the story going’ also contributes to where the story is going” (2000: 142), in other words how the hows of storytelling implicate the whats of the story. Elsewhere in this chapter I discuss my awareness of the importance of my role in the interviews, and the shaping of the information which interviewees gave me. I often offered information or opinions which I hoped would elicit exchanges, and these had an obvious influence on the course of the interviews. They also highlighted

\textsuperscript{59} I was faced with the complexity of the spectrum of cognitive competence, and the unpredictability of fluctuations in individual competence, an issue I take up in my discussion of ethical dilemmas.
the importance of creating solidarity in order to encourage a self-conscious storyteller. The discovery of shared experiences or interests, of having things in common, gives the storyteller the confidence that the listener will welcome and make sense of the account. I discuss elsewhere in this thesis the fact that members of this cohort were not accustomed to introspection or even to talking about their thoughts to others. Their less powerful social position led them to be hesitant and sometimes passive in interviews (initiated by me, for my purposes, even recorded on my machine). Anxiety about performing well was also an inhibitor. I needed to establish rapport, build confidence, and encourage my informants to think about themselves and to share their thoughts with a stranger (see Minichiello, 1995).

I interviewed each resident for an initial period of half an hour to an hour, and as explained above, interviews were active, a kind of narrative collaboration between myself and the informant (Holstein & Gubrium, 1995). They took place privately in residents’ rooms, staff offices, sitting rooms, and in one case an apparently deserted corridor. There were frequent interruptions, and in most cases I stopped the recorder until the source had moved on. After the initial interviews I recorded two or three residents a second time, looking for richer data, but in most cases simply maintained regular informal contact. I noted important elements of our later conversations in my daily fieldwork diary entries. The reasons for not attempting further audio-recording were many. It was difficult to pre-arrange a time and place which suited the resident and where private recording could take place; some residents were more stiff and self-conscious when they were being recorded and I found that spontaneous conversations offered new insights. In addition, it was hard to predict which conversations were going to flourish and which to wither, either because of resident fatigue or loss of interest, background noise or interruptions by staff, residents or other visitors.

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60 Five of the key informants have since died, but data from their narratives is included in discussion of my findings.
Staff-resident interactions

My original intention was to audio-record one-to-one staff-resident interactions with a view to discourse analysis. This plan was abandoned after a period of participant-observation revealed that there were very few predictable, sustained non-public interactions. The longest such interactions took place in private, usually during intimate personal care. It was not appropriate or ethically acceptable for me to be present on such occasions, and although other researchers have been able to make arrangements, for example for staff to wear microphones or recorders (for example, Gibb, 1990; Grainger, 1995), the administrator of the nursing homes and I decided that it would not be an option for me.

As a result, I monitored staff-resident interactions as part of my participant-observation, and became increasingly interested in how staff understood resident autonomy, and how they resolved the tension between respect for autonomy and concerns for duty of care. This interest was further sharpened by the explanations staff offered me for certain decisions, for example, for preventing a resident from sitting in his preferred place opposite the nursing station, for not getting a resident out of bed for Bingo, or for taking residents to activities which they appeared not to enjoy.

Amendments to the study design

Interested in how staff made decisions, and encouraged by their interest in discussing this and other aspects of my project with me, I decided to amend the research plan to include staff interviews. I also decided to extend my participant-observation to include a number of cognitively impaired residents. Over time I had realised that many of the interactions I wanted to describe included residents with dementia, and of even more importance for the community as a whole, the families of the same residents. Families who came every day were important catalysts for interaction with other residents, and a real source of support for both residents and staff. I spoke to the legal guardians of the residents concerned, and with their agreement took the necessary steps to gain approval from the nursing home management and the two ethics committees.
Staff interviews

Sampling of staff was purposive. I chose people with whom I had built a degree of rapport over a six-month period and who I believed would provide me with rich data. They were all permanent staff because I did not meet agency or casual staff frequently enough to have that knowledge or rapport. To an extent they were also self-selected. These were the people who had shown interest both in me and the research project over the preceding months. Their questions and comments had stimulated me to expand my research design in order to explore their views and insights further. Nonetheless, even with the rapport we had built, I felt some trepidation at making what I saw to be a major request. To my surprise and gratitude, all of the 23 I asked agreed to give me half an hour outside their work shifts. In total, across the two sites I interviewed 15 care staff (from all levels), five Allied Health staff and three housekeeping staff. Anticipating refusals, I had only planned to interview sixteen, but all agreed and a form of impromptu snow-balling brought extra staff to my attention.

Semi-structured interviews lasted between half an hour and an hour, and were interactive collaborations. I had prepared an interview guide, including “Is there anything else you would like to comment on?” and when I found that most wanted to comment on the same topic, I included that as an extra prompt for the rest of the interviews.

Data analysis

Data analysis, following the practice of grounded theory (Glaser & Strauss, 1973; Strauss & Corbin, 1990) accompanied the data collection from the beginning of fieldwork, directing new lines of enquiry and influencing decisions to return to certain informants and to follow up on emergent themes (Bernard, 2002). I typed up my observations and reflections at the end of each day in the field and listened to

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61 Two were chosen because I had observed incidents which made me wonder how and why they made their care decisions.
interviews (transcriptions were done on days when I was not in the field). I took time to read and re-read my notes and transcriptions and identify new themes to explore, and possible new informants to interview. I also identified questions which had been answered indirectly or had hinted at further disclosures, but which I had not followed up adequately at the time of interviews and conversations.

Using standard grounded theory methods (Rice & Ezzy, 1999), I coded and categorised themes as I read my notes and transcripts. This process allowed me to identify unpredicted directions of enquiry (Ezzy, 2002), and to eliminate some which had proved unfruitful. To preserve rigour and authenticity I used triangulation of multiple data sources (Rice & Ezzy, 1999) in the form of staff and resident interviews, written nursing home documentation, and notes from professional development workshops, meetings and conversations with staff and families of residents. I also took account of my own reflexivity in the interpretation of data, aware always of my role in all aspects of the project. Analysis stimulated wider reading and reflection, and this in turn informed my discussion of findings. Although one of my principal methods of gathering data was through interviews and conversations, I transcribed these in order to employ textual analysis which identified thematic patterns. My selection of this method was driven not by debate within linguistic analysis (Brown & Levinson, 1987; Hymes, 1977; Moerman, 1988), but by my search for the self. As an engaged ethnographer, my major concern was the process of revelation through interaction, and content was explored for what it revealed.

**Feeding back on findings**

I offered transcripts of their interviews to residents, but the two who accepted were worried by the responsibility and glad to return the scripts. I continued to remind residents of the stories they had told me, and our continuing relationship was based on the rapport we had developed in the early stages of the study. After the conclusion of the intensive fieldwork period (eight months), I continued to support the residents by
visiting, initially on a fortnightly, then a three-weekly, and finally a monthly basis, and at the same time gave continuous feedback on the progress of the study.

These regular visits also enabled me to continue personal feedback to staff. I had originally offered them the option of reading their interview transcripts, but all declined. I spoke to each person post-interview, and told them my major findings and how they had contributed to the study. I also prepared an academic poster, and used it initially for a presentation to my peers. I subsequently showed the poster to a number of staff and left it with the manager of the two nursing homes to be displayed for several weeks at each site. She used it to report orally to the CEO and members of the board of management, and it was included in the written report submitted to the same officers. I made copies of the poster for staff who were interested and pleased to find that their comments had been reported. My findings from the staff interviews were reported in a paper presented and published in conference proceedings (ERA 2004, Australian Centre on Ageing, University of Queensland), a copy of which I gave to the manager of the two homes. I remain available for contact by the nursing home management, and am in regular electronic communication with two of my principal staff informants.

**My self in the project: agent and subject**

I was the primary tool for collecting primary data (LeCompte & Schensul, 1999), and accordingly this project reflects my personal influence and involvement in all aspects of the data gathering and interpretation. On top of my role as designer and instrument of the research I was also responsible for the instigation of and participation in many of the interactions which I monitored. My personality and communication style affected how people viewed and responded to me, and there are many other personal factors which made it possible for me to narrow the age and experience gap between me and the residents who make up this story.
A primary concern was my moral commitment to an ethics of human respect, not a question of procedural issues as much as a visceral response to human individuals. My approach was based on a foundational principle of anthropology, an understanding of shared humanity where the nature of the subject matter becomes a shared basis of understanding and compassion. I was willing to accept the heavy burden of moral and ethical responsibility entailed in ethnography.  

My story

I was brought up in a small conservative Australian rural farming community, with five siblings and innumerable cousins and aunts and uncles. My parents maintained contact with this large extended family and took responsibility for older relatives as well as elderly neighbours and members of the church community. As children we were expected to be able to visit and converse with old people, and even to take on special responsibilities. From early childhood I was encouraged to visit a neighbour who seemed impossibly old to my eyes, but to whom I was still sending cards up until her death thirty-five years later. Each visit involved the laborious picking of a bunch of violets, and a wobbly bicycle ride over the corrugations in the gravel road, jars of jam and biscuits rolling about in the basket. As a small child I was fascinated by the lack of conveniences in her house, her unusual style of dress, even her appearance. Most strange of all to me, a child used to adults wearing full dentures, was her almost toothless smile. When I think of her now it is with gratitude for what she taught me about acceptance of what life brings. She had had her share of tragedy and misfortune, but her optimism was undimmed. It was in her house that I first saw and accepted disability. Her sister had been badly burnt as a child in an open fire and always wore a mob cap to hide her forehead and hair, but not her badly disfigured face. Family legend is that I showed no fear of her, and that was what made me special to Peg.

As I reflect on how my upbringing and experience made it easy for me to relate to old people, I see why I can also recognise and relate to some of their values. This made it easy for me to develop rapport with residents, but may have also made me hesitate

62 Kleinman (1999: 78-9) sees ethnography as offering, even in its failures “a profound form of moral-emotional-professional autobiography. This is the contribution that ethnographers make to ethics”.
where boldness would have furthered the research ends. My respect for privacy and my fear of doing harm by probing sensitive areas were limiting factors in my interview strategies. There were questions I did not ask, times when I let topics lapse, and directions I did not follow. My feelings about what was and was not appropriate behaviour may have been unduly sensitive (compare Savishinsky, 1995: 96). I often found myself thinking of my father, who was of the same generation as these residents and had the same respect for privacy. He loved talking, but was embarrassed by personal questions and could never bring himself to ask them. Many of the residents reminded me of him and other old people I have known well, and it seemed only right to let them tell me what they wanted to rather than probe too deeply. I may well have been wrong – the public nature of their lives in care and the lack of opportunities to talk about themselves might have made them less reticent. Nonetheless, I responded to the signals I was receiving, and when a resident cried over the long-ago loss of an infant child and then said she did not want to talk about it, of course I did not ask her to. Equally, I found it impossible to ask how it felt to be paralysed by a stroke, to have a life of activity stopped in a second. I deduced the answers from residents’ bodies as much as from our long conversations about their lives ‘before’ and now.

My experience with horse-drawn vehicles, pre-electric lighting and refrigeration, fire-heated coppers and mangles for laundry, prop clothes lines, and a multitude of other features of a post World War II country upbringing, meant that I could understand what a resident 102 years old was talking about when she described her first job. When she said, “Do you remember?” I could more or less honestly answer that I did. My rural roots meant that I could listen and talk knowledgeably about farming, sheep dogs and small towns. I had followed my brothers around the farm and dodged ‘women’s work’, so am not very good at baking or knitting, but my mother was on the state executive of the Country Women’s Association, and the model was there for me to follow had I wished to. When a resident said to me “The cakes I’ve baked!” I could see the sponges and lamingtons and butter cakes, and recognise the pride she took in her skill.
Not least important was my gender. In the mainly female nursing home world I could exchange stories of being a daughter, a sister, a wife, a mother, even a grandmother. A common ground with all of the residents was the fact of my mother being in residential aged care. It was always something to ask me about – her health and the care she was receiving – and a point of comparison with their own health and mobility. Another feature of my experience, one which made it easier for me to speak to people with communication difficulties, was my background in teaching English to speakers of other languages. I have the experience, the eliciting skills, and the listening skills to make the most meaning from the least amount of decipherable language. As well, I can speak slowly and enunciate clearly, a practice which stands me in good stead with my own very deaf mother.

Relating to the staff

Again, my personality and communication style were important in relating to staff. I am generally an outgoing and friendly person, and I was eager to help, eager to learn, and tried to be supportive and tactful. I explained my research in non-threatening terms, was grateful for staff help and any thoughts they offered, and showed interest in their work lives. As previously discussed, the positive response to my presence and research interest led me to add staff interviews to my research plan. The cooperation was total, the interviews generous, and many staff expressed thanks to me for being interested, for listening, and for stimulating their thoughts by the questions I asked. When I gave feedback on those interviews, I was thanked again for continuing to include and inform them.

My influence on the nursing homes

I believe that my presence at the nursing homes affected practice to the extent that some staff became more conscious of how they communicated with residents, and how they formed their decisions concerning resident choices. Some told me that I had made them more thoughtful in their practice, and I observed changes in the attitude and practice of one person which I attribute to our discussions and the questions I asked.

63 Some staff I had not interviewed also expressed thanks for the feedback poster.
raised at interview with her. Individual staff continue to thank me for my interest and involvement and welcome my visits. As one nurse told me “You’re part of this community too”.

The influence of the nursing homes on me

I approached this task expecting to be confronted by my own ageing, as indeed I was. It was challenging, even threatening at times, but my ‘guides’ have left me feeling enriched and optimistic, or at least philosophical, about the ageing process and the years that lie ahead. It was, and continues to be, a deeply moving and humbling experience, and this thesis expresses a small part of my gratitude and acknowledgement of the residents who showed me their lives and laughed and cried with me. I found such life in old, tired, sick and disabled bodies, and such unquenchable spirit - truly ‘ageless’ embodied selves. I found pain and suffering, grief and loss and sometimes despair, but I also saw courage, generosity, undimmed humour, and warmth. There were people hoping to die soon, and regretting that they could not choose the hour, but many whose optimism and curiosity kept them wanting to see what might come next. In no case was there any fear of death. Acceptance was expressed in various ways, all of them without fear. The manner of their dying was an occasional preoccupation, though expressed as a hope rather than a fear. “I hope when it is the end it isn’t a spitter-spatter. I hope it’s quick”.64 I have to agree with this resident, but partly thanks to him and to other residents, I feel more able to imagine and accept with equanimity the prospect of my own death, and in particular the dying process.

Other aspects of the fieldwork experience which have left an indelible impression on me are my respect for the staff and families of residents who work so hard, give so generously, and try so hard to maintain the care and support of the residents. I was unprepared for the sense of community between residents, staff and relatives and the generosity with which staff engaged with families and families with both staff and other residents. The pre-Christmas Carols by Candlelight service was one of my most

64 Conversation with Charles: 13/4/04
deeply moving experiences. I went to help with wheelchairs and walking frames, and found myself marvelling at the ways in which the community itself triumphs. It was a glorious celebration of spirit over adversity.

Not all families are attentive, not all staff are willing to engage either with the whole community or with the whole person in their care, not all are sensitive to residents’ dignity and privacy, and not all residents are well or competent enough to tell the researcher how they feel about anything, least of all their own impending death. My experience simply suggests that there are many loving, courageous and supportive families, unquenchable elderly spirits in care, and dedicated and hard-working staff in nursing homes. My exact research experience will not be replicable, but other researchers bringing their own personalities and perspectives to the field are likely to find the same kind of people doing the same kind of things. Just as there are better and worse nursing homes, there are happier and unhappier residents and more and less well-trained and supported staff, but human nature does not change so greatly from one situation to another.

**Ethical and moral dilemmas in the field**

There are warnings from other researchers that “ethnographic or qualitative research with the elderly presents an array of ethical dilemmas for both the novice and experienced researcher” (Kayser-Jones & Koenig, 1994: 15). These warnings, however, do not and cannot forecast the myriad daily challenges involved in each researcher’s ethnographic experience in nursing homes. Each site is different from all others, and each day can be different from the day before. The warnings are like road signs that alert the driver to danger ahead, but not to the exact nature of the trouble or what to do about it. The larger sign posts include the ‘grand’ ethical issues: the complexities of determining cognitive competency; obtaining freely given informed consent; privacy and confidentiality; beneficence and non-maleficence; dealing with disclosure and the blurring of researcher role boundaries; and issues of reciprocity and advocacy. They go part of the way towards preparing the researcher, as does
recognition of the tensions involved in insider-outsider participant-observation, although these warnings may be daunting in themselves.

Because I had done a previous smaller scale study in a nursing home, in many ways I was prepared for what I would find in the field. However, I was not really prepared for the tension involved in the role I would take. This lay mainly in the degree of responsibility for the safety and welfare of residents, and in the ongoing daily balancing and soul-searching involved in recognising the dilemmas, thinking them through, and making choices for how I would be and act in each situation. My prime concern at all times was to do no harm, either to residents or staff or the organisation, so the degree of self-consciousness which I experienced involved constant personal monitoring and questioning and analysis. Like Bland who expected to find herself uncomfortable initially because she was a novice at participant-observation:

I knew I would need to be constantly on my guard, have to think about the consequences of every action, take care with every sentence I spoke and each step I took (2002: 43).

However, I was not prepared for the intensity of the personal scrutiny to be so enduring, and for the dilemmas and challenges to be not just daily, but at times hourly. This experience is widely shared by other ethnographers, but somehow it seemed unique to me.

Informed consent

The principle of informed consent is the cornerstone in most guidelines for conducting ethical research, but there is considerable debate about what this means in practice (Green & Thorogood, 2004). I find the concept problematic, given that the expert in any given situation cannot share all of his or her knowledge, and shared factual understandings must always be limited by the unshared understandings of the concepts implicit in the information. Additionally, the outcomes of whatever the ‘informee’ is consenting to can never be fully known in advance. Nursing home research is particularly problematic because of the dependent relationships residents have with staff and other authority figures, and the consequent risk that they will consent to
participate in order to please staff or researcher, or out of sheer loneliness (Kayser-Jones & Koenig, 1994). The social interaction involved in being an informant may well be an inducement in itself, contrasted with fear that refusal could compromise their relationships or the quality of care. The researcher is faced with determining not only whether the resident is competent to consent (having fully understood what is being consented to and why) but also whether such consent is truly free from pressure. Guidelines from ethics committees and the literature on conducting ethical research do not necessarily offer solutions to day to day dilemmas (see Higgins, 1998; Bland, 2002), although advice from some researchers suggests that anticipation is the key. Kayser-Jones advises the researcher to plan ahead “to ensure an informed consent process which is tailored to the varied levels of decisional capacity found among elderly persons” (1994: 30).

My research design called for interviews with ‘cognitively competent’ residents, to be identified by the Director of Nursing at each site. I was not planning for “varied levels of decisional capacity”, so found myself in a troubling quandary. Did my approved plan mean that cognitively competent residents had to demonstrate their competence every minute of the day? Did they have to be able to remember exactly what I was interviewing them for? If they told me during interview that they had no family but I subsequently met a relative, did that indicate lack of competence, a memory lapse, a choice not to give the information, or an interpretation of the term ‘family’ which was different from mine? Should I have simply accepted that the people identified by the DONs as competent were indeed so, or was I to follow my own instinct which told me that certain amongst them were not as competent as I had expected, and that I was not comfortable about interviewing them? As it happened, the cognitive capacity of two of the residents I decided not to include declined rapidly over the ensuing months, but for one or two others I am left wondering if, considering the debate around issues of competence, my research design was too narrowly conceived. If I were to begin the project again I might well be less exigent.
Debate around informed consent acknowledges that a large proportion of nursing home residents suffer some degree of cognitive impairment, but many researchers question whether a degree of impairment prevents a person from making a freely informed decision. Cassell (1988), citing Lidz et al. (1984) points out that although memory problems and even mild impairment lead observers to question whether a person has the capacity to make informed decisions, examples of failure to remember information given in a consent interview are found in much younger non-institutionalised people. Cassell also notes the inconsistency of standards for determining decisional capacity.

An additional challenge for the researcher is “fluctuating decisional capacity changing over time, even within the course of a single day (e.g., sundowning, or declining capacity in late afternoon hours)” (Moody, 1988: 65). Kayser-Jones points out that it is not an all or nothing situation, and when we are making judgements about decisional capacity we “must pay careful attention to timing and other circumstances” (1994:26). She supports Dubler (1987) in his proposal that, even with diminished ability, many elderly people are legally competent and capable of giving “acceptable” consent, depending on course of the complexity of the research. Lyman (1994) also argues that the benefits involved in social research of and on behalf of the elderly outweigh the risks involved in non-invasive observation or even sensitively conducted interviews.

Another dilemma inherent in the notion of informed consent is just how ‘informed’ it needs to be, and how often the researcher needs to reintroduce herself and remind all participants in the community of her researcher status and goals. I introduced myself to every new person I met, whether resident, staff, family member, or visitor, and regularly reminded people who I was. Some residents needed to be told every day, and some knew me by name from the beginning. They knew who I was, but what did they think I was there for on any particular day? Because of the porous role boundaries inherent in participant observation (Bland, 2002; Lipson, 1994), I slid between a plethora of roles. At times I was staff member and colleague, at times friend and confidant, at times entertainer, comforter, helper, messenger and advocate. When I

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65 Cassell (1988) gives the figure of 60% which may be a conservative estimate given the greater longevity and increased dependency levels of nursing home residents in Australia.
was reading to residents, helping them in and out of chairs, taking them for walks, giving them food and drink, did they remember that I was a researcher? Did staff who saw me as a valued colleague remember?

An area initially fraught with self-questioning was my serving of food and drink at social occasions such as Happy Hour. I had agreed not to spoon-feed residents, but when food and drink was part of a social activity, and the only way that some residents could share that activity was with assistance, what was I to do? Was spoon-feeding a thickened beer to a resident who could not do it for himself the act of a hostess, a friend, a concerned human being, or was I crossing into the zone of caring? I believed not, any more then wiping food or saliva from faces was. There was dignity and respect in my actions, and in the acknowledgement from the residents. I was nervous about my lack of skill, and apologised to a resident to whom I was feeding a thickened coffee at Happy Hour. She smiled and said, “You’re doing all right”.

The same dilemma arose over touching, especially in intimate areas. Was I to pull up the trousers of a male resident and fix his belt when he asked me to? Could I tuck in flying shirt-tails? I eventually decided the answer to both was yes, if the alternative was risk of a fall or loss of dignity for the resident. For these on-the-spot decisions I grew increasingly more confident of my own judgement, the ‘gut feeling’ which Lipson (1994) recommends as a fall-back point. The questions remained, but the solutions seemed more obvious.

On the other hand, I never had to cross the boundary regarding taking residents to the toilet. I took them there, making sure first that there was a staff member to take over. It embarrassed me to refuse to help the husband of a resident with dementia, but I found someone else to do so. I remain profoundly grateful to the administrator who decided that I should not be involved in intimate care. Higgins (1998) describes her distress.

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66 This resident died suddenly a few days later and I felt bereft – I had not known her long or well, but we had shared human concern for each other.
and regret at having irrevocably changed the relationship with one of her informants by witnessing his nakedness and vulnerability during the bed-bathing routine.  

Privacy and Confidentiality

Privacy in nursing homes, particularly in the older-style buildings with shared rooms and no private bathrooms, is very hard to maintain. At Greystone I had difficulty in finding places to interview residents in private, and even to keep confidential the identity of residents who were giving me interviews. I told residents their information would be confidential, but found that they were not concerned. I think their lives were already public (see Savishinsky, 1991: 117). Much of what I learnt from residents was already in the public domain, but I kept other information to myself except when I was able to suggest ways in which the Activities staff could offer better-targeted support.

Information about residents’ health status was available in Care Plans but I did not seek authorisation to read these. Occasionally I asked questions to be sure of handling residents safely and sensitively, especially where the resident had communication difficulties. In the Allied Health office I was given access to the Lifestyle Profiles. These had general comments about health status – just enough information for Activities staff to handle social activities – and it was not only appropriate but essential that I share that information. Nonetheless I read the Code of Ethics regarding confidentiality of nursing home records to be sure that I was an ‘authorised’ person. In everyday interactions I was told a lot about residents’ health, and now feel that perhaps I should have read the Care Plans from the outset. I was reluctant to gain information about the residents which they had not given me, or which they did not know that I had, but in fact for safety reasons I needed to know when dependency levels were upgraded.

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67 My one major embarrassment occurred when a nurse exposed the legs and underwear of one of my informants in front of me, saying “I’ll check if she needs changing”. It was an absolute breach of the resident’s privacy and affront to her dignity. I fled, and later the resident and I both pretended it had not happened. Was the nurse’s failure to recognise the stranger in me the result of my success in becoming familiar?
Reciprocity

“The dilemma is not whether to reciprocate or intervene, but what to do and how to do it responsibly” Lipson (1994: 351). I was occasionally faced with requests to help either residents or staff which I found difficult to refuse but difficult to fulfil. I have already mentioned my embarrassment at not helping to feed residents at meal-times, and I could not always give the concentrated special attention to residents suggested by staff. I declined a suggestion that I conduct the mini-bus excursion with only the nurse-driver, long before I had mastered the hoist or the belts and bolts required for stabilising the wheelchairs. On the other hand I met most requests, and could usually compensate by offering help in other ways. Some residents would have liked more of my individual time, and more individual outings, but in general they were grateful for any help I could offer. Most requests related to things wanted from rooms, the wish to be moved to another place, to have lighting, temperature, television or radio adjusted, or to have me ask a nurse to come.

Advocacy

Many researchers find the issue of advocacy more troubling than reciprocity. Part of the problem lies in determining where reciprocity ends and advocacy begins, but the issue is more complex than that. It has implications for the well-being of all participants at the research site; the threat to the integrity of the research process; and the wisdom and propriety required to know and take the right actions (Kayser-Jones, 2003; Kayser-Jones & Koenig, 1994; Savishinsky, 1995). I was fortunate in not being confronted with life-and-death choices such as Kayser-Jones (2003) describes. However, there were times when I wished I could intervene more directly on a resident’s behalf over issues of respect, dignity and personal control rather than anything related to residents’ physical well-being.

Most resident requests were for me to ask staff to come. I took the messages, aware that it often involved interrupting staff, explaining that I was keeping faith with the residents and not suggesting that I thought they were not doing their jobs. As staff came to trust me, most were relaxed and grateful for the extra pair of eyes and ears.
Only then could I sometimes suggest that the request really seemed urgent, or that the resident had already asked twice. I did my best to inform staff when I knew that residents had particular preferences, for instance *not* to be taken to an activity, or to be left in a particular room. That did not always work, but I felt I could not take a more active advocacy role without risking damage to staff-resident relationships or to my own relationships with staff. In fact, I believe I achieved more for the residents through talking to staff about my research and the issues that it was raising for me, including the larger questions of resident independence versus duty of care.

**Summary**

In this chapter I have explored the evolution of my project, described my fieldwork experience, discussed the influence of my background and personality on the project and the impact of the experience on me, and explained the range of ethical and moral dilemmas which I encountered.

In the next chapter I explore constructions of the ageing self and the significance of narrating the self and forming linkages between the past and present experience. I also look at how the values of their generation help to form concepts of a Good Life for this cohort of residents.
Chapter 5 – The Social Self: “Still here, still me”

The focus of my story now moves to the main character, the self. In looking at how this self experiences ageing, and interprets that experience of ageing, I raise questions about its essential nature. What do people in this culture mean when they talk about the self? What are the implied concepts on which they operate? I suggest that in their explanations, people operate with the idea that the self has intrinsic elements which are expressed in different ways at different times. The self is modified by experience, but at its core are certain constants: personal dispositions, essential psychological outlook, consciousness, individual approach to life and moral capacity. All of these are expressed by the self as agent. In my exploration of this self, I return to the central theme of my thesis – the meaning of being old and in care – arguing the case for this essential self, modifiable by all experience throughout the life span, able to accumulate layers through social relationships, but in turn vulnerable to the loss of these layers through the loss of those relationships.

Embedded in this chapter, the first of a trilogy, are the stories of Harry and Frederick and the relational self which each reveals. I explore the social construction of the relational self and its variable modes of expression, with attention to narrative as a primary means of recreating and communicating this self. In Chapter Six the mood darkens as I describe the paring back of the relational self, the diminishment caused by the loss of loved ones and the relationships which helped to create the younger self. In Chapter Seven, hope for the diminished self returns, with the prospect of renewal through new relationships within the nursing home context. Through all three chapters the intrinsic core self I describe is continuous, but open to modifying influences. That is, there is an essence which reflects core dispositions and personal qualities, although modes of expression and engagement with the world may change. As seen in the stories I recount, and the core values espoused by residents and as far as possible expressed within the institution, this self has the strength to continue to engage with the world even when diminished by loss.
In Chapter Two I argued that old people are essentially social selves, and rejected the notion that they form a separate group, different from the rest of society. They are simply themselves grown older. Now, I elaborate the notion of the ageless self by exploring residents’ self concepts, demonstrated through the stories they tell. The core values of my cohort reflect their shared past – the cultural and historical context of their experiences. These individuals see themselves as survivors of a hard but a good life, and on so doing recognise that they are still the same selves. In their stories we see how narrative is a key tool for maintaining the self and for constructing meaning: for forming linkages between the past and present; for integrating whole-of-life experience; and for enabling these old people to make sense of who and where they are in the present. Above all, in recognising themselves in old age they find validity in past experience and meaning in the present.

**Constructions of the ageing self**

The self I present is a socially constructed relational self. In Chapter One I discussed the contribution to this thesis of Cohen’s vigorous, motivated self, one constructed through social experience but with “the authorial power of agency, the capacity to be self-directing” (1994: 99). I take Cohen’s notion of selfhood, “an essential continuous core of experience”, and agree that it is not the transformable self suggested by Goffman (1962). In describing the stripping of identity suffered by entrants into ‘total institutions’, Goffman conflates the externally represented self with the whole self. He suggests that after the stripping, there is no self left and it has to be replaced by a new one, hence the ‘transformable’ self. I reject that argument, and link Cohen’s essential core self to Kaufman’s ongoing, cumulative process of identity forming (1986: 149-50).

68 “A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” (Goffman, 1960: xiii). They include prisons, army barracks, mental hospitals, nunneries and nursing homes.
While not denying the trials suffered by the self in old age, a subject which I explore more fully in the next chapter, Cohen emphasises “the enormous effort which, as a consequence, they put into self-maintenance”. He cites Myerhoff’s (1980) tenacious elderly retired Jews whose individuality lay partly in making themselves audible and visible, but also “in the demonstration of the continuity of their past lives in which their identities rested on the more secure bases of occupation, parenting, and place and family of origin” (Cohen, 1994: 102).

**Locating the self in the past: context and social interaction**

I argue, with Frank (1991), that it is the process of telling and retelling the life story which enables the recognition and reinforcement of the self. Looking back at a life lived, with the mix of growth and loss, of triumphs and disappointments, we begin to understand how the different pieces fit together, to see ourselves and know ourselves better. The act of narrating, of sharing, of co-constructing the story with others, enables “the mutual recognition on which relations with others are grounded” (ibid: 89).

I draw also on Cohen and Kaufman’s discussions of the ageless, continuing self which thrives on narration of the past. Kaufman’s ‘ageless self’ (1986: 26) depends on its capacity to connect past and present lives and to find “the present significance of past experience, the current rendering of meaningful symbols and events of a life”. Storytelling is “narratively productive of aging as it reproduces the received wisdom about what it means to be old” (ibid: 6). I draw too on Gubrium’s (1993; 1995; 2001) argument concerning narrative linkages which make the present meaningful because of connections with the past. Kaufman argues that storytelling helps to reveal what it means to be old, and Gubrium (1995: 24) offers the notion of “interpretive horizons of the social settings”, which in this case are constituted by the nursing home. I link these two elements throughout this thesis. The residents in my study recognise themselves in old age, and experience institutionalisation as one more life event.
The relational self: Harry’s story

Harry was nine years old when his father was reported Missing in Action during World War I. He resolved then to take care of his mother and see that she had a “decent” life. This included taking responsibility for his brother and sister and an unborn baby. Hard years followed, with post war privation, then four years of unemployment and economic hardship during the Great Depression. To protect his mother Harry took any work he could, no matter how irregular, badly paid and unpleasant. With better employment and financial security after the Depression, Harry set up house. His mother always lived with him, and he took in other family members in need. He put off marriage for many years because of these responsibilities. When he did marry in his late 30s, it was to a woman who was prepared to share a house with his mother. The marriage was a good one, and Harry was proud of how his wife coped: “She was very good to my mother”. He entered the nursing home at 94 years of age, having lived alone for six years after his wife’s death. The niece he had brought up lived interstate, so a neighbour of many years acted as next of kin in practical ways, helping to settle him in, and seeing to appointments and shopping.

Harry was cognitively alert but hearing impaired. He was shy, modest, extraordinarily unassuming and grateful for every attention paid to him, but his deafness and shyness prevented him from initiating or sustaining interaction with other residents. Because he had few teeth he did not articulate clearly, and this, combined with his breathing difficulties, made his speech difficult to understand. His reluctance to wear hearing aids (as well as their failure to make communication much clearer) meant that he did not hear or understand other residents’ speech either. He blamed himself for his isolation, but did not realise that the three men who shared his room were cognitively impaired. With encouragement, he would take part in group activities such as Bingo, bocce and the exercise class. He was less willing to participate in conversation groups or quizzes, and his speech offerings (as with most of the residents) needed to be conveyed through a facilitator. He disliked going to the dining room for meals, afraid of not hearing and perhaps giving offence, either through not answering, or giving an inappropriate answer. He spent most of his time in his own room, and since the most comfortable place was on the bed, he tended to lie there, fall asleep and be dissatisfied with himself for sleeping so much. I once took him to the dining room to talk to a friendly resident. With me acting as a facilitator they exchanged personal information, discovered that they had lived near each other and, I hoped, formed the basis for future conversations. He told me he had enjoyed it, and would get out of his room more, but I do not believe that he did.

Harry had a keen interest in current events and valued his right to vote. He was glad he had his sight and could read the daily newspaper, but felt he had nobody with whom he could discuss the news. Starved of meaningful communication, he was extremely grateful for my regular visits, though at times the noise from other residents (one sometimes had two radios on different stations), and staff involved in performing care tasks, made it very difficult for him to hear. I had to speak very loudly and clearly, and was very conscious of the lack of privacy when other staff were in the room. However, I also hoped that they might become aware of how communicatively competent he was. I told several floor staff how much he needed people to talk to, and one said “That’s the sort of information we should have in the Care Plans”. The Activities coordinator suggested that perhaps a special visitor might be arranged for him. I was initially surprised that it was not general knowledge that he had full cognitive capacity and unmet communication needs. However, though he spoke to me of his loneliness, he would never have “complained” to staff. He constantly told me how good they all were to him, and how lucky he was, but then made wistful comments like “I never expected to end up in a place like this”. I did not discuss Harry’s health with him (or with staff, until
He became visibly very ill). He was determined not to complain, but after a fall in the toilet when he had found himself unable to get up, he told me with bitterness, “I hate old age”. When he died, no-one at the nursing home was told of the funeral arrangements. Presumably his interstate relatives did not realise that he had a role at the nursing home, and relationships, however tenuous, with staff and residents. People may not have known him well, but they liked and respected him. Staff would have liked a small memorial service for the residents to mark his death, but missed the appropriate moment. That quietest and least demanding of men was sincerely but not publicly mourned in the place where he lived his last six months, for much of the time lonely.

Harry, in telling his story, relived his past, in particular his life devoted to helping, supporting and protecting his family. The self he re-created in that telling was a self formed through relationships, relationships which were vital in building his own value. Being responsible, and having that responsibility acknowledged in his relationships, constructed his strong sense of self. When the relationships no longer existed he no longer had the same modes of expressing that self. The self remained the same but ceased to be actively relational, sustained instead by pride in the past and the memories of his relationships. The roles, that of devoted son/provider/protector, brother, uncle/father substitute, and good husband were strong in his memory. Letters, cards and photographs from his niece sustained the role of uncle, and visits from his wife’s friend served in part to sustain the memory of being a husband. I never heard Harry and this friend Lily mention his wife, never heard her name. However, Harry told me that he would be grateful to Lily as long as he had breath in his body because she had been so good to his wife. In his memories, as they were told to me, he was also a loyal friend, a sociable person, a hard and reliable worker, and an honest man who did his best to do no harm. He had overcome adversity on many fronts and emerged with a positive appreciation of his own value. Talking about his life gave him something real to hold on to when so much had been taken from him, but absence of opportunities to talk left him lonely.

Harry embodied many of the virtues espoused by his generational cohort (see later discussion) and was proud of the life he had lived. Yet he found that there was no-one to tell his story to. In earlier chapters I discussed the importance of the discourse context as a primary factor in the way that “individuals actively create, negotiate and manage their selves through interaction with the social world” (Williams & Nussbaum, 2001: 152). Giles, Fox et al. (1994) and others have shown how a hostile
or unsympathetic discourse environment can contribute to the construction of frail identities in older people. As I saw with Harry and others, there are important consequences for boosting or lowering morale in locating the self in the past, linking it to the present and future and being heard (see also Coupland, Nussbaum et al., 1991). Savishinsky, in highlighting the need the institutionalised elderly feel for their stories to be heard, could have been describing Harry.

For those whose speech and memory were intact, polite conversation was usually not sufficient. They needed to be able to share their stories and their lives: listeners were witnesses who affirmed a person’s history by hearing, laughing at, commiserating with, and participating in reminiscence (1991: 241).

Harry’s memory was intact, his speech too, though it was indistinct. He desperately needed to be able to share his story and his life, but he lacked witnesses to share in the reminiscence. His morale was boosted when he told me his story, but lowered by his loneliness and failure to be heard by others. Frank’s (1995) ‘wounded story-teller’ speaks of narratives of illness, but the illness, pain and disablement of old age is also in need of a voice, one to be found in the notion, still an ideal, of the communicative body. This is “about recognition which is enhanced through the sharing of narratives which are fully embodied” (Frank, 1991: 89). I argue, with Frank, that relations with others are based on this sharing.

**Constructing the self through narrative**

In Chapter Four I discussed the ways in which I elicited the narratives I use in my discussion, and the active role which I took in co-construction of the stories. My interest in the speakers and my prompting of their memories and reactions to their own memories were part of the relationship building which led these people to trust me enough to talk to me, to want to remember and to reflect on their experiences. My role in co-constructing resident narratives was both essential to and the result of relationships which were also being constructed.
Reflective extended narration is not a well-practised art in Australians of this generation, particularly those who have had relatively few years of schooling, and their recounted memories were often episodic rather than narrative. However, even without coherent, linear structures and logical beginnings and ends, they tell a story and work to construct identity. Seemingly trivial comments often lead to profoundly important statements, important, that is, in laying claim to the storytellers’ lives and their selves. In my own interviews the most unlikely of questions produced a line of narrative which, while not always told as a coherent story, nonetheless revealed important elements of the self of the informant as he or she constructed it. One informant who spoke more readily was Frederick, and I tell his story in part as a contrast to Harry’s.

**Frederick’s story**

Frederick, born in the years after World War I, had a secure and comfortable early life, with parents able to provide him with a good education and to impart strong personal values for which he admired both them and himself. At school he had learnt the importance of behaving as “a member of a team” and imbibed a thirst for knowledge and a commitment to “the betterment of society”. He had been strongly influenced by a number of teachers and by the lives of some of the people he learnt about. He developed a great admiration for those he felt had made a contribution to society, philosophers and poets and statesmen like British Lord Nelson, American President Lincoln and German Chancellor Bismarck. He admired “the German way of looking at life, of discipline”, although he deplored belligerence. A modern hero was Nelson Mandela. Frederick served in the army in World War II and found the experience formative. It taught him discipline and reinforced his regard for placing the good of all above individual interests. He believed he had a duty to continue educating himself, but also to act as a mentor to young people, and to help others. His goal was to contribute his own personality and talents. His professional life was a source of pride – he had done his job well, continued his life-long learning, and contributed to the lives of others. He called his life story “the Anatomy of a Personality”, and felt that at each stage he had become a better and more useful person. Above all he believed in filling his time and his life usefully, being tolerant of others, and making a contribution, however small.

Frederick had never married and did not mention any living family. A friend who appeared to be a former professional colleague visited him regularly and sometimes took him out. In the nursing home Frederick continued to work for the common good. He helped other residents by informing staff of their needs, helped staff with newsletters and speeches for important occasions, and took a leadership role in speaking for residents. He enjoyed ceremonial occasions and discussion and debate, mainly with staff and visitors. He took part in quizzes at Happy Hour, but otherwise was not interested in organised activities. Resident to resident conversation was limited by a

measure of hearing impairment on his part and that of others, but in any case there were few residents able to share his interest in books. Consequently he was often alone, usually reading, but never appeared lonely.

Frederick’s socially constructed self was built around his relationships with society rather than with individuals, and when he was separated from most of the people he had known he remained comfortably committed to the greater good. His relationships, in not being firmly attached to individuals, were to a large extent transferable. His pride in himself, his past achievements and present goals, and the leadership role which he assumed in the nursing home, revealed a sense of self intact in the new environment.

**Analysing the narrative**

I have based the analysis of my informants’ narratives on a grouping of themes and values which appear to shape their self concepts. In identifying and grouping these themes and values I establish what is important to members of the cohort about their past and present lives and how they understand who they are now. This is similar to the approach used by Kaufman (1986), in that my analysis does not use the rules and properties of narrative analysis. I use both the words ‘narrative’ and ‘story’ to describe my informants’ accounts of their lives, looking for the meaning that they find in the experience of narrating. Both terms are widely used in similar contexts, for example by Frank (1995), Kenyon et al. (2001), Gubrium (2001), and Taylor, (1989). In my discussion I use the terms interchangeably. Some of these stories seem not to have been told before, or not in the recent past, and they are slow, halting, even painful in the recollection. Others are more polished performances, stories which have been told often, which run in well-rehearsed grooves, and which are significant because of what the telling means to the story-teller as much as for what they convey in factual information. Benner (1994: 119) suggests that the oft-told story is closer to shared memories, ideology and beliefs than the unrehearsed first telling. In fact my informant Charles reverted to the same theme, his childhood and his admiration of his parents, on many different occasions, and was more fluent, consistent and expansive on that theme.
than on the less rehearsed ones. It seemed that he found greater meaning in that formative stage of his life than in subsequent relationships and experiences, though there were some signs that recalling the details of some of his middle years was more difficult for him.

My analysis is based on narratives transcribed to text, and is driven by my search for the self.\(^7\) As an engaged ethnographer, my major concern is the process of revelation of self, and I explore the interaction and content for the way in which it reveals the self. I take the advice of Kenyon et al.: “Questions about what makes life worth living to individuals are only answered by asking the individuals themselves” (2001: viii). My goal is to give voice to the individuals I interacted with, as did Gubrium (1993), “representing their personal stories as truthfully as possible to the contexts of their original telling” (Coupland & Coupland, 1995: 99). There is no question of right or wrong, of establishing veracity or objectivity. The narrative is necessarily ephemeral, given that “the life is not something distantly set in stone, which the researcher more or less accurately retrieves and records…the constructed lives of nursing home residents…are conceptually hyphenated lives: versions-of-life-subjectively-pertinent-to-the-nursing-home-situation” (Gubrium, 1993: 178, cited in Coupland and Coupland, 1995: 99). In the next section I use my data to support the key themes of this chapter, starting with the notion of qualities of the self which residents identified and claimed as theirs, in the past, but also now. Retention of these qualities is integral to the retention of a self which they can claim and admire.

**The Self: being ‘good’**

Most significantly, what my informants saw as virtues and qualities were those which, in the main, they felt they still possessed. Their physical circumstances and capacities and opportunities were limiting factors, and in particular this affected some residents’ perceptions of themselves as Being of Use. This is a common theme in other studies.

\(^7\) I am aware of Michael Moerman’s analysis of conversation as a tool for cultural analysis, and of the debates within narrative and linguistic analysis and within the field of reminiscence and life review, but do not incorporate them in my discussion.
for example Gubrium (1993) and Nay (1993). Some expressed frustration over this loss, a topic which I discuss in a later chapter. Their comments included: “What purpose do I serve? What use am I? What do I produce?”, reflecting the strong value which they had always placed, and still placed, on being useful in practical ways. A related and common theme was Helping Others (also similar to Being a Good Friend). This commitment to helping fellow residents is also reported in other studies, although under different names. Savishinsky (1991) describes the ‘helpful role’, Gubrium (1993) uses the word ‘supporters’ and O’Brien (1989) ‘watchers’. They all put their vigilance to good use. There were others in my study besides Frederick who looked out for fellow residents in small ways, or tried to support staff. In one striking case I saw a resident with dementia lovingly showing another equally confused resident the way back to her chair. Residents asked after each other’s health, visited those who had been bereaved, were interested in the well-being of other residents’ families, and shared newspapers and news. They also attended organised activities, partly as an act of social responsibility. Frederick’s life-long goal had been ‘contributing to the betterment of society’, which he felt he was still doing within the nursing home.

Another group of virtues was related to interacting with other people, Getting on With Others. This had relevance to earlier working and family lives as well as present institutional lives, and included: telling the truth, taking responsibility for others, being a good member of the team, respecting the rights of others, not hurting others, being kind, minding one's own business, coping with people, being nice, being friendly, and even having a sense of humour.

A group of personal virtues, ones which I attribute very much to the age of the cohort and the influence of the hard years between the wars as well as the Great Depression, included: being frugal, a good provider/wife/mother, modest, honest, strong, disciplined, hard-working and, as reported by a number of residents, not drinking. It was also important to be uncomplaining, to do things well, and to be able to learn from others. A final group of themes, more reflexive, included being yourself, ‘having a brain’, seeing your own weaknesses, being patient, tolerant and flexible. It also,
sometimes implied rather than explicitly stated, included being grateful (related to not complaining) and recognising that there are others worse off.

These virtues and qualities continued to shape these selves. The residents recognised themselves as being good people, as having good intentions even if they could no longer carry them out, and those present selves were the same as the past selves. When Harry said he could look in the eye of any person he met in the after-life with the knowledge that he had been honest, it was Harry speaking in the present of himself, not Harry describing some past self. When Frederick spoke of contributing to society, he was speaking *in* the present of the *present self*.

**The values of their cohort: historical and social background**

Turner, speaking in the first person, claims that “[m]y aging takes place within the context of the cohort of people whom I regard as part of ‘my generation’ and thus in relationship to previous and coming generations” (1995: 254). Because of the age range of my interviewees, the cohort can more properly be described as two ‘generations’. The older group, born before 1925, are sometimes classified as the Federation Generation, and the younger group, born before 1942, fit into the category of the Depression Generation (Strauss & Howe, 1991). Most of the members of my cohort were old enough to remember the Great Depression, or to be aware that their lives had been affected by their parents’ experience at the time. One who was born during the Depression uses the well-worn line, “born in the Depression and been depressed ever since”. The oldest residents had clear memories of World War I, and all residents except one of World War II. Several had been marked by personal history during these and other key periods. However, like Kaufman’s informants (1986), they saw significance in these personal events rather than in grand moments of history. The scope of experience of the residents aged over 100 was so great that they resembled the ‘time-travellers’ cited by Coleman (1995: 47). The changes they have lived through are dramatic. These oldest informants share a world with people who have been fed, housed and educated differently, have received different medical
treatments, have experienced huge social changes, and are confronted by changes in culture and values. These include “the rise of the so-called permissive society, the decline in church attendance, and the growth of television and the media” (ibid: 48). In addition there is the stunning impact of globalisation of trade, communications, even war and terrorism. However, Coleman cautions against exaggerating “the extent to which the experience of old age is different now than it was in previous generations. It has probably always been a challenge to older people to adjust to the changes they experienced in their own lifetime” (ibid: 48).

For the most part, my interviewees did not lament the changes they had witnessed and experienced. One exception was the oldest, Winnie, who complained of the physical changes which had taken place in the city of Melbourne. The geography of the city was strongly linked to her memories of her childhood and working life. A comment about her work during the Depression elicited more details about her relationship with the city and the experience of getting to and from work than about work conditions. As well, she described the place where one of her brothers had disappeared in the sea, and the holiday houses which the extended family used to share by the beach. Naming of streets, relationships between places, and descriptions of transport were very significant as part of her memories of the past (compare Howell, 1983: 98).

In considering the impact of major historical and social events, it is important to remember that Winnie was more than 30 years older than the youngest resident interviewed, and as Hareven (1995: 126) points out, responses to changing social and economic conditions vary significantly between younger and older cohorts because of their significantly different individual and social experiences. As well, “historical events and social conditions would not be expected to affect all members of a generation in the same way, and we must be mindful that generations are made up of subgroups who may hold contrasting and conflicting values” (Williams & Nussbaum, 2001: 144).

71 For example, most of the residents in my study, like my parents, had most, if not all, of their teeth extracted at a young age.
World War I

World War I for Winnie meant the death of a brother, and shared family grief, but not a profound shift in her lifestyle or sense of who she was. Nonetheless it became part of her family narrative, and her memories remain amazingly clear, to the extent that her brother’s military number, date and place of death, and details of the funeral are all fresh for her. She expresses some of the futility of his death in the words “he died”. This contrasts with how war was represented and understood in 1917, when the public found some consolation, despite the huge death toll, in the “heroism of the Anzacs” (Macintyre, 1999: 164).

Winnie Well I lost a brother at the First World War. He died on the 3rd December, 1917. He was shot at Gallipoli. We hoped he’d come back, you know. I always remembered his number, it was 613. That was his number. He was in the 6th Battalion. Of course they practically got wiped out. He got shot in the leg. We did have a photo of him.

JT So he died of injuries later, did he?

Winnie Well he was in…we didn’t know he was in France at the time. He got moved into the 5th Field Bakery, and my mother got this letter on the 10th of December 1917. It just read “We regret that your son has died of…” He died. He was sent from France to England with meningitis and pneumonia, after being at the war all that time. And then they got a letter from the matron of the hospital, I suppose just a form to show that they didn’t think he had any chance. And he had a full military funeral in Aldershot, in England. And they sent us a copy of the…

Harry’s experience was very different and devastating. His life-long behaviour was shaped by the events of World War I, and the self he showed me bore indelible marks of that experience.

Harry And I was only about eight or nine, and that was… That period of time had a very bad effect on me. You know that? I was only nine, but I remember quite distinctly, that (tape unclear)…things all being wrong?

JT You felt lost?

Harry I felt so sorry for her, you know.

JT More sorry for your mother?

Harry Yes, being left behind when my father was killed…
Commenting on his mother’s grief and distress, he continued:

Harry  It had a great effect on me to see people so upset at that period of time, and only if I had known. I was the oldest boy.

JT  So that was your first understanding of adult emotions.

Harry  Beg pardon?

JT  So that was your first understanding of adult relationships and feelings.

Harry  Yes. I felt terrible… It’s many, many years ago now, and I’ve got over it now, but I’ve still got, it makes a difference, that period of time, quite distinctly down there (pointing to middle of body).

JT  You feel it strongly.

Harry  Yes, that’s always been, a certain time…

Harry’s narrative was wound around caring for his family, his sense of responsibility sparked by his father’s death and the posthumous birth of his brother. His sister and her child automatically became his responsibility too. In times of hardship, it was up to him to care for all of them.

Harry  Her husband died, in Myrtleford and that set the whole thing back. And when he died she didn’t know what to do, so they came back with the little girl to our place, and they brought the little girl, she’s more a daughter you know, she spent her whole life with me until she was married. That’s the one that’s in Darwin now. She’s a pretty good girl.

JT  So that’s the same niece?

Harry  Yes, that was my sister’s child.

JT  So she was close to you as a small child?

Harry  Oh yes. Well she was only 18 months old when they brought her down to my place. And then my brother got married and he didn’t have any place and he moved in. He was battling…

Harry’s devotion to caring for his mother lasted for her entire life, one which he ensured was more than ‘reasonable’.
The Great Depression

Today, few can comprehend what it was like to live through the trauma of the Great Depression as a child. Grinding poverty meant that many children had to work – they had no option, for there was no social security, and an extended childhood was an unaffordable luxury… These are the people who collect plastic bags, elastic bands, because you never know when they’re going to come in handy (McLaren, 1999: back cover).

Most of my informants took the Depression for granted. It happened, it was hard, harder for some than others, but they lived through it. Nonetheless, in most cases it seemed to lay the foundations for a careful frugal life – rejection of waste, respect for saving, fear of debt, and the need to be prepared for the future. The most deeply affected was Harry, already marked by the privations his family had endured immediately after World War I. He suffered from the uncertainty and discomfort of unemployment and poverty, a phenomenon well-documented in published accounts of the Depression years (Lowenstein, 1978; McCalman, 1984; McLaren, 1999). An additional source of grief lay in seeing the mother he was determined to protect obliged to go out and scrub floors. Harry’s use of the word ‘battling’ to describe his brother’s financial difficulties has a sense which has been lost in modern Australian political usage. The Australian Prime Minister has appropriated the term ‘battlers’ to describe a group of ‘aspirational’ voters, middle-income earners with mortgages who aspire to own a bigger house, a second car, or to send their children to private schools. ‘Battling’ in the sense that it is used by my cohort, means struggling to find even irregular and often hard and unpleasant employment, to earn enough to pay for a roof over their heads, to put food on the table, to buy shoes or medicines for their children. It is no surprise that Harry’s lifelong concern was to be prepared, to be secure, to save for the future, although this single-mindedness was a source of regret and sorrow to him after the death of his wife. He felt he had been wrong to save for the future when he could have made the present more enjoyable.

JT You had a good life.
Harry Yes, but I was very, very sorry when the time come that we had to part... I said to my wife one time, we’d had a car one time, I was good with the car. I said “We’ll save a little bit of money, and if we do retire, we can have a bit of money and we
can have a bit more pleasure than we have at the present. Because we’ll put the money away”. And to me, that was a wrong thing to do.

Harry returned often to the same theme, always with regret for ‘wrong’ choices made. His frugal, responsible self should somehow have been able to throw caution to the winds and run financial risks. As a planner he had failed.

I said to my wife, “and we’ll put a few bottles of wine, and when I do retire, when I retire, I’ll sell the wine. She’ll be as good as gold. But if we have a few bob to spare, it will make it a little bit better for our retirement”. It never came to that, because she… she got very, very sick.

In caring for his wife properly, Harry felt he should have foreseen the possibility that he might lose her. It was consistent with the demands he placed on himself, the sense of responsibility he always felt for others, that he would see it as a failure or a weakness to not have taken care of everything better. It was especially hard to find himself with more than enough money when he no longer had people to provide for.

Others had been less obviously marked by their experiences during the Depression. Frederick did not include it in his narrative. Jack’s father had been in work and the Depression “didn’t seem to be a problem”. Winnie’s work week was cut back to three then to two days, but her life, which revolved mainly around her large family, went on. Sarah’s wage, already low, was cut by half, but throughout her childhood her family had always struggled to manage on little money, so making-do was not new “and you walked everywhere and you used to take any job you could get” (see similar accounts in Lowenstein, 1978; McCalman, 1984; McLaren, 1999 and others).

Nellie’s schooling suffered during the Depression, and with it her self confidence. However, in her narrative it is entwined with, even overshadowed by, the loss of a much loved older sister who entered a religious order at the same time.

Nellie Oh yes. I really used to be terribly sad after she went.
JT It must have left a hollow.
Nellie Oh it was terrible. And during that month...Mum was paying off the house that we lived in, and in the Depression she couldn’t keep up the payments, and to save her from losing the house, we moved to a house in Kensington and rented it. And that
was cheap and then having the instalments of the house paid, and we stayed there in Kensington for about three years. And I had to go to another school which was far away.

**JT** Was that difficult for you?

**Nellie** Oh it was a bit.

**JT** Were your school days happy days?

**Nellie** Oh, I wasn’t very good at school. I didn’t think I was very clever.

**JT** You probably didn’t have the right encouragement.

**Nellie** No, my mother could have helped me, when I wanted to know things. She used to help me, my sister. She used to read to me, and everything like that. Well I missed her.

These narratives are significant because they reveal experiences which marked the selves which were presented to me. The effects of hardship, negative or positive, had contributed to current views of self. Nellie still had little or no self-confidence. She felt inadequate socially, unable to be at ease amongst people. She found fault with herself and was saddened by it. Harry was still proud of himself because of how he managed to rise above adversity and look after his family. He saw himself as strong, capable, responsible and hard-working.

**World War II**

Although Millie reported being “a bit scared in that World War”, most of my informants were relatively untouched by the Second World War. Only one of the men served in the armed forces, and only two women had husbands who were away from home. Nellie’s husband returned from New Guinea with malaria but recovered quickly, found reliable employment and began further study. Sarah’s had health problems related to alcohol and tobacco, both of which he had been exposed to during the war, and died suddenly shortly after his return.

Frederick, the one member of the cohort who had served in the army, felt that he had benefited from the experience, and saw it as part of the development of his character. It was the personal experience of being in the army, however, not the war itself, which was formative.
Are these the same things that you valued when you were younger?

Precisely. I have, throughout my army time, when I was in the army – that’s a testing time of anyone’s character – I believe that the army has helped me to understand how people think and how people discipline themselves in adverse circumstances…

So, the war years. Were they a very formative period for you?

The war years? Oh yes. Quite definitely formative. I learnt to see, with the army as part of my growing up, learning to accept orders even if you weren’t giving orders, you have to accept them. Not blindly, but in the Australian army you do have the opportunity of expressing your feelings about certain things which you may not agree with in civil life. You have to say that that’s part of the army tradition, and you have to lose something of your own independence, but it’s for the greater good of everyone.

The same backdrop of the war affected the employment of men too young to serve. Jack left school in 1945, and initially had plenty of work choices, including on the site of the new Royal Melbourne Hospital being built in preparation for the returning soldiers. Later, he lost his job to one of these returning soldiers (see Macintyre, 1999), but it was not a threat to his self-esteem.

See, when I was working on [public works organisation] – I had the bad luck to fracture my thigh. When I went back, the Menzies government was in then, and they said, “We only employ Returned Men”, you know. I wasn’t a Returned Man so I had to go and make room for a bloke that was.

How did you feel about that?

Well I thought that he was a thorough idiot…

There was no self-pity in his narrative: he told the story with himself cast as the superior worker, finding humour in the incompetence of his successor. Nor were there any catastrophic financial results from his job loss. He was young and flexible and had a spirit of adventure. He simply moved interstate to where other work and new challenges were available.

Both Jack and Frederick’s narratives highlighted the consistency of their responses throughout their lives: the selves they revealed were the same selves, the connections between past and present experience made visible as they were by Kaufman’s (1986)
‘ageless’ selves. Jack’s story was remarkable for its self-acceptance, and a willingness to put the past behind him. There was never a victim in his stories, even when his active life was suddenly restricted by ill health. Frederick’s preoccupation with the well-being of society, the greater good of everyone, had been a life-long concern. The years in the army helped him to define his goals, but he held the same values both before and after that experience. In telling their stories, and in their daily behaviour, both men demonstrated that the past was very much part of the present and their present selves. They were both good raconteurs, finding frequent opportunities to be heard, both able to take on new social roles and find Gubrium’s (1993) “horizons of meaning” in the nursing home setting.

**Themes: still here and still me**

**A Good Life (and a Hard Life)**

A sense of achievement, of pride in things done well, underpinned many informants’ views of a Good Life. That, along with recognition of the value of relationships, of people who had been and continued to be important in their lives, was a main theme throughout the narratives. Most expressed pride either in achievement, or in personal qualities which they felt they demonstrated, and gratitude for any combination of ‘good parents’, spouses and children, siblings and friends.

**Marriage and Children**

Harry, like most of the cohort, assured me that he had had a good life. Amongst the factors related to a Good Life, the most commonly mentioned was marriage, and Harry too felt his had been good. Good parents were also high on the list. For some people, children were a major source of satisfaction and happiness. Of the twelve people interviewed, eight had been married, and one of those, widowed early, had married a second time. She did not list marriage as a source of satisfaction, and described her second husband as ‘not very helpful’. Another had only been married for
a very short time, and still felt anger towards the doctors she blamed for her husband’s
death. She had no children, but did not express regret, any more than the four who had
never married did. One of the women had been very involved in the lives of all of her
siblings’ children, and one man had a close relationship with his sister’s children and
grandchildren. One married woman’s husband was still living in their family house,
something which made it difficult for her to see the nursing home as a home, much
like Gubrium’s resident: “I don’t feel that I’m part of this place at all” (1993: 56).
Amongst those who claimed to have had a good life was Peg. She repeated it four
times in the initial interview, and reverted more than once to the theme of ‘never
wanting for anything’, although it was clear that her parents had not been not well off.
Family harmony was more important to her than wealth. She emphasised the
importance of a good husband and of sharing in marriage. Hetty’s real story began
with meeting her husband, and then with the years they spent together, and her pride in
his skills and achievements, their saving together to get a house, and her pride in their
children. Talking about him made her cry, so after the first conversation I never
introduced his name again. Charles spoke more of his parents and brothers and his
childhood than his marriage, though he praised his wife, and expected to be reunited
with her in the after-life. Charles’ Good Life theme included satisfaction with himself
as a good worker, and work was a recurrent theme in other informants’ stories.

Work

Harry was proud of his work skills, and the perfectionism which he brought to every
task. The pain of not having had regular employment during the Depression was partly
off-set by his pride in the later years of his working life. Career success and
demonstrated abilities to provide well for his family had been necessary to obliterate
bad memories and consolidate his self-esteem (see Hockey, 1993: 138 for the
conceptual links between work and identity). Harry had retired reluctantly, but was not
forced out before the statutory retirement age, so the loss to self-esteem was mitigated
in spite of his lasting regrets.

JT You’ve always had that [sense of responsibility]?
Harry Yes
Towards your work as well, your employers?

I had the name, too, with things at work, you know. I wanted to see everything right. I’d see some people working, and the, “Oh, that’ll do”.

That was never enough for you.

No. If I set on something, I wanted to see that it was almost as perfect as what I could possibly do, you know. I enjoyed working. I still wish ... I thought that I would work much longer than I did.

When did you retire? At what age?

68. I worked three years…three years over my time. I wish I could have stayed a little bit longer at that period of time. I enjoyed working.

Frederick too defined himself largely in the frame of his career, and the contribution which he felt he had made, and endeavoured to continue to make, to society.

I would say there was no really high point. It was a question of developing, hopefully, hopefully (sic) towards maturity, understanding of the rights of other people and learning, continuing to learn, and to hope that in the future, whatever you do, or in my case, whatever I did, was going to lead to a finished personality and to making a contribution as I explained before, to making a contribution, however small, to the rest of society.

Jack was also proud of his work skills and willingness to try his hand at anything. His life course had been largely determined by his pursuit of varied and rewarding jobs. None of the women felt defined by their work, a reflection of the role of women and the expectations of the society in which this cohort grew up. Even Winnie, who had worked for 46 years, defined herself in other ways. Her family relationships and her roles as daughter, sister, aunt and cousin were far more important than any role as a factory employee. Hetty had worked in a department store before the births of her children, and then after they were all at school. She felt she had been good at her job, and was proud of that, but made it seem less important than her real career, which was wife and mother.

**Hobbies and Interests**

Much of people’s sense of a Good Life was made up through their social and other activities. These included voluntary work, breeding and showing dogs, membership of groups such as the Senior Citizens’ Club, spending time with friends, dancing (four
people had gone dancing regularly for years, often more than once a week, and three had met their spouses that way), sport, holidays, and travel. Harry, for all the hard times he reported, had still had a ‘good time’. He described the pleasure of spending time with friends as well as the other hobbies he had enjoyed.

Harry: I enjoyed myself. I went out dancing.
JT: You did dancing. Did you play sport?
Harry: Oh yes, I played sport. I was very keen on cricket. I tried all the different sports. I was never actually … I was never actually good at any sport.
JT: But you tried.
Harry: I enjoyed my sport, and I was on all the committees associated with sport.
JT: Would you say you’re a very sociable person, Harry? Do you like being with people, being friendly?
Harry: I do like being friendly.

For Frederick, who called himself “an undergraduate in the university of life”, and whose narrative is peppered with quotations from philosophers, essayists, historians, poets and other literary figures, it was reading which brought the greatest satisfaction. According to him, “if you don’t read you can have very little”. He quoted Kipling’s poem *If* to stress the importance of using time and opportunities usefully.

> If you can fill the unforgiving minute with sixty seconds worth of distance run
> Yours is the world [sic] and all that’s in it, and what is [sic] more you’ll be a man, my son. 72

**Pride in achievements**

Pride in achievements was linked to overcoming challenges and hardships, and reflects the educational and economic disadvantage many of the informants suffered during their youth (see also McCalman, 1984). Many took pride in the achievements of their children, evidence of their own success in having been able to offer them more opportunities and a better education than they had had themselves. Gubrium (1993)

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72 *If* first appeared in Rudyard Kipling’s collection *Rewards and Fairies* in 1909.
reports this same commitment. Even if children dropped out of college at least they had been given the opportunity. A large proportion of the children of my informants had professional careers, and graduation photographs both of children and grandchildren held a prominent place in many of the rooms. Saving and paying off a house was another source of pride, being able to afford to travel, and not owing anybody anything.

Harry took pride in having looked after his mother throughout her life, and in his honesty and reliability and the quality of his work. Daisy was proudest of her homemaking skills, and of her strength of character. Jack was proud of his flexibility as a worker, his ability to tackle any task, and the skill he had with animals, particularly young horses. Frederick saw himself as a mentor and guide, a contributor to ‘the betterment of society’. The fact that these people could view themselves, their selves, with pride is integral to my thesis argument. They saw their lives as a connected past, present and future, their achievements as part of their ongoing selves. Through telling their stories they re-created these younger selves who had been so ‘achieving’ and could continue to feel the same esteem for themselves. They could admire who they were and what they were, both in the past and in the present.

The Ageless Self: the past, the present and the future

Most of my interviewees spoke mainly about the past and the present, and appeared to see the future in limited terms. Nonetheless they spoke of the future and planned for it, confirming that “[m]emory is not just related to the past but to the present and points towards a future” (Heliker, 1997: 74 paraphrasing Heidegger, 1968). Residents who say they want to die, who reflect with satisfaction on their lives, even while claiming that their useful life is over, will still plan for the next visitor and expect to see the next season. One resident, even when telling me that she expected to die that night, in fact that she expected to die every night and always woke up surprised to be ‘still here’, asked me to lodge an order for the Christmas cakes she planned to give as presents months later. Others made appointments for the next visit of the podiatrist or hair
dresser, discussed the expected birth of the first great grand-child, looked forward to activities, family and other visits. Life was continuing, and the self which had stood strong through past and present experience was still strong, in spite of adversity, and would be included in the future. My mother, at a bad moment of wondering if life was worth the struggle with pain, immediately rejected the thought: “I have to stick around if that little baby is coming in November.” There is insatiable curiosity about what might happen next, and even the resident who most frequently states his readiness for death suggests that while life is worth living he will be willing to stay. For him, for now, it remains worth living.

Residents I asked about their views of the self had generally not thought about it, but on reflection offered a view which was remarkably consistent. Sarah felt that the current self, although wiser through experience, was nonetheless the same self of her youth. Hetty’s answer was “Still me”, although she suggested that she was more experienced. Millicent, when asked if there was a difference between the 18 year old and the 94 year old Millicent, replied “I don’t think so. I’ve just got old and gone along”. Charles was emphatic: “I’m still here and still me. Definitely the same person”. Others who did not give an explicit view of how they saw the self told stories which implicitly revealed the connection between the past and present self. Frequent use of the Present Perfect tense, “I’ve always been” was more common than the Simple Past “I was” to describe selves and feelings. In contrast, discussion of activity, especially that which was no longer possible, was located in the past. This was sometimes a regret – for example, Charles expressed the wish that he could simply vault a fence the way he used to, and Daisy regretted that she could not see to sew. However, in general, in re-telling past pleasures there was present pleasure, with the memory kept alive by the sharing. Even if sometimes the final comment was: “Of course I can’t do that now”, it was still a good memory, polished by re-telling.
Summary

In this chapter I have presented an ageless self, one both socially active and socially constructed, a relational, cumulative self which has the strength to withstand loss and bereavement. Using data from interviews I report my informants’ emphasis on the good experiences of their lives. This attention to the achievements and the virtues which they espoused (and believed they shared) supports the notion of Kaufman’s ageless self. It also reflects Cohen’s active agentic self. Even while regretting their loss of capacity, my informants saw merit in their own past deeds and present intentions, and in so doing could respect and admire their continuing selves.

In the next chapter I explore the fragility of the uprooted resident and the loss and grief involved in growing old and entering into nursing home care. I present my case for a diminished but unvanquished relational self, one pared back through the loss of the relationships, but which retains the strength of its essential core. The discussion encompasses the embodied self, loneliness and isolation, and residents’ views of death, dying and life after death.
Chapter 6 – The Vulnerable Self: bending but not breaking

In this chapter, the second one in my story of the ageing self, I follow it through its greatest trials. How does this vulnerable embodied self, diminished by adversity, survive the multiple losses of ageing and institutionalisation? How does it endure and adapt to living with illness, pain, and loss of physical and sensory function? On top of the grief and loneliness involved in loss of loved ones, support systems, role, lifestyle, home and possessions, the uprooted self must somehow adapt to new living space, new routines and to dependence on the care of strangers. In my reflection on these questions, I draw on the stories of Winnie and Peg, one finally worn out by great age and adversity, the other strengthened by her determination to be of use, up to and beyond her death. The themes of loss and bereavement and the communication issues surrounding them remain central to the main subject of my thesis – the meaning which people make of being old and in care. In troubled times, they struggle to find and hold onto “acceptable meanings” (Coleman, 1995: 66). Some, while retaining pride in their past lives, do not succeed in finding meaning in their present circumstances. While conceding that other factors play a part, I nonetheless claim that the main reason for this failure is lack of meaningful communication. Successful adjustment to nursing home life takes time and energy on the part of the resident, but the self also needs to narrate itself and be heard, to feel recognised and valued.

In the midst of gloom I see hope. It lies in the relational self’s capacity to withstand the challenges of ageing, to bend but not break. It is diminished by loss and the shrinking of the social world, but diminished, not annihilated. Its essential core remains, and as I argue in the following chapter, under the right circumstances it can maintain and regenerate itself. The ‘right circumstances’ include the quality of care and support provided in the nursing home, opportunities to maintain old relationships and develop new ones, and above all, a supportive communication environment.
Body, self and society: “I never wanted to be alone”

In the previous chapter I discussed how my findings support the notion of the ageless self, one constituted by a continuous core of experience, and in this chapter I highlight the embodied nature of that ageing self, as conceptualised by Csordas (2002), Turner (1991; 1992; 1995), Leder (1990) and others. Csordas, following Merleau-Ponty’s phenomenological approach of the ‘lived body’ as the “general medium for having a world” (1962: 146), explains consciousness as “the body projecting itself into the world” (1988: 8). Merleau-Ponty’s collapsing of mind-body duality means that “we cannot perceive anything and our senses cannot function independently of our bodies” (Nettleton & Watson, 1998: 9), though we are not obliged to be aware of these perceptions and functions.

Peg’s Story: The Body as Self

Peg was born after her father’s return from World War I. She was a member of a large family, brought up in love and security, and seems not to have suffered loss or adversity in her youth. Although not affluent, the family “never wanted for anything”. She had a happy marriage to “a good husband” and said repeatedly that she had had “a good life”. She was, however, indelibly marked by the still-birth of her first child. The effect of this loss caused her to question her religious faith and she “fell out with God”. She had two surviving children, a son and a daughter, but was closer to the latter, having lived near her, with her in fact after the daughter’s marriage failed, and been involved in the upbringing of her grandchildren. The daughter was a regular visitor and major source of support, as was a nephew who paid weekly visits.

A predominant theme in Peg’s narrative was body-as-self. She was determined to give her body to science, on the grounds that it had served her well, and she wanted it to continue to be of use. This body-as-self view precluded any possibility of an afterlife. Peg saw death as final, nothing to be feared, but the end of self and sociality. She did not want burial or cremation, because that would not be useful. A memorial service would cause inconvenience and grief to her family, and she wanted them to be happy. In fact, when Peg died, attempts to arrange a memorial service came to nothing, and in that at least she had her wish. She could not, however, stop her family and friends from feeling grief over their loss.

Peg’s decision to donate her body was partly because of her wish to do good, expressed through a life committed to supporting family, friends and neighbours and an involvement in community service groups (for example, hospital auxiliaries). In care, with failing health and restricted opportunities to help others, she felt the loss deeply. It was a double loss because she missed the social aspects of community involvement. She worked hard at finding a new sense of purpose, her ‘career’ as a resident including a willing acceptance of the helping role. She saw this act as both an assertion of her independence and ongoing physical capacity and as a contribution to easing the staff workload. Taking part in organised activities was a way of encouraging other residents
and supporting staff in their efforts to meet residents’ social needs. In her helper role, to some extent she was enhancing her self-esteem by distancing herself from more dependent residents. Her independent helping self was one which she could admire, and was evidence that her contributions still mattered.

Peg’s story was of a body which had served her well by not making itself felt: “I never had a thing wrong with me until I was 80”. It was indeed Leder’s (1990) ‘absent’ body, one which in circumstances of good health and lack of pain requires no conscious direction. However, for most nursing home residents in care because of their illness or bodily frailty, there is a constant monitoring and control of bodily functions and performance. Giddens (1991: 56-58) argues that routinised control of the body is a condition of everyday communication – the self is more or less permanently ‘on display’ in terms of its embodiment. I maintain that in residential care the control is far from routinised. Illness and frailty can make it very difficult for some residents to control body functions, even facial movements, integral to both communication and the public ‘presentation of self’ (Goffman, 1971). Peg was troubled by vertigo as well as pain and restricted mobility, and the act of standing, sitting, getting on or off a bed was carefully planned and slowly executed. Her body was no longer absent, and the effort to maintain her public presentation of self increasingly costly.

Winnie’s story: ‘your soft skin’

Winnie, born very early in the 20th Century, was a teenager when her brother died during World War I. She grew up in a large extended family with seven brothers and one sister and an aunt and cousin who shared their house (following the death of her father of whom she had very little memory). As the unmarried youngest daughter she was given, or automatically assumed, the role of support and helper to her mother, her siblings and their many children. This service to family was never questioned.

Her real life was one centred in family, in spite of her employment in factories from the ages of 14 to 60. Social activities outside the family were relatively limited, though she did mention trips to the cinema and Sunday School and membership of a Lodge in her younger days. Annual two-week family holidays by the sea were a major source of pleasure, and she had a five-week holiday with her sister and cousin just before her forced retirement at 60.

Apart from these holiday excursions, Winnie’s life was centred in inner Melbourne. She had rarely gone anywhere beyond walking distance, and readily accepted having to take retirement because her factory was about to move to an outer suburb. Like her social world, her geographical world was small, and her attachment to the streets, buildings and landmarks of her youth made her regret the changes of modern.

73 Compare Cracknell’s comment on her single aunt’s life: “[T]his was an era where duty didn’t sour, was performed without rancour” (1997: 29).
Melbourne. Her story is one of loss of loved ones, and of being left. All of her immediate family had died by the time she was in her mid 70s. She then lived in a flat behind her cousin for 12 years, and entered the nursing home when her impaired vision made it impossible for her to manage alone. When I met her, Winnie was very old and very frail, very tired of life and increasingly desirous of death. She had a strong religious faith and belief in the after-life and was not afraid of death, but in her pain and loneliness did not want to be alone. I sat and held her hands for extended periods. When her sight failed and she was too tired to pick up other cues, she recognised my hands by their “soft skin”. In silence, except when she asked for help or reassurance, we were together, embodied self reaching out and meeting embodied self.

Viewed through the prism of May’s (1986) threefold meanings of the body, touch takes on new significance. It remained Winnie’s primary “means of savouring the world” (ibid: 47), almost the sole one since she suffered severe pain, could no longer walk or even sit comfortably, was severely vision-impaired, had pronounced hearing difficulties, and could no longer swallow easily or enjoy food. Touch gave the strongest meaning to her body, too diminished to function effectively as an “instrument for controlling the world”. Touch, along with speech, also guaranteed her body a “means of revealing [itself] to the other” (ibid). Winnie’s example is not isolated. Illness and institutionalisation commonly threaten the performance of the body in all three of May’s categories, disrupting “embodied access to the world” (Benner, 2000: 6). The loss of control over both body and the environment, the loss of stimulation of the senses offered by the ‘outside’ world, and the loss of confidence in the acceptability of the sight, sound, smell and feel of the body are devastating for self-esteem. May suggests that “[o]ne’s body, therefore one’s self, no longer feels lovable, touchable, huggable, cherishable”.

Loss of confidence in the performance and acceptability of the body has major implications for institutional design and practice. Respect for the body, and for the modesty of the resident, can only be protected and enhanced by respect for privacy and tactful and supportive handling of the body. In Western cultures notions of privacy of the body are linked with shame, and intimate knowledge of another’s body is reserved for those with whom the embodied self has intimate, trust relationships. Privacy establishes boundaries and preserves identity (Arendt, 1998), whereas bodies exposed to careless view (Kayser-

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74 Peg was able to separate notions of attractiveness or lovability from the ideal of usefulness. Her body remained an object of value, a gift to be offered to others when she was no longer able or willing to ‘use’ it herself. This adds a dimension to the notion of an “instrument for controlling the world”.
Jones, 1981) or even accidentally made public (Higgins, 1998), are selves degraded and humiliated.

Bodies isolated and segregated by illness and institutionalisation are selves isolated from society. Kleinman, however, is optimistic that in illness and therapy there is the possibility of a ‘symbolic bridge’ between body, self and society (1988: xiii). I argue that this possibility of reconnection also applies to the world of the sick and disabled elderly, and that the quality of care and the respect and warmth of the social experience interact to help the resident maintain the self in the face of the losses of old age.

**Being alone**

The loss of loved ones is both a physical and emotional experience for the embodied self. When those who were part of the ‘young’ world are gone, the socially constructed self shrinks into the smaller networks which remain, and is grieved by its diminishment. My mother, having outlived her parents and siblings, grieves because there is no-one left who knew her when she was young. This theme was also common in resident interviews. Harry’s wife had died six years earlier of breast cancer:

> And my sister, she finished up with a cancer on the breast too, and she died in the Melbourne Hospital, and my mother... I said to the doctor I said – “My two brothers and my sister, and my mother” I said “ they all died with a cancer-related…”. I’m the only one left.

Harry was also the last of his friends.

> I’ve finished up, I’m the last one of the bunch. You can have the friends you know, and we had some very good friends, and one goes away and another one goes away and suddenly we’re into a different phase.

Harry’s case illustrates the isolation felt by many who outlive their social intimates. With his relationships severed, his self was deprived of its former modes of expression. It was diminished by the loss of recognition and support, of conversation
about shared knowledge, lives, experiences and memories. Maintaining communication is maintaining links with the past and the elements of yourself that you deem important. In the radically different communication environment of the institution, the new resident has to start again. For some, like Harry, this proves almost impossible. There are no shared personal experiences, no shared reminiscences, and individual personalities, capacities and health status are obstacles to discovering what shared ‘public’ experience and knowledge there may be with other residents, or to build on this knowledge and form new relationships.

For many the sense of ‘aloneness’ is exacerbated by the absence of affectionate touch, a finding also reported in other studies (for example Nay, 1993: 213; O'Brien, 1989: 174-5). Residents in my study responded warmly to physical signs of affection from staff, with many saying how much they liked to be kissed or hugged. Because I was a regular familiar presence, I learnt who liked and did not like to be touched, and what kind of touch was welcome. I patted, hugged, kissed or touched residents’ hands, and found warm responses, including from residents with dementia. One, responding to my kiss, called me by her daughter’s name. She had lost both physical and cognitive capacity to operate independently in the world, but she remained an intensely social being, an embodied self, responsive to other selves expressed through touch and voice. I also found that hand-holding, and forms of hand massage calmed agitated residents, stimulated apparently non-responsive residents (see Kitwood, 1997; Hudson & Richmond, 2000) and comforted people who were simply lonely or frightened. Allied Health therapists used hand massage with aromatic oils, aromatherapy and spa baths, and the music therapist used her voice and hands to make contact with non-communicative residents. She was able to break the cycle of one woman’s agitated, repetitive singing of a single line of a song by joining in and completing the verse, singing until the resident was calmed.

75 All comments on resident behaviour are from observation notes, conversation notes, and personal communications.
76 The daughter told me that her mother never called her by name during visits, but recognised her as loving and lovable. She may well have known her without naming her.
77 Staff interview #1
Many staff believe that voice, as well as touch, is an instrument which can reach brain-injured residents, and in fact will speak constantly and consciously, working to recognise the humanity and preserve the dignity of unresponsive residents.\textsuperscript{78} These are the same staff members who believe that by studying the body of a person, even one who has lost the capacity for verbal communication or overt sign language, they can still read the wishes of the embodied self. They believe in the powers of voice and touch to break through even unconscious states, and in the power of their own perception to read the responses. Their conviction fits well with Kleinman’s (1988) vision of therapy as a ‘symbolic bridge’ between self, body and society.

**Bereavement, loss and grief**

Most nursing home entry is accompanied by loss and grief. People do not want to lose their independence, and loss of independence is usually caused by the loss of either loved ones or of physical or cognitive function. However, to most old people loss is neither a new phenomenon nor the only factor influencing their well-being. As Coleman reports:

[Loss] is seen as a common denominator in many experiences in later life: loss of home and possessions in moving to residential care; loss of relationships, spouse, friends, and neighbors; and the loss of memory in the early stages of dementia where there is still insight into what is going on (1995: 54).

Coleman argues that loss is not the only stress factor in old age\textsuperscript{79}, and the resilience to loss demonstrated in my study confirms this. The losses identified in old age are part of a continuum of loss\textsuperscript{80} experienced throughout the life span. The adjustments which people make to these losses prior to becoming dependent are gradual and incremental,

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\textsuperscript{78} Staff interviews #2, #5 and others. Also observation notes on staff behaviour with unresponsive residents.

\textsuperscript{79} Other stress factors are listed as attack, restraint, and threat. Some aspects of health loss can be linked to these other categories, but ‘daily hassles’, irritating daily events of life and relationships are sometimes ‘more strongly related to psychological distress that major life events’.

\textsuperscript{80} Rowles and Ohta (1983) cite Pastalan’s (1983) “age-loss continuum” with the series of losses including children (leaving home), spouse, age peers, health, physical mobility, income and social roles.
most commonly only intensified in old age (Savishinsky, 1991). Above all, reaction and adjustment to loss is subjective, and, as is seen from my data, the individual meaning which the elderly attach to similar life events and situations varies enormously (compare Coleman, 1995: 61). In interpreting their losses, my informants showed the capacity to envisage a new way of being-in-the-world (Heliker, 1997) and to “create new meaning as they reformulate and build viable selves” (Kaufman, 1986: 163). The struggle to reformulate and build viable selves was not always won, as Harry’s story shows. He was too new, too lost, and then too ill to ‘make a go of it’ in care. Nonetheless, I believe that with time and adequate support he could have begun the process of renewal, and found new meaning in so doing.

Institutionalisation: the uprooted self

“But it isn’t easy, oh, it isn’t easy for the person who will eventually make a go of it here in the old people’s home to make the decision to give up all they possess, pack up their clothes and be brought in the taxi to a place like this” (Blythe, 1979: 134).

Blythe’s Matron Robbins reminds us how hard the uprooting is, even for those who voluntarily make the choice to enter the nursing home and have the time to prepare and pack for themselves. In comparison, where increasing numbers of nursing home entries are determined by crises, the stress of relocation is greatly magnified (Johnson & Grant, 1985; Pastalan, 1983). The abrupt severance of connections with home and possessions (and with loved ones where bereavement is also involved) makes adjustment to the isolation and regulation of an institution more difficult for the new resident (Kingsley, 1998; Minichiello, 1989; Nay, 1995). Some of the residents in my study, particularly single men, found new security and comfort in institutional care (compare Gubrium, 1995). Others adjusted less well. Harry regretted leaving his house and belongings and the nursing home never gave him a sense of home. It might have been easier if he had had a private room. Instead ‘home’ had come to mean his own narrow bed, his only personal space in a shared room with non-communicative strangers. Previously proud, and confident in his health, but also very shy, he found that in the shrinking of the physical space available to him, there was what May calls shrinking in the psychic life:
The institution swallows them up; its limited room prevents them from bringing many of their valued possessions and other tokens of identity. The new location often removes them from their communities. It condemns them to a kind of premature burial. (May, 1986: 46).

Harry at least knew his possessions were still in his house, awaiting his decision to sell. Residents admitted involuntarily are not always so fortunate, and grieve for the loss of mementos of their past lives (see Gubrium, 1993; Kane, 1990 and others). Some residents had regret for gardens left behind, but Sarah was one who had had time to divide and pot her favourite plants to give to friends and felt that her gardening skills were still being recognised. Some had left pets on the ‘outside’, and regretted the loss, but others were able to see their animals on visits to the family members who had taken over their care, or to enjoy the pet visits arranged by the nursing home (see Savishinsky, 1991).

**Threats to adult status**

As I have argued throughout this thesis, the community has the capacity to enhance or degrade residents’ sense of value. If residents are subjected to overt ageism through stereotyping, social avoidance or neglect, if they are not accorded privacy, respect and dignity, if they are addressed in patronising or infantilising terms, both their self-esteem and their health are at risk. Low self-esteem is a major factor in psychological health (Coupland, Nussbaum et al., 1991: 18; Giles et al., 1994; Williams & Nussbaum, 2001), even a major cause of vulnerability to depression (Coleman, 1995). Kastenbaum argues that a therapeutic milieu should have as its goal “a systematic and encompassing network of positive expectations on the part of everyone in the environment” (1983: 13). Negative expectations of a geriatric patient’s adequacy “confirm the patient’s own doubts and fears” (ibid: 13), a view supported by Whitbourne et al. (2002) who also consider perception of personal control an important element in psychological health.

I saw occasional evidence of unhappiness in communication-impaired residents after negative, patronising experiences with staff, usually agency staff or new trainees who underestimated their capacities. Without opportunities to demonstrate their
competence, the residents had no means of effective resistance, hence no means of salvaging their self-esteem. Those with good communication skills and a strong sense of self are better equipped to assert their adult status. Peg, for example, employed distancing strategies to safeguard her self-esteem (compare Williams & Nussbaum, 2001). She frequently made positive comparisons between herself and residents she perceived to be cognitively less able, and was quick to correct school volunteers who she felt were disrespectful of the group of residents playing Bingo. She was indignant that they would behave so badly, but offended that they took her for one of ‘them’. Nursing home studies have reported acts of defiance from dependent and otherwise powerless elderly people, acts which tend to confirm staff assumptions about the child-like nature of old people and are unlikely to elicit respect (Hockey & James, 1993: 181-2; O'Brien, 1989: 191). Nay (1993) found that staff gave less attention to aggressive residents, attending to necessary bed-and-body\(^{81}\) work, but not giving any extra time to social needs. One of my staff informants described ‘obnoxious behaviour’ as a barrier to communication but tried not to give in to the irritation which it aroused.

Negative expectations of residents’ cognitive capacity are not limited to nursing home or medical staff. Families may also expect little of their relatives in care. A close relative of one of my interviewees was surprised that I would have “got anything out of him”. From conversations with family members of other residents I came to the conclusion, supported by staff observations, that memory loss, confusion or any other perceived diminution in cognitive function was sometimes overestimated. The fact that their relative was not exactly as he or she had been before the stroke or whatever other event or illness had led to nursing home admission was often perceived as a global loss of capacity. One wife, when I explained that part of my project concerned the maintenance of the self, said of her husband: “There isn’t much of that left at this stage”.

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\(^{81}\) A term first used by Gubrium (1975).
Making a go of it

Many residents chafe at the regulation, lack of privacy and lack of choice involved in institutional living, what Coleman (1995) calls the daily ‘hassles’, the irritating daily events of life. Not only do they often share rooms with people they do not like, but the routines of the nursing home largely determine what, when and where they will eat, and when they will go to bed and get up. As with the loss of home and possession, residents who are involved in the decision making and preparation to enter the nursing home are likely to adjust more easily to the loss of independence, and even to the new rules and regulations and the constraints of communal living, than those who are forced to relocate because of health or family crisis or other loss of support (see Johnson & Grant, 1985; Minichiello, 1989; Nay, 1993).

Anxious to avoid encouraging resident dissatisfaction, I did not ask questions likely to elicit complaints about staff or the quality of care. Most residents expressed satisfaction with both, and brushed lightly over the things which they found hard to bear. Apart from loneliness, the chief complaint was the noise and the intrusiveness and insensitivity of other residents, particularly those who wandered in and out of others’ rooms. One resident tried to keep the door to her shared room shut, and others expressed fear, one because she maintained that she had been attacked (see also Newton, 1979, who found night-time intrusions alarming). The lack of privacy, violation of personal space and the forced proximity with people seen as annoying or threatening, emerged as key issues, also reported in other studies (Foldes, 1990; Gubrium, 1993; Powers, 1995). There was occasional criticism of individual staff members but most of the time there was praise. Nay (1993) and others report the reluctance of residents to criticise staff, almost as though they fear that their treatment will suffer as a result. Consequently the true meaning of residents’ comments is hard to reach. When Hetty said, “They’re all nice. Of course you like some more than you like others”, I guessed from the slight hesitation in her voice that she was making a distinction between the ones she liked and the ones she did not (see Shield, 1988), but
her actual words did not commit her, and she certainly did not refer to any staff members by name.

I occasionally heard complaints about the food, particularly from those who were on ‘soft’ or very bland diets, but other complaints were rare. Residents who had close family members able to visit regularly were less likely to detect deficiencies in the meals. Families often brought in favourite foods, or took residents out to eat (as described in Newton, 1979), so that the institutional food lost significance, and the connection with home and former routines was extended. Daughters, and in one case a son, who attended to their mothers’ grooming of hair and fingernails, were maintaining links with past habits and the preferred personal presentation of residents. Residents who had room to arrange their favourite possessions around them (for example Peg, Daisy and Charles) expressed less regret for the loss of their homes than others whose space was limited and threatened by incursions from other residents (Harry and others), confirming Foldes’ contention that “[e]veryone’s sense of self, of personal integrity, rests on a certain level of privacy and personal space” (1990: 29).

One of the greatest frustrations for residents considered frail or at risk was the loss of independence and their freedom to go outside unattended, a problem reported in Kane’s (1990) discussion of everyday ethics in nursing homes. The enclosed ‘dementia’ gardens gave the space for contact with plants, but not for the long walks which some residents were used to. Staff and volunteer availability for accompanied walks could not match the wishes of such residents, whose stress levels were consequently often high.

**Loss of loved ones**

The residents had all suffered bereavement during their lives, not just in old age, and both the individual meaning they attached to the losses and their adaptation to them showed the variations discussed above, described also by Gubrium (1993) and Coleman (1995). For Peg, the loss of her baby had caused, or at least been accompanied by, a loss of religious faith.
Peg       I had one…another son but it was still-born.
JT        Right. And that’s not something that you forget.
Peg       No, no. And that’s why I think…I’ve carried that for years. You know, it’s
         been…I’ve always thought, well if there’s a God, why did he do that? And then
         I’ve thought over the years, it wasn’t his fault. It was…. it was really the nurses.
         They should have got in touch with the doctor quicker. Instead of leaving me,
         trying to have this baby… and it’s…
         (Taping interrupted because of resident distress)

The death by drowning of Winnie’s brother was the third in a long chain of losses, all
of which she had survived and surmounted, despite her sadness at being ‘left’. She told
the story of his disappearance from a lonely beach, her pragmatic narrative another
testimony to the survival of her self – a sadder self, but still a strong self.

Winnie    And we never ever got his body. He was 42.
JT        So he must have got into trouble with nobody there to help him.
Winnie    Yes, they said it was rather a rough day.
JT        So you didn’t know for days.
Winnie    Yes, but of course by that….so long ago, when I was 25, it’s a long time ago, down
         at Carrum there was all bushes and shrubs and all sorts of things.
JT        Yes. There wouldn’t have been people close.
Winnie    No. So whether something happened in the water.
JT        Nobody would know.
Winnie    Course they say the bodies usually rise in seven days. So I can remember the
         seventh day. It was Cup Day. My brothers went down and sat on the beach all that
day, thinking his body might float.
JT        What a terrible vigil.
Winnie    Nothing was ever heard of him. So there’s the seven brothers. So that’s what
         happens. We live too long, that’s the trouble. We do.

Harry had been deeply marked by his father’s death in World War I, but his regret in
his old age was the more recent deaths of mother and siblings, and most particularly
that of his wife.

Harry     She got very, very sick. She got the cancer in the breast…
JT        So it was a painful, and long.
Harry     She couldn’t really breathe, see, and oh it was a hard point in time.
JT    Such a heartbreak to watch.
Harry    Oh, I couldn’t do anything at all. The nurses came down there …

In spite of loss of both family and friends, Harry held to the view that he had had a good life.

I’ll never complain about life, but…I’ve enjoyed life. I’ve had the ups and downs, I don’t know what anybody else tells you…there were decent times too.

Nellie grieved over the loss of her older sister, a loss caused not by death but by the sister’s entry into a convent many years earlier. It was clear that for her this was a symbolic death, and her language reflected that of other residents’ mourning physical deaths. Daisy was nostalgic for the companionship she had had with her husband, but her immediate grief was for the recent loss of one of her two sons, and she needed to talk about it. This need to narrate and be heard is confirmed in many accounts, for example by Frank (1991) and Savishinsky (1991). Daisy told me about the events leading up to his illness, the relief she felt that he would have no more pain, but also of the sorrow that she was experiencing. However, even with her sadness, her frailty and pain, she was open to experience, to further visits and wheelchair outings, and had plans for the future. She ended this interview on a note of optimism about future meetings: “Well you come and see me when you want to take me anywhere, and I’ll go with you.”

Loss of social role and support systems

Several residents were open about their loneliness. Harry’s sad “I’m the last one left” was echoed by Daisy’s “I never wanted to be alone” and Winnie’s “I got left”. With their bereavements, they had lost the roles of brother or sister, son or daughter, husband or wife. Some regretted the loss of the support of friends or relatives no longer well enough to travel to visit them. Others seemed to find enough support from siblings, children and grandchildren and friends to not comment on loneliness. Silence about it did not, of course, mean that the loneliness was not felt, as Kingsley (1998) also reports. Most residents were anxious enough to prolong conversation with me, or to at least know when I would be returning, for the loneliness and lack of social
support to be at least implied. Others were more open in their need, finding excuses to delay me, or things for me to do for them. Charles, who usually claimed to be satisfied with his life, one day expressed his loneliness, suggesting that the remedy would be “more people like you”. This represented a desire for regular contact with conversation partners who had time and the interest to collaborate in meaningful relational communication, factors identified as crucial in other studies, for example Coupland, Nussbaum et al. (1991) and Holstein and Gubrium (2000).

In losing loved ones and friends, Harry also lost some of his sociable, communicating self. He had lost most of those who had collaborated in the construction of his ‘young’ self and was badly equipped to replace them with new ones. In his loneliness he found our conversations of as much interest and value as I did. We talked about a range of issues, including what was in the news or other matters which were preoccupying him. As a shy man, he found all of the difficulties inherent in “enforced contact with complete strangers in unfamiliar public settings” (Gravell, 1988: 108). Despite this, and the shrinking of his social world, Harry’s core self, as expressed through his narrative and his interest in life around him, was strong and continuing. In his own words: “I just hang on to, you know, being…I might be wrong in this respect, but I think that to be yourself…”

Often losses were understated or simply not mentioned, especially loss of home, possessions and independence, which contrasts with reports from other studies where such loss was salient in residents’ accounts (Gubrium, 1993 ; Nay, 1993). Harry, whose house and possessions were waiting to be sold, was sad at the “waste” of all that he and his wife had built up with such love and effort. As a life-long protector of others, he found his inability to stay in his own home, always the refuge for family members in trouble, very difficult: “I never thought I’d end up in a place like this”.82 Others, like Peg, were more philosophical about loss of home. She had moved in stages, first from her house to a flat in a retirement facility. Some time after her husband’s death she had moved again, though she was vague about the factors which had precipitated her entry into full residential care.

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82 See (Gubrium, 1993: 67): “How’d this happen to me? Bein’ in this place and all. God only knows.”
Sarah had the photographs and medals to prove that she had bred champion dogs. Other residents prominently displayed photographs of former homes, of weddings and graduations, of friends and families, and were happy to talk about them. Possessions were less in view – Peg explained that she had given away her jewellery because others might as well have the use of it. She was proud of a book of her life, compiled by her grandson, with photographs and captions from all periods of her life. Daisy wore her jewellery, and had trinket boxes and many photographs, including of her childhood home, her wedding, and her young children. Mira, speech-impaired and partially paralysed, had a photograph of herself in nursing uniform with a television celebrity at her side. Her self was represented for her in her former role as an active, useful, valued member of the community. Kaufman (1988a: 86) observes that “[p]ersons who have had strokes face the task of integrating the profound disruptions that have occurred into their self-image, so that a continuous sense of self emerges”. Mira had succeeded in the task, demonstrating a remarkably strong sense of self in spite of the physical losses and the abrupt curtailment of her active social life.

My questions were not designed to elicit tales of loss and regret, but some narratives were dominated by them. Others reflected social and work life as it had been rather than what it now was. It was entirely in keeping with Jack’s laconic, self-deprecating conversational style to be silent about current troubles. He had spent most of his life in physical outdoor employment in rural Australia, and when asked if he had found it hard to settle into the nursing home simply replied, “Yes”. I never heard him complain about his health, his well-being or his living circumstances. He read his paper, took part in social activities and interacted with staff and other residents with good humour, and had regular contact with his family. Others who seemed resigned rather than sad about changed circumstances included Charles, who reported that he was perfectly satisfied. He had no regrets: “No, I think I’m already too old, really. I had my life and I’m now satisfied, satisfied with it. Yes. And I don’t want to go back and shift.”
But what use am I? That walking stick is of more use than I am"

Charles was nonetheless anguished by the existential doubt of the elderly described by Coupland et al. (1995: 97). This same doubt is part of the central issue identified by Savishinsky, the importance of understanding the meaning residents find in their losses, and “the effect of these experiences on their current behaviour and morale” (1991: 55). Charles’ morale fluctuated, and for some residents, like Harry, there was insufficient time to know if they could have found and continued to find “acceptable meanings in their lives” (Coleman, 1995: 66). Harry’s rapid decline in health, including the stroke which hastened his death, cut short attempts to find suitable support for him. Coleman cites an informant who said “he felt useless, but at his condition and at his age he was entitled to feel useless. He did not struggle with the thought at all and he accepted it with equanimity” (ibid: 66). Charles found it harder to maintain that equanimity. He sometimes spoke of ‘a great emptiness’, comparable to the ‘void’ reported by Powers (1995: 187).83

The threats to self esteem involved in loss and institutionalisation have been well-documented, both in nursing home ethnographies and in theoretical studies. Hockey (1989), cited by Cohen (1994: 101), records that “the very fact of entry into a residential home for the elderly…posed a crisis of identity. For men, it marked the definitive break with their occupational past; for women, it signified the end of their caring and domestic selves.” Hurd (1993) suggests that friendships with other women play a vital role in a woman’s reconstruction of her identity after bereavement, a fact highly relevant to the nursing home environment where most staff and residents are women, and most residents have suffered bereavement. A primary threat to my informants’ sense of worth was their lifelong regard for hard work and good deeds. Many felt they had become what Peg called ‘takers’ rather than ‘givers’. Still dominated by what Coleman calls “the so-called functional work ethic” (1995: 67), they were troubled by idleness, finding difficulty in reconciling what they felt they should be doing with what they were actually capable of doing. They were harsh

83 See also Gubrium’s informant: “I’ll tell you, life looks pretty empty” (1993: 61).
judges of their ageing selves, and several questioned why they were still alive (compare Gubrium, 1993: 45).

Illness, pain, sensory deprivation and loss of function

The physical body does age and there comes a point when individuals cannot accomplish the physical tasks that once came “naturally” to them (Thomas & Ahmed, 2004: 11).

This physical ageing, especially when accompanied by illness and pain, brings an awareness of the body to the forefront, a consciousness of the need to consider the body’s capacity before embarking on a course of action, perhaps one as simple as getting out of bed. Leder’s ‘absent’ body is absent from conscious thought, but bodily states such as disease, pain and paralysis are constant reminders of a very present and, in many cases, exigent body. Few of my informants referred directly to their bodies, speaking of their pain or loss of capacity in terms of the whole person. Loss of capacity was generally expressed as “there are things you can’t do any more”, although at times certain body parts were named, as in legs, eyes, ears, and hands. Daisy spoke of her frailty and weakness in terms of self: “Oh I’m not very strong now. I lose the impulse”. She saw danger and insecurity in her frailty, with an acute awareness of the risks of falling and breaking a hip.

If I get out of bed by myself, I might get there but I’ll fall over before I get there and break a hip or something more serious, and I’ll be no good for anything any more.

Charles also expressed the danger, and the irrevocability implied in injury from a fall: “I have to watch out for danger all the time now. If I fell I wouldn't mend easily”.

Several residents suffered from chronic severe pain. Winnie was one, and as she became weaker and more fragile the pain became overwhelming. At an earlier and less troubled stage, she had referred to her health problems, including impaired vision, as “all this trouble”, something which she could have avoided if she had followed on behind her siblings when they died. Sarah had back pain related to arthritis and osteoporosis, and stooped and leant heavily into her walking frame. I knew not to adjust her chair, as I knew not to adjust Peg’s position or attempt to help her up. Partly
because they were more mobile than some residents, and this mobility was so important to them, both, like Daisy and Charles, respected their fragility and were fearful of having their pain exacerbated. Pain, however, was not what Peg complained about. She suffered from vertigo, which she found distressing, and she confided that her main fear was of becoming “funny in the head”. She had observed the vagueness and distraction of another resident, a close friend, after the death of his wife: “He got that way that...it wasn’t working. I could see it, and I thought “Gee, I wonder if mine’s stopped working?”

Although a number of residents spoke of their loss of capacity, others said nothing about their physical or sensory losses and little about their current state of health. Jack, who never complained, expressed the significance of his physical loss by implication:

JT Are there other things that you’re proud of?
Jack I’m not proud of having a stroke I can tell you!

Many residents had hearing loss, but Harry’s sensitivity about the issue made it of greater importance to him. He avoided situations where he feared that he might say something inappropriate (see also Coleman, 1995; Jang et al., 2003). Because of the symptoms of her illness, Nellie had a similar lack of confidence, even extreme discomfort, in the company of others. Where they differed was in the extent to which this impinged on their quality of life in the institution (see Gravell, 1988). It had less importance for Nellie because her social support from other sources remained regular and satisfactory.

**Memory and self**

Harry’s core self, supported by pride in his personal qualities and past achievements, remained intact in spite of his diminished physical and social circumstances. I believe he was aided in this by his excellent memory, even without the presence of familiar objects from his past. While some of my informants appeared to have total recall of all aspects and events of their lives, others had quite marked but inconsistent memory

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84 Peg monitored other residents for cognitive decline, describing one as she used to be when she was ‘normal’. See also Shield (1988) and Savishinsky (1991)
loss. There was a significant loss of detail about events and people. As Heikkinen describes it, “someone or something is erased out every now and then” (1996: 198). Precise details of a working or domestic life were not always available, for instance, and this loss of memory in part reduced the possibilities of fully sharing and reliving the past (Coleman, 1995). Nonetheless, they retained the positive view of their personal lives and achievements important for self-esteem (Coleman, 1988), for example pride in having been a good worker or a good wife and mother. Some were more troubled than others by their inability to remember names and events. Peg was philosophical about not remembering what had caused her entry into residential care. Daisy accepted the memory losses as part of being so old, and laughed about them. Charles had much clearer recall of his youth than of his middle years, was sometimes mildly embarrassed about memory lapses, but in the main shrugged them off without the anguish described by Savishinsky (1991).

**Death, dying and the afterlife**

The Near Departed

Hallam et al. raise questions about the social identities of the elderly who are socially marginalised “as a result of changes to their bodies which are associated with the approach of death” (1999: 44). They introduce the term “socially dead” for those who appear to survive in bodily but not social form. Rather than viewing “social death” as a state or an event, Hallam et al. argue that it is a social process which marginalises the socially disadvantaged and is therefore an imposed condition (ibid: 48-9). While agreeing that many of the institutionalised elderly have undergone a form of social death, they argue that the term fails to account for embodied selves, and for the strong sense which individuals retain of their own subjectivity. Citing Hockey (1990), Hallam et al. claim that these older people reflect on their situation in a markedly different way from younger people.

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85 Heading used by Hallam et al (1999: 55) They are ‘near departed’ because “[i]n addition to an assumed state of poor health, therefore, those with old bodies are also assumed to be faced with the proximity of death”.
Rather than feeling excluded from the living, they noted the strangeness of remaining alive when ‘most of my friends are dead’; ‘all my generation has gone now, only the dregs are left’ (Hockey, 1990: 109-110).

With regard to their embodied experience, Hockey’s informants took questions of health as seriously as any other adults and did not see themselves as ‘ripened fruit’ waiting to fall. They exerted their agency over whether they chose to accept or reject institutional and medical regimentation, refusing pills if they caused unwanted side-effects “having a model of health which admitted to the possibility of death but warded off unnecessary suffering” (Hockey, 1990: 109-110). Charles felt the same need to exert his agency, reluctant to take tablets which he thought might prolong his life if they made no measurable difference to the way he felt. My informants also noted the strangeness of remaining alive after the passing of most of their own generation. None, however, referred to themselves in terms as pejorative as ‘dregs’. Several spoke of their sense of solitariness in terms of being the last ones left.86 Daisy said she had never wanted to be alone, and although she had support from family, she was badly shaken by the death of her son.

“This clock can’t be rewound”

These residents did not fear death, which supports research suggesting that fear of death is lessened in old age (for example Blythe, 1979; Coleman, 1995). Shaw makes an association between old people’s acceptance of death and the experience of an accumulation of losses, suggesting that “much of the grief work commonly associated with dying is often accomplished, as it were, vicariously with grieving and mourning for significant others” (1991: 27). Shaw also finds that older people express fewer death fears than younger people, citing studies by Kastenbaum (1969) and Kalish (1976). According to Neuman (1982 21): “Most of us do not fear death. The far greater concern is to what degree will our capacities decrease and how will that be met when it afflicts us?”87 This common view (see Gubrium, 1993; Porritt, 2001) was

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86 See Savishinsky (1991: 62): “the last old tree in a blown-down forest”.
reflected by my informant Charles, who had no fear of death but frequently expressed his wish to remain in his current state of health until he died.

Hallam et al. (1999) suggest that older people’s fear of their own death and grief at the loss of contemporaries is often invisible. This is more likely to be true in environments where those working with older adults find it hard to cope with the phenomenon of death (see Hallam et al., 1999; Hockey, 1990; Shaw, 1991). In the nursing homes I studied, deaths of residents were spoken of openly, residents were encouraged to talk about their feelings and staff were not afraid to show their own grief. This contrasts strongly with “a conspiratorial silence” regarding resident deaths (Gubrium, 1975; Savishinsky, 1991; Shield, 1988: 70). Residents in my study were told as quickly as possible about deaths, were able to contribute to the cost of flowers and were included in memorial services (compare Wettle, 1990). There were, however, discreetly closed doors for the removal of bodies, comparable with the screening reported by Komaromy (2000). This appeared to be due to respect for the sensibilities of visitors as well as residents. Most of the residents spoke willingly and openly about the prospect of their own deaths, as they did about the loss of contemporaries. Residents like Daisy felt that their active lives were over, and voiced acceptance, even impatience for death. She often suggested that it was more than time for her to go, making comments such as “There’s nothing wonderful about being 100. You can live too long, you know”. She told me that she was ready, waiting and thought every night might be her last, but each day found herself still there. She laughed as she said, “You can’t make it happen”. We joked, and when I asked her to warn me, she said “Oh, you don’t get any warning... Well, I do, but nothing happens”. Charles frequently expressed impatience for death, but more as a longed-for experience than as an escape from any unbearable aspects of living (compare Porritt, 2001). Part of his impatience came from his feeling of having finished one life and not being admitted to the one to come. He compared himself with a parcel which had been untied but nobody wanted. It could not be returned to the sender, but the addressee did not want it either.
The manner and meaning of death

Winnie longed for death. She had asked “the Good Lord” to take her, and despaired that he had not. She asked me to pray that she could go, so that she could have rest. That was the meaning of death for her – escape and rest. In her earlier accounts of the deaths of her siblings and her mother she was sad but pragmatic about the loss to the living, but for herself death held no fears. Daisy also felt no fear, assuming that she would simply not wake up one morning. She also saw death as rest and relief. Charles saw death not only as rest, but as ‘the end’, as a reward, a ‘winning post’, as the entry to the next stage of his life, and as the next real event. He often discussed the manner of his dying, expressing the universal desire for it to happen peacefully. He did not wish to live beyond the time that he had consciousness of the fact that he was alive, and that included the wish not to become incapacitated. His wish was to lie on his bed, cover himself with a warm blanket, and then find rest. He expected to wake up in a different place. Peg too had no resistance to the idea of dying, though she also imagined it as a something which would happen in her sleep.

The afterlife

Charles, like Winnie and Hetty, had a strong religious belief in a life after death, and all three believed that they would be reunited with loved ones and other people they had known. Winnie expressed a great wish to see her mother, and Charles expected that his wife would be waiting for him. They foresaw an extension of their social selves and a restoration of previous sociality. Their notion of the afterlife was the Christian heaven, though as Charles said, he had no idea ‘how it would be there’, but believed it would be joyous. He did expect to be judged, but felt he had done nothing wrong. Harry, who did not discuss death or dying, discussed accountability in the next life, and the likelihood of meeting people he knew. His use of ‘down there’ echoed traditional concepts of heaven and hell, and he did not presume to claim that he would be in heaven, though he had lived a good life. He and Charles shared the view that, although expecting judgement, they had been good. Perhaps the confidence was not

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88 Some staff interpreted her wish not to be alone as fear, but for Winnie it was fear of being alone in pain rather than fear of dying.
total, given Charles’ statement one day that perhaps ‘I mightn’t have been good enough’ and Harry’s use of ‘down there’.

Harry I’ve never…there’s nobody. I’m not afraid of meeting anybody at all, down there, you know.

JT (Laughter) Down there or up there?

Harry …I’m prepared to be judged, I said, by somebody…(tape unclear) I’ve never injured anybody and I’ve never taken anybody [down]. I’m very, very careful in that. My niece knows, if anything goes wrong, any debt, I don’t want to owe anybody at all.

In contrast to the extended sociality envisaged above, Peg linked the death of the social self with the death of the material body. She seemed to envisage an asocial void after death. However, even without conceiving of an afterlife, she shared the individuation of self with those who did believe that their core selves would be projected into a new context. This was not altered by her decision to leave her body to science, premised on the belief that death brought finality of the self, and only the material body remained to be of possible use to others. Her wish not to be mourned or have her death treated with ceremony confirmed her belief in the body without self, as opposed to the self without body, an ongoing social presence in the minds and lives of loved ones (as described by Hallam et al., 1999, and seen in the accounts of Harry, Winnie and others). Peg’s language lacks all romanticism about the notion of death and care of the body after death, or even the customary solemnity associated with burial or cremation.

JT So you were thinking your organs were too old for donation?

Peg Yes, I was thinking too old, and I’m scrawny. Before I thought they got plenty to hack at, you know. They’ll chase me around the chopping board, but anyhow…

JT It’s interesting that it was important to you to leave your body usefully.

Peg Well, now what good to be burnt in a…an incinerator, to be…what do you call it, cremated…to be cremated? Why not, if somebody can have use. I hope they get a lot of use out of what’s left of me, that I’ve had in my life. I’ve had a good life, I never had a thing wrong with me until I was 80, and I just feel…well that’s what I want to do… It’s what I want to do, and I don’t want people crying over me.

JT It suggests to me that you’re not afraid of death.
Peg reported a conversation with her son where she had repeated her wish: “Now you know that is what I want. I don’t want to do last minute, and I’m there, and whether you’re going to put me in that box or in that paper bag.” Her expressed goal to be of use and not cause any trouble, even, or especially after her death, is a magnificent demonstration of the survival of her self. In old age she is simply her ‘young’ self grown older, tested by experience, but strong and resilient.

Summary

In this chapter I have argued that the embodied self, although subjected to the losses of ageing and institutionalisation, retains its capacity to connect with other embodied selves and is supported by that connection. Adaptation to institutional living is part of life-long adaptation to change and loss, and that adaptation is a factor in the meanings which residents attach to their experiences, their lives and to death, dying, and notions of an afterlife. The essential core self remains intact in spite of the trials endured and residents’ diminished social and physical circumstances – that the old remain themselves, even through the experience of loss and pain and suffering. I have argued that even those who feel they have finished their active living continue to participate socially, albeit with a small circle of family or staff members, and even those most impatient for death do not manifest a loss of sense of self.

In the next chapter, in optimistic mode, I reflect on the regenerative capacities of the self, and possibilities for residents to find new sources of meaning, social, spiritual and other, to replace those lost through their experience of ageing and institutionalisation. In particular, I explore the importance of relationships as key sources of support, the nursing home as a community, and the role of the activities program, church visitors, volunteers and others.
Chapter 7 – Regenerating the Relational Self

Given that my thesis is underpinned by my belief in the primacy of human relationships, it is fitting that the brighter future I envisage for the vulnerable self is to be found in these relationships. In this, the third and final section of the story of the ageing relational self, I am quietly optimistic. The nursing home, viewed in the last chapter as a site of loss, now becomes a site for potential growth and recovery. New relationships offer possibilities for the regeneration of the vulnerable self, for the accumulation of new relational ‘layers’ to replace some of those lost through bereavement and disruption of social networks. There is hope too, that in the nursing home there may be new sources of self-esteem for residents who doubt the purpose of their lives. This hope remains conditional – conditional on the capacity of the nursing home and those who work there to give adequate levels of support. It would be naïve to suggest that the future is wholly bright, or to deny that for some residents the obstacles posed by grief, loneliness, declining health and physical capacity are too great to surmount. I look at the struggle for elderly residents to maintain self-esteem and find meaning in being old and in care, but I do this in the knowledge that it is a struggle which is not always won. I am optimistic, nonetheless, that for many who enter nursing homes there will be a more positive future. There is the possibility that new relationships will provide key sources of renewal and regeneration and the nursing home will be a site of healing for the diminished self. In my discussion of this prospect I continue to argue that the communication environment plays a major part in either maintaining or eroding resident self-esteem.

In the light of Gubrium’s “horizons of meaning” I look at the nursing home as a community, and consider the contributions to resident well-being of the individuals who make up that community as well as the recreational activities which take place within it. Families, friends, church volunteers, and other visitors are all important players, but so too are the staff. In contrast to other reports, many staff members willingly entered into relationships with residents, and indeed found the interaction enriching. They were troubled by time constraints which limited opportunities for
meaningful communication, but acknowledged that not all staff are willing or able to make the most of those that do exist. Some are troubled by the lack of attention to communication in staff training programs, which raises a more complex question for this discussion – the problematic nature of empathy, and the difficulty of teaching the qualities and not simply the techniques of communication.

**Resilience and regeneration**

I argue, following Cohen (1994), that although the self suffers through the losses of ageing and dependence and is diminished by the shrinking of the social world, it has the capacity to renew itself. Newton (1979: 132), herself a resident in aged care, wondered how many times the self could bend but not break. The key to my argument is that, even though subjected to inconsistent care, degrees of humiliation, sleep disturbance and the discomforts of a badly maintained physical environment, she, like Laird (1979) demonstrated that, with support, the self is resilient, capable of resistance and regeneration. The fundamental issue is the nature of the support available. I believe that meaningful communication, as identified by Newton, is an essential element of that support. Newton, herself well supported by loving family and friends, laments the lack of meaningful conversation available for other residents:

*Conversation is a deep, human need. Words can create thought, as well as conceal it. Meaningful speech is one of the essential human freedoms that can be encouraged and cherished in nursing homes (Newton, 1979: 171).*

I adapt the Concise Oxford Dictionary (Thompson, 1995) definition of resilience, interpreting it as the capacity of the self to recover from shock, to rebound or spring back after subjection to “bending, stretching, compression”. The dictionary suggests that the ‘substance’ springs back to its ‘original’ shape, but in my definition I allow for modifications to the shape of the self due to differences between old and new relationships and the ‘layers’ of self generated by these. Regeneration around the core self is like the growth of new foliage around the trunk and major branches of a large tree reduced by forest fire.
Laird, isolated in dehumanising care, deprived initially of all access to her previous life, was threatened by loss of self – “ever so gradually I began to doubt my identity” (1979: 89). She wondered if, like so many other residents, she was “entertaining a delusion” (ibid). Her confidence and sense of self were restored by contact with friends and the tangible proof of parcels of books addressed to ‘Professor Laird’. The meaning in the lives of these two women was easier for them to find and hold on to than that of most of the very old and dependent people in my study. However, I argue that a caring environment can build and support resilience of the self, even in the face of self-doubt.

There appeared to be a strong relationship between these fluctuations and the “impaired abilities and resources” (Coleman, 1995: 66) of the residents in my study. Their dependent status was indisputable, but different degrees of physical dependence, of cognitive and communicative capacity, different personalities and interests and their different lifetime patterns of adjustment to change meant that there was strong variation in the ways in which they coped with re-structuring identities and maintaining the self (compare Heikkinen, 1996). Some had strong and supportive social networks from ‘before’ which continued to operate after their entry to the nursing home, but others turned to what support was on offer in the new environment, with varied patterns of adjustment comparable to those reported by Powers (1995).

**Resident Resources**

**Religious belief**

Charles was waiting for the rewards of the next life. The meaning which he made of his life was largely supported by his religious faith, as was the case with a number of my other informants. This reflects the shared history and values of the cohort, many brought up with a strong commitment to the social as well as spiritual activities of the church. Church attendance was evidence of morality in many communities, and good deeds arose from church committees, fund-raising social activities, and pastoral visits. O’Brien distinguishes between religious and spiritual needs, but given that both relate
to value systems and sense of meaning, “sometimes the two overlap” (1989: 46). Residents Daisy and Winnie could no longer attend any form of service, but expressed great religious faith. It was apparent from the way that they and others in my study dealt with their losses and sadness that religious belief provided them with an emotional buffer. “These residents believed that there was a ‘higher’ purpose to their lives even if they could not understand it, and this seemed to make daily life easier for them to negotiate” (Coleman, 1995: 67). George (2000) too argues that the spiritual self has the potential to enable individuals to transcend the social environment and foster positive views of the self. Residents with the physical capacity to attend church services or spend time with pastoral visitors expressed the comfort they drew from these religious practices, and I observed for myself the importance which residents attached to the joyous communal hymn-singing sessions as well as to the religious services. However, there was not a regular pattern of church services, a fact which one staff member mentioned with regret.

You might get a church service once a fortnight, but it’s not very meaningful. I’m just thinking for people I know that might have strong religious beliefs. They’re normally used to something at least once a week, whether they go to church or whether the minister or the priest or a nun or somebody comes to visit them…I think that’s something lacking, a bit lacking, there with their spiritual needs (Staff interview #3).

I wondered what meaning the residents with dementia made of the words they heard, but the music and the ritual of receiving Holy Communion triggered responses. Prayer and Bible readings were important to the sick and dying, and the visit of a priest for the celebration of mass was an important social as well as spiritual occasion. Victor habitually wore a knitted football club cap, pyjamas and dressing-gown, but appeared in dark trousers and jacket and a white shirt and tie for the service. He presented his ‘self’ as he always had to see and be seen by the priest. Lack of regular pastoral visits from priests and other clergy is felt more strongly by some residents than others. Gubrium, cites an informant who blamed lack of contact with the church for her loss of faith. She admired the church visitors who came in the place of professional clergy, “but it’s not the same” (Gubrium, 1993: 29). Similarly, my informant Hetty enjoyed the regular visits she had from a church volunteer, but expressed regret at no longer
seeing her parish priest. Indeed many of the residents had found much of their previous social life in church activities and although some were able to maintain contact, for instance through visits from volunteers, pastoral workers and ministers, the social networks previously provided by churches were harder to maintain.

**Activities Programs**

Many residents found the organised recreational activities gave meaning and structure to their days. A staff member, musing on what nursing home life might mean to residents, on respect for dignity as well as care, asked me what I thought gave them a sense of purpose:

> There’s a lot of dignity that goes along with that, their personal dignity, but we have to give them a reason for getting up in the morning. There has to be a purpose still to their life, or else they might as well just stay in bed. Why do these residents get up each day? What is there for them?

> I don’t know if you’ve heard residents asking, but a number of them do. “What’s on today?”

> Mm. And that’s their purpose.

O’Brien (1989: 175) refers to the ‘work’ of the resident, what makes a resident want to get up in the morning, and what occupies that resident for the rest of the day. She lists independent activities; rest, nutrition and bodily hygiene; and individualised rituals. She also includes ‘taking the watch’, maintaining vigilance in lobbies and hallways. My findings were similar, though some residents were too ill, or too disabled to pursue many activities apart from rest and therapy, but amongst those were a number who ‘took the watch’, attentive to the activities of others. This included being present, if not engaged, at organised group activities.

**Family support**

Some residents did not look beyond their families for social support, and the hours which family members spent with them each day were the only ones which counted. Powers found that when residents had support which met their needs they often “distanced themselves from the give and take of institutional life” (1995: 189). They
frequently kept to their own rooms, occupying the time between family visits in their own ways. While this was true for some, I found that many residents chose to involve their families, or the families involved themselves, in the lives of other residents and visitors, contributing to a sense of community (compare Retsinas and Garrity, 1985, cited in Nussbaum, 1990).

Volunteers

Church and charitable organisations were one source of visitors for residents, as well as independent volunteers. Some were short term, for instance university students on semester programs or school students on work experience, but others had supported the nursing homes for years. One man came on a daily basis to help a disabled resident with lunch, and another walked to the shops once a week with a resident whose memory loss and disorientation had forced staff to curtail his independent outings. This weekly commitment was the most typical form of volunteer involvement, though some were on call for help with excursions.89

Independent activity

A number of residents had the capacity for assisted ‘independent’ activity, including knitting or embroidery. Two residents enjoyed playing patience on a computer, requiring assistance in opening the program and maintaining the equipment. One resident had her own computer and used it for Internet research as well as to maintain contact with friends through e-mail.90 Some read a daily paper, a few devoting much of their time to the racing form guide, others to current events. A few read books, often in their own rooms, and a larger number spent a good part of their time watching television. Residents’ use of independent resources was dependent on their retention of adequate sensory function, and when function could not be maintained these resources failed them. Harry, who spent most of his time near or on his bed, was grateful that he could still see to read his paper. On the other hand, he was only able to watch

89 The work of the volunteers is of the greatest importance, but their numbers are few in comparison with the need.
90 Few residents hand-wrote letters. Reasons included joint, muscular and sensory deterioration in the hands as well as visual or cognitive impairment.
television after his niece sent him a set of headphones with a high degree of amplification. Other residents who kept mainly to their rooms were grateful for television, even when they found reading no longer possible. Sometimes corrective intervention, in the form of new hearing aids or glasses, or even in the case of one resident, removal of deeply embedded wax from his ears, resulted in improved sensory function, and with it, improved morale.

New meanings of home and space

McHugh (2003: 169) in arguing that identities are “wrapped up in place”, echoes Teather’s claim that “home and the roots that lie there are at the core of our personal identity, even if we are separated from them in time and space” (1999: 5). This separation was much harder for some residents than others. For example, Harry felt his loneliness more than he had when alone in his house following the death of his wife. His cramped, shared space meant not only loss of privacy, but also close proximity to others with whom he could not form relationships, and a commensurate loss of self-esteem because he blamed himself for the failure: “I can’t talk to these chaps”. In contrast to this sense of failure, he was buoyed by the occasional visits of an old friend: “We get on very well. I feel normal with him. He doesn’t make me feel like an old man”. I argue that loss of home as much as loss of privacy and independence contributed to his increased awareness of being old and his general lack of well-being (compare Howell, 1983). To meet the needs of those disconnected from home and the past, nursing homes have the challenge of fostering a feeling of “being in place” (Rowles & Ohta, 1983: 237).

Other residents seemed to find it easier to adjust to their new circumstances and let the past go. Charles had had a nice house, “a friendly house”. The garden had been of particular importance, especially as a means for him to adjust to retirement. He

91 May (1986) suggests that, on the whole, women seem to adjust better to old age than men, and widows often function better than widowers.
92 Factors which might contribute to this include an “aura of humanity, caring and tranquillity” (Kastenbaum, 1983, cited in Rowles, 1983: 237).
enjoyed occasional visits back with his family, mainly to see the garden of which he had been proud. He would have liked a little garden of his own, and speculated about the possibility that there might be one for him ‘up there’. He said he did not suffer from the loss of personal space. His private room was big enough for photographs and a large crucifix, and he claimed to be contented. He asked me often: “What more could I want? I’m well cared for, I have three meals a day, I have a comfortable bed. What more could I want?”

Others were equally cheerful about being separated from their homes, or at least accepting of the fact. Winnie was pragmatic: “Well, of course something had to be done, because I couldn’t be left for a long time by myself.” Daisy spoke nostalgically of her old home, but it was part of a long-ago life, a past rather than a present reality. She had filled her new space with one or two small pieces of furniture, photographs, pictures and memorabilia, bringing with them a sense of home and the past (compare Howell, 1983), triggers for memories essential to maintaining a sense of self, as described by Gubrium (1975). I argue, with Gubrium, that identity is tied up in small things as well as the large ones, not just a house, but the objects within it. Daisy, like Charles, was grateful for the care and attention which seemed to compensate for loss of home and space. Hetty also felt well looked after. She drew support from relationships with staff, residents, and other residents’ visitors, commenting on returning from an outing, “It’s good to be home”. In contrast, the nursing home was never home for Nellie. Her husband still lived in her old home, she was able to visit it, and her emotional connection to the house and its contents excluded any other ‘home’.

The variations in residents’ responses to institutional life were typical of the variations in their personalities and their pre-nursing home experience. Patrick, a quiet and withdrawn single man with no family or friends outside the nursing home, seemed less lonely than many who had family visitors several times a week. Unlike Gubrium’s residents with little past experience of home life who “talk of the quality of their facilities in terms of new meanings of home” (1995: 33), this resident did not articulate

93 Gubrium (1995: 30) makes important linkages between residents’ “lifelong experiences and personal accounts of the qualities of care and of life in their facilities”.

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his feelings and I could only guess that institutional life offered him more comfort and security than he had before. He appeared to be solitary and taciturn by nature, quick to complain and slow to smile. I saw no signs of his communicating directly with other residents, perhaps because of his extreme deafness. When he died I was surprised by the anxiety of Tony, another resident, to let me know, and then to get money to buy flowers for the funeral. Tony also spoke little, mainly because of speech difficulties caused by his illness. Apparently their friendship, or at least fellow feeling, was based more on observation of each other and shared activities and space than on direct communication. As Hudson observes, the frail elderly can teach us “that our identity is much more than what we can articulate about it; our identity is not lost forever when we no longer have the language to describe who we are” (2000: 132). To Hudson’s word ‘language’ I would add the word ‘function’, because loss of speech or hearing also prevents people from describing who they are.

A minority of residents asserted themselves by complaining, either about the food or the actions of particular staff or residents. Clara complained almost constantly, and despite staff attempts to convince her of their concern for her well-being, she often held the perception that she was being persecuted. She hated the incursions of other residents into her territory and the lack of security for her possessions.94 However, she was mainly unhappy because her husband had died, her room-mate had died, and most of her family were far from her. Her spirits could usually be lifted by visitors from outside or from recreational staff or volunteers, but resources were not adequate for her needs, and care staff sometimes found her anger hard to deal with (compare Savishinsky 1991: 166). Most of the residents I observed were not angry and difficult. However, I would argue that anger is one way of expressing the self, not perhaps the way the resident would have chosen, but the only way that he or she has found. One senior nurse I heard discussing a resident with dementia after a display of anger, put it in these terms: “Good, she’s still there”.

94 Savishinsky (1991: 159) suggests that residents get ‘picky and irritable’ because little things do matter to them. They are “powerless individuals trying to practise the art of assertion”.
Supporting the relational self: someone to listen, someone to see

Seeing the individual as a whole person, recognising that that individual has a life story, and listening and helping to re-construct that story, provide much of the essential support that the relational self needs to make sense of loss and institutionalisation. Savishinsky explains the need for residents to remember their pasts and tell their stories as a means of making sense of their changed circumstances:

For institutional life to be endured, people had to be able to explain it, and with their words they had to convince not only themselves but others as well (1991: 166).

Gubrium (1993) encouraged residents to tell their stories both to help him understand and to help them make subjective meanings of their experience, listening to see “how subjects construct their world and its realities” (1995: 36). A number of researchers highlight the importance of listening to residents (Heliker, 1997; Savishinsky, 1991) as a means of recognising and acknowledging them. O’Brien (1989: 89) observed that “inadequate communication, or the lack of meaningful interaction, is a notable problem among the elderly”, a conclusion also reported by Coupland, Nusbaum et al. (1991) and others. A number of my informants, although often involved superficially in conversational exchanges with staff, for example during care tasks (Gibb, 1990) were not frequently enough engaged in communication which held meaning for them (see Grainger, 1995). Meaningful interaction of necessity requires someone to listen responsively, a need highlighted by Nay (1993), who nonetheless noted that not all residents felt that it was the job of nurses to listen. If residents did not form close relationships with each other and had no close family “they were deprived of any avenue for expressing intimate thoughts and feelings” (ibid: 227). Hudson reminds nurses of the need to acknowledge residents as persons with a history, to “take seriously the whole person: body, mind and spirit” (2000: 133), suggesting that this leads to acknowledging their own history as nurses as well as enabling them to provide better care. This need was recognised in the nursing homes I studied, and staff did
attempt to know and recognise the histories of residents. However, the realities of work-loads and time pressure meant that these histories could not always be explored.

**Communicative activity in the nursing home**

Rarely are nursing homes considered to be a place where individuals live active social lives. Recent research, however, has not only found that the majority of nursing homes which maintain proper levels of physical care can be an environment rich in communicative activity, but that this activity is positively related to psychological well-being (Nussbaum, 1990: 157).

Nussbaum uses the words ‘can be’ to describe the potential of nursing homes to be communicatively interactive and psychologically supportive environments, and the challenge remains to find the appropriate solution to the social needs of individual residents. Daisy felt she was amongst friends: “I suppose I’m lucky. I’ve got plenty of friends here, and they’re all lovely to me”. Others were less emotionally satisfied. Charles explained his ‘great emptiness’ as a loneliness which he felt could only be filled by the presence of ‘more people like you’, that is, people able to spend time with him in significant one-to-one interaction. This is consistent with his saying that he did not need many people in his life, with an emphasis on the quality rather than the quantity of social interaction. The implication was that conversation partners would need to be interested in him and to value his thoughts, for example about the philosophical issues which preoccupied him. Harry was also lonely and felt a keen need for meaningful conversation, something he could not find with other residents. Staff did not have the time to sit and really get to know him, and his opportunities to be heard and understood were few. This need for relational conversation goes to the heart of my argument, that meaningful social interactions play a vital role in sustaining the self and helping to make meaning of being old and in care. Over-stretched recreational staff did their best to find time for one-to-one interactions, but were frustrated by their inability to give adequate time to each resident and to meet the kind of need expressed openly by Charles and, less explicitly, by Harry.
The family

Finding the right listener is the challenge. The resident does not always have choices, and opportunities for relational conversation may be very limited. Sometimes families provide the best social support. My own study, like Savishinsky’s (1991), confirms the vital importance for many residents of family social support and the additional power accrued through family advocacy. However, in other cases family support is either not available or not adequate to the residents’ needs. Some families also underestimate the needs and capacities of their relatives and may unwittingly patronise and foster unequal relationships rather than offer the kind of meaningful interaction which supports the resident’s sense of self. Nussbaum describes the resident-family relationship as “one of life’s cruellest paradoxes” (1990: 158), citing research which shows that in spite of the need for family support, “the obligations associated with family involvement into the lives of nursing home residents can be detrimental to the psychological and even physical well-being of those elderly residents” (ibid). I found that some families visited infrequently or for brief periods, and in some cases, longstanding family patterns of communication and ways of relating were not built on exchanging confidences. One resident who appeared to have little to say to his family described family visits as being “like a film you have seen before. You can say ‘I saw this yesterday’”. A staff member in my study commented on the fact that many families do not know very much about their parents’ past lives:

You can’t always say it’s the children’s fault because we have a lot of parents, well the generation now, that are very private. They don’t want people to know that they were in the war or they were unemployed, or they did this job, which to them was pretty lowly (Staff interview #7).

I saw ample evidence of families who did provide the essential social support, devoted and attentive husbands or wives who, no matter how tired they were themselves, made the daily visit to spend as many as four or five hours with the resident spouse. One visiting wife, while never forgetting her husband’s dependence on and joy in her company, became a valued friend of other residents, other visiting relatives and of staff. She was a support to the whole community. Sons and daughters came on a daily
basis, in some cases sharing the week’s visits with siblings, but often alone in their caring and there were also dedicated sisters, nieces and ex-neighbours. They massaged, groomed, exercised weak limbs, held and comforted, told news, jokes and stories, read aloud, listened, laughed and cried. Their presence in shared rooms, dining rooms and at organised activities was enriching to other residents and families as well as to their own family member, and of great help to staff. They became extra eyes and ears, attentive to the needs of the community, fetching cardigans or blankets for other residents, moving wheelchairs, helping with meals, and generally adding dynamism to the social environment. They also provided support to other residents’ relatives, sharing some of the pain of seeing a loved one sick or incapacitated. Real relationships were formed. A daughter, describing how she felt about the resident who shared her mother’s room, told me how they had come to care about and support each other: “She cries when we cry”.

Foner notes that “[p]atients’ relatives, in short, come with the job….They need to be included in any thorough-going analysis of nursing-home life and work” (1995: 178). Most staff in my study were highly appreciative and supportive of family involvement, though some, like Foner’s informants, perceived problems regarding the involvement of some families, for example their inability to maintain a regular presence. One of my staff informants spoke of regularly needing to protect a resident from disappointment when family promised but failed to visit: “I won’t tell her that they’ve phoned, because she really takes it to heart when they don’t come in” (Staff interview #5). Several told me that family sometimes posed bigger challenges to staff than residents did, though most were sympathetic to families who were making their own adjustments to having a relative in care. One sympathetic comment was: “Often I think they’re sort of dealing with feelings of failure or guilt and they sort of over-react to situations” (Staff interview #9).

Apart from one or two isolated negative comments about some families, most of the staff expressed strong commitment to family involvement in resident care, and spent time and effort getting to know families as well as residents. One nurse made the following comment about how she experienced resident deaths:
[A]nd usually the residents that pass on have been here a long time and I’ve got to know their relatives quite well, and I feel like family and they make me feel like family. And that’s really special and it’s a privilege that they let me into that very personal time and I look at it as being an absolute privilege (Staff interview # 8).

Another staff member answered my question about the rewards of working in aged care as follows:

I suppose it’s forming those connections not with one person but the family and feeling that you are making a difference because that person is very special to that family (Staff interview # 11).

The support which families draw from staff and from other families can be through organised information sessions and support groups or through more informal contact such as Happy Hour. As reported by Hudson and Richmond:

[F]amily members found what they needed in the informal community of the regular visitors to the nursing home. This valuable resource of support and solidarity is easily overlooked but can be a powerful component of holistic care (2000: 172).

Other residents

Initially I believed that there was very little resident-resident interaction. I recognised the institutional and individual barriers to communication, the difficulty for non-ambulant residents to seek out the company of others, and for residents to hear and understand each other. In my first impressions I missed the non-verbal communication and the comfort which residents drew from being near others on a regular basis. I underestimated the importance of physical proximity in nursing home friendship formation. As reported by Nussbaum (1995), citing Retsinas and Garrity (1985), people who sit near each other at the dining table, whose beds or rooms are close, are more likely to get to know each other and develop friendships. Initially, I expected those friendships to be expressed in conversation or observable communication. Instead, I came to understand that silence and lack of eye contact between men who shared a dining table did not mean a lack of relationship. It meant lack of openly communicated thoughts and feelings, but not lack of feelings. When silent Patrick died, his table companion Tony bought flowers for his funeral. Charles did not talk to
Richard, his very deaf and forgetful long-term table companion, but told me that Richard was a good person. Some residents could hear each other in more private one-to-one interaction better than in the dining-room. Others exchanged little more than greetings, but recognised the place of other residents in their lives. The apparent failure of residents to hear each other did not therefore mean a lack of friendship. An instant liking sprang up between two women in the same room, and they became as inseparable as the nursing home environment and their health permitted, asking to have their meals served beside the bed of the less ambulant one, happy to eat together and enjoy each other’s company. The sudden death of one of these women reduced the other to great sadness, and Hetty, who had herself lost a close friend in the nursing home, commiserated with the bereaved one. Peg spent time with her next-door neighbour, initially for the companionship, but then as a means of helping him make sense of the death of his wife. When this man died soon after, Peg mourned his loss as well, as Daisy mourned the loss of another of the older long-term resident who had shared her table. Residents took an interest in the high and low points in the lives of fellow residents, congratulating them in times of joy, and sorrowing in times of loss. They wept for those who died, or in the case of two residents, who lost adult children, and attended memorial services when they could.

Residents performed small acts of kindness for each other, and when they could not themselves meet others’ needs, kept a watchful eye on them so that they could alert staff or visitors. For Gubrium (1975) these residents who take a role in helping others are ‘supporters’, and for O’Brien (1989) they are ‘guardians’. I prefer the term ‘helper’ because of the value my informants placed on helping others, but there is no significant difference. All supported, assisted, or helped others. Several helpers from my cohort were Peg, Hetty, Sarah, Frederick and Jack. Peg watched others and reported to staff on their comfort or discomfort. She also took a partly supervisory role in the life of less able residents, and helped in small ways at the dining table. Hetty, another committed helper, visited other residents when they were bereaved or bed-ridden, noticed when others needed a chair or adjustment to seating or wheelchair position, alerted staff when residents needed assistance, and was an unfailingly
cheerful and friendly presence in any gathering. She also applauded others’ successes in recreational activities, and played the Bingo cards of one or two less able friends. This behaviour reflected the personality traits of the friendly peacemaker she said she had always been: “I love to be kind”.

Jack could move his own wheelchair, and when required became the messenger for other residents less able to move or explain themselves. He watched out, particularly at Bingo games, for those who missed the calls, either because of deafness or distraction. He said little about his own needs, but saw and reported those of others. Frederick, able to walk unassisted, sought staff assistance for residents he felt were in trouble. He also felt a responsibility to speak for the community as well as for himself at times of celebration. He believed in “making a contribution, however small, to the rest of society”.

Residents’ enjoyment of and support for each other was most evident during facilitated recreational activities. These activities provided the social setting and the support of staff and volunteers necessary for many of the more dependent residents to interact with each other, and the benefits of such programs is clearly demonstrated both in my own and in other studies.

**Recreational activities program**

My findings in general confirm those of Savishinsky who describes the Activities Coordinator in his study as “organizer, catalyst, translator and character reference”, a person who “wove what might have been scattered threads of talk into a social fabric” (1991: 50). In contrast, Bowker (1982: 51) found that the existence of an activities program did not in itself necessarily make an institution a more resident-centred environment, and that un-programmed social interactions with care staff or with physical and occupational therapists were more important in the lives of residents than rigidly programmed ones (compare Henderson, 1995).

Kayser-Jones (1981), in her comparative study of two nursing homes, one in Scotland and one in the United States, found that in keeping with the generally superior
performance of the Scottish home, activities were meaningful, involved residents in the planning and presentation, and were seen to be of positive benefit. On the other hand, the less well equipped, managed and staffed American home offered boring and demeaning activities, including the showing of films made for children. These were lower quality activities. Shield observed that “[e]ven activities that seem intended for adults are presented as if for children” (1988: 196).

Savishinsky (1991), while praising the activities offered at the nursing home, especially those involving residents in life-history, reminiscence and pet therapy (which invoked memories of residents’ past experiences), noted the failure of some care staff to take seriously the work of the Activities Coordinator. They labelled her the ‘play lady’, undervaluing her contribution to resident well-being. The care staff in my study were generally very positive about the work done by the recreational staff, with many expressing the need for more activities, admiration for the staff concerned and regret that there was not funding for many more such staff. Failing an increase in activities staff, they wished that more volunteers could be found. Some commented on the evident improvement in resident morale after social activities, and others suggested that the actual physical care was easier when residents were happier. One person suggested that increased activities could result in reduced need for care hours “because they’ve found that if people are stimulated and there’s good activities that people are connected to, it’s actually taken a load off nursing staff.”

Some recreational staff, on the other hand, felt that there was a measure of tension and misunderstanding, and that some care staff did undervalue their contribution. It was evident that the importance of the activities to the residents themselves was not always understood. When regular staff were absent, residents were sometimes not made ready in time for morning activities. For those who looked forward to the exercise programs or the bocce games, this was a major source of disappointment. Regular staff tried to be aware and to manage their workloads so that those who took part in activities were showered and dressed in time, but they needed to have the information in advance, and to be reminded of changes in routine. Even with the information and the best of

95 Staff interview #22.
intentions, staff could have their care routines interrupted by events on the floor, changes in resident health, and unexpected medical visits, and residents could miss out on activities. As well, resident health and care needs sometimes meant that, in the view of care staff, some residents could not be out of bed for as long as they wished, and could not take part in all of the activities offered. In addition, some residents were not consistent in their interest or willingness to participate in activities. Some residents would decide to attend because they liked the person conducting the activity, or wished to show their gratitude for being asked. Peg attended all activities offered, on the grounds of reciprocity96: “If they’re good enough to put on a concert, we should be good enough to go”. Recreational staff had difficulty in deciding when it was legitimate to “talk the residents into coming”. At times care staff also felt that if activities were good for some residents they might be good for others, and some who preferred not to be there, or who did not appear to benefit from the experience, were nonetheless brought to the room.

Organised games were the only occasions when silent Patrick smiled and showed real pleasure. He greatly enjoyed bocce, played indoors with plastic balls. He was energised by the competition (between two teams) and, above all, gratified by winning. He was not the only one. In spite of, or perhaps because of, the competitive element, residents really encouraged the efforts of others, and enthusiasm levels were high. Encouragement was particularly strong for the more disabled residents. It was not important that residents could not bowl well, but important that they were happily involved.

Another activity which always fostered successful social interaction was an exercise program which involved patting, kicking, or hitting (throwing for the more physically able), balls and balloons back and forth between residents in a circle. Similarly any group activity which involved music, for example singing, clapping, moving to music, even dancing (‘dancing’ sometimes involved holding the hands of a disabled residents and swaying to the music) seemed to both calm and energise residents. For a period they were not preoccupied by pain or loneliness, and their ‘same’ self was confirmed

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96 On resident-staff reciprocity see also Kayser-Jones (1981) and Shield (1988).
by pleasure in the same sort of activities which they had always enjoyed. Their capacities might not have been the same, and their successes not comparable to those of their youth, but they were successes in the light of their current situation, a confirmation of Heikkinen’s contention: “Sameness and selfness go hand in hand, but things begin to show up differently in light of the life lived. Something is gained, something is lost” (1996: 198).

Bingo gave pleasure to many residents. They enjoyed the group interaction, the challenge and the prospect of winning. It was an opportunity for the more able to help those less so, and for the very disabled to be assisted to take part. It was also an opportunity for a resident to call the numbers, or to turn the handle of the barrel. Two or three residents set themselves the extra challenge of playing two cards at once, and other residents who did not play simply liked being in the room where there was interaction, especially laughter.

Hymn sessions provided a different sort of group activity, with residents sharing their knowledge of old well-loved hymns, taking turns to choose one from the large-print booklets, and then singing with gusto. I observed that some residents, particularly those who had difficulty in connecting words in speech were actually able to sing much more successfully. Similarly, some residents enjoyed concerts or communal singing groups, especially when there was instrumental accompaniment.

Different activities offered different possibilities to residents. Some who did not like or could not take part in the music or the Bingo nonetheless enjoyed the fortnightly group outing to a local pub for lunch. Others took pleasure in general knowledge quizzes, trivia sessions, newspaper discussion groups, card games, or the weekly mini-bus excursions. Destinations included trips to parks down by the river or by the beach. For most of these trips the residents, often very disabled, stayed in the bus but several times groups of more able residents were taken on excursions to art galleries. These excursions were difficult from a logistical point of view, but immensely rewarding for the participants.
Many of the activities involved family members as well as volunteers, and for the weekly Happy Hour this provided variety and invaluable energy. There were wives and husbands, daughters and sons, sometimes grandchildren, nieces, old friends and neighbours. They exchanged news with each other and with residents and staff, helped to serve food and drink, and joined in singing and quizzes. This was the highlight of the week for some of the residents, and it was always made richer by the presence of their own friends and family.

Other highlights included birthdays and special celebrations for Australia Day, Saint Patrick’s Day, Anzac Day, Easter, Cup Day and others. Some residents took active performing roles, making speeches or reciting poems, and others like Rachel did Internet research to provide background information. However, the real highlight of the year was the Carols by Candlelight service just before Christmas. The choir and brass band were volunteers, some from a church group, and some family members of residents or staff. The soloists included the two grand-daughters of a resident, whose pride was shared by all. The readings were presented by staff and family of residents, and the audience was made up of residents, their families, staff, volunteers and friends. Residents without family members present were supported in lighting and holding their candles by ‘spare’ family members or staff, and watchful eyes saw that candles stayed safe. It was a powerful demonstration of the strength of the community, of the mutual support which staff, residents and families offered to each other, and for one night at least, a time of hope. After the service, at the celebration supper with residents, family and friends, a staff member repeated a comment made to me six months earlier:

> I find that some of my dearest friends are residents or family or people I work with, and that they’re …I don’t know. I feel like this is a community, and I feel like you’re part of that too.  

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97 Savishinsky (1991) reports a similar feeling of involvement with residents, staff and families.
Resident-staff relationships

Nussbaum (1990) expresses surprise that researchers interested in social interaction within nursing homes have not paid more attention to the resident-staff relationship, citing two studies (Miller & Lelieuvre, 1982; Noelker & Harel, 1978) which demonstrate a “positive relationship between resident survivability\(^{98}\) and close interaction between elderly residents and staff”. Nussbaum makes the point that “it is the perception of close relationships rather than close communication behaviours which have been linked to survivability and positive regard for the nursing home environment” (1990: 160). One of my staff informants seemed to understand this, when she noted that sometimes meaningful interactions with residents “don’t have to be meaningful for me…but meaningful to them, so I am constantly adapting what I do and how I speak to residents, to make sure that it is at their level, that they understand.”\(^{99}\) Nussbaum highlights the need to further investigate ‘real’ communicative behaviour and its link to positive effects on nursing home residents.

A common finding is that nursing home staff are not interested in forming close relationships with residents (Bauer & Nay, 2003; Nay, 1993; Shield, 1988), although residents often have both the need and the desire to form close relational bonds with their carers. My findings contradict this, with many staff claiming that the relationships with residents are some of the most important rewards of working in aged care. These reports from staff about how they feel and behave towards residents were largely confirmed by my observations of staff-resident interaction, and I found no evidence to dispute them. One staff member explained the rewards of her work:

There are so many. It’s just residents kind of giving you, just opening themselves up to you. They are just so inquiring as well. They really care about you and they like to find out about your life as well. And that’s really nice. You feel a part of their lives and even their family (Staff Interview #1).

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\(^{98}\) Resident health and longevity.

\(^{99}\) Staff interview #1.
Other interviews elicited similar responses, with a heavy emphasis on the importance to the staff member of the relationships with residents.

'Talk’ with residents: quantity and quality

Grainger (1993a; 1995) found interactional starvation in aged care institutions, but makes the point that absence of talk is only part of the picture. She suggests that there is a need for a full critical analysis of institutional communication which looks at the quality of interaction that occurs, not just the quantity. She notes that “relation-oriented talk is, in practice, in the service of task-oriented talk, and thus serves the primary goal of the institution, which is the custodial, physical care of its residents” (1995: 422). My findings, based on self-reported staff behaviour, resident comments and my own observations, both support and contradict Grainger’s comments. I observed examples of absence of talk, and of staff talking over residents, but in the main only involving staff who did not have long-term commitment to the facility or knowledge of the residents. Most of the regular staff were willing to engage in conversation with residents, although the best opportunity was during care interactions, and for some staff it was at least partly geared towards task completion. One staff member explained how interaction served two purposes at the same time, one social and one institutional.

JT: I’ve seen you combining talk with care.

#9: But it sort of makes it easy for me. Because it involves the...some of them can’t do much physically to help me...if they feel as though they’re engaging me in a meaningful dialogue, that’s sort of empowering them, so they’re more likely to be cooperative. (laughter)

JT: Right. But you’re also improving the quality of their life at that particular moment by engaging them in social interaction? Or do you feel that that’s not necessarily constructive?

#9: That’s a two way street though. I enjoy it too, or I wouldn’t engage in the...I just find it natural...because I also find it easy.

100 See also Gibb (1990).
Many research studies suggest that the conversation of residents does not match the needs or interests of staff. Shield (1988) found that residents were more likely to consider staff as family than vice versa, and that staff felt trapped by residents’ expectations if they became close to them. Grainger observed that although nurses blamed the lack of time for their failure to talk to elderly patients, this was not the whole story. They preferred to talk to each other: “For the nurse, talk with patients seemed to involve some effort and did not come as easily” (1995: 149).

This observation confirms those of earlier studies cited by Nay (1993), principally that nurses preferred to talk to each other rather than to residents or patients. Amongst the staff I interviewed and observed regularly that was not the case. It was more often a question of perceiving that they really did not have time to talk to residents as observed and their perceptions of ‘meaningful interaction’. Most, but not all, regular staff made efforts to talk to residents or to touch them as they passed through rooms and corridors, and some managed to maintain relational conversation throughout care tasks, often by talking about themselves and their families. Staff who saw every care task as an opportunity to try to interact with the residents were sometimes critical of those who did not.

It saddens me sometimes when I sit there with someone giving them lunch or doing something and I hear someone else. Well not hear, I don’t hear, I see them sitting there feeding away or doing a chore and not saying anything (Staff interview # 7).

I observed staff administering medication, helping residents to eat or drink, helping with resident transfers to and from wheelchairs or from room to room, adjusting dressings, fitting ear-rings and applying make-up. I also saw staff sharing in recreational activities and celebrations. In addition, some staff sat and chatted to residents at the end of their shifts, and kissed residents before leaving for home. I did not see or hear the conversations which took place in bathrooms or toilets, but I saw and heard the laughter, and often heard jokes when residents and carers returned from such private areas. One staff member, himself an easy communicator, recognised that it was easier for some people to talk to residents than for others, and that personality and communication habits played a part.
Is it just an excuse when people say that they haven’t got time to talk to residents?

It’s probably the way that they perceive it…

Or is it the way that they perceive talk?

I think they…Well, I think…I see all sorts of things. Some people don’t know how to talk to residents, some people don’t see any value in talking to residents. Some people don’t even want to talk to other staff members, but some people actually do take the time and get the pleasure out of the conversations.

Nussbaum (1990: 161) cites research based on self-reported communication behaviours of nursing staff which suggests that “[t]he nursing staff disclosed very little personal information about themselves”. This is not supported by my findings. Many staff I observed talked regularly and easily to residents about their daily lives, about families and houses, holidays, travel, cooking and gardening, dogs and other daily preoccupations including current events. In a later comment, Nussbaum seems to make allowance for this kind of personal communication from nurses who feel high levels of affinity towards residents (ibid: 162). Conversation for my informants was not limited to talking about themselves and their lives. Some reported their pleasure in hearing the residents’ own stories, and found that sometimes the relationships added another dimension to their own lives.

It’s just a really satisfying area to work, like you really feel you are making a difference to people’s lives. And they give a lot back, you know, like just talking to the residents, and like talking about the old days. Not that you get a lot of time to talk, mind you, but you do…Like Jack has been all over Australia and talks about the outback, and, it’s just really…really a nice thing to do (Staff interview #4).

Residents’ comments also supported my observations. Hetty had very close relationships with several staff members, and staff confirmed to me their feelings of closeness to her. I saw other residents’ faces light up when staff they felt close to entered the room, spoke to, or touched them, and I heard conversations which suggested mutual interest and satisfaction with interactions. Residents responded positively to signs of affection, including hugs and kisses from staff. Touch, as reported by Shield (1988) and others, was an important mechanism for positive interaction, especially with cognitively impaired residents. O’Brien quotes a nurse:
We need that love, that touch, and families, I think, are afraid [to touch or hug] sometimes” (1989: 175). One of my informants commented on this lack of touch from certain families, and the doubt which it raised for her: “I sort of felt that because the family weren’t doing it I should be asking her… (Staff interview #19).

Although many of the staff I interviewed welcomed close relationships with residents, some expressed reservations about letting the residents too far into their lives. The reasons given were to keep the staff member’s emotional life separate from the nursing home to prevent burnout and to avoid developing favourites amongst the residents and giving differential care.

Look, basically everyone’s…you couldn’t survive in this job if you hated it, really, and most people like it, but at the same time, realistically, most people are working because they have to live and support a family and things like that. So a lot of people probably come with, enough of their own concerns and responsibilities, and although they want to give and they have good relationships with the residents, a lot…we don’t want to actually become their family. Or I don’t, and I’m speaking for myself probably. And I find some people that do make them very much a part of their family often can get their fingers burnt a bit too. Or they can burn out by giving so much too (Staff interview #3).

Most staff felt that time was their biggest problem, that while it did not prevent them from talking to residents, it did limit the possibilities for giving attentive one-to-one-listening, and meeting emotional needs at times of distress. This need was recognised by senior staff, who saw the solution in making time spent with residents more meaningful.

So it’s a mind shift, is changing that attitude and that mindset and saying “This is not about asking you to spend more time with somebody. It’s about having, making the time that you are with them, more meaningful and pleasurable for them. Although you might be giving them a shower, or even toileting, it’s how you do it that’s important, and that’s what the interaction’s all about.” And I think it is difficult for some staff, and I don’t think that a lot of the training focuses on that kind of thing. (Staff interview #17).
The ‘problem’ of empathy

The above comment on training, added to many other remarks from staff about their own communication goals and skills or others’ lack of skills or interest in talking to residents raises a number of questions. What exactly is empathy? Hardee (2003: 51) defines it as “the capacity to understand another person’s experience from within that person’s frame of reference”. It is not possible to legislate for empathy, but can it be taught? Is modelling and mentoring from senior staff adequate? Can training programs include a component on how to care for people in ways that support their sense of self? How can the qualities rather than the techniques of communication be taught? Hardee claims that empathy and empathetic communication are “teachable, learnable skills” (ibid: 51) and many medical and other health care training programs include a component on empathetic communication. However, he draws his examples from the medical interview, that is, short-term interactions between physicians and non-institutionalised patients. The teachable conversation techniques described are those which reflect back to patients an understanding of their feelings about their illness. They are techniques, not qualities of communication, and as such are not applicable in the majority of high care nursing home cases which involve residents who are very old, very frail, very sick, often cognitively and communicatively impaired, and often very lonely. These people have an increased need for emotional support and recognition of their value as human beings. Communication in this context requires a less intellectual and a more ‘feeling’ response, one in which the staff member listens, feels and reads signs within the resident’s body, and then communicates with that body as much through touch and other forms of non-verbal communication as through conversation. ‘Active’ listening which recognises and encourages resident communication can be taught, and trainees can be instructed in the importance of speaking and touching residents in ways which convey respect, but I argue that they cannot be made to feel that respect, or to want to have relationships with residents.
Summary

In this chapter I have examined the nursing home as a site for growth through the development of new supportive relationships and the maintenance of old ones, and explored the ways in which the resilient self finds meaning in its new circumstances. I have argued that meaningful communication is integral to resident self-esteem, and hence to psychological well-being, and that with support from the community, residents can hold on to a sense of self and a sense of purpose.

The next chapter further draws on the resident-staff relationship in its exploration of power, control and autonomy in the nursing home. I argue that respect and support from staff for independent decision making contribute significantly to resident self-esteem which in turn serves to sustain the self and give meaning to the resident’s experience. I explore the concept of ‘total institutions’ and discuss how codes of ethics can contribute to the delivery of resident-centred, holistic care. In my discussion of staff attitudes and relationships, I highlight the connection between empathetic communication and enhanced resident power, with attention to the delivery of care based on respect and dignity.
Chapter 8 – Respecting the Ageing Self: staff-resident communication

In maintaining that the nursing home is a potential site of growth and recovery for the diminished relational self, I highlight the word ‘potential’. Limiting conditions include not only the resources, but the attitudes of individual institutions. Fostering this recovery is too heavy a burden for staff to carry alone. I argue that staff must be supported by employers who embrace a positive philosophy, preferably enshrined in a Code of Ethics, but at the least a philosophy which espouses the delivery of resident-centred, holistic care. Such a model of care implicitly recognises the whole person, and in so doing recognises the history behind that person. It also entails concepts of respect, dignity and self-worth.

In identifying respect as the vital quality which sustains the self in institutionalised old people, I complete the connections between the main themes of this thesis. Communication, respect, self-esteem and personal control emerge in an integrated pattern. In making the claim that respectful communication is the key to resident self-esteem and well-being, I question concepts of autonomy in dependence. I argue that ‘autonomy’ in the traditional sense of the word, is not a realistic goal for aged care delivery for reasons which include residents’ high levels of dependence, the institutional setting, and the professional, legal and ethical constraints on carers. A more realistic and attainable goal is the maintenance of resident dignity and personal control, ethically derived and deliverable via the practices and communication of respect. In exploring this ‘enactment’ of respect, at both institutional and personal levels, I bring my discussion finally to the staff-resident relationship.

Staff need time and encouragement to try to meet residents’ communication needs, and especially to provide opportunities for the lonely and bereaved to tell their stories. This story-telling serves many purposes: it enables residents to recognise and recover

101 “Respect, person or personal and privacy” are the three most common words used in a British study which describes ‘dignity’ (Jacelon, 2003: 544, citing Mairis, 1994).
the self; to project the self through new relationships; to be confirmed in their acceptability as embodied selves; and to exert their agency despite diminishment of their capacities and the imbalance of social power in the ‘total institution’. I conclude with my starting point: empathetic, respectful staff-resident communication is crucial to enhancing residents’ personal control, which in turn serves to sustain the self and give meaning to being old and in care.

A context for resident empowerment

Communication and the maintenance of the self

To explain how empathetic and respectful communication reinforces the sense of self, I now examine more closely what is entailed in the process of communication. I choose the word ‘process’ deliberately, because in comparison, the language content of a communicative interaction is relatively unimportant. This is especially relevant in an environment where non-verbal communication, particularly through touch and silence becomes salient: “What doesn’t get said also has to be heard” (Savishinsky, 1991: 159). What matters, according to a staff informant, is that the interactions should be meaningful. She added an important rider: “[O]nce again I feel like sometimes they don’t have to be meaningful for me…but meaningful to them” (Staff interview #1). Communication involves recognition of the other person, and ideally, that recognition involves the whole person. Implicit in such recognition is acceptance of the embodied self, but also a capacity to see beyond illness and disability and accept that in cases such as paralysis after stroke there is a mind-body dislocation. As my data, and research studies such as Kaufman’s (1988a) confirm, a person does not need a body to function perfectly to maintain identity.

Communication also carries, beyond the affective message of recognition and acceptance, willingness to engage with the history and the ideas of a partner who is able to express these. The demonstration of interest conveys a positive valuation of the person as a worthwhile conversation partner, and confirms that the story is worth
telling and worth hearing. In the warmth of relational communication, conversation partners form bonds which strengthen the relational self. As I argued in Chapter Five, the ageing self is reinforced through narration, and in the process of making explicit the links between the past and present self is the possibility of making sense of the present, especially a present where losses have diminished self-esteem and sense of purpose. The forging of new relationships allows the social self to project itself into the future. The sense of uselessness described in Chapter Seven is partly offset by the newly created social network which offers support in the accommodation of long-held values to the changed conditions. The reformulated values take on new meaning and promote a sense of continuity of the self, contributing to “an integrated and salient account of the life course” (Kaufman, 1986: 148).

Balancing the ledger: obligation and reciprocity

Communication also offers a means of reducing the imbalance in power and agency inherent in the nursing home context. If the resident’s conversation is seen to be valued, it is a gift to be offered in exchange for the care received. I argue this is an extension of anthropological theories of exchange: the lack of relationship with strangers imposes a much greater burden of reciprocity on the receiver of care and services than that involved in family care, where the ideal of love produces a notionally balanced reciprocity. Consequently, reciprocity and perceived obligation in the nursing home is a complex issue, connected to the desire of many residents to be liked. Daisy was weighed down by her feeling of obligation to be cheerful and friendly to everyone. It was difficult at times: “I used to be funny. But I find it’s hard to be nice all the time.” This obligation to be cheerful is commonly felt by residents, and indeed by staff themselves. Macklin (1990: 60) asks: “Does becoming a resident of a nursing home invest a person with a set of responsibilities toward the staff and other residents?” (see also May, 1986). Feeling productive and being able to reciprocate mattered. “Things that people gave in return for what they got” (Savishinsky,

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were important to residents obliged to ask for and accept so much help, and to be aware for most of the time of the imbalance in their relationships with carers. Other researchers report that residents’ self-esteem and well-being are positively or adversely affected by whether they feel they have anything to offer staff, and in some of the worst cases, delivery of care is also affected (Kayser-Jones, 1981). Shield concludes that where old people have “little or nothing considered valuable to exchange, dependency increases, and the value of the old person declines” (1988: 154). While I found no evidence of loss of resident value in the eyes of staff, and none of staff treating residents differentially, there was, nonetheless, a marked desire on the part of the residents to find something to offer to carers and volunteers – even a joke or a story, and it is reasonable to believe that they felt less worthy when they had nothing to exchange. I found that, along with residents’ offering of good humour and cooperation, there were sometimes tangible offerings, such as a biscuit or a sweet. Occasionally residents attended organised activities out of the sense that they owed their participation, but also out of a desire to please the Activities staff. Staff who became aware of this had to walk a very fine line between persuading residents to join in activities which they felt they would enjoy and giving them permission not to: “I never thought that a resident would actually say ‘yes’ because of me, to make me happy” (Staff interview #1).

I do not deny that powerlessness, loss of confidence, loss of identity and fear of retribution may be factors in residents’ desire to please staff, but argue that these same wishes to please, or at least to retain the favour and services of, the professional figure are reflected in many other professional-client relationships. Most elderly people are not accustomed to questioning or behaving assertively with health professionals, and do not expect to have equal status in health care relationships, as is reflected in studies of medical encounters (Adelman et al., 1990; Allman et al., 1999; Beisecker, 1996; Beisecker & Beisecker, 1996; Coupland, Nussbaum et al., 1991; Haug, 1996). Additionally, in residential care, residents’ lack of social power and diminished sense of self can contribute to a kind of social passiveness, a receiving rather than a giving pattern of interaction. I found that I was most frequently the initiator of conversation,
and had to take an active role in co-constructing the interviews I recorded. At first I attributed this to the artificial social situation created by the recorded semi-structured interview, but it was also true of many unrecorded conversations with residents. My impression was that the residents, polite, reticent, and socialised into institutional patterns, tended to wait for attention to be turned to them. They had absorbed certain realities of the social environment: staff ratios and work routines determined how much time might be available for individual residents; social interaction tended to be initiated and ended by those with more authority and social power. Nussbaum, Pecchioni et al. (2000: 53), discussing power and control in social interaction, suggest that deferential behaviour from elderly people is due to fear that the other will stop interacting. For this reason they may also be easily open to persuasion. Fortunately, I also found that the better residents got to know me, the more willing they were to initiate contact, and it was evident that with staff they trusted and with whom they felt they had developed relationships, they were much more forthcoming and socially assertive.

Most residents also felt an obligation to feel and express gratitude for the care they received, one which would easily explain their general reluctance to criticise staff. The unwillingness to criticise staff, reported in other studies (Nay, 1993; O’Brien, 1989), is generally attributed to fear of retribution, or at least of fear of withdrawal of liking and support, and even of care, and highlights the gulf between the relative power of staff and that of residents. I saw Daisy’s wish to please others and be ‘wanted’, like that of Hetty and other residents who praised staff and tried to get along with everybody, as reflections not only of the sociable behaviour which their cohort valued, but of the sense of obligation which most felt to give something back to the community which was caring for them.

**Paradoxes: autonomy and long-term care**

Communication also enhances resident agency: expressing personal choices is an act of agency, and there is empowerment in having them heard and acted on.
recognition of personal control, or autonomy, as a key value in aged care is central to
the aged care legislation and to government ethical guidelines. The use of the word
‘autonomy’ in this context is paradoxical on two counts. Firstly the etymological basis
of the word, usually translated as ‘self-government’, demands that an autonomous
person have the capacity to act on his or her own wishes. Secondly, traditional liberal
theories of autonomy are largely based on the concept of being independent from or
beyond the control of others. A heavy weight is given to notions of agency, with
autonomy as agency characterised by Johnston (1994: 71) as a capacity to conceive
and act upon projects and values. Agich summarises the Western cultural ideal “which
involves a vision of individuals freely living their lives according to their own beliefs
and values with minimal interference by the state or others” (2003: 14). The scope of
this thesis does not allow a full exploration of this subject, but I question whether
autonomy under this definition is realisable for anyone, as did one of my staff
informants.

It probably reflects us in our society as well. We think we’re totally in charge of everything we
do, but we’re not really. We’re still restricted by policies and local governments, you know, all
sorts of things…and also because you’ve got to consider other people as well, so you can’t be
entirely autonomous (Staff interview #3).

It is, however, indisputable that “they’ve got less autonomy of course than what we
have” (ibid). Residents in aged care are by definition dependent and in need of care,
and generally limited in their capacity to act on their own interests and desires. The
term autonomy is nonetheless current in aged care studies (Agich, 2003; Caplan, 1990;
Collopy, 1988; Shield, 1995), usually in discussion of limitations to autonomy of
residents, or ways of enhancing existing autonomy.

Agich (2003) mounts a case for reconceptualising autonomy in dependence, arguing
that traditional liberal views are too narrow and too concerned with non-interference.
His emphasis is on making explicit the positive entitlements of autonomy (including
knowledge of one’s own best interests, beliefs and reasons for acting), not merely
negative freedom from interference which needs re-examination in the context of
long-term care.\textsuperscript{103} His proposed complementary framework for autonomy in long-term care takes into account everyday realities and brings into focus “the full range of care-giving interactions as well as the structure of care-giving relationships” (ibid: 11).

**Tensions and polarities within autonomy**

In his argument Agich draws on the first of six polarities within autonomy in long-term care identified by Collopy (1988). This distinguishes between *Decisional* autonomy (having preferences, making decisions) and *Executional* autonomy (being able to implement them or carry them out)\textsuperscript{104}. He argues, and others (Benjamin, 1990; Caplan, 1990; Jameton, 1990; Kane & Caplan, 1990; Priester, 1990) support this view, that decisional autonomy is too easily lost when autonomy of execution is diminished or lost. When a person who is physically incapacitated has no assistance in executing tasks there is simply no opportunity to exercise decisional autonomy. I find this a useful distinction, but although I used the word autonomy in staff interviews (to ask for staff opinions on what limited resident autonomy) and the word was used in our subsequent discussions, I argue against its general use to describe the limited control which most residents are able to exert over their everyday lives. The personal control which residents in aged care can be helped to acquire can not be anything but a restricted form of autonomy.

**Tensions within the nursing home**

The restrictions in resident autonomy are apparent in all of the day to day routines of nursing homes. Many residents are constantly reminded of their dependence: their loss of physical capacity is only too evident. Even the maintenance of appropriately clean and mended clothes requires the assistance of others. Charles once showed me how the detached belt-loops on his trousers no longer held his belt, which in turn no longer held up the trousers securely, causing him embarrassment and distress and limiting his mobility. I said “Somebody could easily fix that”. He replied sadly, “But somebody

\textsuperscript{103} Agich, citing Berlin (1969) and Dworkin (1988) on the positive concepts implicit in negative autonomy.

\textsuperscript{104} Collopy’s polarities also include: Direct versus Delegated, Capacitated versus Incapacitated; Authentic versus Inauthentic; Immediate versus Long-Range; Negative versus Positive.
doesn’t”. The staff I went to for needle and thread were unaware of his problem, and assured me that they would have been happy to fix it. Nonetheless, his need had not been noticed, or not by those particular staff members, and he had not mentioned it to anybody who had the time or inclination to act on it (or perhaps to anybody at all). Consequently, his dignity and sense of self were under threat in an entirely banal and remediable situation (see Caplan, 1990). His capacity to have his wishes recognised and carried out failed him, and without anyone to carry out his decision, his autonomous choice was negated.

Sometimes care needs, or what are perceived as care needs but may be also a matter of staff convenience, take precedence over residents’ choices. Mira, a physically incapacitated resident with speech difficulties, was taken more than once to Bingo sessions after she had told me that she did not wish to go. When I mentioned this to the carer involved she said that it was good for her to be with other residents. Mira appeared resigned. Perhaps she accepted that it might be good for her to be out of her room, but I think it was more that she was powerless to protest. In the absence of a family advocate, especially an assertive one like Savishinsky’s (1991) Katina, there was no guarantee that her wishes would be heard. Later in this chapter I explore the processes by which staff balance conflicting concerns in their decision-making, with the recognition that they have a duty of care even when they wish to respect resident decision-making.

An additional complication is that one resident’s wishes may conflict with another’s, and the exercise of one person’s autonomy may be an infringement of another’s. Staff are frequently called upon to maintain the peace, to protect some residents, and to negotiate compromise when there are competing wishes (see Kane & Caplan, 1990).

**Empowerment through respect**

Having argued that autonomy is not a realistic target for residents in aged care, I now propose my alternative. I maintain that respect provides a viable means for enhancing
independence and personal control. This respect, although ‘enacted’ through local care practices and communication, should also be demonstrated at the higher level of government guidelines and Codes of Ethics.

**Respect as policy: Codes of Ethics**

One of the stated purposes of the Australian government ethical guidelines for residential aged care is to encourage aged care providers to develop their own written protocols. Key rights outlined in the Code are “the right of individuals to be treated with respect; the right of competent individuals to self-determination, and the right to privacy and confidentiality”\(^\text{105}\). These goals are laudable but unenforceable, given that they are voluntary and self-regulatory, and the extent to which they are put into practice depends on the level of awareness, the personal interpretation and the good will of individual providers. However, the provider organisation behind Wisteria Grove and Greystone had formulated its own Code of Ethics, and made all regular staff aware of it through orientation procedures for new staff and on-going in-service workshops.

The section of this provider’s Code of Ethics which I wish to highlight involves resident rights. For discussion with staff I chose an affirmation that the organisation “encourages personal independence in everyday life and respects every person’s right to privacy, dignity and individual decision making”. I asked general questions about the rewards and challenges of working in aged care, the possibility of meeting residents’ communication needs, and more specifically, responses to the affirmation. I also asked how staff balanced the tension between safeguarding resident autonomy and resident health and safety. All of the twenty-three staff respondents were aware of the Code of Ethics and of this affirmation. When asked to comment, most expressed support for the goals although their interpretation of what could or should be achieved

to safeguard autonomy varied widely. Some felt that having such a Code of Ethics increased their satisfaction in working for this organisation, one staff member going so far as to say “I think it’s crucial. I wouldn’t want to work for an organisation that didn’t believe that” (Staff interview #10).

Personal independence can not, however, be promoted if residents are rendered powerless, either by the ‘totalism’ of the nursing home (see later discussion), or by denial of adult status as expressed through staff attitudes and behaviour (Hockey & James, 1993; Hummert, 1994; Nussbaum & Coupland, 1995; Williams & Nussbaum, 2001). “If those who live in nursing homes have relatively little control over the content of their own lives, then a critical element of the quality of life – autonomy – will be absent” (Caplan, 1990: 39). Personal control enhances subjective well-being, hence quality of life, and residents who are denied this are denied the chance to find positive meaning in this stage of their lives.

**Communicating respect: preserving dignity**

I think we should all be striving harder to give as many choices as possible, because otherwise the person just doesn’t have any dignity left (Staff interview #10).

Many staff expressed commitment to preserving resident dignity. Some felt it should underpin every aspect of care delivery. It was linked with recognising resident individuality, getting to know residents well, and treating residents as equals. One person, condensing his philosophy of care into the word ‘dignity’, also saw empathetic care as reflective of his own humanity.

In some ways we do meet their communication needs by taking care of their basic needs...it is a communication need which in actual fact is a reflection of maintaining their dignity. If we are human in the proper sense, everyone tries to maintain their sense of dignity (Staff interview #18).

Others saw this as the most important lesson to get across to new staff and trainees.
I suppose something around respect and dignity, that...I think if you approach aged care with that – with those two things in mind – that these people are worthy of respect, and that we need to, as much as we can, maintain their dignity (Staff interview #9).

Unlike those described by Shield (1988), the residents at these two nursing homes were not viewed or treated alike, or spoken to as non-persons. Although I saw occasional examples of ‘talking over’, a number of the staff I interviewed vigorously rejected the practice as well as the use of patronising or infantilising language.

**Patronising language: ‘ageing talk’**

That’s why you’re not supposed to call people ‘love’ or ‘darling’, and that’s really hard to correct. I do that (Staff interview #4).

I suggest that it is simplistic to condemn all terms of endearment as patronising, because it is evident that some residents respond well to such language and do not feel diminished by it. For those who have long-term relationships with certain staff, who have always used terms like ‘love’ and ‘dear’ themselves, or who have always been spoken to that way, the use of such terms is seen as nurturing, and a mark of solidarity. Caporael et al. (1983) found that the positive response of some care receivers to patronising language was related to their degree of cognitive dependency. Those less dependent preferred other kinds of talk, as reported by O’Brien (1989) and Laird (1979). Laird praised a staff member who “never talked down to me, never addressed me as ‘honey’ or ‘dearie’ – which, on the lips of the nursing staff, sounded as insincere as the endearments of prostitutes” (ibid: 87). Being patronised made Laird angry, but in many cases the effect on elderly residents is to make them feel less powerful, less competent and less worthy of respect. “Aging talk” (Giles et al., 1994: 142) which highlights incapacity or powerlessness can reinforce dependent behaviour, as can the practice of talking down, or using directive parental language (Kayser-Jones, 1981; Nay, 1993; Shield, 1988). I did not observe such practices, and have only second hand reports of their occurrence. Several staff told me how much they disapproved of
‘talking down’ and ‘bossy’ language,\textsuperscript{106} and tried through their training practices to foster respect for residents’ adult status as well as their individual rights.

Do as You Would be Done By

Many staff members expressed their commitment to speaking to and about residents respectfully. This piece of advice to new trainees reflected a common practice, treating the residents as they would like their own family members to be treated, or as they would like to be treated themselves.

My sort of standard thing is to tell people, “Just look at these people as your mother or your father or your grandmother or yourself. What would you like? Would you like people treating your parent or yourself like a little kid? Just put yourself in their place” (Staff interview #4).

Other staff echoed this sentiment. They felt that empathetic imagination was the solution to knowing what residents might like if other attempts to learn their wishes failed. If they could not understand speech, or read residents’ bodies or faces, they believed that imagining themselves in the other person’s place, or “in their shoes” (Winchester, 2003), would enable them to deliver the best care. For some staff this was an emotional theme which reflected the degree of attachment which they felt for the residents. For others it was a way of providing the best of professional care, and of attempting to ensure that that standard of care was consistently delivered by all staff:

And I like to put myself in the position, and I say to the staff, “Imagine if that was your mother or your father or someone you really care for in your family. Imagine they were on the receiving end of that” (Staff interview #3).

Recognition of the individual

Staff rejected the labelling of residents by their illness or disability, a ‘Parkinson’s’ or a ‘dementia’, a practice also described in other studies (see Kayser-Jones, 1981).

\textsuperscript{106} Coupland, Nussbaum et al (1991: 95) use the term “excessively regulatory talk”.
I really reject that attitude of looking at someone and saying “Oh, you’re an ankle…that’s your problem, or you’re a hemiplegic. You’re not a hemiplegic ..you’re a lady who happens to have, amongst other things, a problem with hemiplegia” (Staff interview # 6).

This awareness of, and respect for, resident individuality was fostered by the institution and supported in training practices of senior staff, and described to me as follows:

It’s around people actually asking the question of direct care staff: “Do you realise that’s a person who has a name, who has a family and has a life, and who has probably contributed significantly to the world that we live in, and in their own world?” So it’s about identifying the older person as somebody specific, and that holistic thing, rather than an old person (Staff interview # 17).

Many staff, like Heliker (1997), expressed the need to value the past lives of residents, and respect their talents and achievements:

You may only see that person as, or in a particular state, but they have led a whole past life from where you find them now (Staff interview #18).

Several felt that this was the most important lesson to teach new trainees. Others also expressed concern about seeing the resident as part of a family, and trying to meet the needs of families, but ultimately the “frail old person” is the one staff have to listen to (Staff interview #10).

**Difficulties around communication: age, disability and the nursing home**

Throughout this chapter I have maintained that communication is the key to enhancing personal control. However, there are very real limitations to the communication which takes place in the nursing home context. In Chapter Two I discussed the institutional and personal barriers to communication, highlighting the fact that staff cooperation is a vital factor, and that staff work-loads and routines interfere in staff capacity to know and meet residents’ communication needs. In interview some staff expressed
reservations about residents’ cognitive and communicative capacity to make and convey decisions. Others felt it was vital to continue to try to communicate even with the brain injured, assuming that non-responsive residents might hear and understand what was said to or about them. Some had had experience of working in rehabilitation with stroke and other brain injury victims and had first hand reports from recovering patients of their experiences of being ignored, talked over or spoken to disrespectfully. One was very affected by a resident’s experience of staff silence:

When she first had a stroke she couldn’t speak. And she said the nursing staff didn’t speak to her, because they just saw her as somebody that couldn’t respond, and all she wanted was, even though she couldn’t speak back, she wanted people to speak to her (Staff interview #5).

‘Knowing’ residents’ wishes

All staff supported residents’ right to personal decision-making, but many felt that the limitations for residents with cognitive impairment made it impossible for staff to know or in some cases to value the decisions made. They nonetheless respected the need to see each person as an individual. Others felt that it was worth making every effort to know and execute the wishes of all residents, as far as that was possible given the number of residents and the number of staff available to meet their needs.

I think it’s vitally important. I think that every one of these residents, how incapable they may seem, have all got rights of decision. And I think that as nurses we have to value that (Staff interview #5).

They made conscious efforts to find ways of communicating which were not demeaning, no matter how impaired the resident. This contrasts markedly with the attitudes expressed in some earlier nursing home studies, for example the “big babies” label used by Gubrium’s informant (1975: 127).

When I am communicating with people it is an effort, like I really, really think about the ways, especially people with say dementia or Alzheimer’s in the later stages…where I am constantly thinking about the best way to approach them in a way that is not going to demean them at all (Staff interview #1).
Some relied heavily on the information provided by families and others and recorded in the resident profile as described by Hudson (2000). Admission procedures concentrated on gathering as much information as possible about the present and past identity of the new residents, of their history, activities, interests, tastes and preferences. There was an attempt to retain as much as possible of each resident’s individual identity, and filling in a comprehensive resident profile was seen as a means of ensuring future care which respected that resident’s wishes. This history-taking was most important in the case of residents with cognitive impairment who could not express their wishes. The institution saw it as a means of respecting resident decision-making, believing that families would be best placed to know what residents might want. Other practical cues, such as the clothing brought in by the family helped staff to know some of the resident’s tastes and habits.

So if we can’t engage the resident, then we will engage the family in that dialogue. And I think that at the end of the day, I don’t know what else you can do and if the person can’t tell you, the assumption is that the loved ones will know the person well enough (Staff interview # 17).

Activities staff members kept their own files on individual residents, constantly adding notes arising from casual conversation with the residents, families, other visitors, and other staff. To this they added their observations about which activities, objects or conversations seemed to trigger memories for the residents, and what seemed to interest and stimulate them. Sometimes, as in Savishinsky’s (1991) study, the triggers were visiting pet animals, but even a fur jacket across a resident’s knee seemed to arouse happy memories.

Some staff were confident that, given enough time, they could always determine what even a speech-impaired resident’s wishes might be. They concentrated on listening and watching the ‘communicative body’ (Frank, 1991: 88). Staff needed to be patient and vigilant, knowing that “[s]ometimes movement alone could be eloquent” (Savishinsky, 1991: 131).

I think it’s very important, even if somebody can’t talk. It is one thing that I’ve learned in aged care…is to listen, and to communicate. It doesn’t matter what, because there’s always a sign,
somewhere in their bodies, their eyes, their lips, their hands, their touch, that gives you the answer (Staff interview # 2).

Know your resident

Staff believed that knowing residents well was the key to understanding them and anticipating their needs before the resident needed to try and articulate them. By comparing their long-term knowledge of residents with other long-term partnerships, they highlighted the part that time and familiarity played in acquiring this knowledge.

There’s lots of non-verbal communication that goes on too, so I guess it’s like living with a partner where you learn to…know what that person’s thinking. Well, we’re doing the same thing here. We’re probably anticipating people’s needs…I believe, working in an aged care facility, we need familiar faces. We need people that do know what their needs are and get to know the residents, and that’s how they get quality care. It’s those familiar faces and the same people coming in (Staff interview # 11).

The emphasis on staff continuity as a means of enhancing resident agency was a recurring theme. Knowing residents well was the key to empowering them and offering them respect, and included knowing how to address them in ways which engaged them, both in the relationship and in their own care. Listening was the most important part of knowing the residents and the means of establishing relationships, “the thing that really makes you click together” (Staff interview # 7).

Respect in practice: supporting independence

Like Kaufman (1988b), I argue that loss of personal control is a threat to identity. On the other hand, self-esteem is boosted by validation and an increased sense of personal control. Resident control is increased by encouragement and the opportunity to make autonomous choices, to find roles, routines and responsibilities, and to exert agency even in such actions as saying no to Activities (Savishinsky, 1991: 119).

107 Gubrium’s staff informant sees knowing the resident as a care issue: “I question whether you can intelligently make a care plan unless you know the patient very well” (1975: 42).
May reminds us that professionals, those whose job it is to care for the elderly, vary greatly in the respect that they show for the care-receivers. The power imbalance “tempts the insensitive to condescension” (1986: 45), but even the well-intentioned are at risk of reinforcing the negative self-perceptions of the elderly if they are not highly aware of the potential effects of their own language and behaviour patterns. Their wish to nurture can in fact reinforce dependent behaviour in residents and conversely fail to reward independent behaviour (Baltes & Werner-Wahl, 1987; Nay, 1993; Nussbaum, Pecchioni, Robinson et al., 2000; O'Brien, 1989). Baltes and Baltes (1990) found for example that independent self-care behaviour was not rewarded with social interaction in the way that dependent behaviour was. The residents who appeared less able to look after themselves received more carer time and attention (see Powers, 1988). I found that staff were aware of the risk of not paying as much attention to the more independent residents, and said they tried to exchange a few words with them often as they came and went in the course of their daily routines. They were also aware of the potential benefits to general health and mobility as well as the increased self-esteem in residents recognised as competent and rewarded for their independent behaviour. However, there were some reservations about time and efficiency, and they conceded that it was not easy to allow time for residents who were slow in helping themselves.

Many very ill and disabled residents cannot act independently or contribute to their own health care. Their physical dependence is already established, and their self-esteem and any associated health benefits rest on recognition, not of their capacity to act independently, but of their adult status and their basic rights, including rights to have their decisions respected. As I have argued throughout this thesis, the recognition of adult status, and positive evaluation of the worth of the individual resident and his or her life, is best conveyed by respectful communication. Staff who communicate sincere respect, as described by Kastenbaum (1983) for the adult status of residents and positive expectations of their capacity and worth are instrumental in the maintenance of the resilient self. Their encouragement for residents to make decisions and trust carers to help execute them gives residents the confidence to believe that their wishes are worthy of consideration, and reinforces resident identity. I discussed
respect with Charles, who was emphatic in his reply: “Oh, we’ve got that here”. In the perceptions of both Charles and his carers he had respect. He also returned that respect to the carers, and in consequence not only was his self-esteem preserved, but also that of the carers who felt they were meeting both the professional and the human needs of the residents.

**Resisting ‘Institutional Totalism’**

The degree of personal control which an individual nursing home is able or willing to guarantee individual residents is dependent on a number of factors. These include the philosophy and communication practices of that organisation; the structures and routines; the staffing mix and levels of staff training and experience; and the degree to which the home provides an environment in which staff are encouraged and assisted to consider residents’ dignity, privacy and personal choices in their daily care. Staff have to know the residents well enough to be able to understand them, and to know the preferences of those who are inarticulate, and the relationships have to be empathetic enough for the respect for resident rights to direct execution of resident choices. Ultimately, it depends on someone being willing and able to help execute the resident’s wishes, once they have listened hard enough to know what those are.

I owe the expression ‘institutional totalism’ to Bowker (1982) who, following Goffman (1960, 1962), identified points of comparison between nursing homes and maximum-security prisons. He concluded that it is the extent to which the medical model of care predominates over the humanistic model of care which magnifies or reduces the degree of similarity between a nursing home and a prison (Bowker, 1982: 31).\(^{108}\) Amongst other factors, he highlights the socially structured gulf between residents and staff members which leaves residents powerless to control their own living conditions; and the nearly total absence of privacy and personal space (ibid: 45-47). Bowker does not set out to criticise the nursing home industry. Rather, his intent is to show that “the total-institutions perspective” does apply to nursing homes and

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\(^{108}\) See also Henderson (1995) and Johnson and Grant (1985).
that, understanding this, we can work to combat the negative effects of “institutional totalism”. Other studies such as Savishinsky’s (1991) accept the “total institution” label, particularly because of residents’ loss of control, loss of self, separation from society, and precedence of institutional routines over individual needs (see also Shield, 1988). Following Bowker, I argue that there are many ways in which nursing homes can work against the intrinsic ‘totalism’, starting with a philosophy of resident-centred care which ensures that residents are treated with respect and dignity. As I have argued throughout this thesis, the key to breaking down the social distance between staff and resident roles and reducing the powerlessness of residents lies in effective communication and respect for resident choices, best known and fostered through supportive resident-staff relationships.

Another key direction for reducing the prison-like aspects of nursing homes is in combating resident isolation and segregation from the community. In fact, most residents are not absolutely segregated from the community. The comings and goings of relatives, friends, health professionals, church visitors and others, and the visits of residents to outside destinations mean that they have access, even if in a limited sense, to the community. The factors which limit this access, apart from residents’ own health and levels of disability, include the necessity for others to cooperate, either by visiting the nursing home or by facilitating outside excursions. In the case of those who have no relatives or other willing person, or whose level of dementia makes outside excursions risky, access to the community is indeed very restricted.

**Greystone and Wisteria Grove: measuring up**

The two nursing homes matched Goffman’s model in that residents were subject to the control (through rules and regulations) of the institution, all activities (such as eating and sleeping) took place under the same roof, activities were scheduled by the institution, and there was a division between the roles of staff and resident. Privacy was also hard to maintain, particularly at Greystone with its shared bedrooms and bathrooms. Nonetheless, the *right* to privacy was endorsed by all staff. Some
discussed bodily privacy and spoke of the need to use shower capes in public areas, and to close curtains around beds during intimate care tasks. Others saw it as an issue of personal space, and felt the need to ask permission before entering a resident’s room or private area: “We have to treat their bedroom as their house, to knock before we enter, because it’s their private area to do as they wish, and we have no right to invade that space (Staff interview # 7). This right to privacy was extended by some to include the right to decision-making, and in particular, the right to freedom from interference in their personal space and their right to personal solitude rather than participation in groups if that was their preference: “You don’t force people to come to an activity” (Staff interview # 10). The word ‘force’ here is worth noting, since the means of ‘force’, as in actually moving someone’s wheelchair, was rarely physical. Any pressure was most usually applied through the use of persuasive language. In this context, where the motivation was the desire to give pleasure to the resident, I do not think compliance-seeking can be seen as the face-saving described by Grainger (1995: 431).

On the whole, care staff saw preserving privacy as a difficult issue. Some were optimistic, with comments like, “It’s hard, but I don’t think it’s impossible.” Others, more pessimistic, saw issues such as building design and layout (for example shared rooms and bathrooms; inability to protect personal space and belongings from other residents; lack of private space to discuss health problems or entertain visitors) as intractable. They echoed Foldes’ conclusion that the nursing home exacerbates “the violation of personal privacy and space set in motion by residents’ physical dependence” (1990: 29). Surveillance of residents, a threat to privacy, was never obtrusive and never a source of complaint, but nonetheless, nursing homes share this feature of ‘totality’ with other total institutions, with the justification that they have a responsibility to protect residents from adverse consequences of their own or others’ actions.

Differences from the Goffman model included the willingness expressed by staff to vary schedules to fit in with resident preferences where possible. An example given frequently was getting up times and shower or bath routines, but it was notable that
meal times were not really flexible. Staff saw the desirability of giving choices, but justified serving all meals at the same time because there were so many residents and there was so much to do – in other words, it was staff-resident ratios and the work routines which ruled “the autonomy thing” (Staff interview #10). Offering choices in other areas could at least partly compensate for this lack of flexibility. Additionally, residents could be involved through a Residents and Relatives group in some of the planning and reviewing of the practicalities involved in the daily organisation of the homes. Relatives were encouraged to be advocates for residents who were reluctant or incapable of speaking for themselves, and residents were consulted on a wide range of issues. In general everyday interactions, staff made genuine efforts to find out what residents wanted and solve problems for them.

**Staff-resident relationships**

As I have argued throughout this chapter, staff-resident relationships are crucial to reducing the ‘totalism’, or ‘autonomy-restricting aspects’ of the nursing home (Foldes, 1990: 34). The findings from my study confirm the existence of meaningful staff-resident relationships, the willingness of staff to enter into these relationships, and the beneficial effect on residents of care delivered with respect. Indeed, as Aroskar suggests, “given the intimate nature of the care required, it is hard to believe that personal care could be rendered happily or received comfortably in the absence of some relationship of mutual respect” (1990:278).

Staff, while willing to form relationships, also faced the question of how they could best respect and protect the residents in their care from emotional dependence: “How can you build a relationship that supports people and then doesn’t make them dependent on you?” (Staff interview #22). There is no easy answer to this question – the relationship between staff and carers is inherently unequal, given staff responsibility for resident health and safety, the dependence of residents on staff for all of their care needs, the closed world in which they live, and residents’ relative vulnerability and powerlessness. Thoughtful staff are aware of the risk of increasing
resident dependency through building social relationships that are too close and absorbing, but recognise that “you become people’s life” (ibid) and try to handle that gift responsibly. Some of my informants saw residents almost as family and were proud to be part of their lives, suffering as a consequence when residents died, but considering the investment worth the pain. Others preferred to not become too close. With these variations, there was still a general conviction that knowing individual residents well enough to establish effective communication was the key to furthering resident independence.

Staff awareness and skills in communicating effectively and respectfully with residents depend on adequate training as well as on a commitment at management level to delivering care based on a Code of Ethics. Shaw outlines some of the features which have been incorporated into general training courses, for example: “Staff, of course, must always recognise the presence of the resident and not cast the person into anonymity while conversing over him or her” (1991: 181). To most of my respondents this was self-evident. They had strong views, however, on the need to train personal carers before they entered aged care, and to continue the training after they started work. It was not expected that new staff would automatically have positive attitudes towards resident-centred care or the awareness and skills to communicate empathetically and respect resident decision-making.

The Time Factor

Even with the confidence that they could always communicate with residents they knew well enough, staff saw time as the most significant barrier. They needed time to be with residents; to learn their likes and dislikes; to gain their trust; to make contact with the hearing impaired; and above all, to listen to what the residents’ voices or bodies were trying to communicate. “It is time-consuming. You might have to wait for five minutes for a long blink to give an affirmative answer, so it is time consuming” (Staff interview # 3). Time was the main obstacle to their being able to know and

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109 Other recommendations include calling residents by their preferred names, making eye contact, and not leaning or standing over a person in a bed or chair.
execute residents’ wishes. Savishinsky (1991) reported similar findings, including staff regret that they lacked time to show compassion. That same lack of time to show compassion and give emotional support to residents in distress bothered a number of my informants.

I suppose the challenge is also wanting to spend more time communicating with people rather than, you know, when somebody does have an episode where they’re feeling particularly depressed and confused, and you know, they’re tearful, and you’d like, I feel I’d like to be more there for them, to go into more…You know, to support them (Staff interview #11).

Staff were troubled by lack of time to determine the wishes of residents with sensory impairment (compare Kane, 1990: 9). One informant felt divided by two imperatives: knowing that she should stay and listen to residents who had trouble in making themselves understood, but also that she had other residents waiting for her attention.

There are some who are trying to talk and you have trouble understanding, it’s a real challenge to make yourself stay there and find out what it is that they wanted…I think that’s probably one of the worst things about it. That you don’t have the time to actually understand, to stand there and…because when you do make yourself stand there and listen to what they’re going to say, all the time I’m thinking, “Oh, I’ve still got so many other medications to give out” (Staff interview #4).

Explicit in the words “make yourself stand there and listen” is the conflict felt between the sense of medical professional duty and that of recognising social needs and the resident’s right to be heard. This highlights the basic dilemma of the conflicting roles of a nursing home (Foldes, 1990). Is it a medical facility or a place of residence? If it is a medical facility, then professional care goals will inevitably take precedence over social needs. If it is a residence, then social needs will take a higher priority, as indeed will concern for resident autonomy. Time is also a factor in communicating with the cognitively impaired, with thoughtful staff anxious not only to communicate effectively, but to communicate respectfully, as far as possible in ways which were meaningful.
We always seem to be rushing from one thing to the other. Then because you can’t really rush when you have someone with a dementing illness, you have to sit down, be on their eye level, and make it meaningful (Staff interview #10).

Many staff felt the effort well worth making, even if they could not know what meaning the interaction held for such residents. Cassell sees this as relating to the person who is there rather than the person who used to be there: “What the contact and the caring mean to the demented person is undoubtedly an affirmation of basic humanity, reducing isolation and paranoia. It may contain as well a mystery, to which the code is not yet broken” (1986: 184).

The balancing act: resident independence versus Duty of Care

Some staff interpreted the aspect of the Code of Ethics which “encourages personal independence in everyday life” literally, referring to Activities of Daily Living. They told me they encouraged residents to take part in their own daily hygiene routines, washing their own faces or cleaning their own teeth, and in eating and drinking. Others encouraged residents to maintain strength and mobility, and to participate in social activity. Most saw individual decision making as part of personal independence, and supported the ideal. However, the list of limitations to resident self-determination included safety issues, other people’s rights, residents’ own physical or intellectual capacity, lack of time for staff to determine residents’ wishes and, above all, lack of resources to implement these wishes. Some were very frank about recognising that they were in control, and that autonomy in aged care was very much something to be granted, or “allowed to happen” rather than something residents could automatically claim. The word ‘give’ in the context of “give them autonomy” and “give them choices” also highlights the power of the staff to control both the expression of resident choices and the execution of those choices.

Well I think safety issues probably limit it of course. We’ve got a duty of care and to be responsible for people’s safety and security. Other than… and also if it impacts negatively on other people. And I think we all like to think: “Yes we give them a choice”, probably at the end of the day we’re still in control to a certain extent. But yes, you can, and again, I think a lot of
that autonomy…it’s not easy to give autonomy because again you’ve still got to be aware of their needs *(Staff interview #3)*.

This staff member highlighted the basic conflict between resident independence and the imperatives of a protective care environment. Staff have a duty, both legal and moral, to preserve resident health and safety, to protect residents from adverse effects of their own behaviour, and residents from others’ behaviour. They are *required* to be responsible for decisions about care, as opposed to residents who are not. This is epitomised in the above staff member’s conclusion that extra staff and extra time are probably the key to furthering resident autonomy, still expressed in terms of staff control, “to be able to let them, allow them to do whatever it is that they need to do for their independence” *(ibid)*.

The balancing of resident independence against concerns for Duty of Care cannot be divorced from two key issues. One is the quality of resident-staff relationships and the other the degree of reconciliation between medical and social understandings of the nature and role of the nursing home.\(^{110}\) Staff who see their Duty of Care as the first priority may be totally risk averse, and unwilling to allow competent residents to weigh up the implications of decisions they make for themselves, but others may perceive some risks as worth taking. Shaw argues that a person cannot be protected from all possible risk, and that “[s]taff who work in institutions need to be assisted to understand the difference between the resident’s right to live with risk and staff negligence” *(1991: 182)*. When old people are stereotyped as pathetic, powerless and mentally incompetent, risk factors may seem much greater and the need for protection consequently greater, justifying the denial of autonomy. Resisting this, Norman *(1988)* argues that although risk avoidance increases someone’s physical safety, excessive protection might endanger that person’s psychological well-being. This is a view which I strongly support. Residents are angered and distressed by the denial of what they see as their right to make their own choices, and this has a profound effect on their well-being and quality of life. Staff at Greystone and Wisteria Grove were well

\(^{110}\) Shield considers that in the American nursing home at least, “the medically-oriented regime and an institutional routine hold sway” *(1995: 114)*.
aware of this. One person, explaining how she understood Dignity of Risk and Duty of Care, emphasised the importance of accepting that accidents happen to everybody, but of reducing foreseeable risk factors so that residents’ choices can be executed and their autonomy protected as safely as possible. Her understanding of autonomy included assisting the resident “to live a full life as a human being”.

Duty of Care meaning that we care for the person as far as we can, bearing in mind the dangers and Occupational Health and Safety issues, and Dignity of Risk of say, walking with a person across the street to have a cigarette, putting everything in place to make it as less dangerous as possible, but just allowing the fact that accidents happen to everybody (Staff interview #10).

Most staff saw their relationships as essential to the process of understanding what residents wanted and helping to implement choices. This supports Shield’s (1995) contention that relationships are crucial to staff and resident decision-making processes (1995).

“At the end of the day you can only do what you think’s best”

In balancing risk factors against residents’ wishes, staff had to decide how important a perceived risk factor was. They tried to involve the resident in the decision, or at least to make clear their reasons for making the decision themselves. The words “let them do what they want” remain as a reminder of the custodial aspects of nursing home care and the control ultimately held by staff. Different aspects of resident health and safety emerged in interviews. Some staff felt that they needed to intervene if residents chose not to bathe or shower, or to get out of bed. This was justified as acting for their own sake. “There’s choices to be made but they have to be the right choices” (Staff interview #5). Others were concerned with perceived safety risks, particularly those involved in residents’ desire to leave the building unaccompanied. Most of those who wanted to leave were cognitively impaired, and lacked the capacity to perceive or weigh up the magnitude of the risks involved. When staff believed that a resident was incapable of making a rational decision there was less weighing up, but more need for strategies which enabled them to distract or deflect the resident who wanted to act ‘dangerously’. All staff believed that they should not simply refuse residents’ requests,
and had a range of strategies for dealing with denial of autonomy with as little conflict and as much respect as possible.

But you have to treat it with dignity as well, you have to know ways where you can coax a person away from a door situation where it’s not being closed in their face, where it’s being done with subtlety and gentleness as well. That’s a hard one (Staff interview # 10).

For cognitively aware residents there were other strategies. For example, when a resident who was considered at risk of falling declined to wear hip protectors, she and her family were counselled, and then her right to take the risk was supported. The time factor emerged as a reason for not spending too long making decisions, or debating decisions with residents. When staff felt that there was a safety risk they tended to act rather than deliberate. In the words of this informant, you have to do your best and “do what you think’s best”. The concession to resident well-being lies in the words “as happy as they can be”.

There’s all sorts of issues in this environment and you’ll never get the staffing. That would be just impossible to get the staffing mix that you need to cater for all of these things. At the end of the day you can only do what you think’s best. Do your best, I mean, and make sure that everyone’s safe and warm and comfortable and as happy as they can be (Staff interview #3).

The reality of “in this environment” is that under current government guidelines for the provision, and especially for the funding, of nursing home care there is limited capacity for individual providers to put into practice the ethical guidelines espoused by that same government. The pessimism reflected in “you’ll never get the staffing” reflects the realities of the budget restrictions on nursing homes and the shortage of qualified and dedicated staff which is partly due to low salary levels and partly to the low status of gerontic nursing as a profession. My informants knew what they would like to do for residents, and that included assisting them in their independent decision-making and in carrying out their wishes where possible, but they did not feel that they could meet resident needs as well as they wished. In the interim, they were obliged to make their own judgements and accept compromises. I argue that these compromises mean that our potential as a society to deliver care which best respects the ageing self and gives meaning to being old is also compromised.
Summary

In this chapter I have argued that communication and positive staff-resident relationships hold the key to ‘enacting’ the respect which enhances residents’ personal control, and with it, self-esteem and an appreciation of the value and meaning of their own lives. Staff awareness of, and capacity to meet, resident needs and safeguard their rights depend on institutional expectations and practices. These include ethical guidelines and ongoing training and mentoring of new and junior staff, as well as adequate and appropriate staffing levels, an essential element of meaningful staff-resident communication.

In the next chapter I will draw this thesis to a close with a review of the themes and arguments of earlier chapters, and discussion of implications for the well-being of nursing home residents and the future of residential aged care.
Chapter 9 – Conclusion: Respecting Aged Care

In concluding this thesis with my reflections on the themes and arguments raised in earlier chapters, I return to my main reason for conducting this study. I believed that social and communicative interactions in aged care settings would play a significant role in maintaining residents’ sense of self and enhancing their autonomy. With this belief confirmed by my research, I now argue the need for greater public awareness of social and communication issues in ageing and aged care.

Many aged care staff are willing to enter into relationships with residents, and are committed to the delivery of care which respects the whole person. This respect, however, can only be adequately communicated when staff are well-supported by government and institutional philosophies and structures. I conclude with a discussion of these issues, and the implications for the delivery of care which best supports the ageing self. I also reflect on the significance of my study, its limitations, and possible directions for further research.

The power of communication

My intention at the outset of this study was to try to determine how old people made sense of their lives in institutional care, and to do that through exploring the role of communication in the nursing home, paying particular attention to resident-staff relationships. As the thesis has unfolded, communication has indeed emerged as the most significant theme, the thread connecting all of the other elements and arguments. In weaving these connections, I have moved my discussion backwards and forwards between theories of ageing, of the self, of respect and autonomy, of the losses of ageing and institutionalisation and of the challenges confronting providers of aged care. I have, however, been conscious always of the dominant role of communication: in residents’ adaptation to the losses and stresses of ageing; in the delivery of aged care which respects the whole person; and in the maintenance of resident self-esteem.
and personal control. In short, communication is paramount in the process of making meaning of being old and in care.

**Communicating ageism**

Communication serves to both construct and transmit the ageist stereotypes which contribute to the belief that old people are different and therefore have different social and communication needs from the rest of society. These stereotypes provide an easy justification for patronising and marginalising treatment of old people both in and out of care. Even more worryingly, they carry over into the attitudes of policy-makers responsible for legislation, funding and regulation of government-subsidised aged care. The result of patronising attitudes at a personal and systemic level, and of an under-funded system, is the neglect of the social and communication needs of many residents in aged care settings. This entails sub-optimal levels of care. Patronising communication which conveys low expectations of the cognitive and communicative capacity of the elderly tends to confirm these low expectations. It negatively affects both self-esteem and the communicative performance of the recipients. It also risks overlooking or trivialising legitimate health or personal concerns of residents, and restricts the range of social and communication opportunities open to them. Communication which denies the adult status of those deemed to be child-like denies respect for their humanity as well as their rights.

**Communicating the self**

Everything about the self is part of the same narrative; it is a narrative about one’s relationship to oneself, to others, to the world, to the past, present and future…it is a narrative of changing and not changing (Heikkinen, 1996: 203).

The self is communicatively constructed and narratively projected, sustained by relationships, and by the opportunity to tell and retell its story. Telling stories and sharing memories of the past recreates that past and links it to the present. It reminds the narrator of the younger self, reinforces the present self, and helps to make meaning of being old and in care. Creating new relationships offers the prospect of a future in which this relational self can be socially active, that is, continue to grow and engage
with the world. The self that is communicated is confirmed in its own continuity, and able to admire the constant elements of its own ‘virtues’. The thought, “Still me, still here” brings comfort to the self which, because of loss and bereavement, can no longer express itself in the same ways. It can still engage with the world in new contexts with new social partners, and find new modes of expression. These new modes of expression perhaps reach a narrower audience than in former times, for example, the ‘helpers’ amongst the residents may see the help they offer as less significant than that of their younger lives, but they recognise and are comforted by their own consistency. “I’ve always tried to help people” and “I’ve always tried to be kind” are statements which connect the past and present, articulating a constant moral stance of the relational self. They are, in themselves, a direct communication of the ageless self.

**Communicating respect**

In my discussion of dependence and autonomy I argued that respect is the key to enhancing resident autonomy and sense of self. This respect does not necessarily come easily or naturally in a society which is complicit, or at least passive, in the construction and projection of ageism. Like empathy, the capacity to “put yourself in their shoes”, respect can be described, modelled, and encouraged, but it cannot be taught if there is no space in either the individual or collective personality. One nurse mentor, quoted by a staff informant who had been profoundly influenced by the example, constantly instructed her students to imagine themselves in the position of the older person, and to behave accordingly.

Respect cannot be enforced by legislation, but its importance can be highlighted in training programs, the mentoring of staff, and the regulations underpinning aged care provision. I argue that it must be felt to be genuine, but I accept that use of respectful forms and language content in communication about and to residents in aged care is a good start. More difficult to encourage is the will to communicate, and the skill to do so in a way which meets residents’ needs for adult, relational conversation.
Staff-resident communication: attitudes and practicalities

Dilemmas in staff-resident communication

There are many reasons why staff and resident expectations of communication do not always match, and there are dilemmas in this for both parties. Staff who have busy work schedules and social lives, family commitments and preoccupations, are also frequently much younger and have vastly different life experience from the residents in their care. They may also have very different styles of communication, and can find it hard to establish common ground with older people whose lives are constrained by the institutional environment. In addition, staff have the responsibility to provide care, not just to one resident but many, and often work in stressful conditions where task completion takes priority over recognition of residents’ social needs. In such an unequal relationship residents are not in a position to demand either more communication time, a higher relational content in what communication there is, or even more respectful communication.

Some staff feel that, because they do not have time to sit and talk, they do not have time to talk, and are therefore excused from trying to make more than very superficial conversation concerned with task implementation. Residents, however, value communication which recognises them as individuals and which conveys warmth, interest and acceptance. Thus staff who feel they do not have time to ‘talk’ might overlook the simple acts which reinforce residents’ self-esteem. Recognition and acceptance can be conveyed through a touch, a wave or a quick word as staff pass through lounges and corridors. More experienced and empathetic staff, even when there is no time for extended conversation, take every opportunity to maximise one-to-one communications with residents. They value the time they spend on care tasks, and make this an opportunity for relational conversation.

A more difficult problem to solve is finding time to really listen, to hear residents’ stories and engage in the exchange of ideas. Residents who have few outside visitors
often feel this lack acutely, especially if they feel that they cannot communicate with other residents. Many staff are aware of the loneliness and lack of stimulation of some residents, especially the ones who complain about their boredom or frustration. However, they do not always recognise the needs of the more shy and reticent ones, especially those who are new to the institution. Residents’ attempts to engage staff in conversation depend on their personal confidence, both in themselves as interesting conversation partners and in their communication skills, and their general health and psychological and physical state. Many, like Harry, do not assert themselves or make demands. When he told me “I can’t talk to these chaps”, he was expressing his own perception of incompetence, but it would not have occurred to him to complain, or ask busy staff to stop and talk to him. When Charles said he needed “more people like you”, he was not complaining about staff. He was simply accepting that there were no people with the free time to spend in his room or the garden, sitting with him and discussing his thoughts and the state of the world. I am sure he had made no complaints or demands, and indeed generally claimed to be contented. When Harry thanked me for every conversation I had with him, there was no criticism of staff, just an admission of his loneliness and gratitude for my time and interest. As a researcher with a reason for engaging both of these people in regular conversation, I had the unique opportunity of discovering how they felt about themselves and their lives in care. Activities and other Allied Health staff are often best placed for one-to-one relational communication with residents, but also under the pressure of being too few amongst too many. Otherwise, most care staff find their opportunities limited to the duration of care tasks and the relative ‘down’ time of night shifts.

Communicatively and cognitively competent residents are clearly not satisfied with communication which is restricted to task implementation of a bed-and-body nature. Those who are cognitively or communicatively impaired are also more likely to respond to communication with an emotional content, to recognise facial and voice cues and react to empathetic touch. They are least likely to be responsive when care tasks such as feeding are carried out in silence, a practice which is strongly criticised by many of the staff in my study, but which nonetheless occurs.
Staff views of communication with residents encompass a wide range. There are some who do not value residents’ conversation, or lack the language or communication skills to communicate easily. In either case they appear unwilling to engage in relational conversation. One of my informants suggested that this was unsurprising, given that some staff do not even enjoy talking to other staff. None of my staff informants were unwilling to talk to residents, and staff who were unwilling to engage with residents were in a very small minority in the two nursing homes. There were isolated instances of ‘talking over’ the residents during meal times, including talking about them as though they were not there. The worst cases of such behaviour were from agency and trainee staff, and although the trainees gradually got to know the residents and some learnt to communicate effectively with them, it was rare to hear agency staff trying to talk to residents. Many regular staff thought that working with agency nurses increased their supervision and stress loads (also reported by Nay et al., 1998). Most of my informants, however, were sympathetic to the difficulties faced by agency staff who knew neither the facility nor the residents, but found fault with the system which put those nurses and Personal Care Assistants in that position. Some also gave credit to good agency nurses they had met.

Many conscientious staff worry about residents who seem lonely but can not see how they can solve the problem. They recognise the residents’ need for emotional support, for someone to listen, but feel compromised by the need to be that ‘someone’ for too many people. While committed to providing the best possible care, care which recognises the whole person and residents’ communication needs, some staff nonetheless do not want to make close friends of the residents. They feel that they should not establish intimacy, partly because of the emotional burden and the risk of burnout. For many this is because the heavy workloads and responsibilities are already a strain on their emotional resources, and they see a real need to husband them. They feel they will be better able to provide good care if they are in good mental and physical health themselves. In this they are realistic, given that “burnout and exhaustion can produce behaviours counter to the mandate of the care-giving professions” (Stack, 2003:11) and are particularly serious issues in aged care.
Finally, there are the many aged care staff who willingly engage with residents and knowingly take on the emotional burdens and risk of burnout. They recognise the pain they feel over resident deaths as an essential element of their own personal and professional selves. This group sees it as a privilege to be taken into residents’ lives, and to be able to share the final stage of those lives. They willingly cultivate friendships with the residents, and see these relationships, as well as those with the families of residents, as the principal reward of working in aged care. They try to be aware of burnout, and take steps to deal with it. The positive pleasure which my informants took in the relationships they shared with residents reflects the views reported in a Commonwealth Government-commissioned qualitative study of nurses’ views of the quality of their working life. The factor identified by all groups of participants as having the most positive impact on health and well-being was relationships with residents.  

The most common complaint from staff is that they do not have time to talk, and as discussed in Chapter Seven, perceptions of ‘talk’ with residents vary greatly. Some staff feel that if they cannot sit and hold a sustained conversation that they are not talking, while others are happy to combine conversation with care tasks. Those who have the facility for generating laughter enjoy and create enjoyment in residents from even the most banal care situations. Although researchers remind us that jokes and reassurance are not enough (Gibb & O'Brien, 1990), joke-telling by staff is an inclusive relational activity. It is sometimes matched by residents, but most frequently simply enjoyed for what it indicates – acceptance as an equal, in both personal and conversational terms.

The effects of the institution on communication

I argue that it lies within the capacity of the institution to foster communication through thoughtful planning and an emphasis on holistic resident-centred care. In Chapter Three I discussed some of the major institutional barriers to communication, both physical and social. Many of these result from inherited problems with old buildings, or with traditional medical models of care which privilege the body rather than the whole person, and consequently favour the physical rather than the social needs of residents. However, increasingly planning decisions are based on economic fundamentalism (see Stevens, 1999) and managerial theories which encourage attempts to cut costs, streamline care delivery, and minimise time and numbers of staff required for task completion. There is a pervasive ‘audit culture’, typified by various types of surveillance in government departments, whereby ideas of ‘quality’ and ‘accountability’ are assessed by reporting and auditing. These procedures increase the administrative workload of staff and reduce the notion of ‘quality’ to sets of specific, measurable ‘criteria’. In this context, measurable outcomes related to ‘quality of care’ often do not go beyond numeric indicators. Stack (2003) criticises these ‘top down’ definitions of quality and other performance indicators, giving the example of accreditation standards which have preset targets for car parks and en suite bathrooms in new facilities. To highlight the mismatch between the expectations of care staff and administrators, Stack cites an informant complaining about the lack of a benchmark which requires a minimum number of staff: “If we don’t have sufficient staff it won’t matter how many en suite bathrooms we have, we won’t be able to help residents use them” (ibid: 10).

It is inevitable that the relational needs of both residents and staff will be disregarded if the system is driven by economic models which prioritise deregulation, cost-cutting and the streamlining of care delivery. Here I reflect on more positive alternatives, where decisions relating to building design and layout, room allocation, furniture distribution and above all, control of ambient noise, would be made with an awareness of the social and communication needs of residents. At this point it becomes clear that
the physical and social environments cannot be evaluated separately. The philosophy of care, attitudes of management and staff, communication, work routines, staff training (including communication skills), and supervision and support of staff are part of the social environment, but they are executed within a physical framework. If both physical structures and work routines are modified in ways which suit rapid care delivery but do not facilitate resident interaction or foster independence (as described by Johnson, 1993), then both the physical and social environment have a negative impact on resident well-being. In concentrating on the streamlining of care delivery and cost reduction, institutions are tempted to reduce staff levels to a minimum, and favour the employment of cheaper less-skilled staff. This can be counter-productive in economic terms, given that a number of studies indicate that there may be long-term cost-benefits in employing more expensive qualified and skilled staff which can outweigh the cost savings in taking on cheaper less qualified, or unqualified staff (Nay & Closs, 1999). However, of more immediate concern, cutting overall staff numbers, and employing a greater proportion of unskilled staff increases all work loads, especially those of the few more expensive senior staff retained (required by law to administer dangerous drugs) whose supervision responsibilities become enormous. Thus the time for interaction of experienced senior staff with residents is reduced to the minimum, as is that of the cheaper, less experienced staff, and the quality of care of residents is inevitably compromised.

What does this mean for relational care? As I have argued throughout this thesis, relational communication is the key to enhancing resident health, well-being, sense of self and autonomy. It also provides many staff with the greatest possibility of job satisfaction, as seen in a number of other studies. Stack (2003), for example, highlights the connection between effective caring and the relational aspects of care which staff find intrinsically satisfying, noting the importance of the time that it takes to establish personal relationships and knowledge of the individual as a person. My study confirms these findings, with my staff informants overwhelmingly identifying continuity of staffing and knowledge of the resident as the best means of knowing and meeting
residents’ needs. Time to spend getting to know the residents is an essential element in this process.

**The way forward**

The means by which elders are cared for reflects the moral integrity of a society – and is an expression of the quality of our humanity (Heather Gibb in Nay & Garratt, 1999: ix).

It’s unfortunately the forgotten part of the health system really, isn’t it, that aged care rates very low? *(Staff interview #11).*

In a resident-centred model of care provision there is an underlying philosophy of respect for residents as embodied individuals. It is difficult to legislate for philosophies and attitudes, but more prescriptive definitions in the legislation which regulates aged care provision would emphasise the requirement to balance the physical needs of residents with social, relational ones. In terms of the practicalities of care delivery, as a starting point there is an obvious need for minimum levels of staffing and skills mix. There is also need for a tighter system of regulation and monitoring of aged care facilities which ensures that the minimum standards of care are not sacrificed in the interest of economic imperatives. Both of these measures were recommended in June 2005 by the Australian Government Senate Inquiry into Aged Care, but the Government is yet to respond.112 I argue that a more relational focus in care also provides greater work satisfaction for care staff, and helps to reduce burnout and attrition of the aged care workforce, thereby helping to maintain continuity of staffing and quality of care. As Nay and Closs report, “just as poor relationships can result in reduced job satisfaction and resignations, good relationships seem to be integral to enhanced job satisfaction and retention of staff” (Nay et al., 1998: 27).

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112 In a television interview (ABC 7.30 Report: 21.2.06), the Minister for Ageing, in reply to questions about another recommendation, one relating to the mandatory reporting of abuse of residents, said “I intend to proceed with expediting the Government’s response”. www.abc.net.au/7.30/content/2006/s1575315.
Staff recruitment and retention

Among the most common complaints from nurses in aged care, apart from the lack of time to care adequately for the old people in their charge, is that they are not valued enough by the community, not paid enough, and there are not enough skilled staff. The work is physically and mentally hard and exhausting, and the situation is exacerbated by funding cuts resulting in poor care practices. Other issues with negative impacts on job satisfaction and retention of staff are lack of respect from senior staff, poor communication, lack of support, and failure to recognise and reward the level of skills involved in their work (ibid: 1998). Some of these issues have been brought to public attention through government-commissioned inquiries and reports, including the final report of the Review into Recruitment and Retention of Nurses in Residential Aged Care\textsuperscript{113} and the Hogan Review.\textsuperscript{114} To address the shortage of skilled aged care nurses the Commonwealth Government has announced a number of initiatives, including the allocation of funds for increased specialised university training places. Their efforts to date are considered inadequate by bodies such as the ANF, particularly because even the projected funding, to 2008, and the number of nursing places which it will provide, falls well short of the recommendations of the Hogan Report.\textsuperscript{115}

The status of aged care

Both the Senate Inquiry into Nursing (2000)\textsuperscript{116} and the Review into the Retention and Recruitment of Nurses (2002) found that the poor public image of nursing, and in particular, aged care nursing, was an important factor in the recruitment of nurses into the profession. The lack of parity of salary with the acute care sector makes aged care even less attractive. I argue that the inadequate funding of nursing training, along with that of aged care services in general, is also linked to the low status of ageing and aged

care. While we, as a society, do not fully respect the needs of old people and do not reflect that respect in the vision, leadership and accountability we expect from governments, aged care policies and solutions to shortfalls in funding will not be found. The Government is still considering the measures it will adopt to augment the shortage of capital in the industry, with bonds, “refundable deposits”, under consideration following the recommendations of the Hogan Review. Meanwhile, the problems of daily running costs and new infrastructure required to meet the accreditation requirements by 2008 are exhausting the charitable sector. Some providers have reduced their participation (for example the Salvation Army has sold 15 of its facilities) and others are likely to follow suit. In the words of a newspaper editorialist, “if the voluntary sector stops caring for the aged, the prospect of a fortunate outcome for those seeking a place in a home may well become even more elusive” (The Age, 15/2/2004). The way forward in the provision of aged care must include support for providers as well as stricter guidelines and regulation, so that the quality of care essential to maintaining residents’ quality of life is encouraged and supported and poor care rapidly identified and penalised.

Research implications

The main significance of my study lies in its demonstration of the importance of communication in aged care. Communication plays a major role in maintaining resident sense of self, supporting resident-centred care and enhancing resident autonomy. Conversely, a hostile or communication-starved environment is destructive of resident self-confidence and well-being, fostering dependent behaviour while at the same time compromising the quality of care.

In addition, I have highlighted the significance of staff-resident relationships in the delivery of care which not only respects and sustains the ageing self, but which is also rewarding for staff. Recent studies into nurse recruitment and retention support my view that the relational aspects of aged care are a major contributor to job satisfaction. I found that, when adequately trained and supported, staff were willing to enter into

these relationships, and positively enjoyed them. The major limitation on their capacity to meet residents’ communication needs was lack of time, and this lack of time was directly dependent on staffing levels, workloads and work routines.

The limitations of my study lie in its size and scope. My account of what it means to be old and in care is a snapshot of the world of the residents in two aged care sites. It does not claim to represent all old people in all care environments, but it does reflect the meaning which old people can make of their lives in care when that care environment is positive and resident-centred. As I explained in Chapter Four, I chose to study sites where I believed I would find a communication environment conducive to empathetic care delivery. This I found, and for me it constitutes evidence that communication can and does sustain sense of self and quality of life in the dependent elderly.

An expansion of my study could include residents from Low Care facilities (hostels as opposed to nursing homes), rural as well as metropolitan facilities, ethno-specific aged care facilities, and examples from the for-profit sector. It could also be widened to include interviews with family members and volunteers, and administrators and policy makers. Interviews with residents could be expanded to include a wider range of subjects, for example, residents’ perceptions of the quality of their lives in care. There is also a need for further exploration of the social lives of residents with dementia.

**Conclusion**

In closing this chapter, and the thesis, I return to the subject of communication, the common thread which links all of the themes and arguments of the previous chapters. Communication lies at the heart of the problems as well as the solutions involved in aged care. If society is to ensure that the elderly receive the relational care which helps them to make meaning of being old and in care, there must be a much wider debate about issues of ageing and aged care, and acceptance of the notion that old people are simply themselves grown older as we ourselves will be in our turn. Envisioning the
future of aged care must go beyond economic projections of burgeoning health costs and the threat of an increasing burden on the non-old sector of society. It must instead look at the much larger questions of equity and justice, and what it means to be human with the capacity to recognise and respect the humanity of others.
BIBLIOGRAPHY


Gibb, H. (1990). This is what we have to do, are you ok?: nurses' speech with elderly nursing home residents. Geelong, Vic.: Deakin University.


LeCompte, M. D., & Schensul, J. J. (1999). *Designing and conducting ethnographic research*. Walnut Creek, Calif.: AltaMira Press.


APPENDICES

A: Approval of the research application by the administrator of the two sites

B: Public notification of the presence of the researcher in the institution

C: General information and opt-out consent form for residents and relatives (participation in the project)

D: General information and opt-out consent form for staff (participation in the project)

E: Reminder letter for staff, residents and visitors (observations and note-taking)

F: Information for residents (interviews, note-taking and recording)

G: Resident consent form (interviews)

H: Checklist for resident information (oral)

I: Resident interview schedule

J: Information letter for guardians (observation of residents)

K: Guardian consent form (observation of residents)

L: Information letter for staff (interviews)

M: Staff consent form (interviews)

N: Staff interview schedule
31st October 2003

Ms Jean Tinney
The Centre for the Study of Health and Society
Melbourne University

Dear Jean

We are happy to accept your application to conduct research at our two nominated sites — [Redacted] have approved your application.

We look forward to your presence in our services over the next year or so and feel sure you will enjoy the interaction with the residents. We look forward to stimulating and insightful feedback.

Regards

[Redacted]
General Manager
Aged [Redacted]

c.c. Human Research Ethics Committee
Melbourne University
TO ALL VISITORS

Notification of presence of researcher in the institution

Re: Research by Jean Tinney from the Centre for the Study of Health and Society, University of Melbourne

I am enrolled at the University of Melbourne in the postgraduate degree of Doctor of Philosophy. The aim of my study is to gain a better understanding of the role of communicative interactions in the daily lives, health and well-being of residents in aged care.

In this study I will observe daily activities within the nursing home with a view to understanding the social environment. I will observe communicative interactions, and speak informally to residents, families and staff as I assist in voluntary tasks. No direct quotations from any person will be used without obtaining individual formal consent.

If you wish to obtain further information about the study, you may contact me through the Director of Nursing or on (03) 9347 4134, or one of the people named below.
Dr Martha Macintyre and Dr Marilys Guillemi, (supervisors) Centre for the Study of Health and Society, University of Melbourne – (03) 8344 0827
Any concerns may be addressed to The Executive Officer, Human Research Ethics, University of Melbourne – (03) 8344 7507

Permission has been given by the Chief Executive Officer of Melbourne Citymission to conduct this study.

Signed ……………. Jean Tinney, researcher.
Date ……………..

Appendix B
INFORMATION FOR RESIDENTS AND RELATIVES

Research project: Communication in aged care

My name is Jean Tinney, and I am studying for the postgraduate degree of Doctor of Philosophy. [REDACTED] has given permission for me to conduct this study and I invite you to take part.

My project is about how, why, when and with whom people in aged care communicate, and I aim to gain a better understanding of the daily lives of residents. I am also interested in gathering life stories, and in discovering how talking about the past might be of value to people as they grow older. I hope that this study will be of interest to residents and of educational value for nurses, and therefore of benefit to future residents and their families. I will be happy to report my findings back to you after the project is completed. The project is for research only, and there will be no costs of any kind.

What will this mean for residents?

In the first stage I hope to observe and take notes of daily activities and interactions within the nursing home, and to gain an understanding of daily social life. The observation will be in public areas and will not include private rooms, or toilet or bathroom activities. I will, however, as part of becoming familiar with the nursing home, visit and meet residents in private rooms and help out as a volunteer if that is appropriate. This will not be a note-taking or recording activity, and no resident will be expected to do anything, or to talk to me if they would prefer not to.

In the second stage of the study, I will ask some residents to consent to being more closely observed and tape-recorded, and perhaps interviewed, preferably in a private space. Choice will depend on circumstances at the time, including individuals’ health and mobility and interest in talking to me, and the availability of a suitable time and private space. No direct quotations from any person will be used without obtaining that person’s consent. No other recording will take place, and no person will be pressured in any way to take part in my study.
I will take all steps to protect privacy and confidentiality of data. All names, dates and details of incidents will be changed, and files and recordings will be kept in a locked cabinet at my house. Any person who agrees to take part will be free to withdraw consent at any time, and to ask for any notes or recordings already gathered to be destroyed. There will be no disadvantages of any kind for that person.

If you wish to obtain further information about the study, you may ring me on (03) 9347 4134 or contact any of the three people named below.

Dr Martha Macintyre (principal supervisor) Centre for the Study of Health and Society, University of Melbourne Tel (03) 8344 0834

Dr Marilys Guillemin, (supervisor) Centre for the Study of Health and Society, University of Melbourne Tel (03) 8344 0827

Ms Susan Feldman, (supervisor) Alma Unit for Research on Ageing, Victoria University Tel (03) 9688 4868

If you have any concerns about the study, you may contact Ms Kate Murphy, The Executive Officer, Human Research Ethics, University of Melbourne, Parkville Tel (03) 8344 7507

______________________________

For any resident/relative who wishes NOT to be associated with the study

I, ........................................ (name in block letters) of ..........................................................

........................................................................................................

do not wish to be associated with this study. I understand that no disadvantages will occur as a result of my request to not be included.

Signed........................................... (date)

Please return this slip to Jean Tinney through the Director of Nursing
Appendix D

INFORMATION FOR STAFF MEMBERS

Research project: Communication in aged care settings

My name is Jean Tinney, and I am studying for the postgraduate degree of Doctor of Philosophy. The Chief Executive Officer of [redacted] has given permission for me to conduct this study and I invite you to take part.

My project is about how, why, when and with whom people in aged care communicate, and I aim to gain a better understanding of the communication experiences of residents. I am interested in how relationships develop, and also in discovering how talking about the past might be of value to people as they grow older. I hope that this study will be of practical help and educational value for carers in the field as well as for social gerontologists and nurse educators. I will be happy to report my findings back to you after the project is completed.

What will this mean for staff and residents?
I hope to observe daily activities and interactions within the nursing home, and to gain an understanding of daily social life. No staff member or resident will be expected to do anything, or to talk to me if they would prefer not to, and no direct quotations from any person will be used without obtaining that person’s consent. The project is for research only, and there will be no costs of any kind.

In the second stage of the study, I will ask some staff to consent to being more closely observed and tape-recorded speaking to residents. No other recording will take place, and no person will be pressurised in any way to take part in my study. No real names will be used, and dates and details of incidents will be changed to avoid tracing to any particular person. Data will be kept in a locked cabinet at my house. Any person who agrees to take part will be free to withdraw consent at any time, and to ask for any notes or recordings already gathered to be destroyed. There will be no disadvantages of any kind for that person.

If you wish to obtain further information about the study, you may ring me on (03) 9347 4134 or contact any of the people named below.

Dr Marilys Guillemin, (supervisor and postgraduate coordinator) Centre for the Study of Health and Society, University of Melbourne, Parkville Ph. (03) 8344 0827
Ms Susan Feldman, (supervisor) Alma Unit for Research on Ageing, Victoria University. Ph. (03) 9688 4868
Any concerns about the study may be addressed to The Executive Officer, Human Research Ethics, University of Melbourne Ph. (03) 8344 2073

For any staff member who wishes NOT to be associated with the study

I, ............................................. (name in block letters) of ...........................................................

do not wish to be associated with this study. I understand that there will be no disadvantages for me as a result of my request to not be included.

Signed............................................. (date)

Please return this slip to Jean Tinney through the Director of Nursing
Information for Staff, Residents and Visitors

I have been visiting [redacted] for the past two months as a volunteer, and have got to know most of the staff and residents and many family members in that time. It has been a great pleasure and I very much appreciate the welcome I have received.

I have discussed my research project with many of you, particularly my interest in social interactions in aged care, and their importance for resident well-being and sense of self.

I am now ready to try to record what some of these social interactions are, and although I will be continuing to spend some time as a volunteer, I will also be observing and collecting information. I will look at how social interactions happen, and with whom, whether through resident contact with residents, with staff, in group activities, with family or with other visitors.

If you would like to know more about my project, please ask me or the Director of Nursing for further information. I can be contacted here or on 9347 4134.

Jean Tinney

Centre for the Study of Health and Society
School of Population Health
University of Melbourne

16\textsuperscript{th} January, 2004
INFORMATION LETTER FOR RESIDENTS: NOTETAKING AND RECORDING

PhD Research project: Jean Tinney

The aim of my study is to gain a better understanding of the role of communication in the daily lives of residents in aged care (details in previous information letter). This should benefit carers, residents and their families.

I would like to ask you if I can take notes and tape-record some of your conversations with some staff. Staff will also give consent, and I will negotiate with you and the staff member what sorts of conversations and where and when.

If you agree, you can change your mind at any time and all notes and recordings involving you will be destroyed. Otherwise, all steps will be taken to protect your privacy. All names, dates and identifying details will be changed, no information will be given to any other person, and all my notes and materials will be kept in a locked file at my house.

I would also like to conduct some interviews with some of you and record your stories and thoughts about your lives up to and including the present stage. For example, I will ask you to tell me about important events in your life, or something about your childhood or schooldays. There will be absolutely no pressure for you to tell me anything you do not want to, and you will be free to change your mind and withdraw at any stage.

If you agree, the choice of the time and place, and the length of any conversation will be yours. If it suits you we may have more than one conversation, depending on how you feel about it.

Transcripts of conversations will be made available for you to check and will not be used without your consent, and I will be happy to report my findings back to you at the conclusion of the project.

If you have any further questions I will be happy to answer them, or you could contact any of the people named in my first letter of information.
Appendix G

Consent form for resident participants: interviews

PROJECT TITLE: The nature and effects of communicative interactions in residential aged care settings.

Name of participant: ________________________________
Name of investigator: Jean Tinney

1. **I agree** to take part in the research project named above. It has been clearly explained to me, and a written copy of the information has been given to me to keep.

1. **I agree** to be interviewed about my life and for the researcher to use a tape-recorder during our conversation or conversations. The choice of time, place and length of any conversations will be mine.

2. **I understand that:**

   (a) I will not be asked to perform any other tasks.

   (b) I will be able to read the transcripts of the tapes to check them, and to decide if I do not want the material to be used.

   (c) the project is for research only, and that there will be no costs involved.

   (d) I can change my mind at any time and can withdraw from the project. There will not be any disadvantages of any kind for me, and I can ask to have notes, recordings or information about me to be destroyed.

   (e) All steps will be taken to protect my privacy and the confidentiality of my information. My name and personal details will not be used in any reports of the research. All files, notes and recordings will be kept in a locked cabinet at the researcher’s house.

Signature __________________________ Date __________________________
Appendix H

CHECKLIST FOR RESIDENT INFORMATION (ORAL)

1. What the project is about

2. Why it is being undertaken

3. By whom it is being undertaken

4. How the findings will be of benefit

5. How much time it will take for participants and when and where

6. How any costs will be met

7. Steps which will be taken to ensure privacy, with an explanation of the limitations entailed eg legal requirements

8. Where the information will be kept

9. Advice that participants can withdraw at any time

10. Advice that participants can ask that the information they have given not be used

11. Who the researcher is and how that person can be contacted, and the non-interventionist nature of her role eg in the case of complaints or incidents, participants will be advised to follow protocols for complaints and/or speak to their relatives

12. The name and telephone number of a contact person who can address any concerns raised by the project itself

13. How participants can have access to the findings
Appendix I

Resident Interview schedule

Prompts for in-depth interviews to be used selectively and in any order, with variations in wording to reflect the focus of individual narratives.

1. Could you tell me some of the things which have made your life interesting?

2. Could you describe some of the most important events of your life?

3. How do you feel about calling school days “the best days of your life”?

4. What things do you remember the most clearly about your childhood?

5. Can you tell me about some of the most important people in your life?

6. What do you think are the most important things in life? Are they the same now as they were when you were younger?

7. What do you think of the changes you have seen during your life time?

8. What things about your working years do you value?

9. How do you describe yourself now? What sort of person are you?

10. What are some of the things you learn as you grow older?

11. To what extent is it true that you become wiser?

12. How are things easier or harder for young people today than they were for you?

13. What advice about life would you give to a young person today?
INFORMATION LETTER FOR GUARDIANS

Ph D Research project: Jean Tinney

The aim of my study is to gain a better understanding of the importance of social interaction in the daily lives of residents in aged care (details in previous information letter). This should benefit carers, residents and their families.

I would like to ask you, as the legal guardian, to give your consent to my observations of social interactions involving the resident for whom you are responsible. These observations will not be of any private personal care situations, but will be centred in the public areas of the nursing home. They will include organised activities and casual encounters, and may involve other residents, staff, family or other visitors.

If you agree, you can change your mind at any time and all notes involving the resident concerned will be destroyed. Otherwise, all steps will be taken to protect privacy. All names, dates and identifying details will be changed, no information will be given to any other person, and all my notes and materials will be kept in a locked file at my house.

If you have any further questions I will be happy to answer them, or you could contact me, the Director of Nursing, or any of the people named below.

Jean Tinney
9347 4134

Dr Martha Macintyre (principal supervisor), Centre for the Study of Health and Society, University of Melbourne, Parkville Ph (03) 8344 0834

Dr Marilys Guillemin, (supervisor and postgraduate coordinator) Centre for the Study of Health and Society, University of Melbourne, Parkville Ph. (03) 8344 0827

Ms Susan Feldman, (supervisor) Alma Unit for Research on Ageing, Victoria University Ph. (03) 9688 4868

Any concerns about the study may be addressed to The Executive Officer, Human Research Ethics, University of Melbourne Ph. (03) 8344 2073
Centre for the Study of Health and Society

Consent form for observation of social interactions

PROJECT TITLE: The nature and effects of communicative interactions in residential aged care settings.

Name of participant:______________________________________________________________

Name of Legal Guardian:__________________________________________________________

Name of investigator: Jean Tinney

1. **I give my consent for** ________________ to be part of the research project named above. It has been clearly explained to me, and a written copy of the information has been given to me to keep.

2. **I agree** to allow the researcher to observe interactions involving ____________ and other residents, staff, family members and other visitors.

3. **I understand that:**

   (a) Neither __________ nor I will be asked to perform any task, just to agree to the observation.

   (b) The observations will not be of any intimate care situation. Resident privacy and dignity will be respected at all times.

   (c) The project is for research purposes only, and that there will be no costs involved.

   (d) I can change my mind at any time and can withdraw ________________ from the project. There will not be any disadvantages of any kind for _____, and I can ask to have notes or information concerning ____ to be destroyed.

   (e) No names or personal details will be used in any reports of the research. Files and notes will be kept in a locked cabinet at the researcher’s house.

Signature________________________________________ Date____________________________
INFORMATION LETTER FOR STAFF PARTICIPANTS: INTERVIEWS

PhD Research Project: Jean Tinney

As part of my university study into the role and significance of communicative interactions in aged care delivery, and the way that elderly residents make sense of their lives, I would very much like to hear the views of some of the key staff working in the area. If you were willing to give me 30-40 minutes of your time, to discuss some of your reflections with me, and to allow me to record them, I feel I would gain a more complete understanding of how staff manage the huge challenges involved in providing care to the aged.

If you agree, the choice of time and place will be yours, you will be free to withdraw your consent at any time, and to ask for the destruction of notes and recordings involving you. There will be absolutely no disadvantage, personal or professional, for you as a result.

I will take all steps to protect your privacy and the confidentiality of the material by changing all names, dates and details of interviews. Data will be kept secure in locked files at my home address, and only for the duration required by University of Melbourne Research Guidelines. Contents will not be communicated to any other person, subject to legal requirements.

I will be happy to report my findings back to you at the conclusion of the project.

If you have any further questions I will be happy to answer them, either in person here at the nursing home, or by telephone. My home number is (03) 9347 4134.

You could also contact any of the people named below.

Dr Martha Macintyre (principal supervisor), Centre for the Study of Health and Society, University of Melbourne, Parkville  (03) 8344 0834

Dr Marilys Guillemin, (supervisor and postgraduate coordinator) Centre for the Study of Health and Society, University of Melbourne, Parkville  (03) 8344 0827

Ms Susan Feldman, (supervisor) Alma Unit for Research on Ageing, Victoria University.  (03) 9688 4868

Any concerns about the project may be addressed to The Executive Officer, Human Research Ethics, University of Melbourne, Parkville  (03) 8344 2073
Appendix M

Centre for the Study of Health and Society

Consent form for staff interviews

PROJECT TITLE: The nature and effects of communicative interactions in residential aged care settings.

Name of participant: 

Name of investigator: Jean Tinney

1. I agree to take part in the research project named above. It has been clearly explained to me, and a written copy of the information has been given to me to keep.

2. I agree to be interviewed and recorded by Jean Tinney. She will ask my permission to begin recording, and will stop if requested to.

3. I understand that the project is for research purposes only, that I will not be required to do anything except give 20 to 30 minutes of my time, and that there will be no costs involved.

4. I have been informed that I am free to withdraw at any time, with no professional or personal disadvantage to me, and that I can ask for any notes, recordings or information concerning me to be destroyed.

5. I understand that all steps will be taken to protect my privacy in any reports of the research. Names and dates and incidents will be altered and the data will be kept locked at the researcher’s house. No other person will have access to this information, subject to legal requirements which have been explained to me.

____________________  ____________________
Signature                      Date
Appendix N

Staff Interview schedule

Prompts for staff reflections on their experience of working in aged care. These will be used to guide the interview and will not necessarily be used word for word. Staff may prefer not to answer a particular question or to add points they think are relevant.

1. How long have you worked in aged care?

2. What are the rewards of working in this area?

3. What are the biggest challenges?

4. How well do you feel it is possible for you to meet residents’ communication needs?

5. What, if anything, limits your ability to have meaningful interactions with residents?
   - what you would most like to be able to do differently

6. The [Code of Ethics] includes this affirmation:

   “encourages personal independence in everyday life and respects every person’s right to privacy, dignity and individual decision making”.

   Could you comment on that?

7. What do you think limits resident autonomy?

8. How do you balance residents’ everyday care needs with respect for their autonomy?
   - examples from everyday practice

9. Is there anything else you would like to comment on?
Author/s: TINNEY, DOROTHY JEAN

Title: Still me: being old and in care: the role of social and communicative interactions in maintaining sense of self and well-being in residents in aged care

Date: 2006

Citation: Tinney, D. J. (2006). Still me: being old and in care: the role of social and communicative interactions in maintaining sense of self and well-being in residents in aged care. PhD thesis, Faculty of Medicine, Dentistry & Health Sciences, Population Health, The University of Melbourne.

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