TALKING THE TALK BUT NOT WALKING THE WALK: BARRIERS TO PERSON CENTRED CARE IN DEMENTIA

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THESIS
Submitted in total fulfilment of the requirements for the degree of

Doctor of Philosophy

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July 2004
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ABSTRACT

La Trobe University

TALKING THE TALK BUT NOT WALKING THE WALK: BARRIERS TO PERSON CENTRED CARE IN DEMENTIA

by Heather Hill

While the concept of person-centred care in dementia has been around for 15 years or more and has attracted much interest and enthusiasm, aged care facilities continue to have difficulty in actually implementing and maintaining person-centred practices. In this study I explore the experience of one aged care facility in order to identify the barriers to changing care practice.

The research took place in an ethno-specific (Jewish) aged care facility, Star of David, which was in the process of setting up a program for its residents with dementia based on person-centred principles. The methodology used in the research study was ethnographic, involving participant observation and interview, with a particular focus on a limited number of participants: four residents and their families, four senior staff, four personal care attendants and the executive director. Interviews were also conducted with staff members from three other aged care facilities.

The findings showed that Star of David was unable to bring about substantial change in its care practices, while the external interviews and the literature suggest that other facilities have similar difficulties. I identify three major types of barrier: procedural barriers within the institution itself; (government) policy; and barriers relating to hegemonic values and beliefs which underpin established health care practice. These three types of barrier interact with and reinforce one another. I conclude that if we are to change
care practice in institutions, we must address all of these barriers at the same time.

Finally, I suggest that person-centred care itself, which continues to place emphasis on professional service provision, may only be the beginning of necessary change. In order to be truly person-centred, we need to move towards a more community based or public health approach which recognizes the need of all persons to be treated both as significant individuals and accepted as part of a community.
STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma.

No other person’s work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the Faculty Human Ethics Committee, Faculty of Health Sciences.

HEATHER HILL

5th July 2004
ACKNOWLEDGEMENTS

In the writing of a thesis, as in the provision of care and indeed in the experience of life generally, it is the people and the quality of relationships which count. I have been fortunate in this respect, having come in contact with many people – Tom Kitwood being one – who have inspired me with their commitment to the personhood of people with dementia, as well as their willingness to share their insights and knowledge with others.

I have also been blessed with two wonderful supervisors, Professor Elery Hamilton-Smith and Dr. Bruce Rumbold, who in their own very individual but complementary ways have inspired, guided, encouraged and supported me in the highs and lows of this journey.

I am very grateful to the participants in this study – the residents and their families, staff and management of Star of David, who warmly accepted me into their community and allowed me to observe and analyse their experiences. I am mindful of the privilege they afforded me.

Finally, I must thank my husband, Harald Dingnis, and daughter, Stefanie, who have supported me in ways too numerous to mention.
TALKING THE TALK BUT NOT WALKING THE WALK: BARRIERS TO PERSON-CENTRED CARE IN DEMENTIA

Chapter 1

THE STARTING POINT: A PERSONAL AND PROFESSIONAL PASSION

There is something about engaging with people with dementia which is very humbling. They draw us into a world in which we recognise the limitations of our own power and competence. We are forced to face up to parts of ourselves that we often prefer to remain hidden, and they invite us to respond to them in ways which take us by surprise. (Goldsmith, 1996, p.10)

My involvement with people with dementia dates from 1985 when I first worked with them as a dance therapist in a large, old-style psychiatric hospital. My dance therapy sessions were one of the few bright spots for patients who otherwise lived in drab physical conditions with little attention to them as persons. The ward staff seemed to have no time for patients beyond their physical care and barely recognised those of us who ventured in to provide activities or therapy. It was not uncommon for staff to simply walk into a dance therapy session to give medication or cut toenails.

Happily, over the years, the institutions I work in have in the main become smaller, brighter and more open places. There is now an awareness of the need for something beyond custodial care and the satisfying of basic physical
needs. However, routine continues to rule institutions, and the priority given to physical care remains. My sessions still remain a bright spot – but now, by no means the only one – which offers the person with dementia not merely activity, but also a relationship which affirms his or her personhood.

I’ve often likened my experience of working with the person with dementia to mining for gold: hard work, challenging, but with golden opportunities. To finally make contact with a person with dementia, to see that person be himself or herself, has been one of the most fulfilling aspects of my work. While the work in dementia may seem “end of the line” to many health workers, to me it is a gold mine of creative opportunities and of strong emotional connection. What riches are to be found in these people who some consider the living dead.

In 1993 I carried out a research project as part of a masters program (Hill, 1995, 2003), to look at the experience of dance therapy for a person with dementia. Prior to this, I had carried out a study on the benefits of a group experience (Hill, 1992) but wanted to look beyond the benefits that I as a therapist identified, to the benefits as perceived by the person with dementia. I therefore chose to study the experience of an 85-year-old woman with dementia over four individual dance therapy sessions. The results confirmed some of my expectations in terms of the value of the experience in the moment and enriched my understanding of the nature of these moments. However they also broke down my prejudices, based on conventional biomedical wisdom, about the unlikelihood of growth and renewal for people with dementia. During the sessions, in what I identified as “significant moments”, my partner in dance was able to function in a more integrated way. She seemed to be more of her “old” self, at ease and confident, in contrast to the anxious and unsure person she appeared to be at other times. She also was able to remember and reflect on her experiences in the sessions. During the period of the research she grew in self-esteem as she seemed to find and re-integrate aspects of her pre-dementia self. In her own words, she
came “out of the cupboard…to the brightness” (Hill, 1999) These findings seemed quite at odds with traditional views of dementia as an inevitable and irreversible downward spiral.

During this time, I came across the work of Tom Kitwood (1992) of the Bradford Dementia Group in England and of Eley Hamilton-Smith and Sally Garratt (1995) in Australia. These writers introduced me to an alternative to the purely biomedical view of dementia, namely person-centred care. This greatly inspired me, for here was a conceptual framework which, with its emphasis on the person and relationship, was compatible with my own personal and professional philosophy.

What also inspired me was the fact that this work was not limited to special moments such as the particular and rarefied atmosphere of an arts experience. It had always upset me that after the very affirming experience of the dance session, the person with dementia could immediately be reduced again to a “patient” by the actions of the ward or nursing home staff intent on carrying out their tasks. For instance, they might whisk residents away in wheelchairs without giving them time to take in what was happening or to say goodbye. My readings on person-centred care suggested that it was possible for everyday care – whether eating, dressing or socialising – to be equally person-centred and creative. Clearly, people could not dance all day, nor was that the kind of experience most staff members could give, but it was possible for all staff to treat people with dementia as people and to provide care which was truly person-centred. The desire to explore further how this might be done led me to undertake the current study.

1. HISTORY OF THE STUDY

My dance therapy research studies with a group and then an individual had shown that within the dance therapy process, the person with dementia could often appear more functional and integrated, more like his or her old self. My
interest in this study was to look at ways in which the self could be maintained in the course of the day to day care.

One of my supervisors introduced me to Star of David, an aged care facility which was in the process of establishing a new program for people with dementia. The Executive Director had been inspired by the ELTOS model of Garratt and Hamilton-Smith (1995) and this person-centred model was a prime influence in the development of the program. Management and senior staff welcomed the research study as a way to develop and improve their new program and also benefit other facilities which might learn from Star of David’s experience. Star of David therefore seemed an ideal setting for the study, and I was warmly welcomed to the home and included in some of the planning meetings. Early in 1998, shortly before commencement of the program, my supervisor and I offered a series of three training sessions which aimed at developing a common understanding of dementia within a person-centred framework. I then withdrew for a few months to give the program some time to establish itself.

On my return to Star of David, I undertook a reconnaissance phase, planning to move on to an action research process, working with staff to improve care by focussing on the maintenance of self. However, during this initial phase, it became apparent that the program was not functioning adequately and that until it did, I could not begin my research study proper. For the moment, I was only documenting what was not working in the program. This led to quite some despair and desperation on my part and a questioning of whether a change of research site might be necessary. However, on reflection it seemed to me that here was a question which was more immediately relevant not only to Star of David, but also to many other aged care facilities. After discussion with my supervisor and management at Star of David, we agreed on a reframing of the study to explore the issues and difficulties which arose in the implementation of person-centred care. It was to be an ethnographic study looking at the overall program and its participants. This was personally
challenging for me as I was essentially a practitioner, with a focus on people and relationships, rather than on the totality of an organisational culture.

This was to be the first of many challenges, for through the study and the writing up of this thesis, I have experienced many shifts in focus, in the first place a shift from practitioner in relationship to client to researcher of the institution as a whole. In the course of writing and reflection, my attention has moved from the institution to the larger context of government and community, and beyond to the even larger issue of the values, thinking and beliefs of Western society. In doing so, I have questioned my own long cherished beliefs about therapy and my role as a therapist, my focus on individuals and individual responsibility for bad care with less regard for the wider contexts within which individuals work, and I have had to re-examine the concept of person-centred care itself.

2. FLOW OF THE THESIS

The process described above is very much reflected in the format of the thesis. Chapter 2 reviews the main writings and theories – biomedical, person-centred and social constructionist – on understandings of dementia and dementia care practice. This sets out the context of the study and demonstrates the inherent tension between biomedical and person-centred approaches. While the main focus of the study is on the meeting of the biomedical and psycho-social approaches to care, I have included social constructionist arguments which offer a more extreme challenge to the biomedical in their rejection of the notion of Alzheimer’s as a discrete disease entity. In their view of the person with dementia, they challenge both the biomedical (the lost self) and the psycho-social or person-centred (damaged self), by suggesting rather that dementia is a different, albeit often difficult, state of being.
Chapter 3 describes the methodology of the study. In keeping with a person-centred philosophy, I chose to view residents, management and staff both as individuals and within larger systems, believing that people to a degree embody larger systems and as individuals interact with the larger systems.

The material reported in chapter 4 looks at both the micro and macro aspects of Star of David: the people (residents, family members, staff and management) and the larger context of culture, environment, organisation and the interpersonal.

I have had to recognise that while my study was looking at person-centred care, Star of David had its own particular aims for the program, and I therefore discuss how far the program fulfilled its own aims and objectives. This then is the subject of Chapter 5.

In Chapter 6, I describe the model of person-centred care in more detail and compare it with the experience of Star of David. I conclude that the dementia program at Star of David fell short of the model of person-centred care, and that a significant barrier to successful implementation was the lack of appropriate care priorities and of supportive management and organisational structures. However, I note that while there might have been some issues peculiar to Star of David, the literature and the reported experience of other institutions suggest that it was not alone in facing these difficulties.

In Chapter 7, I develop my argument that similar procedural barriers exist in other aged care facilities experience. I note that government regulatory and funding requirements represent another type of barrier and this is also discussed in the chapter.

These procedural and policy issues would seem in themselves to represent considerable barriers, but I suggest they still do not fully explain the difficulties which prevent even the smallest and seemingly simple changes to
care. Given that Star of David was generally well regarded as an aged care provider, had made quite some efforts and shown considerable enthusiasm for person-centred approaches, it was surprising that only superficial change occurred. Surely here if anywhere, person-centred care could have taken root. In chapter 8, I argue for a deeper level of barrier which has to do with values and beliefs hegemonic in our society and which, in interaction with the procedural and policy issues, presents a significant barrier to change.

In the concluding chapter 9, I discuss and make recommendations for change at the institutional level and go on to address the need for change in the wider context of government and community in relation to person-centred care. Governments have yet to recognise person-centred care in its legislation and accreditation processes. Community attitudes which label and stigmatise continue to make it difficult for the person with dementia to be treated as a person. Both of these impact on the care practices in institutions.

Finally, I suggest that person-centred care itself may only be the beginning of change. Both the biomedical and person-centred approaches focus on service provision and this is not only limiting, but is ultimately unsustainable. I argue that in order to truly meet the needs of the person with dementia, we may need to rethink our understanding of person, of community and of the relationship of professionals and community in providing care for the person with dementia.
LITERATURE REVIEW

Central to this study are two contrasting models of care in dementia, one informed by biomedical, the other by psychosocial or person-centred understandings of dementia. It is therefore important to review the literature on these different understandings of dementia and associated approaches to care.

Harding and Palfrey (1997) suggest that there are two stages to understanding the “world of dementia”:

The first stage comprises the messages that are given – the construction of dementia as a gerontological illness; and the second stage concerns the recipient – the construction of the person as a dementia sufferer. (p.30)

In this chapter, I review the literature on biomedical and person-centred understandings of dementia and the way in which the biomedical and person-centred approaches view the person with dementia. I also include discussion of the social constructionist perspective, which challenges both biomedical and psychosocial understandings. Finally, the practical implications of such understandings for dementia care are addressed.
1. UNDERSTANDING DEMENTIA – BIOMEDICAL PERSPECTIVES

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation.

The primary requirement for diagnosis is evidence of decline in both memory and thinking which is sufficient to impair personal activities of daily living.... The above symptoms and impairments should have been evident for at least six months for a confident diagnosis of dementia to be made. (World Health Organisation definition of dementia, cited in Cheston and Bender, 1999)

Dementia has at least sixty known causal factors (Snowdon, 2001) and is considered to be a “global syndrome” resulting from a number of disorders rather than a specific disease (Ministerial Task Force on Dementia Services in Victoria, 1997). Dementias can be “fixed” in time, for example due to a single episode of head trauma or can be progressive, as in the case of degenerative dementias; some dementias are reversible, for instance in the case of an operable tumour, while others are irreversible and the disease process is ongoing (Whitehouse, 1992).

The degenerative dementias are the more typical form of the dementias, and of these Alzheimer’s is the most common (Whitehouse, 1992). Vascular dementia, caused by a series of strokes, is the next most common.
Alzheimer’s, vascular dementia, dementia with Lewy bodies and combinations of these represent 80-90% of all dementias (Black, LoGuidice, Ames, Barber and Smith, 2001).

Incidence of dementia increases with age, doubling every 5 years after the age of 60 (Marin, Sewell and Schlechter, 2002). In one of the few studies of the Australian rate of incidence, it was found that in the 75-79 year age group, 43 people per thousand were diagnosed (at early dementia stage), compared to 170 people per thousand in the 90 plus age group (Waite, Broe, Grayson and Creasey, 2001). Taking into account the increase in the ageing population, it is estimated that in Australia, numbers of people with dementia will increase from 148,000 in 1999 to 258,000 in 2021 and 450,000 in 2041 (Black et al., 2001).

Of all cases of dementia, Alzheimer’s disease alone represents at least 50% and has attracted the most public attention and research effort. In a Medline search for the years 2001-2002, there were 2076 articles on Alzheimer’s disease, compared to 666 on vascular dementia, 105 on dementia with Lewy Bodies and 879 on dementia. In the public mind, dementia and Alzheimer’s are almost interchangeable. Because of the significance of Alzheimer’s, I will give it separate discussion in the following section.¹

1.1. Alzheimer’s Disease

Alzheimer’s disease was first described by Alois Alzheimer in 1907 and the term was applied initially to dementia in people aged 40-60 (early onset). Senile dementia, that is dementia in people over 60 (late onset), was seen as part of the normal ageing process. However from the 1970s, the two were brought together under the term “Alzheimer’s disease”. Early onset

¹ In this thesis I will generally follow common usage and use the term dementia except where it is necessary to distinguish the type of dementia, as in the following section which deals specifically with the Alzheimer’s form of dementia.
Alzheimer’s is much more rare than late onset, representing only 5-10% of cases and appears to be linked to genetic factors (Marin et al., 2002).

Alzheimer’s begins slowly, imperceptibly, and involves biological, cognitive and behavioural changes. It is characterised by the destruction of nerve cells accompanied by the development of beta-amyloid rich plaques and tau-rich neurofibrillary tangles in the brain. Although plaques and tangles also increase in the healthy ageing brain, the location and density distinguish the Alzheimer’s brain from the normal ageing brain. (Marin et al., 2002). As the brain is progressively damaged, more and more function is lost. “Alzheimer’s increasingly shuts down the vital cross talk (among brain cells) that makes us who we are” (Snowdon, 2001, p.93).

Classically, Alzheimer’s involves at least three stages of ever-increasing impairment and loss of function. It has been suggested that the location of tangles could indicate up to six distinct stages of Alzheimer’s and that this process could start in very young people (Braak and Braak, 1999). These researchers suggest that the changes in the brain follow a specific sequence, thus providing “a basis for distinguishing stages in the evolution of the changes” (p.68). They have further found that these neuropathological changes may be correlated with assessments of the intellectual status of patients. They do however allow for individual differences in the extent to which brains may compensate for the damage, thus delaying clinical symptoms (p.70).

In terms of clinically observable stages, four pathways of the disease are generally identified: early difficulties (the pre-diagnostic phase), emergence of significant difficulties in daily living, reduced capacity for independence, high dependence on care and incapacity (Ministerial Task Force on Dementia Services in Victoria, 1997).

While the process may vary from person to person, each person will inevitably experience a “slow downward course of mental, physical and social
deterioration” (Snowdon, 2001, p.87). The person will ultimately die, although often death results not directly from Alzheimer’s but from some other cause such as pneumonia or a chest infection (Garratt and Hamilton-Smith, 1995, p.22).

A key source of reference for biomedical research in dementia is the Nun Study (Snowdon, 2001) which is an ongoing research program with a population of about 675 U.S. nuns belonging to the School Sisters of Notre Dame. In addition to giving researchers access to their medical records and having regular medical screenings, the sisters also agreed to donate their brains at death. The study, begun in 1986, was originally intended to focus on ageing but has since expanded to include the study of Alzheimer’s. The particular value of Snowdon’s research, which differentiates it from earlier Alzheimer’s studies, is that he is able to compare “normal” as well as Alzheimer’s brains. Reference to Snowdon’s work will appear throughout the discussion which follows.

1.1.1. Causes of Alzheimer’s Disease

There is no clearly identified cause (or causes) of Alzheimer’s disease. While brain pathology is seen to cause the symptoms of Alzheimer’s, it is not fully understood why neurons begin to die and how the plaques and tangles of normal ageing develop into the pathology of Alzheimer’s. A recent paper prepared for the Alzheimer’s Association Australia (Black et al., 2001) suggests that, as there is no single cause for Alzheimer’s itself, it should be described as a syndrome for which there are a number of possible risk factors relating to education, intelligence, genetics, ethnicity, lifestyle, environment. Garratt and Hamilton-Smith (1995) also suggest the use of the word “syndrome” as they consider Alzheimer’s not as a single medical condition but as a “state of being which can be medically diagnosed” (p.16).
1.1.2. Diagnosis

There is no specific diagnostic test for Alzheimer’s. Brain imaging may show brain shrinkage. However, this also occurs in the normal ageing brain. Diagnosis is often therefore a process of eliminating possible physical causes, such as a brain tumour, and is based on cognitive and functional aspects. Three factors generally form the basis of diagnosis: memory impairment and one other type of cognitive impairment such as language, along with impairment in social or daily functioning (Snowdon, 2001). Several types of screening tests are used (Black et al., 2001): interview with the person and with a family member; screening tests such as the Mini-Mental Status Examination (MMSE); functional, neuropsychological and behavioural assessment; Xrays, CT scan or MRI (Magnetic Resonance imaging).

At the moment, the accuracy of diagnosis of Alzheimer’s Disease is estimated to be about 80-90% (Black et al., 2001, p.6). Marin et al. (2002) suggest that this sort of accuracy is possible in the primary care setting, but the report of Black et al. notes the difficulties of accurate early diagnosis by general practitioners. A study conducted by Hobson, Coyle, Leeds and Meara (2001) found that general practitioners were often unsure of the procedure to follow in order to accurately diagnose Alzheimer’s. Given that inadequate diagnosis may lead to failure to recognise and treat conditions which may be reversible, and that there are now drugs available which can slow the disease in the early stages, it is vital that there is correct and early diagnosis.

Only after death can diagnosis be confirmed by evidence of plaques and tangles which are said to be the signs of an Alzheimer’s brain. Even at that point “there is room for debate… Which of the two Alzheimer’s lesions (plaques or tangles) are more important in damaging and killing brain cells? How many plaques and tangles must be evident, and in which parts of the brain, before it is considered to be an Alzheimer’s brain?” (Snowdon, 2001, p.89). Snowdon also points out that evidence of pathology at death does not necessarily equate with dementing behaviour evident in life. While some of
the nuns he studied “fit our tidy conclusions, with their clinical and pathological statuses dovetailing” (p.99) he acknowledges that Alzheimer’s is not a “yes/no” disease (p.100).

Rather, it is a process – one that evolves over decades and interacts with many other factors. We have shown dramatically how pathology alone often can mislead. Sister Bernadette had widespread damage and no symptoms, and our data now tell us that about a third of the sisters…have shared her “escapee” fate. And then there is Sister Maria, who had obvious symptoms and only modest damage. (p.100)

1.3. Treatment

Until fairly recently, there was little that could be offered to the person diagnosed with Alzheimer’s apart from drug treatment of accompanying medical and psychiatric conditions. Now there are drugs which can help slow down the course of Alzheimer’s when given in the early stages and which may even have an effect in the later stages. Marin et al. (2002) identify two main thrusts for current medical intervention: cognitive enhancement and neuroprotection.

In recent years cholinesterase inhibitors – the drugsTacrine (Cognex), 1993; Donepezil (Aricept) 1997; Rivastigmine (Exelon); 2000 and Galantamine (Reminyl); 2001 – have been developed which appear to slow down the progress of the disease in the early stages of dementia (Zurad, 2001; Ancill, 2001; Jorm 2001; Ballard, 2002). The cholinergic system is just one of the neurotransmitter systems affected in Alzheimer’s, but it seems to be affected earlier and more consistently than other systems. These changes are closely correlated to the presence of plaques and tangles and are thought to be key factors in the cognitive and functional deficits associated with Alzheimer’s (Zurad, 2001). Cholinesterase inhibitors increase cholinergic transmission
and therefore the availability of acetylcholine, which is a chemical messenger important for memory in people with mild to moderate dementia (Alzheimer’s Australia, 2003a), thereby slowing down the disease process and improving cognitive function. Winblad et al. (2001) note that within clinical trials treatment success has tended to be viewed solely in terms of improvement in cognition and therefore considered to be of only limited success. However they suggest that a wider view be taken to encompass “functional abilities, behaviour, caregiver burden, quality of life and resource utilization” (p.653). Based on these criteria, the studies reviewed of the efficacy of these cholinesterase inhibitors demonstrate multiple benefits. Lopez et al. (2002) in their study on the effects of cholinesterase inhibitors conclude that one long-term benefit is a significant delay in nursing home admission. Yet they note:

The fact that we did not see a protective effect on functional or cognitive outcome, suggests that these scales, at least, did not capture properly the aspect of the syndrome that affected the decision to admit to a nursing home. (p.313)

Recently a new drug has been developed - Ebixa (memantine) - which appears to slow mental and physical decline in people with moderate to severe dementia. This works differently from the cholinesterase inhibitors in that it targets another neurotransmitter, glutamate, by blocking its activity (Reisberg et al., 2003; Tanne, 2003; Alzheimer’s Australia, 2003a).

Oestrogen, anti-inflammatory drugs, vitamin E and gingko biloba have been identified as possibly offering protection against the development of Alzheimer’s. Research results on these are mixed and will be discussed further in the section on research below.

There are currently no treatments which cure or prevent Alzheimer’s Disease.
1.1.4. Research

Biomedical research concentrates its efforts on two major areas: understanding the pathological processes in order to develop appropriate drug treatments and identifying causes and risk factors with a view to prevention of the disease. These are discussed below.

Scientists continue to investigate the underlying pathology of Alzheimer’s Disease with a view to understanding pathological processes of the brain, their causes and the relationship to symptoms and the progression of the disease. Stafford (1991) identified two major areas of research: the structural and chemical composition of the neurofibrillary plaques and tangles and investigation of the neurochemical and neurotransmitter aspects of Alzheimer’s Disease (in particular the cholinergic system).

Snowdon (2001) has carried out research as part of the Nun Study to explore the relationship between Alzheimer’s and vascular dementia. His study revealed, at least for this population, only one person with true vascular dementia. But most significantly it demonstrated that stroke seemed to act as a kind of “trip switch” (p.156) for the appearance of dementia, “but only if their brains also had enough plaques and tangles to meet our criteria for Alzheimer’s disease” (p.155). Thus a person who had sufficient plaques and tangles, but no strokes, might well escape the appearance of dementia. De la Torre (2002) in his review article concludes that there is strong scientific evidence for a vascular basis to Alzheimer’s disease; that is, that Alzheimer’s disease is not a neurodegenerative disorder but rather a vascular disorder. “Clinical management of patients, treatment targets, research designs and disease prevention efforts need to be critically reassessed and placed in perspective in light of these findings” (p.1152).

There has also developed an interest in researching Mild Cognitive Impairment; whether it represents a pre-clinical stage of Alzheimer’s or a separate condition which may or may not go on to Alzheimer’s (Collie and
Maruff, 2000; Black et al., 2001). This research to establish the relationship of Mild Cognitive Impairment to Alzheimer’s is important, given the development of drugs such as Aricept which are most effective in the early stages of Alzheimer’s Disease.

While scientists continue to work towards identifying causes, there appears to be no one cause or group of causes. However, some risk factors have been identified: genetic, environmental, nutritional, education and intelligence, ageing.

1.1.4.1. Genetic

Much progress has been made in recent years to uncover genetic connections, and mutations in four genes have been implicated in Alzheimer’s. There are over a hundred mutations in three of these genes – amyloid protein precursor, presenilin 1 and presenelin 2 – which have been shown to cause early onset Alzheimer’s, though these are rare. There are also mutations in one gene (apolipoproteinE) which affect susceptibility (Milward, Kratiuk-Wall, Creasey and Shanley, 1998; Tunstall, 1998). However, recent research suggests that there may be many more genetic factors to be identified (Bertram and Tanzi, 2001).

1.1.4.2. Environmental

Aluminium was for some time considered a cause of Alzheimer’s but now is considered unlikely (Milward et al., 1998; Snowdon, 2001). Where previous studies suggested there was a certain protection against Alzheimer’s Disease for smokers, more recent studies suggest that there is in fact an increased risk (Milward et al.).

1.1.4.3. Nutrition

Reynish, Andrieu, Nourhashemi and Vellas (2001) review nutritional factors in Alzheimer’s disease and identify links between Alzheimer’s disease and low vitamin B12 or folate levels. However the question remains whether this is a result of the disease or a contributory factor. They also consider the role of
cholesterol and fat. There is some but not conclusive evidence of a link between high dietary cholesterol intake and Alzheimer’s. They conclude that it is likely all these factors play a role, but Alzheimer’s “remains a disease with a complicated, multifactorial pathology, and, at the moment, exactly how such factors interact with various genetic, environmental, and biological factors is far from clear (p.7). There is also some suggestion that oxidative stress may play a role in Alzheimer’s but studies remain as yet inconclusive about the value of vitamin E and Vitamin C supplements (Morris et al., 1998; Reynish et al., 2001).

1.1.4.4. Education/Intelligence

In a study of linguistic ability in the nuns participating in the Nun Study, Snowdon et al. (2001) conclude that low linguistic ability in early life is strongly associated with the development of Alzheimer’s and may suggest increased susceptibility to the disease.

1.1.4.5. Ageing

Of all the factors, ageing “appears to be the most powerful predictor of its (Alzheimer’s disease’s) presence” (Stafford, 1991, p.401). Yet, as Stafford also points out, all the research and public health policy is based on the premise that Alzheimer’s Disease is not part of normal ageing.

In terms of treatment, the focus of research is on developing treatments which target the brain pathology producing the symptoms of dementia (Zurad, 2001). There are four main strands:

1.1.4.6. Cholinergic Drug Treatment

This continues to be researched (Gauthier, 2002). There is no doubt that the cholinesterase inhibitors represent a major advance in Alzheimer’s research, but Frisoni (2001) in his review suggests that medical attitudes are mixed on the subject and that much more research remains to be done in terms of observational studies rather than simply clinical trials.
1.1.4.7. Preventive Treatments

Treatments using vitamin E, slegeline and gingko biloba (Marin et al., 2002); anti-inflammatory drugs (NSAIDS) (in’t Veld et al., 2001; Etminan, Gill and Samii, 2003); steroids, COX II inhibitors, high and low dose aspirin and oestrogen replacement therapy (Seshadri et al., 2001) are all being studied but so far with mixed results. Lifestyle aspects which may be protective are also being researched, for example one research study has found that certain mind-stimulating activities such as dance, board games and puzzles appear to have a protective effect (Verghese et al., 2003).

1.1.4.8. Vaccine

A new approach has been to design small peptide molecules which can interfere with the processes of amyloid plaque formation (Milward et al., 1998). In clinical trials on humans, some participants developed the symptoms of brain inflammation. However, these trials have shown the potential of such vaccines to reduce amyloid plaque inflammation (Janus, 2003; Munch and Robinson, 2002).

1.1.4.9. Stem Cell Research

This may offer new possibilities of treatment for many of the degenerative diseases. However, there have been few human trials to date and none specifically targetting dementia (Nova, 2002; Kuehnle and Goodell, 2002).

Jorm (2001) believes that even if science cannot eliminate Alzheimer’s, it is very possible that current research efforts will help delay onset of the disease.

1.1.5. Alzheimer’s – Disease or Developmental Process?

As we shall see in the following section, the view of dementia as disease has been challenged from outside the medical establishment. However, even within the medical realm, there is disagreement as to whether Alzheimer’s is a disease or part of the ageing process. I have already noted that ageing is the most common predictor of Alzheimer’s Disease. Chen and Fernandez (March, 2001) equate the occurrence of plaques and tangles with other ageing
markers such as loss of bone density and gallstones and suggest research should focus not on pathology but on understanding the normal ageing process. Plaques and tangles are a normal part of ageing and therefore quite different from disease processes such as cancer. Building on this view, they suggest in a second article (August, 2001) that it has been incorrect to merge the early onset (Alzheimer’s disease proper) with late onset, since the former is a conventional disease, and the latter a “senile condition”. By viewing the latter as a disease, researchers have been misdirecting their efforts and the authors conclude that for this reason senile dementia remains a mystery even after 25 years of intensive research.

Jobst et al. (1994) note excessive atrophy in the medial temporal lobe and in a longitudinal study looked at whether brain atrophy was due to acceleration of the normal ageing process or due to a catastrophic event. They conclude that the “atrophic process is so rapid that it probably does not just represent acceleration of normal age-related atrophy, or if it does, it must be triggered by a recent insult” (p.830). They postulate that this excessive atrophy is probably the result of one or more pathological events such as the amyloid plaques, neurofibrillary tangles, or oxidative stress, which other researchers have suggested. They conclude therefore that Alzheimer’s may in fact be a “consequence of a true disease process” (p.829).

Stafford (1991) refers to Wurman’s likening of the search for cause and cure to the story of the blind men and the elephant – each touching a different part and not seeing the whole animal. He concludes that “as research progresses, it becomes clear that the model is of necessity going to be more, rather than less, complex than imagined. The possibility that Alzheimer’s ‘disease’ represents several different clinical entities is now seriously entertained” (p.400).

While a survey of the literature reveals that there are differing perspectives within the biomedical model and by no means general agreement even on the
basic issue of whether Alzheimer’s is a disease, views as expressed by Chen
and Fernadez remain on the fringes with little recognition from most
biomedical researchers, medical/nursing practitioners and the general public.
Essentially the orthodox view is that Alzheimer’s is a progressive and
irreversible disease of the brain, resulting in loss of function and loss of self,
and is not part of the normal ageing process.

2. UNDERSTANDING DEMENTIA –
PSYCHOSOCIAL PERSPECTIVES

In the last decade or so, psychosocial understandings of dementia have emerged to challenge the dominant biomedical understandings. Kitwood was at the forefront of articulating an alternative perspective and I will therefore focus here on his writings.

2.1. Kitwood and Person-Centred Care

Kitwood’s work is situated very much within a psychological framework emphasising individual psychology and the individual in relationship (social psychology). He argues that brain pathology and brain function contribute only part of the experience of dementia (Kitwood, 1987, 1988), and that other factors need to be considered. Indeed even within the medical community itself there was not always such a strict focus on brain pathology. Before the mid-1970s there were writings on dementia which also considered psychological and social aspects in dementia but from the 1970s the favoured approach has been to explain dementia in terms of neuropathology (1987).

According to Kitwood, brain pathology provides an incomplete explanation of dementia and one needs to look beyond pathology to understand the experience of dementia. By acknowledging biological and psychosocial aspects of dementia, it is possible to remain “true to neuroscience and yet be true to the person as well” (1997, p.36). Some of his arguments are discussed below.
2.1.1. **Criticism of Brain Pathology as the Single Cause of Dementia**

Kitwood argues that even on scientific grounds, there are difficulties explaining dementia solely in terms of pathology.

In the first place, the presence of brain pathology is not a necessary or sufficient condition for dementia.

> The data from post-mortem research show consistently that the state of the brains of some dementics is well within the range of those of well-preserved persons of comparable age; and that a clear identifiable condition of dementia can accompany widely varying degrees of neuronal degeneration. (Kitwood, 1988, p.168)

Thus Alzheimer’s dementia and the other primary dementia, vascular dementia, do not meet the classical criterion for disease, namely “that distinct pathological features should be present in all cases where the symptoms appear, and in none of the cases where they do not” (Kitwood, 1997, p.25).

Neuropathic changes usually occur relatively slowly, whereas a person can deteriorate from “normal” to severe dementia in a very short time, for example witness the changes when a person is hospitalized or put in a nursing home. This suggests that more than pathology is implicated in the development of dementia.

Kitwood (1997) also points out that there is “a lack of strong and consistent correlations between the degree of dementia, as measured in the living person, and the extent of neuropathology found post mortem” (p.25). This is reflected in Snowdon’s findings (2001) from the Nun study noted earlier. Kitwood rejects a “billiard ball” model of causation. “At the very least we need that view of causation that looks for the set of interacting conditions – all necessary but none sufficient in themselves – that are required for an event
to occur” (p.36). He concludes “the view of causation is not linear, but multiple and interactional” (p.36).

2.1.2. The Individual Nature of the Experience of Dementia

Kitwood (1997) believes that biomedical perspectives do not take into account “the way in which brain function is translated into brain structure; it ignores those aspects of nerve architecture that are developmental, and thus closely related to a person’s experiences and defences” (p.35). Each person may therefore have a different experience of dementia regardless of similarities in pathology. While there may come a stage when the amount of damage occurring in the brain inevitably leads to dementia – and each individual’s threshold will be different – “to assert this, however, is a very different matter from attributing dementia uniquely to neuropathology” (1987, p.127).

In addition to the distinctive nature of each person’s brain as formed developmentally and through experience, there is also the aspect of brain plasticity – the brain’s ability to regenerate and compensate and indeed to be moulded or altered by present experience. There is even the possibility, Kitwood (1989) believes, of people “rementing”.

Under certain circumstances sufferers from Alzheimer’s disease who had, apparently, gone far down the path of behavioural and cognitive impairment, can regain some of their lost faculties…The best-known indicator of rementia is the re-gaining of urinary and faecal continence, but it is possible also to observe moderate recoveries of memory, social skill, and ability to complete simple tasks, together with a general reduction of signs of anxiety. (p.5)

He also gives the example of “transitory rementia”, moments – often just prior to death – of “short-lived and fragile restoration of near-normal function” (p.5). Both possibilities – rementing over a period of time or
transient clarity – present a challenge to the biomedical model. “The implication is that even a brain which is carrying severe pathology may have more reserve and flexibility than is commonly assumed” (1997, p.63). The biomedical response is often that the person did not have true dementia. This answer is problematic in a logical sense, since it makes it impossible for any adverse data to prove, even in theory, that rementing can happen. That is, wherever there is rementing, the person is then automatically assumed not to have true dementia. “The assertion ‘the true dementias of old age are irreversible (and hence incurable)’ has now become a logically necessary proposition” (1988, p.171). Such a stance on the part of biomedical researchers is at odds with a science based in empirical evidence.

Some empirical research findings support Kitwood’s suggestion that in dementia, there may be a degree of brain plasticity, perhaps even possibility of regrowth of brain cells. The research of Hyman, Damasio, Damasio and Van Hoesen, neuroscientists and researchers of the dementia brain (1989), suggests that even in Alzheimer’s the brain “is still capable of mounting a neuroplasticity response to the enfolding cell damage in entorhinal cortex” (p.127). In other words, the brain has the possibility of regenerating and compensating for damage.

Each person is an individual with more or less resilience in biological terms – brain tolerance, plasticity and scope for adaptation – as well as in psychological terms of emotional resilience and coping abilities. Each person will therefore respond to the effects of brain pathology differently. Snowdon (2003) would seem to suggest something similar. He uses the concept “cognitive reserve” to explain the discrepancy between the appearance of dementia in his study participants and the amount of pathology discovered on post mortem. This “cognitive reserve” lies in brain plasticity and in “biological buffers” (p.453), the organism’s ability to resist the effects of brain pathology, which may be explained by a number of factors, biological, environmental and social.
Kitwood goes further and suggests that in a sense one may even predict that certain people, in view of their personal histories, will inevitably develop dementia. In looking at the resilience of self, Kitwood (1990b) talks in terms of the adapted self (that is the roles one assumes in society) and the experiential self (the self as agent), linking the latter to robustness of self in dealing with brain pathology. Some people may have lived entirely within the adapted self, that is, living within the roles conferred by other people and on losing these roles with age do not have a strong experiential self to fall back on. He concludes from one “psychobiography” he carried out on a person with dementia that

the experiential self, which might have sustained her sense of ontological security, her sense of agency, and her capacity for relatedness despite some degree of brain failure, was only poorly developed; and her adapted self, as with the great majority of people who survive into their seventies and eighties, underwent progressive decline; in her case, to vanishing point. Psychologically, it would seem that dementia was the inevitable consequence. (p.72)

This begins to sound uncomfortably like a type of psychological determinism, not unlike the biological determinism Kitwood is rejecting. Kitwood himself admits that there are methodological problems with his research and that much more research would need to be carried out in this area.

2.1.3. Malignant Social Psychology

In addition to brain pathology, brain structure and individual coping mechanisms, people with dementia are also influenced by the people around them. Kitwood (1997) introduces the concept of malignant social psychology, that is, the interactions between people with dementia and carers which disempower and diminish. He lists 17 elements of malignancy such as disempowerment, infantilization and labelling, based on research of “critical
incidents” (p.19) which illustrate these and suggests that their impact is not only psychological but may indeed impact at a physiological and neurological level. He is careful to point out that “the term malignant does not, however, imply evil intent on the part of caregivers; most of their work is done with kindness and good intent. The malignancy is part of our cultural inheritance” (p.46). Dementia is not just a feature of the individual, then, but also of the interaction with other people such as family and professional carers.

Kitwood thus expands the understanding of dementia beyond purely pathological and biological explanations, by suggesting that the experience of dementia lies in the dialectic of neurology (brain structure formed developmentally and through learning, and brain pathology) and psychological factors (1990a, p.177). He also takes our understanding beyond individual factors to the social and relational factors affecting the experience of dementia. The experience and the progression of dementia therefore depends on many factors and does not preclude possibilities for rementing, learning and psychological growth.

3. SOCIAL CONSTRUCTIONIST CRITIQUES OF DEMENTIA

Kitwood has argued from a psychosocial perspective that an understanding of dementia must include not only the biological and pathological, but also incorporate individual psychological and social aspects which impact on the experience of dementia. While he does raise questions about validity of the Alzheimer’s as disease concept, his principal concern is to broaden the understanding of dementia beyond the biomedical in order to provide a basis of care which addresses the needs of the whole person. His approach is therefore practical and pragmatic, focussing on improving care. The social constructionist arguments of Harding and Palfrey (1997), whom I will discuss later, represent an essentially epistemological critique of dementia which questions the dominance of biomedical understandings of dementia. This
needs to be seen in the context of challenges to medical dominance and a critique of the very foundations of medical knowledge within the wider literature of sociology of health and illness, which critique the very foundations of medical knowledge. I will discuss some of these writings, therefore, before going on to Harding and Palfrey’s social constructionist perspectives on dementia.

3.1. Critique of Medical Knowledge

The favoured status of medical knowledge as being self-evidently based on the reality of natural science and therefore not open to sociological analysis, has been challenged from several sociological perspectives. White (1991) notes:

> These three points – that medicine is not a natural science, but rather acts to transform what are statements of values into apparent statements of fact; that professions are the outcome of social and political struggles rather than being shaped by natural objects of which we can have scientific knowledge; and that medical belief systems are specific to the society which produces them form the background to a sociology of health and illness. (p.2)

According to White (1991), scientific and medical knowledge arise from a “tradition of shared assumptions” (p.58). Already in the 1930s, Fleck (1935/1979) suggested that scientific knowledge was not an individual, but a social, activity. “Cognition is therefore not an individual process of any theoretical ‘particular consciousness.’ Rather it is the result of a social activity, since the existing stock of knowledge exceeds the range available to any one individual” (p.38).
The scientific fact is not a reality waiting to be discovered but emerges from a “thought collective” situated within a particular historical, cultural and social context.

If we define “thought collective” as a community of persons mutually exchanging ideas or maintaining intellectual interaction, we will find by implication that it also provides the special “carrier” for the historical development of any field of thought, as well as for the given stock of knowledge and level of culture. (p.39)

Fleck (1935/1979) points to the importance of looking to history because “concepts are not spontaneously created but are determined by their ‘ancestors’” (p.20). Harding and Palfrey (1997) echo this observation. It follows that there is no ‘natural history’ of a disease or of medicine, as there is no unfolding of intrinsic biological determinants; but there is a ‘social history’, determined by the meaning a culture ascribes to a disease” (p.20).

Within the literature, there are several writers who have explored the history of Alzheimer’s disease as a social construction rather than a medical and scientific fact.

3.2. The Construction of Alzheimer’s Disease

I have noted on page 10 that until the 1970s, Alzheimer’s disease was considered to refer to pre-senile dementia, a relatively rare condition. Cheston and Bender (1999, p.38) quote Maher’s (1970) judgement that “Alzheimer’s disease is statistically infrequent and of relatively little interest to students of psychopathology”. This disinterest lay in a number of factors including the falling out of favour of an organic view of mental illness, the lack of evidence of Alzheimer’s being separate from normal ageing, and the lower life expectancy of people who did have Alzheimer’s before the advent of antibiotics to treat infections.
However in the 1970s, with the increasing aged population, age-related illnesses began to attract more interest and with it the fear that the health services would be overwhelmed by the health needs of the elderly. Cheston and Bender (1999) comment on the level of panic which seemed to take hold at this time, panic not justified by the numbers involved and note the appearance of articles or reports with titles like “Rising Tide: Developing Services for Mental Illness in Old Age” and “The coming epidemic of dementia” (p.39). It was in this context that the “alzheimerisation of dementia” (Kitwood, 1997, p.22) took place, whereby “a social movement, based upon alliances among scientists, caregivers of persons with dementia, government administrators, the media, and members of the general public and Congress … transformed Alzheimer’s disease from ‘an obscure, rarely applied medical diagnosis to a characterization as the fourth or fifth leading cause of death in the United States’ (Fox, 1989, p.58)” (Binstock, Post and Whitehouse, 1992, p.1). The term “Alzheimer’s” was from then on used to encompass both pre-senile and senile dementia and was “elevated” to a disease rather than forming a normal part of ageing.

Herskovits (1995) points out that Alzheimer’s status as a disease did not occur by chance or by political manipulation, but because of its very effective ability to satisfy certain human needs and interests. Its elevation to a disease meant a considerable increase in research funding and availability of care and support services. Politically, socially and culturally Alzheimer’s time had come.

Gubrium (1986) addresses the discourse surrounding Alzheimer’s, using the term “descriptive security” to refer to “the means by which those concerned secure – decipher, delineate, and sustain – the realities of interest to them (p.207). Even though the description attributed to Alzheimer’s could be attributed, though not to the same degree, to old age, “descriptive security provides differentiation, the preservation of a distinct disease in a category by itself” (p.207). The “fact” of disease is not only talked of in medical circles, but in the public at large. It has become a not-to-be questioned reality.
This discourse is intimately tied not only to the realities of people’s experience but also to their need to make sense of what is happening.

There is no doubt that, for those concerned, the terms and the discourse are about something, things often at the very center of daily living, day in and day out…The descriptive organisation of the disease articulates two sides of the same thing: it represents and destroys their loved ones; it also informs them of the practical meaning of these matters. (p.205)

Gubrium (1986) concludes that it is not science which has established the reality of Alzheimer’s as disease (thereby differentiating it from normal ageing), but the discourse surrounding it. Rather than political manipulation as some have suggested, there is a more benign force. “Whether the concern is professional, a labor of love, or a combination of both, the need for elaboration is part-and-parcel of the attempt to do something about the suffering believed to be caused by Alzheimer’s” (p.71).

These descriptive activities reinforce the unity of the concept, despite contradictions which occur in the actual experience, for example the mooting of distinct stages while recognizing that people experience the disease differently. The inter-relationship between discourse and the daily reality facing caregivers, professional and family provides further insight into the power of the disease model and the needs it fulfils at many levels.

It is interesting that even the original naming of the rare condition of presenile dementia as Alzheimer’s was not free of the influence of social context. Cheston and Bender (1999) point to the limitations of Alois Alzheimer’s research which eschewed any investigation of psychological or social aspects. This no doubt reflects a bias towards organic explanations. They suggest, too, that Alzheimer himself did not see his discovery as being the discovery of a new disease, but rather they attribute the creation of Alzheimer’s as a disease
process (albeit at that time as a sub-category of senile dementia), to the ambitions of Kraepelin, the Director of the institute Alzheimer worked in, who was seeking kudos for his institution and theoretical support for his own work.

In conclusion, Kraepelin’s representation of Alzheimer’s discovery as a distinct subtype of senile dementia contrasts with Alzheimer’s own account of his work, in which it is clear that he was describing a particular and unusual set of clinical behaviours and corresponding brain pathology, not a new brain disease. It seems clear that by depicting Alzheimer’s account of Frau Auguste D in this fashion Kraepelin was seeking to lend weight to his own descriptive categories, and that it was Kraepelin, not Alzheimer, who created Alzheimer’s disease. (p.37)

3.3. Harding and Palfrey’s Social Constructionist Critique of Alzheimer’s Disease

Harding and Palfrey’s critique (1997) of a biomedical view of Alzheimer’s is in line with the sociological traditions noted earlier. They question the hegemony of the biomedical understanding of Alzheimer’s as a disease and the impact of this view on the identity of the person who exhibits behaviours labelled as pathological.

The critique which we present is in line with social constructionist and post-modernist paradigms: that to arrogate to one system of beliefs a natural precedence over any other is to confine observation of human behaviour and experience to a blinkered conceptual lens. (p.144)
They argue that the biomedical view of Alzheimer’s as a disease is simply one of several possible perspectives, is historically, culturally and socially based and as such is open to criticism.

Even from a biomedical standpoint, they argue, Alzheimer’s does not fulfil the criteria for disease.

3.3.1. The Cause
The proliferation of plaques and tangles has been noted as the most obvious change in Alzheimer’s disease. Yet correlation does not necessarily mean causation. Furthermore, there does not appear to be an absolute correlation between brain pathology and dementia. The search for simple linear causality is itself a product of a biomedical paradigm.

3.3.2. Diagnosis
Diagnosis is made on the basis not of physical symptoms but of behaviour and can only be verified post mortem. However, basing disease diagnosis on behaviour is problematic, being dependent on interpretation as to when behaviour is abnormal. They also criticise some of the common tests for cognitive deficit, which again rely on subjective judgements about what is normal. From their literature search Harding and Palfrey (1997) conclude: “that there is therefore a need for a diagnostic tool which can accurately identify the existence of the disease, its severity and its prognosis” (p.37).

3.3.3. Prevalence
Lack of a proper diagnostic tool makes it also difficult to establish prevalence of the disease.
Problems in using existing tools have been shown by Little et al. (1987), who compared three existing measures and found that although the tests revealed similar overall prevalence rates, they had identified different people as suffering from dementia. The authors therefore advise, “caution when examining epidemiological surveys which use different tools to identify cases. It is incorrect to presume that because studies report similar prevalence rates they are considering equivalent groups” (p.813). (Harding and Palfrey, 1997, p.38)

Garratt and Hamilton-Smith (1995) also point out that this apparent rise in the incidence of dementia is not so much due to the ageing of the population (which happened considerably earlier) but rather to redefinition of the boundaries between illness and health. While Granny might once have been a “bit strange”, she is now “dignified” by being “ill”. (p.5)

Harding and Palfrey (1997) conclude that, far from arguing against the application of a rational discourse, we would suggest that the construction of certain behaviour as a disease caused by cortical impairment has to be challenged – in the absence of any empirical testimony – as an irrational position judged by its own criteria of proven cause and effect. (p.146)

Their critique of Alzheimer’s disease echoes here much of Kitwood’s argument. However, they go further in questioning the very concept of disease as an independent entity existing outside of a social, historical and cultural context. Alzheimer’s is viewed as a disease because, for multiple
reasons, our society looks at deviance or difference through a biomedical lens. One reason that society needs dementia to be labelled as disease is that “if it is classified as a disease it holds out the prospect of a cure for ageing and for death” (Harding and Palfrey, 1997, p.139). They conclude:

Dementia may be seen as a label for certain types of behaviours rather than a tested diagnosis of a disease. There is, then, no such state as ‘dementia’ – only different types of behaviour considered by medics and paramedics as socially divergent and therefore, from their epistemological vantage point, explicable solely in terms of physiological impairment. (p.145)

Harding and Palfrey (1997) do not deny the experience of people with dementia and their families, but state that there are other ways to view it, ways which are less narrow and prescriptive.

In the context of attempts to define and identify the causes of some human condition labelled by clinicians as “dementia”, the personal dimension of feeling has been largely ignored and the label itself – because it is so prescriptive – has served to exclude other interpretations of what is a multi-dimensional state of being. (p.58)

They are not uncritical of psychosocial explanations which have arisen to challenge the biomedical and suggest that some of these alternative perspectives are not sufficiently disengaged from the biomedical model. For instance, they criticise Kitwood and Bredin for their continued use of “therapy” with its clinical implications. They further criticise Kitwood and Bredin’s hypothesis concerning good care and well-being.
Their hypothesis – that insensitive care serves to inhibit dementia – remains intact because it has neither been proved nor disproved. It may, therefore, take its place alongside the bio-medical “theories”, for in many respects it also adopts a positivist view of dementia as a condition which, in some individuals, may be treated or even cured. (Harding and Palfrey, 1997, p.64)

For Harding and Palfrey, therefore, psychosocial perspectives themselves, while offering a more positive interpretation of dementia, have not separated sufficiently from biomedical frameworks of thought. They conclude that we continue to have a rather limited and limiting understanding of the complex nature of dementia. Within the current frameworks of thought, professionals will remain “confused” about the care they should be offering people with dementia.

It would seem then that at this stage in our understanding of dementia there is no one satisfactory explanation of the nature of dementia, only multiple partial understandings of what appears to be a very complex and multifaceted state of being.

4. PERSPECTIVES ON THE PERSON WITH DEMENTIA

I will now turn to the second aspect of an understanding of “the dementia world”, namely, the differing constructions of the person with dementia.

4.1. Biomedical – the Loss of Self

“The overwhelmingly dominant pernicious effect of the current Alzheimer’s construct is the dehumanization or debasement of ‘self’” (Herskovits, 1995, p.152).
While the biomedical construct of Alzheimer’s disease had a positive impact in terms of offering the reassurance of naming a disease and of increased funding for care and research, the cost has been the rise of the view of “senility as monstrosity” (Herskovits, 1995, p.152) where the person is dehumanised and stigmatised. The destruction of brain cells in dementia is seen as a fragmentation and ultimately destruction of the self. The person with dementia is portrayed as a helpless victim of disease and responses and behaviour are no longer an expression of self, but a symptom of disease. The process of dementia is variously described as “loss of self” (Cohen & Eisdorfer, 1986), “death that leaves the body behind” (Kirwood, 1997), “dissolution of the self” (Symonds, in Gidley & Shears, 1987). In the biomedical model of dementia, the self is most marked by its absence.

Paradoxically, in conjunction with this dramatic focus on the Alzheimer’s “victim”, Alzheimer’s discourse directs attention away from the individual with Alzheimer’s and onto the burden of the caregivers, effectively erasing, or at least minimizing, interest in the burden of the person with Alzheimer’s. (Herskovits, 1995, p.153)

Perhaps it is not so paradoxical as Herskovits suggests, for the carer, unlike the person with dementia, is seen to remain a self.

In reaction to the loss of self view, “in increasing numbers, social scientists have entered the fray, offering theories that reframe and reclaim the ‘self’ in Alzheimer’s” (Herskovits, 1995, p.155). However Herskovits also notes that “the dominant imagery of Alzheimer’s ‘victims’ remains bleak; and there is resistance to the idea that there is any richness or capacity for agency in their subjectivity” (p.157).
4.2. **Psychosocial – the Damaged Self**

The concepts of self and personhood are a crucial part of psychosocial approaches, yet are often not clearly differentiated. For the purpose of understanding their role in dementia, I have found useful the distinctions made by McCall (1990). Self is defined in terms of the subjective experience, the person’s experience of self. This does not mean that the subjective experience is independent of the actions of others. As will be discussed below, the self both in formation and ongoing integrity depends in part on other people and where the self is fragmented, as in dementia, there is even more need of the other person. Personhood on the other hand is “to be found in the public domain. Persons are social beings, created and constituted, and found only in society” (p.12). Personhood is conferred by others and as such has ethical implications.

4.2.1. **The Self**

The biomedical “loss of self” view has come to be challenged by psychosocial perspectives. These perspectives are best viewed within the wider theoretical context of “self” writings. I will refer to some key understandings about the nature of self in dementia, referring to both writings on self as well as on the self in dementia.

4.2.1.1. **The Self is Wider than Cognition**

Many of the theories put forward to counter the “loss of self” view agree that there is an overemphasis on cognition as the core of the self (Herskovits, 1995; Kitwood and Bredin, 1992). The self does not merely consist of cognition. While it cannot be denied that cognitive aspects are progressively lost in dementia, this does not mean that other aspects of self do not remain. The realm of feeling may in fact take on a greater role for the person with dementia. “Dementia strips people down to the essence of their being and frees them to be in more direct touch with their emotions” (Gibson, 1998, p.6).
4.2.1.2. The Self is Embodied

Interestingly, while there are writings in dementia which de-emphasise cognition as defining self and give attention to a wider interpretation of self which includes feeling, there seems little in the literature which interprets self to include the body as an integral part of the sense of self and of the maintenance of self. The work of the neuroscientists would however appear to lend support to a view of self which incorporates the body. Damasio (1996) notes that thinking and awareness of thinking came much later in human evolution. Being preceded thinking. He chooses therefore to change Descartes’ “I think therefore I am” to “We are, and then we think” (p.248).

Thinking arises out of being. Sacks (1991) emphasises the integrative qualities of the mind which allows for a coherent and unified self, a self however which is not limited to cognition. “All these supposedly-separate compartments of brain function are richly interconnected and in continual communication; only with this new neuroanatomy does one understand how the motor, the sensory, the affective, the cognitive, can and – indeed must – go together.” (footnote 114, p.237).

Damasio emphasises that integrity of the self depends on sensing one’s current body state. Levin (1992) notes that the psychiatrist, R.D. Laing describes the existentially secure self as an embodied self.

4.2.1.3. Self as an Active, Meaning-Seeking Participant

Garratt and Hamilton-Smith (1995), perhaps more than Kitwood, emphasise that the person with dementia is not merely a passive recipient, but is actively involved in seeking to deal with the effects of brain damage and make sense of their world. The behaviour of a person with dementia, then, can be meaningful and be viewed as the person’s attempt to integrate and adapt to a constantly changing reality.

4.2.1.4. The Self as Process

“The self is a process, not a thing” (Breytspraak, 1984). From the neurological perspective, the self is a “repeatedly reconstructed biological
state” (Damasio, 1996, p.226). “At each moment the state of self is constructed from the ground up” (Damasio, p.140). Sacks (1991) writes: “One’s persona is in no way ‘localisable’ in the classical sense...it cannot be equated with any given ‘centre’, ‘system’, ‘nexus,’ etc., but only with the intricate totality of the whole organism, in its ever-changing, continuously modulated, afferent-efferent relation with the world” (p.239). The self – even the so-called “normal” self – is not static nor unchanging. We all have to adapt and change, and integrate new experiences. Viewed from this perspective, the person with dementia is doing what every “self” must do, although of course in more extreme circumstances. Garratt and Hamilton-Smith (1995) observe that the person with dementia, faced with extraordinary and extreme changes, tries to maintain integrity of self by calling on his or her usual methods of coping and in so doing, creates a new reality. The role of the carer is not to dismiss this new reality as unreal, but rather to support and validate it.

4.2.1.5. The Continuity of Self

Garratt and Hamilton-Smith (1995) view the integrated self (where there is no dementia) in terms of the following questions:

- **Identity:** Who am I?
- **Abilities:** What can I do?
- **Relationships:** How do I relate to important others?
- **Current reality orientation:** Where am I and why am I here?
- **Memory:** How has all this arisen from my past?
- **Self-esteem:** What am I worth? (p.32)

In dementia, these aspects break down, as do the connections between them. They note that in dementia, one’s identity in terms of familial, social and professional roles is lost, as are abilities, a sense of being capable, and a sense of relationship with others. Memory is fragmented. Those aspects which
“hold” the self are lost and the person’s “sense of self is threatened by fragmentation” (p.34).

While dementia poses a serious threat to the integrity of the self, the self may nevertheless persist. The person with dementia remains a “sentient, relational and historical being” (Kitwood, 1993, p.541). Downs (1997) notes:

There is growing empirical research which affirms that people with dementia retain a sense of self despite cognitive impairment. Mills and Coleman (1994), using counselling skills and reminiscence work, present case study evidence that personal awareness of an individual self remains. “Dementia may fragment the personality of the sufferer, but the personal awareness of individual uniqueness of being remains until death” (Mills and Coleman 1994:213). (p.599)

Sabat and his colleagues have attempted to combat the loss of self view in dementia through an analysis of self discourse. Sabat and Harre (1992) posit two selves, Self 1 being the self of personal identity (as indicated by the use of “I”) and Self 2 the “multiple personae that are projected in the public arena” (p.443). In their study of three people with Alzheimer’s, they conclude that self 1, “personal singularity”, persists despite the ravages of dementia and that self 2 (or rather selves 2 since we have many different social selves) can persist well into dementia with the cooperation of others. Kitwood also talks of two selves, placing the focus of carer intervention on self 2, the social self. Sabat, in a later article (2002), further teases out the discourse on self and now posits three selves: the self of personal identity (self 1), the social self (self 3) and self 2 which comprises mental and physical attributes. Self 2 with dementia acquires new attributes, namely dysfunctional ones. Self 3, as noted above, may persist with the cooperation of others, but will be negatively affected if others focus on the dysfunctional aspects of self 2. In his studies of people
with dementia (Sabat & Collins, 1999), Sabat has used his theories on self to highlight the positive rather than the negative, namely those abilities – cognitive, functional and emotional – which still remain.

Talk of different selves can raise questions about the relationship of these selves and questions about a divided as opposed to a unified self. Rather than positing two or three selves, Garratt and Hamilton-Smith prefer to talk in terms of a continuum which incorporates the concept of a personal self and a social self. Within this complex structure, some aspects remain relatively intact while others are impaired. “In other words, the person with a dementing condition may well retain some aspects of their sense of who they are, while losing others” (p.32). It is the social aspects of self, they note, which are most likely to be impaired.

Savy (1998) writes that while the person with dementia may appear to be a “shell of her former self” to her family, she as an outsider could see “enduring threads” of the person’s identity. She concludes: “On the one hand dementia strips away identifying characteristics, yet, on the other it lays bare, indeed, often accentuates enduring elements that speak of the person, past and present” (p.239).

4.2.1.6. The Relational Self

The emphasis on relationship in person-centred care is based on a view of the self being formed at least in part by relationship. For example, Levin (1992) writes:

Feelings of aliveness, cohesion, agency, continuity (ongoingness), and self-worth come from both within and without. I agree with Winnicott’s and Kohut’s beliefs that the feelings of being coherent, enduring, and worthwhile, indeed of existing, come, at least in part, from the outside. I become a self by being treated as a self. (p.208)
Breytspraak (1998), writing of the development of self in later life, makes a somewhat similar point “People do not make themselves apart from relationships with other persons, the culture of which they are a part and the circumstances and events of the era in which they live” (p.26).

All selves are formed from the inside and the outside, and all require other people to some degree or other. People with dementia however have a more absolute need of the other. “Their personhood needs to be continually replenished, their selfhood continually evoked and reassured” (Kitwood & Bredin, 1992, p.285). In emphasising the relational aspect of self, they suggest that carers through relationship can affirm the identity and value of the person with dementia.

Essentially then the psychosocial view of the self of the person with dementia is of a self under threat, but nevertheless very much still a self. This self is formed biologically, developmentally, psychologically, socially, historically and culturally and is maintained at least in part through relationship. We need to “relate dementia in old age to the larger pattern of life history and to the nature of a person’s social relations and experience” (Kitwood, 1990b, p.61).

### 4.2.2. Personhood

Personhood, as Kitwood (1997) points out, is a complex concept which includes notions of transcendence (mainly in religious discourse), ethics (philosophy) and social psychology. In the latter, it has been taken in a rather broad sense “Its primary associations are with self-esteem and its basis; with the place of an individual in a social group; with the performance of given roles; and with the integrity, continuity and stability of the sense of self” (p.8). He then gives his own definition of personhood, a definition which emphasises relationship and the positive interactions which should be part of that relationship: “It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (p.8).
This necessarily leads on to the question, to whom shall we grant the status of person. Kitwood (1997) refers to Quinton’s (1973) discussion of personhood, in which Quinton suggests five criteria for personhood, these being consciousness, rationality, agency, morality and capacity to form and hold relationships. Kitwood suggests that in recent years in our society these have been reduced to two: autonomy and rationality. Warren (1973, p.55) sets out the following criteria for personhood: consciousness, reasoning, self-motivating activity, the capacity to communicate, the presence of self-concepts and self-awareness. Jenkins and Price (1996, p.87), however, note that these criteria “reinforced ideas about personhood as something that is lodged within the world of reflection and abstract reasoning”, criteria which clearly threaten to exclude people with dementia from the status of personhood. Post (1995), in arguing for an ethics which includes rather than excludes, criticises the emphasis our society places on cognition as an indicator of personhood and suggests we should place more emphasis on feeling and relationship.

Rather than allowing declining mental capacities to divide humanity into those who are worthy or unworthy of full moral attention, it is better to develop an ethics based on the essential unity of human beings and on an assertion of equality despite unlikeness of mind. (p.3)

At the same time, he stresses the essential similarities between all human beings. He notes that Alzheimer himself believed that dementia of the Alzheimer’s type was a part of the continuum of ageing: “It is possible that social attitudes would change if we better appreciated the fact that we are all a little demented” (Post, 1995, p.4). Furthermore, people with dementia are like us in that “they are meaning seeking in the same way that we all are, and their struggles to makes sense of loss are akin to our own” (p.18). Kitwood (1997) also points to the unity of human beings. We are all in the same boat and
“there can be no empirically determined point at which it is justifiable to throw some people into the sea” (p.10).

4.2.3. **Listening to the Voices of People with Dementia**

In recent years there has come to increasing recognition that the person with dementia can have opinions, thoughts to communicate, and indeed that every effort should be made to hear them.

In seeking funding for the project which Goldsmith was to head, the Stirling University team claimed “In order to improve services for people with dementia and to make them more responsive to their individual wishes, it is necessary first to accept that people with dementia have a voice that is worth listening to, second to facilitate the use of it and third to hear” (Goldsmith, 1996, p.ix). Goldsmith points out that professionals still have difficulty coming to grips with the fact that people with dementia may indeed have something valuable to communicate. Part of the reason lies in their understanding of dementia. In his book, Goldsmith describes some small projects which have begun to seek the view of actual consumers of services, that is the people with dementia. The rest of the book looks at what obstructs and what aids communication with people with dementia. Goldsmith’s work challenges the assumptions that it is impossible to understand people with dementia and that they have nothing meaningful to say.

Killick and Allan (2001) have made the issue of communicating with people with dementia a central focus of their work invoking both the verbal and the non-verbal elements of communication. These researchers view communication as a complex process which is not dependent solely on the abilities or disabilities of the person with dementia, but on the staff member’s willingness to listen, sensitivity, and skills in understanding, in pacing the conversation and so on. Not only is the relationship important in the
communication, but also the environment which can either facilitate or impede communication.

Killick and Allan (2001) are also very aware that communication serves a vital personal need for expression and relationship and this is reflected in their work on communication and the arts with its emphasis on creativity and self-expression. “It is no exaggeration, then, to say that communication is a basic human need” (p.19). This is echoed in the work of philosopher van Hooft (1995) who states,

Communication is much more than the mere imparting of information from one person to another. It should be understood broadly as the overcoming of human isolation. To communicate is the verb we use to describe the dynamic processes through which we express our being in relation to others. (p.96)

Communication is basic to human beings and is about relationship.

There has also been an interest in the stories of people with dementia. Writers such as Killick (1994) in the U.K. and Kotai-Ewers (2001) and Goyder (2001) in Australia have written the words of people with dementia in the form of poetry and stories. People with early stages dementia have begun to make themselves heard, giving first hand impressions of their experience of dementia and advocating for the inclusion and participation of people with dementia (Bryden & Friedell, 2001; Boden, 1998).

The psychosocial perspective, then, offers a more positive view of the person with dementia, whose self may be maintained through relationships which affirm his or her ongoing value and personhood. Garratt and Hamilton-Smith further suggest that through such relationships, the person may achieve a more integrated sense of self within his or her new reality. Within the psychosocial or person-centred movement itself there has been a
development from the person with dementia as a passive recipient of care (albeit person-centred care) to a more active role. The recent emphasis on hearing the voices of people with dementia points to a stronger recognition that these are persons who still have something to say and the potential to participate in constructing their own lives.

4.3. Social Constructionist – an Altered State of Being

Harding and Palfrey (1997) argue that the self or self identity of people with dementia is constructed through the medical messages they receive, ageist messages, and the language used about them. This affects both how society views them and how they view themselves. From a biomedical perspective, the self of the person with dementia is constructed as dysfunctional, indeed as a lost self; psychosocial perspectives offer a more hopeful view of self, as a damaged self which can be positively supported. Harding and Palfrey question the very labelling of the dementing self as dysfunctional and suggest that it is possible to apply “a different conceptual lens to the study of certain altered states of mind” (p.141). From their perspective, it would seem that if the person with dementia is a victim, it is not of a disease but of the way society views difference or deviance.

5. IMPLICATIONS FOR CARE

The understandings of “the world of dementia” necessarily have implications for the kind of care offered to people with dementia and in the following discussion I will look at the approaches to care grounded in these understandings. I will focus on the biomedical and person-centred approaches to care, in the first place because these are the two models which are at the heart of this study and secondly, because the social constructionist perspective does not offer a specific model of care. The main aim of Harding and Palfrey’s social constructionist critique is to challenge current ways of understanding dementia and the dysfunctional label applied to the person with dementia.
Essentially their critique is a challenge to certainty and an invitation to a questioning approach to understanding dementia, in recognition of the very real uncertainties which surround it. This too has implications for practice, for Harding and Palfrey suggest that until professionals question the conceptual lenses through which they view the person with dementia, they will continue to be “confused” about what kind of care they should be offering.

5.1. Biomedical Approaches to Dementia Care

People with dementia are viewed as victims of a disease process for which there is no cure and which ineluctably leads to loss of self and ultimately death. What is required therefore is good physical care and treatment of symptoms through medication.

Over the last few years, it has become more accepted – and expected – that some degree of organised activity is offered in care facilities. However, the cornerstone of care in dementia lies in the physical and medical care which provides “a safe environment, adequate nutrition, maintenance of hygiene, adequate exercise and a medical care plan” (Kirksey and Joyce, 1991, p.51). Although these authors do add “of equal importance, the Alzheimer patient needs attention and affection in order to feel secure and loved” (p.51), most of their discussion reflects a focus on physical and medical care.

Behaviour is considered part of the symptomology of Alzheimer’s and therefore meaningless beyond the medical interpretation. This behaviour can include wandering, aggression, agitation, shouting and interfering with the activities of others. Definitions of appropriate and inappropriate, challenging and non-challenging behaviours would appear to be from the perspective of the carer rather than situated in the reality of the person with dementia. Rosewarne et al. (1996), in their evaluation report on care needs and challenging behaviour of people with dementia in institutional care, note that
behaviour is “challenging in the sense that it creates difficulty for the carer, rather than necessarily being aggressive or threatening to other people” (p.5).

These challenging behaviours are often dealt with through medication. Rosewarne et al. (1996) note that psychotropic medication is widely used to manage challenging behaviour. The most common types of medication are anti-psychotic or neuroleptic, anti-anxiety, sedative-hypnotic and anti-depressant. They suggest that rates of use are higher than is preferable in terms of best practice.

Despite this reliance on chemical restrain t, there would seem to be lack of substantial evidence of much positive impact from medication. Rosewarne et al. cite Wragg and Jeste (1988) who conclude that the benefits of anti-psychotic drugs are modest and often no better than placebos. Furthermore, there is evidence of negative effects such as increasing cognitive impairment with anti-anxiety or sedative-hypnotic drugs (in particular Benzodiazepine sedatives) and falls (Benzodiazepine sedatives, and psychotropic drugs in combination with other medications). Anti-psychotic drugs may even increase cognitive impairment in those already suffering some impairment, although there is insufficient research evidence at this stage to definitively establish a causal link (McShane et al., 1997).

Medication may be prescribed without considering other factors which might be involved. For instance, Howard, Ballard, O’Brien and Burns (2001) note that sedative medication is often inappropriately prescribed for agitation without due consideration to other factors, some physical, some environmental. This is in part due to the lack of knowledge about drugs and over-estimation of their effects. “In certain circumstances agitation may be an appropriate response to a difficult environment or situation” (p.715).

Ballard and O’Brien (1999) recommend therefore more rigorous research in the use of such drugs for behaviour management and restraint in the meantime in making use of them.
Given current knowledge, unless symptoms are extremely distressing it would seem appropriate to monitor the disturbances for at least one month before starting pharmacological treatments. The monitoring period allows time for spontaneous resolution, while psychosocial interventions may facilitate better practical management… Better evidence is required before individual pharmacological agents are licensed specifically for managing behavioural or psychological signs in dementia. (p.139)

However, the economic imperative – since medication requires less staff input and time – often means that drug management may of necessity be the preferred option.

5.1.1. Health Services Research
Jorm (2001), an Australian medical researcher, points to the good work being done in biomedical research in Australia “which is essential if we’re to treat and prevent dementia” but suggests that not nearly enough is being done in terms of health services research. “Currently, less than 10% of our research on dementia involves the investigation of services” (p.3). He suggests that evaluation research is important to ensure quality service for people with dementia and their families.

5.2. Psychosocial Approaches to Care
Psychosocial approaches to care have generally been brought under the umbrella term, person-centred care. Although the concept of person-centredness has been known in therapeutic circles for many years, for example in the work of Carl Rogers (1961), it was Kitwood who gave currency to the expression “person-centred care” in dementia. Since then it has been picked up to describe care which takes as its starting points an understanding of dementia which goes beyond brain pathology and a
perception of the ongoing personhood of the person with dementia. Many writers have contributed to building the framework of person-centred care. I will refer to key aspects of person-centred care and the writers identified with them. I will give particular emphasis to Kitwood because of his central role in promoting the concept of person-centred care and to researchers Garratt and Hamilton-Smith who offer an Australian model, which was the model of care adopted by Star of David.

5.3. **Kitwood and Person-Centred Care**

Kitwood (1995) suggests two main aspects of person-centred care: an ethic and a social psychology, one supplying the motivation, the other the knowledge on which to build an effective and person-centred approach to care.

> The ethic asserts, as a statement that is beyond challenge, that all human beings have absolute value, regardless of how “good” or “bad”, how able or disabled, they may be…. The second ingredient – the social psychology – is a body of knowledge which shows in detail how people with dementia can live out their lives in the most fulfilling way (maintaining relationships, exercising choice, experiencing satisfaction, and so on). (p.12)

Some of the major elements of Kitwood’s person-centred care are discussed below.

5.3.1. **Primacy of Relationship**

Kitwood’s major contribution to the model of person-centred care is his emphasis on the important role of relationship, its impact both positive and negative and the ways in which carers may positively enhance the well-being of people with dementia through relationship.
Relationship, then, is central to person-centred care. Kitwood and Bredin (1992) point to three lines of evidence for the impact of relationship: anecdotal evidence of rementing “when their conditions of life, and especially their social relationships, are changed” (p.278); stabilisation of dementia, that is lack of ongoing regression; evidence in studies of “geriatric” rats which showed neurological development when exposed to a more stimulating environment.

Through relationship the carer may act in some way as a prosthesis, making up for the deficits the person may have, filling in the gaps, to help maintain the person and help him or her achieve a sense of well-being. “The Other is needed to hold the fragments together. As subjectivity breaks apart, so intersubjectivity must take over if personhood is to be maintained” (Kitwood and Bredin, 1992, p.285).

The carer’s relationship to the person with dementia should be of a certain quality; it should be a relationship of equals. Kitwood (1997) refers to the Buber concepts of a relationship of I/Thou as opposed to I/It. I/it implies:

- coolness, detachment, instrumentality. It is a way of maintaining a safe distance, of avoiding risks; there is no danger of vulnerabilities being exposed. The I/Thou mode, on the other hand, implies going out toward the other; self-disclosure, spontaneity – a journey into uncharted territory. (p.10)

It is a relationship of I and Thou which is most positive for people with dementia, indeed for all of us.

Post (1995) emphasises a care which is not “doing to” but rather “being with”, that is care which has at its core relationship. His quoting of the French Philosopher Gabriel Marcel perhaps expresses the essence of this type
of care: “‘creative fidelity’, ‘attentive listening’ and ‘the mystery of presence’” (p.8).

Rather than interactions which disempower the person with dementia, Kitwood (1997) proposes more benign ways of interacting which reinforce and promote the personhood of the person with dementia, what he calls “positive person work”. This comprises recognition, negotiation, collaboration, play, timalation (involving the senses), celebration, relaxation, validation, holding, facilitation, and, on the part of the person with dementia, creating and giving. In addition to an empathic relationship, it is important for carers to know the person’s life history; “even if a person cannot hold on to his or her own narrative identity, due to loss of memory, it can still be held by others” (p.84). For Kitwood the maintenance of personhood is a key psychological task in dementia care, and this implies a totally different culture of care from the biomedical model. In person-centred care, “care is concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting basic needs and giving physical care are all essential, but only part of the care of the whole person” (p.136).

5.3.2. Well-Being in Dementia

In an early paper, Kitwood and Bredin (1992) mooted the possibility through person-centred practice, of helping the person with dementia achieve a state of “relative well-being”, based on 12 indicators they had devised based on their observations. These indicators could be distilled into four global sentient states: “a sense of personal worth”; “a sense of agency”; “a feeling of being at ease with others, of being able to move towards them, of having something to offer to them”; “hope…a sense that the future will be, in some way, good” (p.283). Hope does not need to be linked to cognition. Kitwood and Bredin associate it rather with the psychoanalytic concept of basic trust.

In his 1997 book, Kitwood no longer talks of relative well-being, but simply of well-being and adds his construct of basic psychological needs, which he
prefers to depict as cluster rather than a hierarchy of needs: comfort, attachment, inclusion, occupation and identity with love as the core need. Through the satisfaction of these needs, the person with dementia will come to feel valued and worthwhile and achieve a sense of well-being.

Harding and Palfrey (1997) have criticised the arbitrary nature of Kitwood and Bredin’s indicators of well-being and the lack of rigour in selecting them (a rigour which they observe Kitwood and Bredin demand of the biomedical model). “The list is interesting, not least because of its apparent selectivity and freedom from any stated sampling method. Observation of any other cohort or cohorts of diagnosed demented individuals could well produce much different attributes” (p.64). They also suggest that these indicators of well-being “amount almost to a stereotype of the ‘dear old lady’” (p.64).

Kitwood and Bredin (1992) justify their list of indicators on the following two bases: they make sense in terms of the authors’ own (non-dementing) experience, even allowing for individual differences in temperament; and the indicators do not depend on complex cognitive skills and are therefore appropriate to people with dementia (though not exclusively so). The connections of global sentient states to these indicators are not empirical but rather are based on the “inner logic of mental states” (p.283). Kitwood and Bredin admit that this type of conceptual venture is “generally abhorred by main-stream psychology” (p.283).

Harding and Palfrey (1997) make an important point concerning judgments of well-being which relate to the professionals’ values without some kind of input from the experience of the person with dementia. This is also relevant for the closely allied area of quality of life. Brod, Stewart and Sands (2000) note that quality of life is rarely defined, and where it has been, it has “ignored the point of view of those very persons whose QOL is being evaluated” (p.4), being defined rather by the family or professional carers. There is a need then for clarification of key terms such as well-being and quality of life in dementia, as well as input from the people with dementia themselves.
5.3.3. Mapping the Person’s Experience of Care

In an endeavour to evaluate the qualitative aspects of care as experienced by the person with dementia, Kitwood and his colleagues developed a method of mapping the quality of care based on the social psychology perspectives outlined earlier, Dementia Care Mapping (Brooker, 1995; Kitwood and Bredin, 1994). This records what the person with dementia is doing (the Behaviour Category Coding) and how the person feels at that time (state of ill or well-being). There are also two sets of further observations to do with positive events – “instances of positive work by staff members” – and personal detractions – “instances of interaction that detract from personhood” (Moore, 2003, p.308). Though initially a tool to serve as part of quality assurance, it has become useful as an educational and awareness-raising tool (Kitwood and Bredin, 1994), and in the last few years as a research tool (Brooker, 2002; Fossey, Lee and Ballard, 2002). It has been criticised for a number of reasons, such as being time consuming, not sufficiently sensitive, or too subjective (Moore, 2003). Most controversial has been its application in research (Brooker, 2002). Harding and Palfrey’s earlier criticism of Kitwood and Bredin’s global states could equally apply here in that the tool is based on its authors’ values and judgement on the nature of well-being. However, it is significant in that it attempts to address the experience of care of the person with dementia, and is a powerful way “to raise staff awareness of the needs of people with dementia” (Moore, p.312) and bring about change in the practice of care. Dementia Care Mapping continues to be refined and developed.

The writings of Kitwood have therefore contributed much to the theoretical bases underlying person-centred care, in particular his focus on social psychology, the interactions of the everyday and their effect on the person with dementia. His analysis of malignant social psychology and development of the concept of positive person work have also offered a very specific and practical guide to the types of interaction which promote, or detract from, the personhood of the person with dementia.
While Kitwood does make reference especially in his later work to environment and organisation, his major contribution has probably been in his spelling out of the nuances of social psychology in dementia. The work of Garratt and Hamilton-Smith offers a model which takes into account organisational and environmental issues, as well as the interpersonal.

5.4. Garratt and Hamilton-Smith and the ELTOS Model

The ELTOS (Enhanced Lifestyle Through Optimal Stimulus) model was developed by two Australian researchers, Garratt and Hamilton-Smith who carried out action research in a number of aged care facilities. Some of the assumptions which inform this model will be discussed prior to setting out the model itself.

Like Kitwood, Garratt and Hamilton-Smith (1995) emphasise that the experience of dementia must be viewed in relation to the individuality of the person and his or her social, emotional and physical environment. Rather than the person’s behaviour being a symptom, it is in their view an adaptive response to internal or external stressors. In their research study, they found that incidents of “disordered” behaviour were in most cases triggered by some incident in the external environment. “Often it seemed that the behaviour was a perfectly rational response to the event that had triggered it” (p.74). They further note that much of what was described as disordered behaviour in a person diagnosed as suffering from a dementing condition would have been accepted as normal behaviour if carried out by any non-dementing person” (p.74). Viewing behaviour as a symptom has the effect of diminishing the meaning of the behaviour of the person with dementia and ignoring the very real impact of external factors.

James & Sabin (2002) expand on this view by suggesting that behaviour reflects people’s coping strategies, or “safety-seeking behaviours”(p.38). People when faced with the challenges of dementia will fall back on their usual ways of coping with difficulties.
Furthermore, being aware of a person’s repertoire of safety behaviours will help one make sense of the person’s responses (cognitive, emotional and behavioural) to the stress associated with having dementia. Thus if someone with dementia has premorbidly coped with stressors in his or her life by physical activity (e.g. by going for a walk), his or her current desire to pace the corridor and/or attempt to leave the building would seem to make perfect sense; merely reflecting the re-emergence of safety behaviours. (p.39)

Garratt and Hamilton-Smith (1995) relate the ELTOS framework to Antonovsky’s work on wellness. Antonovsky (1987) rejects what he calls a pathogenic orientation to health, which places illness and health as opposite states and seeks causes of illness, preferring rather to look on health and illness as a continuum. His interest was to find out what moved people “toward the health end of the continuum” (p.6), rather than look at what made people ill. He called this orientation “salutogenesis”. He developed the concept “sense of coherence” (SOC) which he believed was a major factor in determining one’s place on the continuum and movement towards the healthy end of the spectrum. Well-being depends to a great degree on a strong sense of coherence, which he defines thus:

The sense of coherence is a global orientation that expresses the extent to which one has a pervasive enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable, and explicable; (2) the resources are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement. (p.19)
In other words, one’s environment, internal and external, should make sense and have some predictability and consistency (comprehensibility); one should feel able to cope with the demands being made (manageability) and one should perceive one’s life and activities as meaningful (meaningfulness). Linked to this sense of coherence is the sense of self. “The person with a strong self and a firm identity will be one with a strong SOC” (Antonovsky, 1987, p.26).

Garratt and Hamilton-Smith believe that rather than bringing the person into their reality, carers must work with the person in constructing a reality which is meaningful and makes sense to the person him- or herself. In this way, the person may achieve a sense of well-being. Hamilton-Smith (1996) answers the question, “Can dementia be successful ageing?” thus:

I would personally argue that we must put aside the pathological metaphor and the resultant myths about the terror of dementia. Every effort should be focussed on ensuring that we do provide the optimal social environment for people with dementia. We may not always succeed – but we can enable most to manage their own condition and lifestyle with pleasure and satisfaction and this probably a very good way of defining ‘successful ageing’.

The ELTOS model comprises two basic preconditions – teamwork and communication – and three key program elements – validation, lowered stress and positive stimulus. Garratt and Hamilton-Smith (1995) emphasise that all five elements need attention; it is not enough to carry out one or two in isolation. Teamwork, encouraged by good management, is essential. “The best results arise out of sharing and cooperation among staff and positive leadership from supervisors at all levels.” (p.86). Communication, not just staff to resident but resident to staff, is a key aim. The program elements
have a broad sweep encompassing the whole institution. For instance, validation is not merely a “therapy to be carried out by one or some staff, but an acceptance of the resident’s reality by all staff as a basic principle of care” (p.88).

Stress is broadly understood to be caused by ambient or environmental factors or social stressors such as staff behaviour, routines or interaction with other residents.

The nature and expression of dementia is largely shaped by the immediate social and physical environment; this may lead to or cause ‘disordered’ behaviour or may even be a sole cause of such behaviour; on the other hand, it can greatly reduce or even eliminate such behaviour. (p.76)

While there are some changes to the physical environment which may be beneficial, “the physical environment is not nearly so powerful as the social environment and the pattern of social interaction” (p.91).

Finally, positive stimulus is interpreted beyond activities or recreation. Rather staff need to gain a sense of what is meaningful for the person and help that person construct a coherent reality, a way of living, in which they will have a sense of personal well-being. The authors suggest that activities – the mainstay of most dementia programs – are not particularly relevant or meaningful for aged people of the current generation who were unlikely to have had the time or resources for leisure in the past. “The stimulus that provides joy and satisfaction will be specific to each individual and will arise out of their past life – often their work or family life rather than just out of previous recreational activities” (Garratt & Hamilton-Smith, 1995 p.139).

Garratt and Hamilton-Smith therefore place great emphasis on the need for holistic care planning which endeavours to know the person in a meaningful way. Rather than have an activities officer who devises group activities,
the activities officer should help to identify the ways in which each person’s activity needs can best be met; the implementation of each person’s program should be shared by all staff, family and friends, volunteers or community organisations. (p.139)

The basis for such care is good management and organisational practices which support cooperation among staff. Good care also involves family and the wider community network.

5.5. Research into Psychosocial Approaches to Care

Kitwood (1995) talked of the need to move beyond the anecdotal, while not discounting the value of these experiences, towards more systematic research. In 2004, it is probably fair to say that there remains a paucity of solid research into psychosocial approaches. Bird (2002) in his address to the Dementia Services Development Centre International Biennial Conference in Sydney attributes this in large part to lack of funding, but also to the lack of good models for this kind of research, research which must necessarily use different methodologies from those of drug studies.

His own research tries to address this issue. In the 2002 study, “Psychosocial approaches to challenging behaviour in dementia”, Bird, Llewellyn-Jones, Smithers and Korten point to the need to move beyond simple belief in the value of psychosocial approaches to systematic research and the development of methods which recognise the complexity of the material being studied.

The psychosocial area generally remains dominated by the unsupported assertion: anecdotal accounts, tips and hints, and barely believable claims of efficacy unsupported by evidence for certain “Therapies”.

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This is not to say that what may be called clinical lore is of no value; it remains the backbone of non-pharmacological dementia care. However, what is now required in the literature is a more rigorous approach in which clinical detail from genuine cases is matched with more scientific rigour. (p.1)

They reject the notion that psychosocial approaches can be researched in ways similar to clinical drug trials.

This is a fundamental misrepresentation of the nature of psychosocial approaches. It also trivialises the important insights these and similar proprietary approaches contain and is contrary to their main thrust, which is more about changing attitudes and providing a consistent humane empathic approach to distressed people with dementia. (p.2)

The aims of the study therefore were threefold. Firstly, the aim was to attempt a series of interventions for challenging behaviour in dementia, using a case-specific approach which was predominantly but not exclusively psychosocial. The end purpose was to be able to describe such an approach in detail and thereby reduce conceptual confusion about the complex nature of psychosocial approaches and their interaction with pharmacotherapy. The second aim was to gather data which permitted more detailed examination of the nature of challenging behaviour in dementia, a topic about which the authors felt there was also conceptual confusion. The final aim was to develop a valid methodology to measure the outcome of the approach trialed in this study.

This is an important study for it not only endeavours to capture the complexity of the material it studies, but also recognises the need to develop appropriate methodologies.
6. SUMMARY
Research and, to a large degree, practice within aged care facilities are based on the concept of Alzheimer’s as a disease caused by pathological processes in the brain. Scientists have been able to identify pathological features in the brain but cannot say what actually starts off the clinically observable expression of Alzheimer’s. Several risk factors have been identified but few have been sufficiently researched to offer conclusive evidence. There remains, too, the question of differentiating the normal accumulation of plaques and tangles due to ageing from those of Alzheimer’s and whether this is a quantitative or qualitative difference. The exact nature of the disease process, then, remains a mystery. The most promising scientific advance in recent years has been the development of cholinesterase inhibitors as Aricept, which slow down the progress of the disease, and current research into vaccines. In terms of the day-to-day care, the biomedical model offers good physical care and control of symptoms through medication.

Psychosocial approaches have challenged the notion that dementia is to be explained solely in terms of pathology, thus opening the way to a more holistic and positive view of the person and more positive role for the carer. “Understanding people with dementia simply as dysfunctional brains is of limited use for day-to-day dementia care” (Cheston and Bender, 1999, p.282). Essentially, person-centred care has its focus on “the person, who they are, how they understand and experience their world, and what they need in order to maintain their sense of self” (Killick and Allan, 2001, p.17). This implies a major change in the culture of care. “The shift from the old culture to the new is not a matter of adding on a few items that were missing but of seeing almost every feature in a different way”. (Kitwood, 1997, p.135).

Many professional carers and institutions have enthusiastically embraced the concept of person-centred care. Yet there remains a disparity between avowed acceptance of person-centred approaches and the actual implementation. Many “‘talk the person-centred talk’ but do not ‘walk the
person-centred walk” (Packer, 2000a, p.19). Packer suggests that person-centred care has opened up multiple possibilities which in turn have engendered multiple questions concerning the practical implementation of person-centred care. She quotes one senior worker: “There’s plenty of information and training that tells us what we should be doing; I really need something or somebody to show me how to achieve all these things in my current working environment” (p.21). These concerns of workers should, she believes, be taken into account instead of leaving them to “make do” in their current situation or else “person-centred care is in danger of ‘failure to thrive’ and will languish in a sea of care worker burnout and apathy” (p.21). She suggests that rather than relegate person-centred care to the bin, which often happens, workers view the current situation as the beginning of a process of change. To further this process, “person-centred approaches need more time and much more methodical development, evaluation and dissemination before they will become widely accepted, and then carried out” (p.21). In studying the experience of implementing a program of person-centred care and the difficulties within it, I hope to contribute to this process.
Chapter 3

METHODOLOGY

Packer noted that the difficulty with person-centred care lay not in the theory\(^2\) but in its implementation in the “real” world of care. The findings from the reconnaissance phase for my initial research question very much resonated with Packer’s words. Despite good will and quite considerable efforts, the new dementia program at Star of David struggled to thrive and to create substantial change in the way care was offered to residents with dementia. It seemed that a research question addressing the issues involved in the process of implementation would offer a point of growth for research in person-centred care.

1. RESEARCH DESIGN

1.1. Choice of methodology

In the reconnaissance phase for my initial research question (refer Chapter 1), I had used participant observation, intending to adopt an action research model for the study itself. However, with my revised question, I was seeking to understand a complex situation requiring observation over an extended period of time and observations which were both wide—incorporating individual, interpersonal and organisational aspects—and deep, that is looking below the surface, getting to know and understand in depth. In other words it was a qualitative study of a culture. It therefore made sense to continue with an ethnographic approach with its emphasis on prolonged engagement and the use of participant observation, which “bears a close resemblance to the

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\(^2\) The person-centred model of dementia care will be discussed in detail in Chapter 6.
routine ways in which people make sense of the world in everyday life” (Hammersley and Atkinson, 1995, p.3).

As a researcher into person-centred care, I believed it was important to view the process of care through the experience of those receiving and giving it, that is the people with dementia, their families and professional carers. I believed that in knowing the individuals one might better understand the interaction of individual personalities with each other and with the larger context. It seemed to me that systemic (organisational) issues were played out or embodied, and could be observed, in the experience of individuals. In this focus on individuals, I was influenced by Savishinsky’s study, “Life and Death in a Nursing Home” (1991), in which he used an ethnographic methodology to focus on a select number of people – residents and staff – in each nursing home he studied. “We treated the nursing homes as expressions of American society, as microcosms of the culture, the people, and the values that shaped and shared them” (p.20). An ethnographic approach afforded me the opportunity to get to know the “culture” of the program through the multiple perspectives of different individuals at the home and my own observations and responses.

While remaining open to all observations, I particularly focussed on the individual’s experiences within three systems identified within the ELTOS model, namely Environment (physical, emotional and social), Interpersonal (that is, relationship and communication) and Organisation (management, staff and organisational structures). These systems appeared to encompass significant areas for change in relation to person-centred care and therefore offered a framework within which to view the material collected. I further developed a matrix which defined core aspects of the person-centred model and contrasted it with non-person-centred models (Appendix A).

It may be argued that this study could only be said to describe an experience at one home. However, I will argue in my analysis of the data that the
literature on dementia care, my own professional experience and the external interviews suggest that many of the difficulties are not peculiar to Star of David but would appear to be shared by other aged care facilities.

1.2. Selection of participants for the study
As Savishinsky had done in his study, I focussed on a small number of participants. The basis for selection of residents and staff was that of their diversity rather than representativeness. In supporting his decision to focus on a limited range of people, Savishinsky (1991) writes, “They were chosen not because of their typicality, but because, in their variety, they reflected the range of individuals and experiences to be found at the home” (p.xvi).

Four residents, four senior/management staff, four personal care attendants and the Executive Director of the home were selected. I chose the residents and staff in consultation with my supervisor and the Executive Director. Criteria for selection were:

- residents: varied in terms of personalities and needs
- senior/management staff: varied in terms of the extent of involvement in the dementia program, work shift, seniority level, training
- personal care attendants (PCAs): varied in terms of length of time working at Star of David, involvement or non-involvement with the dementia program, shift, personal qualities, training or experience.

Later in the research, some individuals (not residents) from other aged care facilities were interviewed in order to offer some comparison of experience.

1.3. Methods: Interview and participant observation
I took on the participant/observer role mainly, though not exclusively, within the dementia activities room, with particular focus on those residents and staff selected for the study.
Participant observation allowed me to play many roles. I could stand back to observe critically, but I could also to some extent “walk in the shoes” of different individuals – at times staff, at times management, at times residents – which afforded me some degree of insight into their experience.

The interviews with staff and management provided an understanding of them as individuals within their professional roles and insight into their understanding and vision of the program. Combined with my observations, the interviews offered a comparison between what was said and what was done. Interviews with the residents with dementia were somewhat problematic due to communication issues. I created a separate interview schedule for the residents, but realised that there could not be a formal interview as such. Instead, I would need to rely on informal conversation, spontaneous comments from residents and my observations of their non-verbal communication. To supplement this information, I interviewed a family member of each resident in order to gain a perspective on the person past and present. This also provided information on the family’s view of the dementia program.

2. DESCRIPTION OF METHODS

2.1. Research Question

What are the issues involved in, and the barriers to, the effective implementation of person-centred care in dementia?

2.2. Methodology

An ethnographic methodology was used which focussed on particular individuals within Star of David and their interactions within the three systems of the environment, interpersonal and organisation.
2.3. **Participants**

The participants in this study were:

1. Four residents participating in the dementia program:
   - Joan, Anna, Eva and Sara
   Four family members of the above:
   - Adam (Joan), John (Anna), Esther (Eva), Jacob (Sara)

2. Five people in management/senior positions:
   - Jason, Executive Director
   - Iris, Director of Nursing
   - Yael, Psychologist, doing final practicum for registration (unpaid)
   - Janet, Registered Nurse, usually on duty during the day on weekdays
   - Mary, Registered Nurse, usually on duty on weekends

3. Four Personal Care Attendants (PCAs):
   - Janice, Maria, Paul, working in the dementia program
   - Paula, who chose not to work in the dementia program

4. Other aged care facilities:
   - Louise, Director of Nursing
   - Sally, Lifestyle/Activities nurse
   - Christina, Unit Manager.

2.4. **Access/Consent**

The research study was approved by the Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University (Appendix F).

The Executive Director and Board of the Star of David gave consent\(^3\) to my carrying out this study, as they believed it would be of benefit to the program.

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\(^3\) The letter from the Executive Director has not been included as an appendix to preserve confidentiality.
and to the residents. They also appreciated that the study of their experience might benefit other homes in the community.

The Executive Director wrote to the families of the residents participating in the program to seek their written consent (Appendix G) for the participation of their relatives. On the advice of the Faculty Human Ethics Committee, I included an option in the consent form for residents to give their own consent. However, it was felt by the facility and the families that the residents would not be able, because of their dementia, to give informed consent. I felt it was important to try to explain to the residents about the research, though I could not be certain how much was understood. I also decided that I would not tape record the words of the residents, unless I could be sure I had their understanding and agreement. Apart from this ethical consideration, tape recording could heighten fears and paranoia among some of them.

All the other participants in this research – staff, management, families and participants from other institutions – were given information verbally and in writing and each signed consent forms for interview (Appendix G).

To ensure confidentiality, the name of the facility was changed and pseudonyms were used for all participants in the study.

2.5. Methods

Methods were participant observation and the keeping of a journal (the research log), and interview.

2.6. Collection of data

The data collection took place at Star of David over a period of 16 weeks (August – November 1999), during which time I attended the home twice a week and sometimes more if interviews were so scheduled. While the framework for observation derived from an ELTOS conceptual framework (in terms of the three systems and the matrix of person-centred and non-person-centred care), I tried to be as open as possible to any other
observations which might arise. It was only later in the analysis stage that I began to relate the data to the conceptual framework.

2.6.1. Participant Observation

As a participant observer, I endeavoured to record as much as possible of what I observed (thick description). My observations focussed on the selected staff, management and residents both within and outside the dementia activities room and were based on the following:

- Conversations with residents, personal care attendants, executive director, senior staff and families
- Observation of residents and their interaction with others
- Participant observation in the dementia activities room
- Attendance at dementia activity program meetings
- Attendance at meeting with the executive director and senior staff
- Observation of the general environment in the home (that is, not just the dementia activities room)
- Attendance at inservice training for staff.
- Resident files and care plans
- Written records on the dementia program activities.

For privacy reasons I was not able to observe the personal care aspect of the residents’ lives, though its effects could sometimes be inferred from the residents’ demeanour on arrival at the activity program.

These observations (August – November 1999) together with my notes on the reconnaissance phase of the research (August 1998 – April1999) formed the research log. The former are cited in the text as RL1, RL2, RL3, relating to each month; the latter are referred to as Reconn.
2.6.2. **Interview**

Interviews were focussed with reference to the matrix of person-centred and non-person-centred care (Appendix A).

I developed separate interview schedules (Appendices B) for senior staff, personal carers, families, the Executive Director and individual interviewees from other institutions. I also created an interview schedule for residents (Appendix B), though as noted earlier it could only be a guide to areas to explore through multiple means rather than a schedule for a formal interview.

I negotiated times for interviews, and all were held at Star of David, except in the case of two family members, one of whom was interviewed in his office, the other in his home. External interviews were scheduled during and after the formal research phase at Star of David.

All interviews were recorded and then later transcribed by me as close as possible in time to the date of the interview. Stumblings and ahs and ums were sometimes omitted if they seemed not to be part of the meaning of what was being said. However, I mainly transcribed verbatim, believing that it was safer to have too much than to cut out something which might verify what was being said. Citations in the text from interview transcripts are prefixed by the interviewee’s name.

2.7. **Data analysis**

Analysis of the data was based on grounded theory. Charmaz (1995) details the major characteristics of grounded theory methods, which she says are “a logically consistent set of data collection and analytic procedures aimed to develop theory” (p.28):

1. simultaneous involvement in data collection and analysis phases of research
2. creation of analytic codes and categories developed from the data, not from preconceived hypotheses
3. the development of middle range theories to explain behaviour and processes
4. memo-making
5. theoretical sampling
6. delay of the literature review.

I will refer to these characteristics in the course of discussing the data analysis in this study.

2.7.1. Analysis of research log data

2.7.1.1. Simultaneous involvement in data collection and analysis phases of research.
My notes as participant observer were usually written up the same day or the following day at the latest. Close to the time of writing up, I re-read the notes, reflected on them and put in preliminary margin notes. Analysis therefore began with the first data and continued throughout the collection phase.

2.7.1.2. Creation of analytic codes and categories developed from the data, not from preconceived hypotheses
1. Initial Coding: Charmaz (1995) describes the creation of analytic codes and categories as being “developed from the data, not from preconceived hypotheses” (p.28). This is not to say that the categories “inhere” in the data; rather, she says, these categories reflect the interaction between the observer and the observed. Lofland and Lofland (1995, p.192) note that the researcher as an instrument of the research is informed by “your commitments, interests, expertise and personal history” (Charmaz 1983, p.112) and (2) your knowledge of and skill with the topics…questions, and interest-arousal considerations” (p.192). This view of the forming of categories as an interaction between the researcher and the material is consistent with my approach to the material. In the initial coding stage, I read the material several times marking with descriptive comments such as “staff attitudes”, “person lost somewhere in this”. I tried to keep my
comments close to what particular pieces of data seemed to say. In that sense, the categories grew out of the data. On the other hand, I am also aware that this was not uninfluenced by my own values, interests and in particular by the principles of person-centred care.

2. Focused coding: Over time, as I re-read and compared bits of data, the categories became more focussed and I grouped the data under the following headings:

- Interpersonal
- Control
- Listening/not listening
- Us/Them
- Group versus individual
- Activity
- Lack of time/busyness of staff
- Task orientation
- Documentation
- Staff resistance
- Staff
- Organisation
- Communication
- Security/safety issues
- Lack of priority given to dementia program
- Resources
- Management
- Perceptiveness of Residents
- Residents’ Lack of Power
- Impact of families
- Ethnic Issues
- Environment.
I then gathered all the data of one category under that heading, thereby creating a new document so that I had all the relevant data for one category together and every piece of data assigned to a category. Where a piece of data fitted more than one category, it was included under each of the relevant headings and cross-referenced.

2.7.1.3. Development of middle range theories to explain behaviour and processes

I re-read each piece of data and recorded any reflections on it. I then reflected and wrote on each category as a whole. This was in part summary but also the beginning of theorizing on the meanings underlying the data. (Refer Appendix C for an example of this.) During this phase, I began to see patterns and inter-relationships within and between categories.

At this point, I returned to my theoretical framework of the three systems – environment, interpersonal and organisation – and was able to subsume most of these preliminary categories under these three more general headings. Culture and family seemed important categories which warranted separate mention. Hence the categories were now: Environment, Interpersonal, Organisation, Family, Culture. There was further reflection on each of these five categories and their inter-relationship by way of memos and diagrams. The diagrams were useful in framing concepts and their relationship to each other in a way which was visual and, above all, non-linear.

I then felt, having looked at the wider framework of the three systems, that I needed to return to the individual people. I therefore collected data from the research log on each of the participants (residents, staff and management) and wrote my response to the material in the form of vignettes giving my perception of each person’s experience. This was a useful tool to help clarify my thoughts on the individual experience within the wider context (Appendix D).
2.7.1.4. **Memo-making**

Analytic memos were written throughout the data collection and analysis process. While they don’t fit completely with the three types of memo identified by Charmaz (1983) – elemental, sorting and integrating – they were of different levels of reflection and analysis, becoming increasingly theoretical as the analysis became more developed. Analytic memos are cited in the text as Anmem.

2.7.1.5. **Delay of the literature review**

Around the time of working with these categories, I consulted the literature in the areas of management and culture, and referred back to earlier texts I’d read on interpersonal and environmental aspects. These helped provide a framework for understanding the dynamics of the different “systems” and their interactions with each other.

2.7.2. **Analysis of interview transcripts**

Similar to the process with the research log, interview transcripts were read, reflected on and coded. Further reflection was written up in analytic memos. Comparisons were also made between interviews and research log, that is, between what was said and what was done, what staff understood and what management thought they understood, what I observed and what others experienced.

The external interviews allowed for a form of theoretical sampling (Charmaz, 1995) in that each interviewee tended to exemplify certain aspects which had emerged from the Star of David material: Sally, demonstrating the separation of “soul” and physical work in traditional care practice; Louise, giving the overall management perspective on implementing and maintaining a program; Christina, demonstrating the difficulties of undertaking change without management and organisational support.

In summary, the methodology was ethnographic, focussing on a limited number of people at the home, viewed individually and as part of a larger
framework of the interpersonal, the environment and the organisation. Methods were participant observation and interview. Analysis was based on grounded theory which included ongoing analysis throughout the data collection and analysis phases, creation of codes and categories from the data, further focusing through the literature, external interviews, reflection and writing.
RESEARCH FINDINGS AT STAR OF DAVID

As was foreshadowed in the methodology chapter, the findings reported here have a focus on individuals and their interactions within the larger systems of environment, organisation and the interpersonal realm. I have chosen to give detailed descriptions of the individual participants, believing that this puts a face to and lends meaning to the “bigger picture” of organisational structures, interpersonal issues and the environment. Furthermore, while I do not look for answers to my research question solely in terms of individuals – indeed my search for answers has led me well beyond the individual and the institution – as a person-centred researcher, I believe it is important to remember that it is individual people who embody and “act out” these larger systems, and who also are either empowered or diminished by them.

I will first establish the context of the study, through a description of Star of David and the setting up and nature of the dementia program. I will then describe the people and the systems, with separate mention given to cultural issues. Quotations from the research log and interview transcripts will be given in italics, to differentiate from quotations from the literature.

1. THE CONTEXT OF THE STUDY: STAR OF DAVID

Star of David was an aged care facility run for and by the Jewish community and situated in a suburb settled in the immediate pre- and post-war period by predominantly Jewish migrants. It had a good reputation among the Jewish community.
The home, while it was Jewish and kosher, was by no means a homogeneous community. Most of the 70 residents had come from Europe, in particular Austria, Germany and Poland; many were Holocaust survivors who came to Australia after the war. Those who had left Europe before the war had inevitably lost family in Europe, so in a sense were also survivors. Residents spoke different languages – Yiddish, Polish, German – and were influenced not just by Jewish culture but by the cultures of the countries they came from. Among the European Jews there was a definite hierarchy depending on country of origin. There were also a few residents who had a history of two or three generations in Australia and of a quite different cultural orientation than those from Europe. There was also a wide range of religious adherence and opinion among the residents; there were religious (orthodox and liberal) and non-religious Jews. While some were very insistent on kosher practice, other residents felt at times inconvenienced by it. The home also had a rich ethnic mix of staff – Anglo-Australian, Greek, Russian, Chilean, Philippine, and Jewish of European, South African and Australian background.

There was a strong European flavour to the home. Residents enjoyed discussions and lectures on political and religious issues and art and classical music performances, which were offered in the general social and entertainment program. Also evident was the Jewish pleasure in traditional music and dance, which would see residents spontaneously get up to dance when music was played. The weekly observance of Shabbath and other Jewish rituals and festivals were an important part of life in the home.

2. THE DEMENTIA PROGRAM AT STAR OF DAVID

2.1. Reasons for setting up a separate dementia program

Following the 1997 Aged Care Act, the Board of Star of David decided to adopt an Ageing in Place policy which meant that residents, as they grew more frail, were able to remain in the home instead of being moved to
another facility. Not long after this, a new Executive Director (Jason) and new Director of Nursing (Iris) were employed and very quickly became aware of a number of difficulties in the home generally, but particularly in relation to the increasing number of frail and confused residents. In the first instance, there was the issue of physical safety. Star of David aimed for a home-like atmosphere, so it was viewed as undesirable to have locked doors. On the other hand, there were insufficient resources to adequately monitor residents, which meant there was an ever-present risk of confused residents wandering out of the home and getting lost. This was stressful for all concerned, for residents, family and staff. There was a need therefore to bring these residents together where they could be adequately supervised. Some residents also required supervision and a more tranquil environment at meal times, to ensure their nutritional needs were met. Because of the Holocaust background, emotional safety was identified as a particular issue for residents with dementia. At that time, the home mainly used agency staff with the result that staff members were constantly changing and did not know the residents well. It was also clear that the activities offered in the general social and recreational program were no longer appropriate for the residents with dementia.

The needs of the residents with dementia were therefore not being met, but nor were those of the other residents, who were becoming increasingly upset by the behaviour of the confused residents, in particular by their intrusiveness (for instance going into other people’s bedrooms and taking things to hoard). The residents with dementia risked not only verbal but also physical aggression from angry or frightened residents.

In the first place, Jason and Iris decided to employ permanent staff and to implement a special dementia program for which they hired new staff. The intent of the program was to address the overall lifestyle of the person with dementia and it was based on the ELTOS principles of Garratt and
Hamilton-Smith. It was called an activities program, although it was intended to go beyond activities.

Yael, who was involved in the program from the beginning and took over from the occupational therapist as coordinator of the program in March 1999 summed up the aims of the program in her final report:

- To improve quality of life for residents with dementia
- To provide a place where residents with dementia feel safe
- To improve self-esteem
- To promote socialisation
- To enhance and reinforce skills
- To structure the residents’ time
- To provide a safe place for fun, relaxation and silence
- To transform disease systems into purposeful activity. (Yael, 1999)

It also aimed to ease tensions between residents with and without dementia by giving them time away from each other for at least part of the day.

2.2. Establishment of the program

A centrally situated room, which had been used for art and craft, was taken over for the dementia activities program and furnished with old-style furniture to give a home-like atmosphere. Three new PCAs were employed specifically to be involved with the dementia program. Following planning meetings early in 1998 in which my supervisor and I were involved, we ran a series of three training workshops for staff. Some staff later attended external workshops. It was planned that further training would be offered in-house by the psychologist as well as ongoing supervision.

The program formally started in April 1998, in the mornings only, but with the intention of eventually running till 8p.m.. By the time I came to do my formal data collection in 1999, it was running from 9am to 6p.m. daily.
2.3. The vision and philosophy of the program

Jason, the Executive Director, saw the dementia program very much as fitting in with the overall philosophy of care at Star of David:

I think there’s a philosophy of Star of David which says that let’s take every person where they’re at and work with them, work with their strengths, look at how their lives can be as satisfying and as comfortable and as happy as it can be within their particular circumstances...it’s not just one program and everyone has to fit into it, but that we need to in fact fine tune a lot of things, everything we do to recognise that this is the home of the people who live here and therefore it’s up to us to adapt to them, not for them to adapt to us.

(Jason/4/27-5/7)

Although the dementia program was based in one room, both Jason and Iris many times expressed their view that the program should extend beyond the activities room and beyond the activity concept to encompass all aspects of the lives of the residents with dementia.

2.4. Nature of the dementia program

The program consisted of group activities in the morning, mainly games such as cards, Jewish dominoes, quoits, giant balloon, sometimes newspaper reading or cooking. Some of the residents with dementia remained in the room for lunch; others went to the general dining room. Initially the same sort of program was to run in the afternoons, but very little happened and some staff suggested it would work better if they did individual activities instead, such as hand massage, walking, manicure. However, this did not seem to happen either, and the afternoons continued to be a problem throughout the period of my research. Residents participating in the program were also encouraged to be part of the general entertainment program, for instance performances by school choirs, chamber groups and the like.
Other residents without dementia began to come into the room. Yael thought that staff perhaps encouraged people without dementia to attend because they were “easier” to work with. These residents tended then to set the agenda, and the people with dementia got lost. At a certain point, therefore, Iris and Yael realized that staff needed to re-focus the program on the residents with dementia. It was not intended to entirely exclude other residents, since management saw their involvement as positive in terms of integrating those with and without dementia in a shared activity. One or two residents without dementia continued to come.

3. THE PEOPLE

The descriptions of the people in this study are based on formal interviews, informal conversations and my observations.

3.1. The Residents and their Families

I have noted already that, with the residents with dementia, it was not possible to carry out formal interviews. In the first place, I could not schedule an interview time with a particular resident. Rather, I had to seize the moment when one or other resident was ready to talk or at least was responsive to having contact with me. I could not follow my schedule of questions – nor had I expected to – but instead followed the thought patterns of the person with dementia, sometimes attempting to channel her thoughts towards some of the issues I was trying to find out about. The interviews were therefore more like informal conversations in which the resident could only be led so far by questions, tending to talk instead about what interested her in the moment. Questions had to be framed simply. Time needed to be given and, if possible, the conversation conducted in an environment with few distractions. As an interviewer, I had to be creative in how I asked questions and how I received the answers. In the latter case it meant being able to fill in the gaps, to replace wrong words with the words I estimated were the intended words, based on my knowledge of the person, the overall context of
the sentence and the subject being discussed. Furthermore, these conversations had to encompass not just the verbal but the non-verbal realm as well. I had to listen with all of my senses. Indeed this is necessary in any interview, but more acutely so with the people with dementia for whom the non-verbal may be the main source of communication and expression. As Goldsmith (1996) observes, “the important thing is that we do not allow ourselves to become all hung up on the literal meaning of words, rather we need to look for the hidden meaning that lies behind the words” (p.56).

I made one attempt to record a resident – Eva – but found that it was not that helpful. It seemed to work better for me to write down my memories and impressions of the conversation afterwards, than to listen to the words on tape in isolation from the overall presence of the resident. The tape recorder seemed to be intrusive and distracting when working with these fleeting moments of interaction.

The following descriptions are based on the words of the residents, formal interviews and informal conversations with families, staff and management and my observations as a participant observer.

3.1.1. Joan

3.1.1.1. Joan’s story (from her son, Adam)

Joan was born in Poland in 1913 or 1914. The family thought she was born in 1914 but in recent years, Joan had corrected this to 1913. She was the daughter of a rabbi. She got married in 1939 and she and her husband came to Australia. They had two sons. Her husband was a tailor, and she helped with book-keeping in his factory and later with the selling in their ladies’ wear shop. She left the shop after her husband’s death in 1984. She started to have some health problems and had difficulty coping at home. After unsuccessful experiences with live-in carers (she deeply mistrusted them), her sons decided, in 1995, that she should move to Star of David. Initially she was very bitter about this but now seemed to have settled.
Joan’s son, Adam, described her as a very devoted mother and very family-oriented. She loved cooking for the family, loved to be needed and lived through her sons. She was ambitious for them, pushing them in their education and in “the right direction”. He mentioned several times that she was a worrier, always worrying especially about the boys. She was social; she used to go out with her husband and have friends in, but was not “aggressively social” (Adam/2/15-16). She liked to sing and would sing along to Jewish music. She had a sharp brain, a good memory and was very good in arithmetical calculation. She had lost all of her relatives during the war and was intensely bitter about it. Since that time she had had chronic headaches. Her son said that Joan had always been preoccupied with various aches and pains and had suffered from some degree of depression. Strangely, there had been a positive side to the dementia. Though Joan still referred to pains, he felt it was more out of habit rather than from any real preoccupation with them. She also seemed to have lost the bitterness she had harboured for all those years.

Nowadays she was not very communicative; her son said you had to “push and push” to pursue a conversation. There seemed nothing which motivated or excited her, except for her son’s dog and her grandchildren. At family gatherings, she took little part and no longer could sustain much interest even in looking at old photos which Adam would bring to show her.

3.1.1.2. Joan at Star of David

Joan participated in the program, though not every day and at times, depending on the PCA on duty and probably her own mood, appeared to be enjoying it. When she was not in the activities room, she was usually sitting by herself in the general lounge. She did not tend to engage with other residents and indeed could get anxious if someone came to sit near her. In the activities room, she was quite intolerant of the behaviour of other residents and made negative comments about them. At times, she also felt threatened by staff particularly Paul, although his was a fairly gentle, non-
aggressive presence. I observed her become quite antagonistic when he
joined us in conversation, and on another occasion, arrive in an agitated and
anxious state after he had helped her with personal care.

She appeared quite passive, yet she was certainly able to assert herself on
occasion, for instance when she refused to let Maria feed her. She also
showed herself quite aware of what was happening around her and had some
caucus and perceptive comments to make about staff: *That one has a big mouth*
(RL3/17/24), or commenting that the staff had not been very nice that day.

Perceptions of Joan both as a resident to be cared for and as a person differed
quite markedly among staff members. Mary found *her a pleasant lady in the sense
that she is not demanding* (Mary/1/10-11). She felt this meant that Joan missed
out on the emotional support. When Joan was not too confused, she enjoyed
conversation and she was also very appreciative of help.

>If I go in at the right time and she’s sitting down for breakfast, I offer
her, would you like me to do this, that or the other, she’s very
appreciative and she’ll say thank you very much…in the sense that
wow, this is done for me. (Mary/1/16-19)

She realised that Joan needed to be motivated to do things and that she had
fallen into the habit of having other people do things for her. Yael saw her as
“cooperative” but commented that she could get very agitated if she did not
get what she wanted straight away. Janet found it hard to get any impression
of Joan’s personality. To her, Joan seemed inflexible, demanding and joyless.
*Joan hasn’t got much joy in her* (Janet/20/8). She gave an example of Joan
having a yelling match with another resident. Maria said Joan was rude at
times and unappreciative of help.

I began to make a connection with Joan through a kind of “transitional
object”, the fish tank in the plaza, which enabled us to interact in a non-
threatening, non-intrusive way. From then on, I always made a point of
talking to Joan and bringing in the odd special thing to show her (for example, some music and some brightly coloured silk scarves). She seemed to enjoy this attention. At times, I felt quite ambivalent about this relationship as Joan seemed to want and to appreciate my attention, but once I would sit down with her, she would put in very little and, like her son, I felt I had to “push and push”. However, I saw evidence that we had indeed connected: in her warm smiles when she saw me, her attempts to catch my attention to greet me and her expressing concern about my well-being, that is moving beyond her own concerns to those of someone else. Our most satisfying conversations seemed to revolve around our common experience of motherhood, where she would nod sagely “ah, mothers”. Several times she complimented me on being a nice person. I felt this said something of our growing relationship.

I could understand why Joan appeared unattractive to staff. She could be unfriendly, intolerant and quite paranoid, and joyless even. People talking to her had to do the work of two people. How much this was because of the communication difficulties of dementia – for instance concealing gaps in comprehension or expression – and how much was a function of underlying personality is hard to ascertain. I particularly noticed when I tried to elicit her likes, talents, and interests, she would shrug them off with statements like “everyone does that”. She seemed to want to shrug off the limelight wherever possible. She also still seemed to me to be troubled by pains which made her withdraw from interaction.

On the other hand, I felt she wanted and needed the contact, the attention and the recognition, but just did not have the skills and the motivation to seek it and maintain it.

Despite the hard work, I found it satisfying to see Joan open up just a little as our relationship developed. Four or five months after I finished at Star of David, I returned for a visit and met her again. Interestingly, while not
remembering my name, Joan was very welcoming, saying she thought she had met me before.

### 3.1.1.3. *Some Hours in the Life of Joan*

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>11.20 a.m.</strong></td>
<td>Sitting at the table in the plaza, looking into space but occasionally elsewhere. Neutral mood, but withdraws a bit when a resident is brought to her table. He’s rather anxious, moaning. Janice strokes Joan’s shoulder as she approaches with the resident. She and Joan have eye contact. Janice smiles though Joan doesn’t.</td>
</tr>
<tr>
<td><strong>12.55 p.m.</strong></td>
<td>Sitting in the dementia activities room, having finished lunch. She is irritated by Anna. She says the following: (To Anna) “Don’t tell me what you like; I don’t want to know.” (To staff member) “Give her what she likes; she doesn’t know what she likes.” Staff member: “She’s ok.” then she leaves. Joan is still irritated. (To man leaving the room) “You’ve done the right thing. You left here, you went away.” (To Anna) “What do you want from me? I don’t want to go with you. She wouldn’t go with you. Stop it, stop it” (as Anna “cleans” the table) (To K, a resident whom Joan does not like) “You go out.” Anna says something. Joan: “Don’t talk to me. I don’t want to talk with you.” Anna humming, gets up and leaves.</td>
</tr>
<tr>
<td><strong>1.00 p.m.</strong></td>
<td>Sitting in chair, still in the activities room. In pain, looks uncomfortable.</td>
</tr>
<tr>
<td><strong>1.55 p.m.</strong></td>
<td>Sitting asleep. She woke as I bent down to pick up my folder. She smiles and said, “getting back to work?” She was asked to go for a manicure. She indicated to me she’d go later, but when Maria came and asked her to go, she did.</td>
</tr>
</tbody>
</table>
2.20 p.m. | At the table in the activities room, having a manicure. Seemed in good spirits.

2.45 p.m. | Still at the table, talking to me. Admired my earrings. Offered some information on herself and semi-smiled when Anna said, “she’s a nice person.”

3.1.2. Adam

Adam kept in regular contact with his mother. Although it seemed harder and harder to communicate with her, he continued to persevere, including her in family events, showing old photos, and talking to her about Poland on her good days. On the whole, Adam seemed to have a certain acceptance of the way she now was, although it would be nice to give her some medication and she comes back to the way she used to be (Adam/9/1-2).

He commented on the hopelessness of the nursing situation (with constantly changing staff) at Star of David two or three years previously, that is, before Jason became Executive Director. However, he felt that now all that could be done was being done for his mother, given the limits due to dementia. He was happy with the care, except perhaps that Joan’s physical appearance was not always as it should be, for instance her facial hair was not trimmed and her hair was sometimes messy. Joan had always taken extreme pride in being well presented so he felt that care of her appearance was important.

In terms of his involvement in care, he was occasionally called in by the home with “a cry for help” (Adam/7/9) and he would rush there and sort things out. Otherwise he did not see much role for family input.

3.1.3. Anna

3.1.3.1. Anna’s story (from her son, John)

Anna was born in 1911 and brought up in an orthodox home. She was a Holocaust survivor, having survived the Polish ghetto and later Auschwitz.
She had lost her first husband and two children and most of her family during the war. Following the war she moved around Europe and met up again with her second cousin, whom she married. They came to Melbourne where they set up a knitting factory in their backyard. They had two sons. The later years of their lives had been good for his parents, except that Anna had been sad to see her son move with his family to Israel. However, she had focussed on going for daily walks and insisted on her husband going with her. His father would probably have preferred to do more social things, such as going on a trip, but not Anna.

Anna was seen in her community as a very wise woman and was much loved by all: by the factory workers to whom she was a second mother and by the Holocaust survivors in Melbourne for whom she became a kind of counsellor. She was a hard worker in their family-run factory and a woman of great energy. She was also a devoted mother and a good cook who paid a lot of attention to healthy eating, always seeing to it that the family got fresh, wholesome food. Family life was a priority. For that reason she had not encouraged her son to become a doctor. She felt that the work took too much away from the family. While she obviously suffered from the past, she said little about it to her sons. Despite her experiences, she retained her faith in God and seemed not to hate the Germans.

Simplicity was another word John applied to his mother. She had simple wisdom, she liked simple things like walking. If people asked what she was doing on her walks, she would answer, *I am turning the pages of my life* (John/6/9).

She liked people who were interesting, she liked meaningful relationships and intelligent conversation, she liked giving advice and dispensing wisdom and was not interested in the trivial and the superficial. She was not interested in being social just for the sake of being social, (she) just liked people she was stimulated by (John/1/26-27). John believed that Anna’s ability to focus on priorities and
her strength of mind had helped her survive the war and all the tragedy she personally had suffered. She did not appreciate people who spoke to her roughly or in an angry way. She told John once that he should speak to her “through a satin handkerchief” (Meetings/8/16).

Anna had begun to show signs of dementia about 10 years ago. She came into Star of David in 1996, at the same time as her husband who had been caring for her. Because of Anna’s anxieties and fears, her son had provided a paid carer to spend individual time with her. Even now Anna seemed incredibly strong and healthy. Of course much had been lost, but her son was aware that she could still be quite perceptive. She did get very fearful and anxious but music, singing, cuddles, speaking gently especially in Yiddish, could all help.

3.1.3.2. Anna at Star of David

Anna spent most mornings in the dementia activity program. She often seemed to doze through the activity or be unable to actively participate in the more cognitive activities. At times she did participate. Indeed, she told me herself once, when the program was cancelled, that she liked the games. Janet observed that she was doing more since the program started than previously.

Anna could get into extremely agitated and fearful states which seemed to be exacerbated by all the activity and comings and goings in the room. During these times, she would moan, rub her hands and scratch herself. Her behaviour, particularly when she was agitated, would sometimes lead to conflict with others, like Joan, who got irritated by her moaning or incensed because Anna would steal food off her plate.

Yet Anna at other times showed her affectionate, warm and humorous nature. Jewish music and songs in Yiddish offered her very positive experiences and also seemed to bring out the best in her. She seemed more aware and alert when engaged in these experiences, more at ease with herself. She also retained her concern and care for other people. On one occasion,
when invited to go for lunch, she would not let go of the hand of another resident. Fortunately, the PCA – Janice – realising this was because the resident’s hands were cold, brought a woollen blanket for him. Anna was then happy to let go.

Anna could be quite perceptive and was aware of staff attempts to manipulate her. The more staff would press her to do something, the more she dug her heels in. She particularly detested being fed; I think she resented such childish treatment. Both verbally and non-verbally she would express a very strong “No”. I also had the impression that when one approached her, one better have something relevant or meaningful to say as she didn’t suffer fools gladly.

Staff appreciated Anna’s affectionate nature but generally saw Anna as one of the hardest people to provide care for. It was hard to know what caused her anxious states. Sometimes it was because of headaches, but at other times there was no obvious cause. Some staff felt intimidated when she got into these states and felt unable to soothe her. Mary, the registered nurse, observed that just being with Anna and perhaps holding her hand was often enough to make her feel secure. Mary never tried to push Anna to do anything, instead giving gentle encouragement, which elicited a much better response from her. Attempting to force Anna to do anything led inevitably to increased anxiety, agitation and aggression. Her most recent privately employed carer seemed to have a very benign effect on her, but she generally spent time with Anna outside of the dementia program. I felt that despite the fears, Anna retained a certain competence and a sense of what she needed. She might soothe herself while having the comfort of another’s presence, she might accept some more active help or she might want simply to be left alone. Despite her cognitive difficulties, there was a strength and determination within her, which one needed to go along with rather than try to deflect.

I found a very joyful connection with Anna through music, singing and dance and the sheer warmth of her presence. I could sense much of the Anna of
the past as described by her son. There was the fear and agitation, certainly, but there were also glimpses in Anna of that wise counsellor.

3.1.3.3. Some Hours in the Life of Anna

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.40 a.m.</td>
<td>In the activities room, sitting in the group. Not feeling good, agitated, breathing fast, talking. Maria insists on throwing the balloon, which hits Anna on the head.</td>
</tr>
<tr>
<td>10.10 a.m.</td>
<td>Sitting in the same place, while others are up at the table having morning tea. Seems more settled.</td>
</tr>
<tr>
<td>10.40 a.m.</td>
<td>Sitting in the same spot, sleeping, then opens her eyes. Reasonably relaxed.</td>
</tr>
<tr>
<td>11.15 a.m.</td>
<td>Sitting in a different chair, sleeping.</td>
</tr>
<tr>
<td>11.45 a.m.</td>
<td>Sitting with me in the hall observing people passing. Warm conversation between us. Anna asks about me and tells of some of her memories. Anna smiles at people passing and seems very relaxed.</td>
</tr>
<tr>
<td>12.15 p.m.</td>
<td>Having lunch in the activity room – the PCA tries to rush people. Anna’s water is whisked away despite her wanting still to drink it. Anna makes a small protest. Anna becomes serious and watchful.</td>
</tr>
</tbody>
</table>

3.1.4. John

John was a regular visitor at the home and well known to many of the residents, who had previously been patients of his or who knew him from his attendance at the home’s Saturday synagogue. As a medical man, he was well aware of the challenges of caring for people with dementia and was generally full of praise for the care at Star of David. He tended not to get involved in care issues so long as things were running smoothly. However, he was a willing and a valuable resource for staff. He attended a dementia program meeting on Anna’s care plan, telling staff something of his mother’s
background as well as giving advice on how to deal with Anna’s anxiety. He painted a very vivid picture for staff of Anna, the person.

John had much admiration for his mother – he called her “an angel” – and kept regular contact with her and his father who was also at Star of David, though not part of the dementia program. In some ways, he felt his mother now needed him less than his father did because of her lack of memory and the fact that someone else caring could equally see to her needs. He had hired a carer to spend a few hours each afternoon with his mother for about six days of the week. He had some concerns about this in terms of the integration of the carer’s work with the general care of his mother by the facility staff. There were problems getting the home staff to accept what the private carer might recommend for his mother. He also wondered how many hours to bring in a carer, thinking that if he brought in a carer for a longer period, home staff might just wait for the carer to come, and you get the feeling if you do that maybe other people will say well she doesn’t need anyone, wait till the carer comes (John/12/15-16). He felt the private carer helped his mother a lot especially when she was very frightened, but he didn’t know what happened when the carer wasn’t there. Sometimes I really don’t want to know…a bit overwhelmed and I just really can’t, I can’t really handle it for long and I know that, yes sometimes I almost don’t want to know (John/12/9-11).

In our interview, John alluded to issues of guilt, the dangers of being overwhelmed by one’s parents’ needs, and the need of families to maintain a certain balance, a certain distance perhaps, so as to be able to sustain their relationship given that that relationship might go on for years. He himself always made sure that he was well rested and in a good mood when visiting so that he could give quality time to his parents.
3.1.5. Eva

3.1.5.1. Eva’s story (from her daughter, Esther)

Eva was born in Poland in 1912 into a very religious family. She did not finish school, and started work at age 13 or 14. Around that age, she accidentally spilled a pot of hot liquid and burned her neck, on which the scars could still be seen. Both her parents and one sister were gassed at Auschwitz; she and her other sister survived. She met her husband after the war. They went to Germany, then Belgium where her daughter was born, and finally returned to Poland, a move Eva seemed to have regretted. It took them ten years to get out of Poland and come to Australia (in 1957). Eva had worked in Poland and continued working in Australia till she was almost 70. In her early 70s she helped Esther, who had fallen sick, manage her new baby. She only started to deteriorate in her late 70s when she developed Parkinson’s. Then after her husband was hospitalised for three months – a traumatic event for her – Eva really started to slow down. She first came to Star of David for respite and finally came to live there in 1996. At that stage she could still do most things for herself. There followed some health problems including a number of strokes which eventually left her completely incapacitated and totally dependent on others for every aspect of daily living.

Eva was a hard worker and a very tidy person. She was a homebody and loved cooking. She did everything for her husband but was also very dependent on him. Eva loved music and loved to dance and she would dance with friends at balls and parties as her husband did not like to dance. She liked watching TV, especially soap operas. Esther thought that perhaps her mother would have liked to do more things than she did; there was a sense of opportunities lost. When Esther’s son was young, she had invited her mother on an overseas trip with her, but her father had thought it a waste of money, and Eva had decided against accompanying her. In later years, Eva wished she had gone. She did however attend her daughter’s wedding in Israel and to everyone’s surprise, she showed great independence, going off on tours by herself, and had a wonderful time.
Eva had been considered bed-bound until, a few months prior to the dementia program, one of the registered nurses had started to bring her out of her room. The same nurse had also had Eva’s bed moved so that she could look out of the window. Once the dementia program started, staff members were encouraged to bring Eva to the activities room. However, even when she was brought– and staff still needed to be reminded to do so – I would see her sitting in her big tub chair facing the window and away from the group.

In her present state, Eva was totally incapacitated needing help with every aspect of life. Because moaning or crying seemed her only means of expression, it was often hard to know if she was in pain, or if she was trying to communicate some other feeling. It was also disturbing to residents in the group and the staff. My impression from observing staff and listening to their comments was that it was hard for them to get beyond Eva’s physical needs which of course were huge. There was such little sense of Eva, the person, when they spoke of her. Indeed her disabilities were such that it was hard to connect Eva as she was now with the hard-working and devoted mother she had been. Yet while Eva’s face was relatively expressionless, her eyes certainly indicated awareness. She might turn her head when I entered the room, she would seem to relax when stroked, she would respond to her daughter’s name and she watched with interest when the group were doing flower arranging.

Even when she first came back from hospital, the girls’d say, oh but she doesn’t know what’s happening and I’d say, don’t ever assume that, and sometimes you know damn well that she knows what’s going on. (Janet/21/20-23)

A resident like Eva seemed to raise many issues concerning total dependency such as the danger of being “forgotten”, the need for others to remember to change continence pads, to keep her clean, to be able to gauge whether she was too cold or too hot, comfortable or uncomfortable. All these decisions
needed to be made by others, and Eva was dependent on their caring and their professionalism. The physical needs were so great, it was all too easy to lose sight of the emotional and social needs. Some staff members saw their work with her purely in physical terms, therefore she represented a lot of physical work but was considered non-problematic in comparison to those with “challenging behaviours” such as Anna. Only a few saw, or allowed themselves to see, the spark of awareness and the unmet emotional and social needs.

3.1.5.3. Some Hours in the Life of Eva

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.30 a.m.</td>
<td>In her room, seemingly asleep. TV is on – Humphrey Bear.</td>
</tr>
<tr>
<td>10.25 a.m.</td>
<td>Activities Room. Sitting in the chair in the circle (she had just been brought in by Maria)</td>
</tr>
<tr>
<td>11.00 a.m.</td>
<td>Activities Room. Sitting outside of circle. Moaning. Then being P.E.G. fed by nurse. Quiet during this time.</td>
</tr>
<tr>
<td>11.45 a.m.</td>
<td>Activities Room. In her chair, sleeping.</td>
</tr>
<tr>
<td>12.45 p.m.</td>
<td>Activities Room. In her chair. Wakes when I arrive. Semi-asleep, eyes open from time to time.</td>
</tr>
<tr>
<td>2.00 p.m.</td>
<td>Activities Room. In her chair near window. Semi-asleep.</td>
</tr>
</tbody>
</table>

3.1.6. Esther

Esther was the only one of the four family members who expressed significant criticism of the care of her mother. Understandably, she was very protective and saw herself as the advocate for her mother. The staff, she believed, cared – but not really. They care more about the people that can look after themselves (Esther/8/11). On one occasion, she had found a large bruise on her mother’s forehead, which had gone undetected by nursing staff. On another occasion, she found her mother being fed when it was obvious Eva had moved her bowels and should have had her pad changed.
She had had to talk to Iris, the DON, concerning such issues and steps had been taken to deal with them. However, while she recognised that Iris took account of her concerns, she felt that other staff resented her interference. 

Maybe they don’t like me because I do kick up a stink, but I’ve got a free right to kick up a stink (Esther/10/14-15). She felt little trust in staff. I mean I’m told that she showers every day, but I don’t know, somehow I don’t know whether I believe all that (Esther/15/4-6). When Eva first had a P.E.G. inserted, Iris encouraged Esther to help feed her mother. Esther was ambivalent about it but did help some times. However, she felt some of the nurses resented her being there.

It was unfortunate that the lack of two-way communication and understanding could lead to further misunderstanding. For instance, when Eva’s bed had been moved so she could have a more interesting view, her daughter had assumed that it was for easy access for the wheelchair, that is for the convenience of the staff rather than the benefit of Eva.

Eva had been her daughter’s confidante, friend and support throughout life and Esther very much missed the close relationship they had. She found it hard to connect with Eva in her present state, and indeed had been initially reluctant to participate in this research, not believing anything could improve things for Eva. Esther found her mother’s dependency hard to deal with and this made her visits a distressing and lonely experience. While her father would come to the home with Esther and her partner, he found it hard to stay very long with Eva and would leave Esther to spend the rest of the time alone with her mother.

3.1.7. Sara

3.1.7.1. Sara’s story (from her son, Jacob)

Sara was born in Poland in 1918. She lost her whole family during the war, and met her husband immediately after the war. One son was born in Poland and one in Germany before the family moved to Australia in 1950. Sara and

4 “Percutaneous endoscopic gastrostomy”: a feeding tube inserted in the abdomen
her husband ran a hosiery business, but as her husband had a chronic illness, it fell to Sara to be the mainstay in running the business, as well as caring for her husband and bringing up her two sons, all of which she took in her stride and did without complaint.

Once they retired, she continued to look after her husband until the physical care became too great for her, and he had to go into a nursing home. He died about three years later. Sara continued to live on her own and seemed to manage. However, by her late 70s, there began some rather odd behaviour and the younger son recognised finally that this must be Alzheimer’s and wanted her assessed. However, her older son, Jacob, was reluctant to “imprison” her in a home and it was only when the situation posed a serious threat to his mother’s safety that she was assessed and came to Star of David in 1998. Apart from the initial upheaval of moving to Star of David, she seemed to have settled in well and appeared content with her life.

Sara, despite her heavy workload with the business and family caring, had always been very easy going and never stressed. She had a good sense of humour, which Jacob felt had stood her in good stead. She had coped with the care of her husband long after he should have been in an institution, and once he was admitted into a nursing home, she was able to come to terms with that as well. Generally, she seemed to have taken life in her stride and with a good dose of humour.

Work and family were her life. She had no hobbies nor outside interests. She never read. She would meet with friends for a game of cards, but she did not develop any strong relationships with people outside of the family. Now she had dementia, according to Jacob, she tended only to remember those she had a loving relationship with. She could no longer, thankfully, remember the war, nor the struggles looking after her husband. These days she only talked about nice things, happy events.
She could surprise Jacob with what she was able to remember, or what she was aware of. For instance when he brought in some “new” clothes for her (which were actually old clothes from home), she immediately recognised a favourite coat.

3.1.7.2. Sara at Star of David

Sara appeared to be universally liked by staff. Despite her confusion and expressive difficulties, staff seemed to find a warm connection with her. Janet related to her wicked sense of humour and thought her “great, really gorgeous” (Janet 21/3). Mary observed some of the difficulties of Sara’s behaviour. She noted that Sara could become quite aggressive when staff tried to shower her. She was “a Houdini with the doors” (Mary 2/20-4/5) – an escape artist – and was quite restless. Mary wondered if this was because she had always been the support to the whole family and now felt bored with nothing to do. She saw her as a very intelligent woman, who couldn’t express herself clearly, but who could be very observant. Staff had found her one day showing another resident how to open the main doors! Apart from the times when she had bad migraines, she appeared happy and content. She just flows in and out (Yael/21/10).

This was very much the way I saw Sara too. She seemed quite self-sufficient and would flow in and out of social situations according to her own wishes. On one occasion she lost her handbag which I helped her find (it was in fact in her room). Although she was certainly relieved to find it, there had been “no drama”, to quote her son. I never saw her distressed in the way Joan or Anna could be. She did simply go with the flow, and it was very much her own flow, not anyone else’s.

She had a certain elusive quality about her, and while she came across as a warm, likeable person, she seemed at the same time a little guarded and, like a
deer, ready to flee at a moment’s notice. She had determination and a mind of her own.⁵

She came when it suited her to the activity room and usually added a dash of humour to the group. She would do things as she wanted to and would not be bossed around by others in the group. Indeed she displayed wicked glee in ignoring the comments of one of the particularly bossy residents. I sometimes had the impression that she was observing what was happening and sometimes having a laugh to herself about it.

3.1.8. Jacob

Jacob had had and still had a very close relationship with his mother. It had taken him quite a while to accept that there was something significantly wrong with his mother and that they needed to have her assessed. It was only during the assessment that the extent of her dementia became clear. *It was at that time that the degree of her dementia came out and really opened my eyes* (Jacob/5/19-20). *It became obvious to me that I was looking at Mum previously through rose-coloured glasses* (Jacob/5/26-28). Once the diagnosis was given, it was a kind of relief and it “made sense of everything (that had happened previously)” (Jacob/6/10).

Apart from a slight deterioration when she first arrived at Star of David, there had been no visible deterioration and for that Jacob was grateful.

*Her condition appears to have stabilised at a level that she still has a sense of humour, that life isn’t nasty and aggressive towards her and she isn’t that way towards life, you understand, and she’s quite content or appears to be that way and seems to be a happy soul…I couldn’t be more happy you know in that regard.* (Jacob/8/10-16)

Overall he seemed quite happy with the care. Staff appeared attentive. He was aware that there were activities at the home, but had been unaware that

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⁵ It is in large part because of this elusive quality and her frequent absences from the program, that I was unable to complete a day record for her.
there was a special dementia program. He had no idea what his mother participated in, if anything, and what activity was beneficial. Basically he judged the care from the way his mother appeared, which was well fed, healthy and in good spirits. He did think it would be helpful to receive feedback occasionally on his mother’s condition and the kinds of medication she was taking.

He had some concern about security at the home; his mother had managed to “escape” on a couple of occasions. On the other hand, he was pleased that Star of David was not institution-like. It was more of a home for his mother and also more family friendly. He liked the fact that the family were free to visit at any time. *In essence, what that gives us I guess is a feeling that she really is staying in her own place and it is no different to when we used to drop in on a casual basis and visit her at home* (Jacob/16/3-6). This he felt was particularly important for the grandchildren.

They would never have coped with having to go through barbed wire and locked gates and all the rest of it. They would have been extremely upset, you know, that their grandmother is literally locked up like that. So this has been a big factor in keeping the family quite happy with Mum there. (Jacob/17/1-6)

3.2. **Staff and Management**

The descriptions of staff are based on interviews, informal conversations and my observations of staff carrying out their work within the dementia program. The role of management I considered to be the Executive Director (Jason) and the Director of Nursing (Iris), although the latter had more input in the day-to-day practical running of the home.

3.2.1. **Yael**

Yael was a young woman who had completed a science degree and graduate diploma in psychology and was doing her supervised practice at Star of
David. This involved working in an unpaid capacity with residents and with families. She had been at the home for about 18 months when I first met her and worked there for about 3 years in total before she finally left.

She was involved from the start in the planning meetings for the dementia program and after the program had been running for a few months, she took over the role of coordinator from the occupational therapist. Her duties were to oversee the running of the program, chair the program staff’s fortnightly meetings and offer supervision and training to the staff in the dementia program. For this task she had about six to eight hours allocated per week.

Yael was very attuned to a person-centred approach.

Ideally it would be great if people would look at people and no matter what their problem was, they would be looked at as a person and not so and so, and not the dementias and not things like that. I get really angry when I hear “the dementia people” – it is the people who have dementia….It’s often forgotten that they are actually people with a history and a life”. (Yael/23/7-14)

Management seemed to put a lot of trust in her and have high expectations that she would be able to pull the program together. I seemed to always hear “Yael will do that” and “we need to wait till Yael comes back and she’ll organise that”. Indeed their expectations were justified as Yael worked very hard to make the program succeed. She was committed to encouraging positive attitudes in the staff through training and supporting them through supervision. She bore a heavy responsibility but did not always have the support from management. While they in theory encouraged and supported her, in practice this was not always so. She was left to deal with the difficult tasks and if things didn’t work out, well then they would say you see I’ve told you how difficult it is (Yael/13/14-15).
At times, management would undermine her efforts by citing higher priorities. This was particularly evident in the dementia training Yael had set up for staff and the fortnightly dementia program meetings. Ideally she had wanted to have several staff in each training group in order to be able to have a more experiential training program and to begin a process of peer support. However, it was often very difficult to get more than one or two participants at a time. Staff would be needed for other work and Yael felt at a loss to stand up for the program’s importance when faced with conflicting – and presumably more important – medical or physical priorities.

A major difficulty, which she herself cited in her final report to management, was that while she had all the responsibility, she had been given no authority over the PCAs who worked in the program. She tried many and varied strategies to implement better practice, going out of her way, I felt, to make it as easy as possible for staff to accommodate her suggestions. She tried in vain to encourage staff to document their afternoon activities, and indeed to do any activities at all in the afternoon. She went so far as to make a list of very simple activities (for example, walking, hand massage) which could be done on a one-to-one basis with each person. Yet those staff who were disinclined to do anything continued to ignore her suggestions.

Yael was a gentle, compassionate person, with all the optimism of youth. Unfortunately, she was unprepared for the reality of the working environment with conflicting interests and values at play and with staff from differing personal and professional backgrounds who did not all place value on communication and open sharing of ideas and feelings.

Over time it seemed to me that she began to feel disillusioned, and some of this is evident in her interview which was given about four months before she left. I felt that she began gradually to distance herself, to start thinking about moving on, although she continued to give valuable input to the program till the end. In her last few months at Star of David, she reduced her hours in
order to undertake another clinical placement outside of aged care. At the end of the year, having completed sufficient hours for her psychology registration, she left.

3.2.2. Iris

Iris was the Director of Nursing and had about 25 years of nursing experience, 15 of which were in aged care, although not specifically in dementia. She had come to Star of David just three months after Jason, the Executive Director, had been employed. Together they instituted a wide-ranging program of change which included implementing an Ageing-in Place policy. From staff and family comments I gathered that much had improved since Jason and Iris had been at the home.

Iris seemed to have a common sense, practical approach to nursing. She was respectful in her contact with residents, responding readily when asked for help by residents or family. She could add nice little personal touches to the home, such as going out to buy kosher cakes for residents to have after a walk, or organising an afternoon tea for all the staff on their return from a study visit to another aged care facility. Over sharing of this afternoon tea, staff members were able to talk and reflect together on the experience and I felt she had made a truly “nourishing” gesture towards them.

Iris had enthusiastically received the ideas related to person-centred dementia care, which were new to her, and was very keen for the dementia program to be implemented. She believed that the program should not be limited to the room nor to activities and that staff could take the program out to those residents who did not come to the activities room.

On the whole, Iris felt positive about the running of the program and there was, on her part, a great deal of good will and good intention toward it. She was aware of some of its limitations and difficulties, but did not always seem to follow up on these effectively. I could understand how Yael felt that there was avowed support but not necessarily support in practice. Some of the lack
of follow up may well have been due to the fact that Iris was always busy, always under pressure, responding to a thousand different demands. Issues such as where to place the care plans so they could be used were left hanging in the air. Communications were often made through memo, but not necessarily followed up.

Iris saw her role in relation to the dementia program as providing a sounding board and support. However, her time was limited given her responsibilities for the home as a whole and essentially she believed that the running of the program had to be left to Yael.

3.2.3. Janet
Janet was the registered nurse in charge on weekdays. She had begun her training in 1970 but this was interrupted by marriage. She spent 14 years at home bringing up a family. In the late 1980s she returned to nursing, working initially as an enrolled nurse in the psychiatric area. She then decided to go to university to complete her nursing qualifications and, after completing a graduate year at Fairfield, remained there working in the palliative care AIDS Unit. When this closed down, she decided to do agency work. This was how she stumbled upon Star of David, liked it and decided to stay. She arrived at Star of David around the same time as Jason and Iris and since then had seen a lot of change in how the home was run.

She was very open about the difficulties at the Star of David, such as the large number of residents (70) and the difficulties of staff communication and of documentation. She was amazed at the intolerance of residents, given their past history, and at how demanding they were. *Yet I love them all to death and they’re what keeps me here in spite of the fact that this must be the most stressful place to work* (Janet/15/25-27). Families too, were exceedingly demanding and she felt at times that there was no recognition of nor respect for the fact that she was a professional. They would nit pick about trivialities when she felt she was doing her best to take care of the health of their relative.
Janet saw her role in relation to the dementia program as being simply to assign staff to run the program. Otherwise, her focus was on her duties as charge nurse. She recognised the value of the dementia program and of treating people as individuals; indeed in her ideal care setting, she said the home would follow the individual’s not the institution’s routine. She saw the need to integrate what happened to residents in the dementia program with their treatment outside of the program, something which was not yet happening.

Janet presented a somewhat jokey and cynical persona, aware of much that was not working (lazy staff, lack of communication), admitting it wasn’t good, but in a curious way distancing herself. She appeared to accept somewhat philosophically that these things have always been and will be ever more, with possibly some hope that improvements might happen over time. Perhaps this was a result of her experience in nursing, perhaps her way of surviving. While she expressed a hope for improvement, it was hard to see that she would necessarily actively promote change. Her view seemed to be one of a somewhat ironic acceptance that the more things change, the more they stay the same.

3.2.4. Mary

Mary was the registered nurse in charge on the weekend shifts. She trained at the Queen Victoria Hospital in the 1970s and nursed in general hospitals till she decided to leave the public service after twenty years, tiring of too much responsibility with too little back up. She took on agency work for a while, and this finally brought her to Star of David where she found she enjoyed geriatric nursing and decided to stay. *I’ve been enjoying it because I get a lot of satisfaction from the way I get treated from the residents here, so I just find it quite rewarding. It’s the only reason I’m still here* (Mary/6/20-22). She felt the residents could be very considerate towards her, and if she was very busy, they would leave her alone so she could finish her tasks.
Mary saw her role in relation to the dementia program as a resource person and as back up to assist, if no one else was around, with any physical tasks such as assisting residents to the toilet. *I see myself as a resource person where they (staff) can go if they’re stuck or if they need help* (Mary/10/17-19). She described herself as a hands-on person and appeared to have more practical, hands-on knowledge of the program than either Iris or Janet. Mary had spent some time in the dementia activities room working with the residents and realized just how challenging the work was. She offered advice and support to the PCAs, for instance encouraging them not to feel pressured to push residents to start the group “on time”. Where necessary she would intervene when she felt staff members were behaving inappropriately, for instance when a PCA’s efforts to get Anna to do something were clearly upsetting her and inflaming the situation.

*When Anna is agitated – last weekend I had to intervene and say, leave her, you are agitating her more and making her red in the face by your presence and by you trying to make her do what you want. I say leave her and I will come to her in half an hour. So that is an understanding some people (staff) do not have, that they (residents) need that space because they feel threatened so they need you to leave so that they recover and they’re all back to normal, and back to what they were and then you start again because they’ve forgotten what they’ve done before.* (Mary/18/1-9)

Of the senior staff, she was the one most critical of the program, believing that the program’s only real achievement had been in the area of physical care, for instance in ensuring the nutritional needs of residents through supervision of and assistance with meals. She believed that lack of understanding of dementia, due to lack of training, was the core of the difficulties, though there were other issues such as individual staff attitudes and lack of resources. Her ideal for those with dementia was to have a one-to-one relationship,
where you know the person so well, you almost become...a part of them so that they feel secure because somebody’s there all the time that they know, they’re familiar with, who attends to their needs, knows what their likes and dislikes are, knows what their routine is and they become soulmates in that sense. So that is my ideal – of course it won’t happen. (Mary/16/29-17/5)

3.2.5. Jason

Jason, the Executive Director, was a friendly, warm and enthusiastic person. He had been employed in 1997 during a turbulent time at the home, and had brought about considerable and positive changes, in particular the employment of permanent staff rather than the use of casual staff and the setting up of the dementia program. He invited my supervisor and me to run the initial staff training sessions and also attended them. Later, he accompanied staff on a visit to the dementia unit of another aged care facility. He clearly was committed to offering good care, which he felt involved amongst other things, creating a home environment and treating people as individuals. Of course the dementia program was only a small part of his overall role in the organisation and among his tasks was the planning of major building works at Star of David. He was a busy man.

He saw himself as a support to the people doing the work, as a sounding board and also as the person who could develop appropriate policies which would help put ideas into action. While the Director of Nursing (Iris) was more directly responsible for the day to day workings of the program, he probably felt the need for more involvement than was related to his role, because of his experience in aged care and human services. So I suppose I like to keep involved and I like to encourage the development of innovations that are going to enhance the program and better meet the needs of people. I suppose that’s what I’d like to do anyhow (Jason/6/1-4). He was a very optimistic person and while he was not unaware of the shortcomings of the program or the staff, he basically felt good things were happening and that through a process of trial and error a
successful program would be developed. I am sure this optimism and energy helped him to achieve as many changes as he had. However, sometimes I found it hard to reconcile the optimism with many aspects of the program that I observed.

3.2.6. Janice

Janice was a Personal Care Attendant (PCA) who had been employed specifically to work in the dementia program when it first started. She was married with four children. Prior to marriage, she had worked in a bank but left to have children, only returning to part-time work when her first child went to school. Family remained her prime focus with work fitting in with her family commitments. For ten years she had been involved in aged care and family day care. She had also done some volunteer work at a centre for people with intellectual disabilities. Finally she went to TAFE to do a course on personal care. She applied for a PCA position at Star of David and I got it and it was easier to take than keep trying for anything else. So that’s where I am (Janice/2/5-7). Janice liked her work, though she commented she certainly did not like pay day.

Janice saw that her role was to motivate, to encourage and to make the life of the residents a little more enjoyable. She felt it was necessary to tune in to the resident, to listen to and focus on what he or she might like. This of course required sensitivity, patience and an ability to work from the moment, qualities she felt some of the other staff lacked.

She was a hard worker with a very acute sense of personal responsibility. To me she appeared the epitome of the mother who does everything for everyone. She was not always very assertive, sometimes just hinting at difficulties, and probably functioned best in a cooperative setting where staff worked more as a team. She had developed a kind of team approach with one of the other PCAs who had been employed at the same time as her, but the latter had subsequently gone on maternity leave. In working with others, not
all of whom shared her hard-working approach, she risked, I felt, being overwhelmed with the work and in time suffering burn-out.

From my observations, Janice’s groups were quite warm and relaxed affairs. She had the ability, as a mother herself of four children, to relate to each of the residents as an individual and to include everyone in the group. She was encouraging and positive and tried to understand the meaning behind behaviour so she could work with rather than across the residents’ wishes. She seemed very conscious of the preferences of residents. One resident, for instance, thoroughly disliked the dependency implied by riding in a wheelchair and therefore Janice tried to walk with her instead; Anna liked to eat food in her own time, and Janice gave her that time. Although she could have benefited from more training, for example, in group skills, her ability to relate to residents as people meant that she was able to give residents a positive experience in her groups.

3.2.7. Maria

Maria had come to Australia from the Soviet Union 10 years previously. She was Jewish but had not been brought up in Jewish religious practices because this was forbidden by the government. She had worked as an accountant in her own country but when she came to Australia found it too hard, because of the language and her age, to take up her old profession. Instead, she took up a variety of jobs – kitchenhand, housekeeper in a hotel – eventually coming to Star of David, first as a cleaner and then as a PCA. She had, in the last few months, finished a PCA training course. When the dementia program started, it was originally only the newly employed PCAs who were to work in the dementia activities room. Maria felt this was unfair and asked to be able to work in there as well. Despite doubts about her suitability, she was allowed to do so and she now was one of the regular staff working in the dementia program.
Maria could understand Yiddish, as she had been brought up in a Jewish area and had heard the language around her. She could also understand a little Polish. She felt that the fact that she was Jewish meant she could understand the residents better than those of non-Jewish background. Her father had been a Holocaust survivor, as were many of the residents, so I know what happened with them during the war, I know the culture...so I know what they feel, I know what they want, so and I like to work with them (Maria/2/9-11).

She thought of the residents with dementia as being “not well” (Maria/3/8). They did not know what they were doing and therefore needed help. The aim of the dementia program was to involve the residents in activity to “forget about their sickness” (Maria/3/5-6). She felt happy in her work when she made the residents happy. However, she felt unhappy when residents did not appreciate what she did and tended to take it as a personal slight.

Maria was a very strong personality and she could be lively and outgoing, singing and dancing (she had a good voice and knew yiddish songs) when she was in the mood and when residents responded as she wanted. She could be kind and loving. However, she could also be quite sullen and unfriendly with those who were not in her favour.

I don’t like one resident. I don’t know. I don’t know, she didn’t do anything for me, but she always complain ... She don’t like me, so what can I do....but when I come into her, you know, I’m not so happy that I should go to her. I don’t know why. I don’t like her, you know, and you know maybe she feel that because I am coming to her. I never smile because I don’t want it, you know, I don’t want it. Maybe she feel it. She can see my face. Her brain is not working well but she can feel – maybe it’s coming something. I don’t know what it’s coming from me. (Maria/19/5-14)

She was aware of and had opinions about many of the issues concerning the dementia program (for example, lack of staff, difficulties with residents in the
group functioning at different levels) but essentially she seemed to me to have a fairly superficial idea of dementia and the needs of people with dementia, nor did she have experience or training in activities or group process.

Management and senior staff had all had doubts about Maria’s working in the dementia program and this was echoed in comments made to me by some of the PCAs, who felt that Maria did very little. Jason, Iris and Janet commented that over time they saw improvement in Maria’s work in the program. Jason said that Maria was smiling more. Maria herself said that she loved her work in the dementia program and would not want to leave it. For me as a participant in her groups, I observed that she firmly controlled everything leaving no room for any spontaneity but her own. In my notes, I likened her to an iron corset; it is meant to support but can also stifle and confine.

3.2.8. Paul

Paul worked part-time at Star of David and had a part-time PCA position at another aged care facility. He was originally from the Philippines. After graduation, he entered a religious order, where he spent ten years, during which time he studied philosophy, theology and other related topics. His first experience of aged care was when he came to Sydney, while still a seminarian, to work with Italian migrants. After leaving his religious order, he worked as a carer at a Jewish home and then a Uniting Church home. In 1997, he went to Europe for six months and returned to work in Melbourne. He stopped this work to do the PCA course and was eventually employed by Star of David. He was about to enrol in a Clinical Pastoral Education course which, he explained, placed emphasis on the need to understand the individual and the need to understand oneself. Whereas his work as a PCA was essentially practical in nature, Paul seemed more of an intellectual kind of person, reflective, a philosopher. He admitted that while he might know the theory, the challenge for him was to put theory into practice.
He had started to do the activities for the dementia program only recently and was still feeling his way. *I remember the first time I was just told, oh you’re in the dementia activity program and I said, what is that* (Paul/20/3-4). He knew nothing of the program nor had he led activities before. He felt ongoing training was vital, was attending Yael’s training program and had been to an external seminar on activities in dementia. Because of his work hours (7a.m. to 1.30 p.m.), he had been unable to attend many of the staff meetings which were held at 3.00 p.m.

He enjoyed the work as a PCA and enjoyed the wisdom of the old. In terms of those residents with dementia, he saw that they had lost control of themselves and that personal care involved thinking for them. He admired that so many of them submitted joyfully and serenely to staff leading them to do this or that.

Paul’s religious background had given him a focus on the interpersonal and on understanding and valuing other people. This applied to other staff as well as to the residents and he very much believed that teamwork was essential in this sort of context. He was acutely aware of cultural issues, particularly the effects of the Holocaust and believed one needed to understand the cultural aspects as part of an overall understanding of the person. In this way, staff could help make that person’s life as meaningful as possible in the person’s own cultural and personal terms. At the same time, he felt that those activities he did do at Star of David – and he had some doubts about the cultural appropriateness of them – were not ends in themselves but rather a means to facilitate positive interactions and validate the individual. Essentially, he saw himself as a facilitator, juggling the different levels of functioning, the residents’ differing interests and the relationships within the group. In order to do this, the facilitator had to be very flexible and ready to change at any moment.
Paul seemed to me a very friendly person and quite open about the difficulties of the job and his own doubts and questions. He admitted he felt more comfortable in the verbal domain and that he did not see himself as the kind of person who could energise a group; rather his skills lay in the one to one relationship.

In his ideal world, Paul would have liked a program focused not so much in terms of activity as in terms of a space where people could be themselves without judgment,

whereby they could be in a different place, in a different time, where residents could freely express their being, their individuality, without being harassed, without being judged by people, or being rejected, just in that a private space where they can be themselves and spontaneously express themselves with the support of the staff. (Paul/26/2-6)

This interview was in early September. Over the months that followed, I felt that I saw some subtle changes in Paul’s attitudes. Paul worries me a bit these days as he tends to laugh at rather than with residents. He’s nice to them in a way, but to me, he seems to stand apart from them (RL3/29/7-9). When I returned in March the next year to give my report to the staff, Paul spoke briefly to me about his work and I had a sense that he had perhaps made compromises in his ideals for the program. He also mentioned that he planned to move out of aged care.

3.2.9. Paula

Paula had initially worked in the office of a nursing home before taking on the role of PCA. She had come to work at Star of David through an agency and had stayed on. She had been there for four or five years and was presently doing her nursing (level 2) training.

Overall she had positive attitudes to older people, which she saw as part of her cultural background (Greek Australian). She said she had benefited from the advice of residents many times and felt that she had changed a lot because
of working with the older people. At the same time, she was conscious of keeping a certain distance, because \textit{as you know the people here that leave only leave when they die. And you know that eventually you're going to lose them} (Paula/7/14-15). She found that people with dementia were easier to look after than some of the other residents, less demanding in many ways. However, the residents with dementia did need constant reassurance and they could become quite physical and aggressive.

Paula had opted not to work in the dementia program. She had done relief work in the program and was clear that her skills did not lie in that direction but rather in nursing, which she interpreted as physical care and assisting with activities of daily living. Unlike some staff, she appreciated the difficulties of the work in the program. She had much admiration for the staff who worked in the room, but believed they needed much more training. Having seen activity programs in other institutions, she felt the program at Star of David left a lot to be desired in terms of variety of activity. However, overall, she saw the positives of the program both for residents and for the staff working in the other parts of the home (who were able to get on with their work without needing constantly to keep an eye on the residents with dementia).

While not unaware of emotional issues, Paula very much placed her work as PCA and nurse in training within the physical realm, work which she carried out, however, with an awareness of the respect and care owed to an elderly person.

These then were the individuals who were part of the dementia program and participants in this research study. As culture was a significant factor in the context of Star of David, I will discuss it below before going on to address the three systems.
4. THE CULTURAL CONTEXT

4.1. The Role of Culture at Star of David

Jewish culture and religion formed a large part of the everyday life in the home through food observances, the weekly rituals around Shabbath and the observance of religious festivals such as Passover. The experience of the Holocaust was very much present within the memory of all the residents at Star of David and indeed even in their bodies, some still carrying their concentration camp number.

Yael, herself Jewish of South African background, remarked:

"I think culture plays a huge part. I think because of the circumstances of a lot of the residents having survived the war and coming to live here. The Jewish culture is very close, very networked and not many people have socialised or been friends of non-Jewish people. All they’ve known is their little world around them. They’re very sheltered, and I think perhaps sometimes they would feel more comfortable with a Jewish person just because they use Jewish words and they feel that Jewish people understand their war experiences."

(Yael/16/14-21)

Residents had a strong survival instinct, not surprising given their past.

"The fact of survival, that these people have beaten all odds of death and they survived, that they’re not prepared to give it up now and they are fighting right up until the end. Some of the nurses don’t understand, like why can’t they just die, why do the children want to keep them alive. And I think the experience the Jewish people have had with death is so horrific that it’s just the worst – anything but death, you know….And they’re just getting closer to it and I think they’re really frightened. A lot of people don’t understand that."

(Yael/18/23-19/3)
Both Janet and Iris commented on a lack of tolerance among the residents, for example vis-à-vis residents with dementia.

For people who have endured – I mean I suppose they learnt to be – they are very ego-centric, they really are, and I don’t know whether it comes because they had to do that to survive…They’re exceedingly demanding, they are…it’s just amazing. Yet I love them all to death and they’re what keeps me here. (Janet/15/20-26)

They could also be exceedingly demanding of their families. Yael suggested that perhaps parents were more demanding because they themselves had never been in the same position (having lost their parents in the war) and had therefore no idea of just how much they were expecting of their children. Adult children felt extreme responsibility for their parents and felt that the parents had suffered so much in the past, they should want for nothing in the present. Guilt was one aspect which some staff talked of:

I know a lot of children felt they had to make their parents happy because whenever they (the children) are sad, it’s like “what are you sad about, I lost my whole family”. Like they felt bad for feeling sad…like they had no right to after what their parents had been through. (Yael/18/16-22)

This extreme sense of responsibility and protectiveness towards parents sometimes caused tension between family members and staff.
They want to do everything for their parents, they want to make sure that the medication is right, and they want to make sure that they’re looked after and not left, that they’re not lonely and I don’t think the nurses are used to that…I think they feel like they’re being watched all the time and they’re not trusted. And if they come and the children have something to say, they take it very personally and feel very criticised. So there are lots of issues which I think come back to the involvement of children with their parents, that is very Jewish.

(Yael/18/2-14)

At times staff members at Star of David felt that their professionalism was not sufficiently respected and that they were under scrutiny by families. *I am a professional and I really hate being treated like I’m not* (Janet/17/12-13).

Mary tended to attach less importance to cultural aspects. She felt that guilt perhaps came in when things went wrong and families tended to overreact with the staff bearing the brunt of that. On the other hand, she felt that guilt to some degree or other was common in all families who put a parent or spouse in care.

4.2. Cultural aspects of the residents’ experience of dementia

For those residents who developed dementia, their past often returned to haunt them. Some residents with dementia re-experienced the fears and torment of the war years. They might start stealing and hoarding food or exhibit, like Anna, feelings of agitation, fear and anxiety. Paul, the PCA, noted the weight of the Holocaust experience on residents:
S, he is a confused man but there is always the element of the experience of murder…even Joan, in this confusion comes in the morning…the first time she would say “you come here to murder”. Words like murder, violence, comes out. I do understand that with the previous, the Holocaust experience, it still places a very strong mark and I think …no matter what intervention or what diversion we would be doing, this would always be coming out, and certainly this is always incorporated in the confusion, in their way of doing things, so that’s the thing, being Jewish and Holocaust survivors. (Paul/9/27-10/7)

Whereas for many people with dementia memory offers reassurance, an affirmation of self and a haven from the uncertainties of the present, for Holocaust survivors with dementia reminiscence was problematic. I remember feeling some ambivalence asking residents about their past.

While talking to him, I was aware of a hesitancy on my part to arouse memories, many of which were certain to be painful – yet everyone has some painful memories. Maybe it’s just that memories such as those of the Jews are of such extremity that one is unsure it is good to let people cry or feel the sadness. (Reconn/27/24-28/5)

In turning the pages of one’s life (to paraphrase Anna), one might only rediscover the horrors of the past.

On the other hand, some of the relatives pointed out that their father or mother no longer remembered the Holocaust, no longer remembered they had lost parents, husbands, wives, children. Their memory reverted rather to an earlier, happier time. In Joan, the positive and negative effects of the Holocaust appeared. She no longer had the bitterness and specific memory of family she had lost, but had feelings of fear and paranoia.
4.3. Cultural differences among staff

There was considerable cultural variety among staff: Anglo-Australian, Greek Australian, Chinese, Philippine, Chilean, Russian. Even among the Jewish staff, there was a variety of national backgrounds. There were divisions among the staff along ethnic lines, for instance the Russian staff (the “old” staff) tended to communicate with each other but not with the others. Maria tended to talk to and work with the other Russians, Janice with the other non-Russian staff. Neither side seemed particularly to approve of the other. Maria, who was herself Jewish, felt there should only be Jewish staff because they understood residents. Janice felt that some of the “ethnic” staff were too loud and not gentle enough.

With residents with dementia returning to earlier languages of German, Polish or Yiddish, it was useful to have staff who could speak their language. Yael felt the language was important, perhaps even more so than being Jewish.

> A lot of them speak their language from home and especially as the dementia develops, they go back to their language and so I think it is really important to have people who can speak their language, whether they are Jewish or not Jewish, but often the culture of the country that they’re born in is similar. It may not be Jewish but they are similar.
> (Yael/16/24-29)

Not only were the Yiddish speaking staff more able to understand but by the very fact of speaking a familiar “home” language, they might also be able to calm the resident or make the resident feel more secure. Staff who were Jewish also had some insight into the cultural/religious customs. Being Jewish and having the language skills was no doubt then an advantage for staff. On the other hand, not talking the language or coming from the Jewish culture might be an advantage too. One non-Jewish member of staff pointed out how she used her non-Jewishness to the advantage of residents by enabling them to be her teacher, to be the one in control. A non-Greek
volunteer at a Greek specific hostel I visited along with Star of David staff echoed this sentiment. In teaching her, the residents felt empowered.

Of all the staff, Mary, the senior registered nurse and of Chinese origin herself, put least emphasis on cultural aspects.

I don’t put my cultural beliefs into my profession because I’m nursing a different culture altogether, so that doesn’t clash with me because that is put aside because I am looking after them. I just find that’s my professional standard. (Mary/15/14-17)

5. THE THREE SYSTEMS

In this section I will look at the three systems of Environment, Organisation and Interpersonal identified in Chapter 3 and the experience of the individuals in interaction with them. The discussion is based on the categories identified within the research data.

5.1. Environment

For clarity’s sake, I have divided this discussion under the headings of physical, emotional and social environments. These aspects however clearly interacted with and affected each other.

5.1.1. Physical Environment

The dementia activities room was centrally placed in the home with three entry/exit doors at different sides of the room, one exit leading out into a small courtyard garden. The room was divided into a lunch area and a sitting and activity area. It was intended to
remind them of a home-like environment where there are those spaces and depending on what the activity is, they can be in one space or the other” (Jason/16/3-5). He recognised however that “it’s still not really that way. Hopefully with our new funding, we can also make modifications to that space and to the furniture that we have there to make it more appropriate for them. (Jason/15/28-16/1)

Star of David was also in the process of looking at a substantial re-building plan at this time. This included a separate area for people with dementia, but which Jason hoped would be much more home-like than what was offered at present. Here they could have their special needs for supervision and support met within a home-like environment.

Hopefully it would be a much more...very much a home-like environment, hopefully where people would be able to have a kitchen where they can cook themselves obviously under supervision and where they would feel very comfortable and secure in that setting and would still have opportunities for participating in other activities in the home. (Jason/15/12-17)

The current room was not very large, especially as the number of residents attending increased, and it could feel quite cluttered. Maria pointed out that they needed a bigger room, not only because of the number of residents now attending the program but also the people with the wheelchairs, people with frames, when they are coming, they (are) squashed (Maria/10/15-17).

The space was used for multiple functions – storage of equipment, podiatry, medical interventions – as well as serving as an activity and lunch space for the people with dementia.

There seemed little sense of the integrity of the space. It was very much a public space through which staff, other than the dementia room staff and residents, felt free to move. It was often quite noisy: talking, music, TV, or
simply people moving equipment in and out of the room. In the course of a morning, there could be several interruptions. The PCA on duty might have to leave to take someone to the toilet or other staff would come in to get something from the room, to give medication to one of the residents, or to ask the PCA on duty a question or have a chat. *I was aware of to-ing and fro-ing and interruptions, voices heard across the room – which at times seemed to distract staff. It certainly did me* (RL/1/10-12).

I have pointed out the difficulties of the open-ness of the space, but its accessibility also had benefits.

*I suppose in particular because of that, that the supported activity room was not a closed room and it meant that obviously residents who were in there were able to move in and out, but it meant that a lot of residents who normally we wouldn’t have thought of as that room being for them were able to come in and they actually felt quite comfortable in there and there wasn’t the same sort of stigma that I think might have been in other circumstances.* (Jason/3/13-20).

The dementia activities room had been set up with the dual purpose of offering a safe place to *be* and a place to *do* things. These at times were functions at odds with each other, since those residents who needed a haven did not always want activity. Yet activity was the dominant function of the room and overall people in the room were expected to *do*, to participate in the activities offered.

### 5.1.2. Emotional: A “Secure and Stable Environment”

One of the main aims in establishing the dementia program was to *create a place for residents with dementia where they would feel safe and free to do what they wanted in a supervised, secure and stable environment* (in-house document, Yael, 15th March 1999).
Yet in the dementia activities room, the environment was often distracting, fragmenting and, for residents like Anna and Joan, quite threatening. During this period, various PCAs seemed to come in and out and this obviously disturbed her (Anna). She was very aware of them and asked me “what these people want” (RL2/7/29-8/3). When Anna was in one of her agitated states, efforts to calm her were often sabotaged by the sheer noisiness and distraction of the environment. My presence, stroking her and speaking quietly did not have much effect, but I think she (Anna) was all too aware of the noise of comings and goings in the background (RL2/8/6-9). The person who might have held things together despite the environment, that is the PCA on duty, was often running in and out of the space herself or was distracted by questions and comments from other staff who passed through. The absence for quite prolonged periods of the PCA on duty was also problematic from a safety point of view. On one occasion, it was fortunate I was present when a resident tried to get up to go to the toilet herself, when she in fact needed assistance to get there, being unsteady on her feet.

These interruptions also created fragmentation of the experience, lack of focus and involvement. Paul in particular emphasised the need to respect the integrity of the program time and space. He believed people should not interrupt during the activity,

   because the time is as important as any other activity, so unless we believe on the importance or I would say the sanctity or the religiousness of the activity, or otherwise it would just be, oh it's just activity and she just comes in. (Paul/24/29-25/3)

When the leader of the program was distracted, so were the residents. If we want a meaningful program, the space, the place is very important (Paul/25/13-14).

There was also the issue of ownership of the space, feeling that this is one’s safe spot where one has some control over what happens. As a public space, it was difficult sometimes to accommodate the needs of all the residents who,
by virtue of their dementia, were brought to the room. *Talking of one of residents – issue of his impatience with others disturbing him – Maria said she had told him, when he had told one of the other residents off, that this was public space for all* (RL1/2/9-11).

Staff activity seemed to form the function of the room. When the PCA on duty had disappeared for quite a long time, I noted: *Since I’m not quite a staff member, I felt a bit lost myself and unsure whether to try and get things ready…or whether to just wait* (RL2/7/21-24). I felt that it was someone else’s space and that I needed to wait for the person in charge. Perhaps this was also how the residents felt. It seemed like the staff were full of activity and purpose, and the rest of us were sitting on the edges.

Paula noted positive aspects of this space:

> Whereas before I found like a lot of the residents with dementia, they were outside in the plaza, were being judged and I believe they feel it, we feel things, and I believe they felt it. Whereas in the dementia activities program, they’re safe, they’re not going to be judged, no one’s going to laugh at them, no one’s going to make fun of them. (Paula/9/7-12)

She also pointed out the security aspect of the room. *It keeps them safe and you’ve got people watching them constantly. We’ve also got our wanderers and keeping them occupied takes the pressure off the other staff as well* (Paula/11/20-24).

**5.1.3. Social**

Although the focus of the room was to offer a safe space and activities for residents with dementia, it also served the function of removing those residents from the general space of the home. Jason felt this had alleviated the tensions between residents with and without dementia. By giving the residents with dementia their own space, and thereby offering the other residents space without those residents, he felt that anxiety about the residents with dementia had decreased.
Many of the residents without dementia still would prefer not to be confronted by it every day, all day, but I think that the fact that those resident are not constantly involved with each other, and I think that …makes them feel much more comfortable. (Jason/3/25-29)

Within the room itself, however, there was little opportunity to “escape” others. The room had only one small divide and this was not enough to allow individuals time away from the group when needed. Personality differences, loss of social skills and behavioural problems meant that relationships could at times be stormy. The PCAs pointed out that they often felt like referees trying to stop conflicts between residents, for example, they needed to ensure that seating arrangement for lunch were such that people who annoyed each other sat as far away from each other as possible. When a resident was brought in to sit at the lunch table, Janice made sure she kept the chair free at the other end of the table. Seating arrangements have to be quite carefully managed to keep people away from each other who would otherwise get into conflict (RL2/4/18-21).

Joan could get quite irritated and threatened by the behaviour of other people. One resident was beginning to repeat over and over that she wanted the quoits – kept pointing to them. This in turn upset Joan a bit – asked “what does she want from me” (RL1/25/22-24). Apart from perhaps going to the other side of the room divide, there was no space to get away and people were generally encouraged to stay in the same space and participate in the activities.

The environment as a public space where many different people were brought together really required social coping skills that people with dementia were likely not to have. After one morning in the room, I wrote:
I've been very aware today of the issue of the difficulties of group living – people forced together who don’t like each other, people through dementia having habits which are unacceptable to others. It’s quite a juggling act for the PCAs, especially within the confined room. I was also aware of this when I briefly stopped to greet Eva – she started to make some sounds, which, knowing what her daughter had said, I felt was o.k., but then I also was acutely aware that the other people were having their lunch on the other side of the centre divide. (RL2/11/3-11)

Having people together in too small a space without other semi-private spaces was more likely to curb social interaction than foster it. Furthermore, the noise and distractions in the environment made it hard to communicate. I tried a bit of conversation with Joan but the TV made what is already difficult communication harder (RL3/17/22-23).

5.2. Organisation

5.2.1. Priorities of Care

There was no doubting the enthusiasm for the program on the part of the Executive Director, who, from his own experience and character, appeared very attuned to a person-centred approach. Having some years ago come across the ELTOS model, he had been inspired to incorporate this person-centred approach within the new dementia program at Star of David. Iris, the Director of Nursing, to whom the ideas were totally new, similarly was keen to promote the program. They had put quite some effort early on to have inservice training for staff and planned to have further training for new staff as well as ongoing supervision.

However, it seemed that the program was still considered marginal to the basic care of residents.
We get a day like today when we haven’t got enough staff and we can’t afford the luxury of the … program, because there’s just not enough hands to do all the physical care, and the mental care unfortunately comes later and it’s the thing that has to suffer if we don’t have enough staff, which is a bit sad. (Janet 3/8-12)

Yet for the residents the program was not a luxury, but offered much needed structure and activity which otherwise was missing. I noted in my journal: There was an atmosphere (so it felt to me) of being at a loss, with nothing to do – comments from the first three women (residents) seemed to confirm that they missed the (activities) program – they commented there was nothing to do today (RL/2/16/18-21).

Yael noted the lack of priority given to the dementia program: When it comes to the crunch, it’s the program that’s always getting it (Yael/14/3). The reason for this lack of priority seemed to lie in the professional orientation of nurses.

I think it’s very hard for some of the staff to understand the importance of the overall well-being of an individual. Their whole training, the nurses’ and PCA training, is the body, the physical – that’s it. And I think so much importance is placed on that. I mean that’s really their job. Their job might be made easier if they did focus on other things and did place priority on it, but I’m not sure they see it that way. (Yael/14/8-14)

The choice of a part-time, volunteer coordinator seemed to me to also reflect a lack of priority given to the program. Yael had only eight hours allocated to the dementia program, and this was further reduced later in the year when she dropped one of her days to do a placement elsewhere. What made her job even more difficult was that she was given no authority over the PCAs.

Iris made it clear in her interview that the dementia program was only a small part of the overall program of resident care at Star of David and therefore could only attract a certain amount of resources. At the end of this research
study, grant money became available and was to be used to hire a Leisure/Activities trained person and to buy more material resources such as better furniture. Yael was hopeful about this, though with an underlying ambivalence which appeared in much of what she said about the program, an ambivalence I shared in the face of often contradictory messages from management.

*I think that there is support because we’ve got the grant and that’s coming for the program, which is very exciting, so there is support and there is value in it. But some of the time I feel that there isn’t support. Other things take priority and these are management decisions.*

(Yael/14/20-24)

5.2.2. Material Resources

Even accepting that time was needed to build them up, I found the material resources surprisingly inadequate. For the first few months, the PCAs in the program had to borrow a CD/tape player from the Recreation Coordinator. There were very few tapes/CDs and only a few games, despite the latter forming a large part of the activity program.

5.2.3. Staff

5.2.3.1. Requirements of Staff

There were six PCAs divided among the three wings at Star of David, one PCA being allocated to the dementia program. PCAs both in and outside of the program talked of how busy they felt; there was always too much to do and not enough time.

*I tend when I go home nobody can speak to me because first of all I’m physically exhausted because it’s a big building and you’re running around. You’ve got 70 residents to look after and you’re running around like a headless chook all day…. It’s a difficult job full stop. Every area. There is nothing easy about working here. And now with accreditation it’s even harder.*

(Paula/4/10-19)
Although in theory, the PCA on duty in the dementia program was supposed to be able to call for another PCA off the floor when one of the residents needed assistance to go to the toilet, this rarely happened. Staff felt that the others were already too busy without having this extra work.

*Sometimes, because the staff are overworked, it’s hard to always get help right there on the dot when you need it in that room... so half the time most of the staff in there just do it themselves, take them, unless it’s two people or whatever. So there’s the interruptions.* (Janice/13/13-20)

The pay for this demanding work was minimal. For about $12 per hour (the normal rate for PCAs), a PCA was required to do personal care work (showering, dressing, making beds). On the days a PCA was rostered onto the dementia program (for instance for the morning program), he or she would stop personal care work in time to start the dementia program at 9 a.m. Apart from a half hour break for lunch at 11.30 a.m., the PCA was kept busy through to end of the residents’ lunchtime. The work in the dementia program involved bringing people from all over the home to the room (in itself time-consuming), running a program of activities, taking people to the toilet when necessary, getting people up to the table for lunch and assisting those unable to feed themselves. Here is Janice’s description:

*I had probably seven or eight people in there for lunch. I had probably 10,12,13 people there during the morning at different stages – I think 8 or 10 at once – and they were all involved in the activity but some lunchtime one lady wouldn’t start till 12.30 to eat and she finished her lunch at 2 o’clock but I allowed her to eat. I didn’t just say, lunch is finished, take it away.* (Janice/11/23-28)

Not included in this description were the many different personalities she had to interact and negotiate with, and the handling of potential conflict among residents who could not get on with each other. No additional time was given
for planning the activities or preparation of resources. It seemed that a lot of skills were required in terms of planning, group and activity skills, empathy and interpersonal skills as well as sheer hard work and dedication, if the work was to be done well.

5.2.3.2. Quality of Staff
The senior staff and management had quite clear ideas about what sort of personalities were most suited to working with the residents with dementia: flexible, gentle, warm, sensitive, caring, energetic (Yael); understanding, patient, sensitive (Mary); patient, tolerant, with a sense of humour, able to communicate at all levels, has common sense (Iris).

Somebody who has the capacity to look for the person inside, to look beyond what's left, to understand the importance of what's happened in the past, that the experiences that have made that person what they were and how they've grown and where they've come to now.
(Iris/14/20-24)

Janet suggested:

patience, intelligence, able to understand concepts, kind – kindness never goes astray, a bit of joy please…I think they have to have inherent joy because if they haven’t, it’s just – yes inherent joy would be good. Articulate would help…Imaginative, that definitely helps.
(Janet/13/26-14/2)

While they felt training was important, they tended to see personal qualities as the foundation upon which training could build. Janet placed the relative importance of personal qualities vis-a-vis training at 70/30.
I think they have to have the personal qualities first and if they've got them, then you can train them and they'll understand and they'll do all the right (things) but if they haven't got any imagination, haven't got any joy and if they're not slightly bright…it doesn't matter how much you train them, it won't help. (Janet/14/9-13)

Yael echoed this belief.

I think attitude and background is maybe more important, because I don't think that you can teach someone how to behave. I mean you can teach them theory over and over again and tell them that this works, but if they don't have it in their personality and in their character, I'm not sure that it would work. (Yael/5/1-5)

5.2.3.3. The Staff in the Dementia Program

I think some of the staff are landed in there (the dementia room) by default rather than the fact they've actually been properly prepared and I think sometimes the depth of understanding of the philosophical issues and the management strategies for behavioural problems …are lacking at times. (Iris/6/8-12)

The PCAs varied in their suitability for the work in the activities room. Some of the new PCAs specifically employed for the program came closer to the ideal in terms of personal qualities. However, often staff were assigned to the program on the basis of availability rather than suitability. Janet, the senior nurse in charge of allocating PCAs to dementia activities, knew that at times she was putting a PCA in the activities room who should not be there.

I think I'm putting you in there but I know that you're not going to do, that you're going to turn on the television set and I know that isn't going to interest them and I know that you're not going to do anything, but I haven't got a choice because nobody else is going to do it either. (Janet/5/3-7).
The level of training was also insufficient. Paul, Janice and Maria had all completed a PCA course, as well as having varying amounts of PCA or related care experience. Iris described the PCA training as “minimal” and “unregulated” (Iris/7/6), with courses varying in length from six weeks to six months. None of them had any significant training in dementia, in activity programming, or in group work. Furthermore, the work of PCAs is by and large task-oriented. Mary pointed out that orientation to task, to getting things done, meant that staff unnecessarily stressed themselves and the residents.

Still some PCAs need to be trained to that way of thinking. You know they've got a certain narrow path of thinking, that they have to learn to be flexible, so to see their needs as well, that aspect of their needs. It doesn’t matter if they (the residents) don’t start playing ball at 9 o’clock, they can sit there and rest, then have a cup of tea, then start. So training is the main, main obstacle in trying to get people to understand what we are trying to achieve, what we’re trying to do and tie it together. (Mary/8/26-9/4)

With this program, the PCAs were being asked to make a huge leap from clear-cut, specific tasks to an unstructured, spontaneous and creative setting. They were therefore ill prepared to undertake the work of evolving a dementia program from scratch. Understandably, the PCAs seized on the idea of activity and stayed with a small, but familiar range of activities, thereby creating their own safe routine. Rather than approach the work in a dynamic way, at times the staff in that room have seen themselves a bit as babysitters rather than as taking a creative role in working with the individuals that are there in trying to maximise their quality of life (Jason/9/1-4).

Jason was generous in acknowledging the positives staff had accomplished but equally acknowledged:
I probably would have hoped that they could have been perhaps more creative at times in things that were done. They could have I suppose tried out different options to see for each individual what works better and what doesn’t work and just to – there needs to be I don’t think it’s really risk taking – I mean in a way it’s risk taking – it’s trying things out that people perhaps haven’t tried before, because each person is different and I think it’s that recognising how we can – it’s taking the work with each person as an individual challenge to find the right thing for that person. (Jason/8/19-28)

5.2.3.4. Individual Staff Attitudes

PCAs had differing attitudes to the dementia program, which to some extent reflected their understanding of dementia and of the possibilities of the work with people with dementia. Senior staff observed that the PCAs were either terrified of the work in the dementia program or thought it was not work at all. In the early days of the program, some PCAs had fought to get to work in the room because they thought it was the easy option. One hard-working PCA said that even now some staff on the floor would look in the room and think what an easy job she had just “playing” with the balloon.

I think attitude is the number one obstacle. If they (PCAs) have the right attitude – and some have a real fear of being stuck in the room with residents and there’s another aspect where some see it as an escape from the work that they do outside. So there’s two conflicting negatives there where one is so scared, that they are so stressed out before it starts, and the other one thinks that it’s a holiday in there.

(Mary/9/9-15)

Finding the staff with the right qualities to work in the dementia program was no easy matter. Despite awareness of the ideal type of staff, Star of David ultimately had to use those staff who were available.
And there are some people there that, if I had my choice, I wouldn't have them working in there, but I don't have my choice. And that's one of the fallbacks, working in this kind of environment, it's not so easy to get people that would work in there and have the right character and energy and creativeness and understanding.

(Yael/5/5-10)

5.2.3.5. Staff Understanding of the Program

There were attempts at developing the understanding of staff concerning the nature of dementia and the purpose of the program. The three-part training session my supervisor and I offered very much emphasised a person-centred approach to the person with dementia. However, not all staff involved in the dementia program attended. Yael provided in-house training for those staff starting to work on the program. Interestingly, other staff, though also having contact with residents with dementia through their personal care duties, were not to receive this training.

The PCAs held varying views of what the purpose of their work was. Janice saw herself as a motivator, motivating the residents with dementia and thereby boosting their self-esteem. She hoped to make life more enjoyable.

I see it as for a person, for example with dementia, as being able to have some enjoyment, happiness in their day. They may have just been left to sit and by me motivating them to do things that they wouldn’t have thought themselves and wouldn’t maybe think they could still do but after a bit of patience and understanding and help that they could achieve things that they might not – something that they can either laugh at or feel good about themselves by having achieved something that there’s no way they would have otherwise done. (Janice/4/19-24)

Maria saw her work as keeping people busy.
We spend with them time, we try to get them busy, because when they are busy they forget about their sickness, they forget about everything, you know because especially this program is for dementia people. The people is not well, so we try to involve them in activities. (Maria/3/4-8)

Paul was aware of the spiritual dimensions of the work.

The aim now is more on giving support to them and a bit of activity, not only in terms of... diversion but also give them something at least to make life meaningful and liveable for them, taking into consideration from where they are now. (Paul/6/3-9)

Activity was seen by some therefore as an end in itself – to keep people busy – or as a means to an end, such as improving self-esteem. Paul took the latter approach somewhat further in that he emphasised relationship and communication, getting to know the person as an individual and as part of a culture.

There seemed some ambiguity concerning which residents should be coming to the program. When Paul started working in the dementia activities room, he had invited anyone and everyone. This was not particularly surprising given that one day without warning or any preparation, he had been rostered on to the dementia program. It was only later when he had started Yael’s training that he came to realise the true focus of the program. Indeed, in the early stages of the program, other staff too had encouraged people without dementia to come in to the room, though whether this was through lack of knowledge or, as suggested earlier, a wish to work with “easier” residents, is unclear. Overall, there appeared to be no common understanding among staff about the aims and objectives of the program. The PCAs who ran the program interpreted the objectives as best they could and within their own understanding of the needs of people with dementia and the aims of the program.
5.2.3.6. **Staff Culture**

Yael’s attempts to make the program work seemed to be constantly thwarted, even when she was offering solutions “on a plate”. For instance because staff were having such difficulties doing anything in the afternoon with residents with dementia, she made up a list of activities specifically for each individual. Yet, in the afternoons staff could still be seen sitting in the dementia room chatting, with the TV on. Yael hoped that through her training she could increase understanding of dementia, but this had been difficult because of the lack of real management support for her training sessions. Even where she had the opportunity to teach staff, theory was not converted to practice. *And you can teach them and they know when you ask them questions, they know what the right answers are to make you think that they do understand, but when you watch them, it’s a bit different* (Yael/5/15-17). There were some real communication difficulties because of the different ethnic origins of staff and their English comprehension, but Yael believed that there was also a fundamental lack of motivation.

5.2.3.7. **Staff /Staff Relationships**

Although there were individual staff alliances and informal support based on old/new and ethnic divisions, staff were very much on their own when working in the room. Each staff member created his or her own routine and got on with it. Janice spoke of mutual support from one other member of staff currently on maternity leave. She related more to the more recently employed staff like Paul, but did not relate much to the other “old” staff (the “ethnic staff” she called them) whose way of working she did not always approve of. Indeed, there seemed to me quite palpable but unspoken conflict between Janice and Maria. There was also a feeling among the new staff, that the old staff not only had the wrong approach to people with dementia but did as little as possible when working with them. They told me that you could tell by the activities written up in the dementia room record book, who was on duty that day.
Yael tried, through her training program, to offer staff opportunities to share difficulties and accomplishments with each other and to develop teamwork, but this was again undermined by the lack of management support. Given the divisions and lack of trust among staff, her work would have been challenging even with management support, but without this support, it became impossible.

Residents at times got caught up in the often unspoken, but acted out conflicts between staff. One resident, disabled by Parkinsons and developing dementia, still retained a strong sense of independence and thoroughly disliked being in a wheelchair. Again and again, Janice needed to remind other PCAs to transfer her to an ordinary chair.

Janice came in and seeing B and A in the wheelchair said they shouldn’t be there. Asked Maria if A had been there all morning. Yes, Maria said, and did not offer to move her. Janice went off seemingly I thought to get A’s frame, but only came back much later – popped her head in and said, ‘Is she still there?” (RL3/19-9-13)

This was typical of their interaction, Maria using what can only be described as passive aggression, and Janice sidestepping direct confrontation. However, not only did this mean that A got lost in their conflict, but A was also very aware of the “vibes” – ‘waves of jealousy’ coming in the door” (RL1/8/21), as A herself described it.

5.2.4. Management Style

5.2.4.1. Management/Staff Communication

Communicating with management was not easy. Iris seemed permanently on the run, busy with meetings and distracted by many things. It wasn’t that she lacked the good will; she just appeared to always be under pressure. I found it quite hard to pin her down and my interview with her was extremely stressful. In the first place she had double booked herself for the interview time, so mine was cancelled, but then suddenly was reinstated when the other booking
was cancelled. The interview itself was interrupted several times by phone calls, other staff and residents, despite Iris’s having alerted the receptionist and having a do not disturb sign on her door.

The following interaction came about after I had come to Star of David to attend a dementia meeting and only found Janice there to meet with. After much to-ing and fro-ing, Janice and I had held the meeting, later on joined by Maria. After lunch,

Just as I was getting ready to follow Janice, Iris arrived (busily) and we exchanged a couple of words… She was most apologetic about the meeting (though I said I was coming down anyway) — she had the meeting which went on and on, and then she’d remembered (the dementia) meeting but of course couldn’t do anything about it. She had some things for the agenda, one of them the outing, which Janice had been heavily pushing for. The impression of Iris was as usual of a very busy person always on her way to something else, between meetings, demands, etc. She said she wanted to catch up with Janice and Maria and when I asked if I could participate in that, she said yes and was I here this afternoon. I said till 2 and she replied that she’d have to do it before 2 anyway as she had another meeting. However, I never saw her again after that. (RL3/3/25-4/7)

5.2.4.2. Leadership

There were times when it seemed that it was leadership which was required rather than following the wishes of staff. For instance, it was at the suggestion of some of the staff that the afternoon program become more of a time for individual activity. However, the group of PCAs who suggested this were the very ones who tended to do little in the afternoons. After this change was approved, they were still seen chatting in the dementia room rather than interacting with residents.
There was a lack of clarity and follow through in management direction. Issues were not fully resolved, nor even partially, by suggesting for example interim solutions or establishing the steps required to resolve the situation. Here is the example relating to the vexed question of writing notes for the 1-3 p.m. period of the dementia program, discussed at the meeting with PCAs, Yael and Iris.

Yael noted that nothing much was written in the notes re the 1-3 p.m. spot and that this would be a time that individual things could be done and these should be noted in the dementia activities program notes, eg of walking L. – attempt to get him walking even if be refused… should be noted down. This led to discussion about whether and what to put in the progress notes and in the dementia activities program notes. Janice noted there was not time to do both. Iris pointed out that progress notes should be for exceptions …Janice suggested writing immediately in the program notes after doing something with a person. Anyway there was some discussion and (it) seemed still somewhat unresolved as to what should go where and when one could do it. (RL1/1/17-28)

When Yael cut her hours and was therefore unable to attend all the dementia program meetings, Iris expressed the hope that in time the program would run itself, even without Yael’s involvement. This however seemed unrealistic to me, in terms of what could be expected of staff, particularly given the divisions and lack of teamwork.

5.2.4.3. Management Support
Despite stated support of the program, in practice management offered little in terms of practical and emotional support for staff who were undertaking this new work. Indeed management’s expectations often mediated against person-centred practice. There was a sense that the staff were put in the room with the people and left to it. This was a lot to ask from staff who were
personal care attendants. The program was basically run by people who often had insufficient understanding of the dementia program and insufficient skills and training.

When staff raised the issue of needing a second PCA in the dementia activities room, Iris, pointed out that the other staff on the floor could be called on to help with assisting residents to the toilet for instance. Yet in reality, the other staff were usually too busy, some maybe even disinclined, to leave their usual work to help. I found that while management acknowledged the difficulty of the task, they were not always there for the staff. In the example above, I felt that Iris was not really hearing the staff concerns, instead brushing them off with the rather unrealistic answer that they could ask other staff (when they felt they could not).

Lack of support was particularly evident in the case of Yael of whom so much seemed to be expected. She commented on the difficulties she had with management, who on the surface gave her support, but then put obstacles in her way.

> Often I feel like I do need support from above, which I don’t get and it’s hard and I feel bad, because if someone is dying, who am I to say “I’m sorry, but you can’t be there, in case something does happen” And if they say to me. “Well, I really think it’s better if you go to the staff meeting” and “so and so’s on holiday, oh did I forget to tell you, I’m so sorry, we’ll have to change it for next week. (Yael/13/20-26)

Her experience with running the training program is an example:
I’m very frustrated and caught because I also don’t feel like I’m getting support from people above me who tell me to do training but then when I ask for people, they give me one or two and then say, this is more important and sorry but you can see how difficult it all is” (Yael/12/9-13)

I observed frustration in various staff at various times when they were simply unable to do the work as well as they wanted: not enough time, not enough resources, not enough ideas for activities, needing guidance from someone more experienced or knowledgeable. It was constantly perplexing to me that there appeared such goodwill on management’s side, while support in real terms was not forthcoming. Appearance and reality somehow did not always coincide.

5.2.5. Communication

Communication in this place is atrocious. It’s all too hard. There’s no time. You’re all so busy doing everything else. We’ve got to get a lot better at that. (Janet/10/22-24)

5.2.5.1. Meetings

Janet pointed out the difficulties of organising staff meetings. Simply, everyone was too busy. Handovers were lengthy because of the number of residents and left little time for other communication. Communication and documentation were also hindered by lack of time.

Proper handover? That won’t happen until, you know – it’s like a vicious circle. Until we get – we’ve got to get our documentation right so that we can get money for residents, so that we can employ staff, so that we have time to document…and it’s a circle and nothing’s being solved in the meantime. And it’s just – you haven’t got time to do all the stuff you need to do, let alone time to actually tell somebody that’s what you need to do. (Janet/11/21-27)
The dementia program staff had a regular meeting twice a month, but only a limited number of staff attended, usually just one or two PCAs along with Iris, Yael and sometimes one of the registered nurses. Paul had not attended any of the meetings because he finished work too early. Iris encouraged staff to attend but for someone like Paul, it would have meant staying back in his own time.

PCAs involved in the program who did not attend a meeting were supposed to read the minutes, but this did not seem to happen and information did not get passed on. Yael got very frustrated by this and on one occasion asked rather pointedly how a certain piece of information could be passed on since people didn’t seem to read the minutes. Iris too had some frustration. At one meeting, she was amazed to find that the PCAs did not know they were supposed to attend the 3 p.m. handover meeting (this was for the home generally not just the dementia program) when she had sent out a memo to this effect. Janice said she’d been puzzled about it; Maria said she hadn’t understood it. Neither had come to ask Iris for clarification, but nor had Iris followed it up.

5.2.5.2. Communication Among the PCAs

Yael described the bulk of staff communication as being of the informal variety, with the only formal communication being at the dementia program meetings. Given the different alliances among the staff, I wondered about the level and value of the communication. I’ve already shown how Janice’s recommendations about A not being kept in a wheelchair were not taken up by all the PCAs. What information was passed on seemed to depend on how good the communication might be between individual staff members and the presence or lack of motivation. As it was, A continued to be left in a wheelchair and Anna continued to be “fed” rather than encouraged to eat.

Again and again, a lack of motivation among staff seemed to undermine whatever frameworks were put in place.
5.2.6. Documentation

Documentation is of course part of staff communication, as well as part of professional accountability and of the provision of appropriate care. It is also an important and vital part of the Federal Government’s funding process.

New care plans were being prepared for all of the home’s residents in order to fit the statutory requirements for Federal Government accreditation but also to be a more useful tool in terms of a holistic approach to care. During the course of my study, therefore, only some residents had new care plans. Care plans for other residents were in the process of being done. Janet highlighted that there was the problem of the care plans not yet all being complete but there was also the problem of their inaccessibility to staff.

Care plans? Well a lot of them haven’t got them. They’ve only got prompt sheets which are not useful. Well, they’re useful for physical activities and some of the other things are on it but they’re only prompt sheets. The trouble with care plans is that they’re not all done and …they’re all sitting in the office, which makes them inaccessible. They need to go in their rooms. There’s great talk of them going into their rooms and one day it may even happen but in the meantime their proper care plans, even the ones who have been completed, aren’t looked at except by those of us who are trying to complete them and the PCAs certainly don’t use them and that’s not their fault, it’s the fact that they’re in the office and they’re not accessible and it’s just silly. (Janet/8/12-23)

There were confidentiality issues related to accessibility, and so for the moment the issue remained unresolved. Another issue was of course whether staff felt the care plans were sufficiently important to take time to read them. Janet again: But then they’ve still got to feel that they’re important enough to look at and that’s another obstacle (Janet/9/11-12).
In looking at the care plans for the four residents I was studying, I was struck how even in the new care plans, it was hard to get a picture of the person as an individual. The life histories and social profile which had been done with the assistance of families (at the dementia program meeting) were supposed to be attached to the care plans, but I was unable to find them there.

Checked Eva’s file notes – the most available information seemed to be on her as she was a few years ago – still able to walk and talk. But (and I checked with Janet and she agreed it was confusing) hard to find the real up to date stuff. (It should be) in the new care plans but not all done at this stage, some in progress notes, etc. Information obtained...Interests music, swimming, discussion. Came to Australia after the war from Poland. I did find some mention of 2 hourly toileting – is this happening now? (RL1/17/10-17)

Janet agreed it was hard to really know the residents, in part due to the large number (70). There had been a suggestion from one member of staff that they have a Life Book which could be made up by the family.

Whether we actually get to that stage or not — but it would be good especially for demented people it’d be a whole lot easier and quicker and all that sort of thing to look through it and say, you know, this is what they were interested in when they were younger — because we don’t, I don’t know enough about a lot of them, you know, what their war experience was. I know some of it but not much. There’s a lot of people here. (Janet/9/23-29)

The plans were not always clear even on physical details.
(I) checked with care plan for Eva to try and see shower and changing pad schedule. There didn’t seem to be any clear indication. There was something about timing of shower (that is, at night) but no clear statement whether every night or not (remember her daughter said they’re supposed to do every night). As for changing of her continence pads, I finally had to ask N. the reg. nurse where I would find the schedule for this. She said this was done routinely when she was turned in her bed — that was according to the file 2-hourly. Interestingly, Eva was noted in the file as being widowed when her husband is very much alive — and it seems not all the staff were aware of this either. (RL3/25/6-16)

Reading the above, one is inclined to feel that perhaps Eva’s daughter’s concern about the physical care had at least some justification. I myself witnessed a situation where one staff member assured me that Eva would not need her pad changed because it would have been done, but then another staff member’s comments suggested that Eva was indeed due to have her pad changed.

The dementia activities room had its own documentation. Here the PCAs were expected to note residents’ names, the activity engaged in and how they participated. My supervisor had suggested it should also contain information on what the staff member found worked or what they learn about the residents’ likes and dislikes. In this way a profile might be built up over time of each resident. However, notes were not always made, and where they were recorded, they were not very informative. They were usually vague even in reference to the kinds of activities used, and certainly did little to increase one’s knowledge of the individual and were of the quality: “group activities”, “chat in group”, or in talking of individuals, “trying to keep Mrs. Z not to be so restless” (Reconn/39/4), without noting strategies which did or did not work.
5.2.7. Organisational Procedures

There was much about the organisational aspects of Star of David which I personally found frustrating, and alternately infuriating and disheartening. I wondered if this organisational environment did not add to the work and stress of staff.

There were organisational difficulties around routine matters, such as lunchtime.

The PCA on duty was expected to go at 11.30 for a half-hour lunch, and during that time another PCA would relieve her. Many times I found myself holding the fort while the PCA went in search of someone to relieve her or simply went off for lunch saying someone would arrive soon (but no one did).

*I had a couple of times mentioned to the registered nurses about having someone to come in and do the lunches. Janet said, oh yes someone should be coming in – I think (which really filled me with confidence). I figured by ¼ to 12 I’d better at least get people up to the tables, so trying to remember who needed to sit far away from whom, I began. At least now I know the people fairly well and had seen what happens, e.g. getting people from walkers into chairs, etc. I must say I was beginning to feel a bit stranded (and also hungry), so I went into the corridor again where H and Janet were there with the pill dispenser. I reminded (them) again that I needed someone. Finally things started happening. H dashed off to get lunches, and I did whatever I was to do. Janet came in to give L his pills and then helped him up to the table. By about ¼ past 12, K came in and the two of us dished out.* (RL2/20/3-17)

At mealtimes, there was the added complication also of the “politics” of the kitchen staff and difficulties other staff had working in with them.
A lot of time seemed to be wasted trying to sort out what was basically an organisational issue, whether, as in this case, it was the lunchtime roster or setting aside time for staff to attend meetings. Trying to get definite decisions and definite pathways to carry out decisions seemed very difficult. For months Janice had been asking about taking some people for an outing, a walk down to a local park. She was determined to get an answer at this dementia meeting.

Iris said, well what do you need to make it happen ... I also felt that while the question sounds good and democratic, it was a bit late in the day given that this had been simmering along for quite some time. Janice thought the recreation coordinator was to be involved, but Iris said no, she had no involvement with (the dementia) activities. Janice and Maria were left with the task to decide on an outing and what they needed to make it happen and come back to Iris. Interestingly, later on Janice said to me that it needed a lot of energy to organise an outing – and she wasn’t sure whether she might just lose interest in it.

(RL3/13/15-25)

This scene demonstrates a lot of the difficulties in organisation – miscommunication and, on the part of Iris, lack of leadership and support, not to mention a lack of realism, since Maria and Janice were two people who had great difficulty working together and communicating. I felt too that Iris had not really heard Janice nor responded to what she was asking. It would have been easy for Janice to just give up and indeed Janice hinted to me later that next time she might just not bother to make the effort. The outing did in fact happen, but was very disorganised as Janice had had no time since the meeting to plan it properly. Her work was made more difficult by another PCA whose comments about the weather raised the residents’ anxieties and made them reluctant to go. For the residents, it ended up being a pleasant enough occasion, to which Iris contributed by going out to buy kosher cakes for morning tea.
There was a sense of good things starting and then being allowed to fall away. There had been a plan to have relatives of residents with dementia come to the dementia activities meeting to participate in filling out the personal and social history aspects of their relatives’ care plans. It was decided to do one care plan a month, which meant that it would take at least a year to have these done – rather too long I felt. For those involved it proved to be a worthwhile exercise, in terms of family involvement and in helping those staff members present gain a picture of the whole person. However after a few months, it was halted “temporarily” as the staff felt they did not get through the practical issues they needed to discuss (they only had two meetings a month in total). It never re-started. Too often, enterprises would start with great hope, but ultimately fade into oblivion. Interestingly, the words “hope” and “hopefully” seemed to occur quite frequently in my talks with Iris in particular and Janet.

A major difficulty which dogged Yael’s efforts to carry out her coordinator role was that despite having much responsibility, she had no authority. In October she told me that she was still unable to get staff to do things with residents in the afternoon.

She felt that one of the difficulties was that she did not have the authority over the staff…The new staff person would have this authority, so she hoped this might make a difference. Yael sounded rather weary and not terribly forthcoming. I think she might be just sick of the whole thing. She’ll be leaving in December.

(RL3/16/20-25)

Interestingly when I spoke to the new coordinator, a few months after she’d started work at the home, she said that the staff were as yet unaware that they were in fact answerable to her.

The organisational aspects then were marked by lack of organisation, vagueness, lack of clear decision making and indication of clear pathways to
achieve aims, lack of follow-up and follow through, and lack of practical support despite stated good will. After one of my days there,

I came away feeling a bit down about the place (in contrast to the week before). I think it’s that old thing of plus ça change, plus c’est la même chose – Maria’s group the same as always; resources still short; and I guess most perplexing of all is seeing efforts being made, decisions being made e.g. Yael (Maybe it’s always Yael) making a list of individual activities, or ordering more materials, but yet it still all seems so ad hoc. How can so much be done, so much good intent but it doesn’t happen? (RL2/29/6-15)

For me and certainly for at least some of the staff, it was a cycle of hope and despair, hope that a new initiative might improve things and despair as it just faded away.

5.3. Interpersonal

5.3.1. Lack of Time

Lack of time was often cited as preventing staff from spending time interacting with residents. Certainly, staff appeared to be under pressure, especially in the morning, as they attended to the many residents. Interestingly, however, when some of the PCAs did have time in the afternoon, they spent it chatting to each other, rather than talking to residents.

The busyness of staff and preoccupation to get the tasks done had several effects. Residents could feel invisible: They don’t see us (Anna -RL1/41/25). On another occasion when I was visiting Eva in her room: “I was just about to go, when Maria marched in (without ceremony, excuse me, or greeting to me or Eva) with a hoist” (RL2/9/21-22).

With staff busily rushing around, residents could find it hard to have their needs attended to. Often residents simply had to wait and be patient.
I saw Janice then, and asked her over. Took off Anna’s shoes – she had a nasty corn. (Interestingly, she had undone her shoelace during the earlier part of the session.) Janice said she would tell the nurse and get a corn pad. She then left for a while. When she came back after quite some time, and was wanting to get Anna to lunch – I think then she was reminded of the corn, and said, again about the corn pad. I wonder what happened in the end. (RL2/4/7-13)

While residents might need to wait for a while to have their request or needs met, they were expected to move at the speed of staff requirements, for instance getting lunch eaten within the required time.

I also was disturbed at the speed of the lunch – why did people need to be rushed to finish off. Maria made a point that Joan was way behind in getting through her food. I also found her behaviour was a real put off to S who I felt disliked being pressured – I think too she may also have wanted to feed him. (RL1/43/29-44/5)

Rushing people with dementia was often counter-productive and with people like Anna, could end up with confrontation and bad feelings all round.

5.3.2. Not Seeing the Person

It was quite common for staff members to talk about residents in their presence.

I felt uncomfortable that E would talk about people in front of them, and also in terms of categories – “level 1” (Reconn/1/18-19). There seemed a lack of awareness on the part of staff that the residents might well understand what they were saying.

With staff focussed on the task at hand, staff could be oblivious to their impact on the resident. The PCA had come in with her sling, came from behind and started to put it on – why do people act like this? She did not say good morning or warn
her she was approaching” (RL3/12/8-13). Even for a person without dementia, someone coming up from behind without warning would be threatening, but certainly even more so for someone with dementia and who was a Holocaust survivor.

Staff members often treated residents as passive recipients of care, to whom things were done.

At one point K (a PCA, who did not work in the program) came in and immediately commented about Joan’s hair which was very unflattering today – flattened on her head and quite straight. She said something to the effect, “what’s happened to your (or her?) hair. Her son will be furious”. She proceeded to try and fluff her hair up. Then she asked where Joan’s glasses were. Joan didn’t know – and seemed a bit confused about it – so K straightway went into the basket on her walker and tossed things around without finding them. She then went off and returned shortly after, put the glasses on and fluffed up her hair some more. Joan sat there passively as all this was done to her. (RL3/18/3-12)

At one level, it could be said that this PCA was a good carer, ensuring that Joan looked good, but at the interpersonal level, this was a completely disempowering, not to mention threatening action, especially with someone like Joan who was quite passive and often fearful.

What residents said might be assumed to be a symptom of dementia rather than an expression of need. One resident complained of pain in one ear.
When I mentioned to Janet, she made light of it saying that she always has all sorts of pains. I hate this kind of response since it tends to make the enquirer (this time, me) feel foolish and gullible, and I feel it trivialises the resident. (even if it is true or likely to be true that this is just one of many pains without source). Indeed one needs to ask why is she having these pains – they are real to her, so can’t be pleasant. Is this another assumption that pains are not real if they have no physical basis/cause. (Reconn/8/18)

Staff at times seemed to act in rather strange ways with residents with dementia, ways which would not be acceptable outside of the home; somehow residents with dementia could be treated differently from “normal” people. For instance, I observed a resident having his toenails clipped a short distance from the table where other residents were eating their lunch. Other private matters were spoken of loudly. N. was also reminded – rather loudly – by Maria about the toilet (RL/3/18/24-25).

5.3.3. Not Recognising the Perceptiveness/Awareness of Residents with Dementia

As I sat with residents, trying to listen to them and to understand, I was quite amazed at how aware they were of atmosphere (for example, people moving in and out of the room), the different staff dynamics (such as the unspoken conflict between Maria and Janet), the way in which staff treated them and the dynamics of interaction.

One resident was about to walk out of the front door (the home was on a busy main road) and three of us staff, one by one, went after her. She rather perceptively and with a large smile on her face said as we all returned together to the lounge: I have one friend, then I have two friends and now I have three! She knew what we were up to! (RL3/21/14-16)

Joan also said, the people here were not very nice today. I asked if it was agency staff. She replied: “Who knows. They don’t care about how you look…they just look at the time”
On one occasion, I went for a walk with Anna and we ended up sitting outside the busy office of the home.

Anna seemed surprisingly communicative – maybe that’s what happens when you listen!! Anna seemed very aware of and interested in people’s expressions and how they responded to her. Mind you sometimes she saw smiles where I didn’t! I also had the impression that she has definite opinions about people – knows who she likes and doesn’t like. She saw M and said to me “I don’t like her. See I don’t smile.” She commented on people – “they don’t smile at us”, “she smiles”. At one point she said: “they don’t see us” and another time “they don’t have time for us.” When I used her name, she was delighted “You know me ?” She then said I must have a kiss. She kissed me then most affectionately, and kissed me a couple more times later on. She actually asked me about me. Asked if I lived alone or if I had someone at home. (RL1/41/18-42/2)

Before staff started to bring Eva into the dementia program, she was considered bed-bound and more or less left in her room with the TV on. Of course, her abilities to express herself or communicate were severely limited, and I think many staff simply could not see the person in there. Often as not, staff coming in to the room would not acknowledge Eva. Around lunchtime Eva is suddenly whisked away – the PCA says excuse me to us, but nothing to her (Reconn/23/9-11). However, some staff could see that Eva was in fact quite aware of what was happening to her and around her.

But Eva if you talk to her and say things to her, she looks at you and I think she understands except she can’t talk. So usually when we do things, I will tell her what we want to do so that at least shows a bit or respect. (Mary/5/10-13)
5.3.4. Listening/Not Listening

Staff often listened to neither the verbal nor the non-verbal messages from residents. From my observations, residents with dementia could not always articulate what they wanted, but they certainly could make it very clear if they did not want something. Non-verbally there were what seemed to me quite obvious cues which either staff were not aware of, or chose to ignore in their efforts to get their work done. Where residents could verbally express their wishes, they were still not listened to. At times staff would go through the motions of asking permission, but be half way through doing the thing anyway. She “asked” Mrs. H if she’d like to join in – tucking her newspaper down the side of the wheelchair without waiting for an answer (RL2/25/21-23).

Staff had their minds on carrying out the task in hand, rather than listening to and observing what the person was communicating. The example below shows also the need to meet the person in the moment rather than re-use old strategies on the assumption that they will work every time.

Anna would not come to the table, so Maria brought a trolley. Tried first to feed her soup – sang as she did so. The singing (contrary to this morning) seemed, if anything, to inflame her further and she got very angry, miming a slap or punch, but not carrying through, then clapping wildly, later also holding her head. It was clear she did not want to eat. Maria said things like, that’s not nice, that would hurt me, do you want to hurt me. I think Anna may have said something about kill, and Maria said, but my family would be sad, you don’t want that, etc. When Anna clearly displayed the agitation, Maria decided to back off. Later she came back and had a second try, this time with the main course. Again more “fighting”, though in between she managed to get mouthfuls into Anna who unhappily chewed. Maria continued to cajole – like mother with young child. Towards the end, as I left, she was starting to eat the soup by herself. (RL1/9/21-10/7)
Anna gave some very clear messages which were by and large ignored; probably Maria was focussed on getting her to eat. It became a power struggle and Anna was forced into being fed, which she hated. Not listening seemed to relate to the feeling that residents with dementia no longer had any sense of what they needed, but perhaps it also reflected a belief that residents should do what they are told. Staff knew best.

Anna looked ill at ease (breathing rapid). When hit by the balloon on the head, she would start in shock, sometimes would say “I don’t want”, sometimes hit the balloon back clearly angry. Mrs. N. and Mrs. M. both, at different times, said she should leave her alone, but although at times Maria would acknowledge Anna didn’t want to play, she mainly continued to throw the balloon at her. (RL1/39/11-16)

It was even hard for me to speak up for myself or on behalf of residents. It seemed so much the staff’s territory; they were in charge.

But I also was aware how difficult it is for residents to make their needs heard – e.g. staff assume they want, need etc. something and omit to ask. Actually I even find it hard to persist and say, no actually, I’m sure this person wanted such and such. (RL1/21/29-22/4)

Not listening also meant that opportunities for relationship and positive sharing were missed. When the PCA poured out the tea, one of the residents said I’ll show you how to make a cup of tea the proper English way (RL/14/26-27). The PCA ignored this. Not only did the resident miss out on being able to be in charge, to teach others something, to give rather than receive, but she also ended up with an awful milky, weak cup of tea.

If being heard was hard enough for people like Anna and Joan who could make at least some of their wishes known verbally or non-verbally, it was next
to impossible for someone like Eva, whose repertoire of communication was mainly limited to moaning. From my observations and from talking to Eva’s daughter and staff members, it seemed that the moaning and crying were expressive of all sorts of feelings positive and negative. So all we get is the crying and you don’t know whether she’s crying because of what she’s lost, or because she’s in pain or because it’s all too terrible and I will cry because of that, I don’t know. It’s hard (Janet/21/14-17).

Eva’s moaning could be upsetting and make staff members feel helpless, as I myself found one time when I was with her and she began to moan.

\[
\text{Part of me worried that I might be making her feel worse, but then another part made me think that perhaps it’s the presence of another human being which allows her to let out her feelings. Who would not want to moan in her situation. (RL1/4/15-18)}
\]

Listening to Eva could be very confronting, as I myself found, and some staff chose to avoid this where possible.

\[
\text{Later when the PCA was in the activities room (looking after things till Paul came in to do lunch duty), Eva started to moan. I went up to her. G. then came over and also patted her hand, but then said to me, seeing people sets her off, it’s best if you just walk away. (RL3/28/26-29)}
\]

5.3.5. Control

One form of control was a kind of benevolent paternalism which conveyed that one (that is the staff member) knew best. One resident despite asking numerous times to return to her room was kept in the activity room to have a manicure. She continually asked to go back to her room. During that time she was chided by various staff that she should stay, it was good for her. Joan, clearly feeling the heat when she was sitting outside in the sun, was
discouraged from moving into the shade by the PCA, even when I offered to help her.

Later as I was about to leave Joan complained re feeling the heat – Maria over-riding with but it’s lovely in the sun, it’s good for you, etc. I suggested she might move a little closer to the table with the umbrella, but although it wasn’t very far, she decided not to and then seemed to say she would just stay where she was. (RL3/6/25-7/1)

In keeping control, staff could miss out on possibilities for interaction and miss seeing the abilities and individuality of residents. Maria was one who kept a tight rein in her group. When Sara hit the balloon with some force, Maria said (in a nice way) not to do it so hard, just gently (RL1/3/17-19). My reflection on this was that she had missed out on the chance to reinforce this very individual response which expressed Sara’s strength and her humour. There was an expectation in Maria’s groups that people would do as they were told. There was no room for individuality or spontaneity.

The atmosphere was palpably different to when R. was running the group. They today still focussed on the balloon, but their faces were closed. I didn’t really see much interaction between Maria and the participants except for Maria instructing them to use both hands, etc. In retrospect, the image which arises to me is of an iron corset. (RL1/39/26-40/2)

Maria’s focus seemed to be on getting the job done and keeping the people in line so that it could be done. The following is one lunchtime I remember with a shudder.
As it was, Maria moved around, again organising and controlling. There was so much that happened which made me cringe and which I felt was downright abusive – I felt quite sad and angry at the end of lunch – Anna’s water being taken away, when she said she still wanted (“No, you don’t need it, you’re having your soup,” says Maria); insisting on feeding Anna the last few drops of soup, when in fact she had eaten fantastically by herself – and despite a small stifled protest from Anna; trying the same with Joan, but she said, “don’t feed me”. (RL1/43/21-29)

Sometimes residents made their own small protest. Shortly after, I heard Maria curtly “order” D to lift her feet and she wheeled her so she could sit and watch TV too. D commented to me later something to the effect that she never thought she’d end up in this sort of situation. Actually, she kept pushing her wheelchair back and back till she was behind the plants (RL3/17/16-21). Mentally I cheered her on.

6. SUMMARY

In this chapter I have described the program and a number of the individuals – residents, staff and management – at Star of David, as well as addressing the family experience and cultural issues. I have also described the program and the people in terms of three systems – the environment, the organisation and the interpersonal.

The following two chapters form the initial part of the analysis of the data through an evaluation of what the program achieved and where it fell short, in the first place in terms of its own aims and objectives and secondly, in relation to the model of person-centred care.
ASSESSMENT OF THE DEMENTIA PROGRAM IN RELATION TO STAR OF DAVID’S AIMS AND OBJECTIVES

There were no formal assessment or evaluation procedures in place at Star of David for the dementia program. Yael’s final report to management offered one assessment of the program based on her experience as coordinator and was mainly in terms of organisational issues. I gave my assessment in a verbal and written presentation to staff and management some months after the conclusion of the data collection in March 2000 (Appendix E). This addressed organisational issues, staff comments on a variety of issues to do with the dementia program and my perceptions of the experience of the four residents with dementia. In this chapter, I will give Star of David’s evaluation of the dementia program based on my interviews with staff and management and Yael’s written report. I will then expand on Yael’s evaluation, by offering my perception of Star of David’s success in meeting the aims of the program in relation to the four residents participating in this study.

1. STAR OF DAVID’S EVALUATION OF THE PROGRAM

From my interviews with staff and management, it was clear there were differing perceptions of the program and of its success. Management, despite being aware of some of the shortcomings of the program, appeared optimistic about the program. Senior staff varied in their opinions. Janet observed some of the benefits for residents, while Mary was much less positive about the program, believing it succeeded in meeting only the physical but not the social and emotional needs of residents. The PCAs pointed to the excessive
demands placed on them in being expected to carry out a program with insufficient staff and material resources, lack of training and insufficient management and peer support.

Yael endeavoured throughout her time at Star of David to acknowledge and build on the positives of the dementia program. However, in her final report to management, her overall assessment of the program was highly critical. These criticisms related principally to organisational issues. She observed that the dementia program meetings did not include all staff (even if only through reading of minutes). She noted in particular the deficits in care planning. While it had been positive to include families in care planning, the benefits could not flow on to the resident because care plans were not read and action plans not implemented. The PCAs had responded well to the training sessions, but these were not as effective as they might have been because of difficulties getting the PCAs together at the same time. She saw supervision as a vital part of supporting the PCAs in the program, but this had not happened due to the limited hours allocated to her as coordinator. Furthermore, her lack of authority as coordinator severely limited her ability to develop the program. She had attempted to monitor the program and encourage the PCAs to change practice, but without success. This was due in part to her lack of authority over the PCAs, but also to lack of motivation from the PCAs and lack of support from senior nursing staff.

Her major recommendation was that an Occupational Therapist be employed for a minimum of 30 hours per week to fulfil the role of coordinator. He or she should have skills in working with people with dementia, should be able to serve as a role model and educator for the PCAs and, importantly, should have direct authority over them. Yael further recommended improved communication channels in terms of interdisciplinary meetings of all staff as well as regular meetings between the coordinator and PCAs working in the dementia program.
As noted in chapter 4, Yael listed in her report the aims of the dementia program as follows:

- To improve quality of life for residents with dementia
- To provide a place where residents with dementia feel safe
- To improve self-esteem
- To promote socialisation
- To enhance and reinforce skills
- To structure the residents’ time
- To provide a safe place for fun, relaxation and silence
- To transform disease systems into purposeful activity. (Yael’s report, 1999)

However in her report, she did not address in detail which, if any, of the aims for residents were met. She did make it clear that she considered the organisational deficits as a barrier to fulfilling these aims. This is, I believe, a significant omission in that it suggests the extent to which organisational factors may not only negatively impact on providing person-centred care, but also may actually distract caregiving institutions from the very people they are meant to serve, namely the residents.

In returning attention to the residents’ perspective, I cannot pretend, on the basis of this present study, to give a detailed account of the resident’s perspective on the quality of care. However, I will offer two perspectives on their experience. Firstly, I will endeavour to fill some of the gap in Yael’s report by offering my assessment of the extent to which the dementia program’s aims were met in relation to the four residents – Joan, Anna, Eva and Sara - whose stories were told in the previous chapter. I will then conclude with a summary of the positives and negatives of the program for each of the residents. This is based on my perception and understanding of the resident developed over the course of the study.
2. EVALUATION OF THE DEMENTIA PROGRAM'S AIMS IN RELATION TO THE FOUR RESIDENTS

I would suggest that the aims for residents identified by Yael may be distilled into the following broad areas of need: safety (emotional and physical), validation or self worth, socialisation, meaningful occupation and wellbeing. I discuss below the extent to which these needs (and the dementia program’s aims for residents) were met in relation to Anna, Joan, Eva and Sara.

2.1. Safety

The dementia activities room offered a degree of safety by providing a space where there could be supervision and more individual and positive attention. It also removed the residents with dementia from possible conflict, verbal or physical, with other residents. However, the small space and the social tensions within the room at times exacerbated feelings of unease. Anna’s agitation was exacerbated by the busy, fragmented atmosphere of the room. Joan at times felt very anxious when confined with residents with disturbing behaviour such as Anna. The behaviour of some staff also encouraged feelings of agitation and paranoia in Joan. Sara seemed to be generally at ease, but she was not confined to the activities room and could move in and out as she chose. It is hard to assess the impact on Eva.

2.2. Validation/Self Worth

Eva was the least recognised and validated of all four residents, being very much left to herself even when in the group. Staff recognised Anna’s anxieties and agitation, but not all acknowledged her strengths and her acute awareness of how others treated her. She had been a wise and competent woman and I believe the sense of herself as being so remained with her. She clearly disliked being treated as a child. Staff often disempowered Joan and reinforced her passivity, although at times she would dig in her heels and revolt. With Sara, staff members seemed to accept her independence and
because of her attractiveness as a personality, tended to reflect back positive messages to her. However, this again was not specifically to do with the program.

2.3. Socialisation

The group activities afforded a degree of social interaction, but the enforced closeness in the room was not always positive for Anna and Joan. Anna because she needed time and space to herself, and Joan because she found the behaviour of some of the other residents, in particular Anna, threatening or simply annoying. Sara just dropped in and out, so was able to socialise when it suited her. Eva remained the most isolated, both from residents and staff. She had people around her, which was an improvement from lying in her room, but little interaction.

2.4. Meaningful Occupation

The activities, even in a generic sense, were very limited and they certainly did not provide occupation which was individually meaningful. Joan, Anna and Sara all at various times appeared to enjoy being part of activities. This may however just have been that it was something to do and a break in routine; many, if not most, of the activities had little to do with who these residents were. The emphasis on games seemed particularly inappropriate. Some of the activities made Anna more anxious, for instance when Maria tried to help her to play dominoes, this seemed to confuse Anna and reinforce her inadequacies. Given Eva’s disabilities, I would suggest that meaning for her needed to be found in relationship and inclusion – and these she very much lacked.

2.5. Wellbeing/Quality of Life

The program gave Joan and Anna time away from negative interactions in the main home, it gave them something to do, some structured time, and more individual attention. It was better than nothing but because it was limited to activities – and a narrow range of activities at that – it was greatly limited in its
impact on the overall wellbeing. For Eva, there seemed only a slight improvement in quality of life in terms of a change of scene and the presence of others. There was not a sense of working towards wellbeing for each individual, merely a general aim to keep people occupied. The happiest of the residents was Sara who flowed into the program occasionally for diversion. Her wellbeing did not particularly attach to the dementia program, but to the fact that she was continuing to live in a way which was meaningful to her.

3. POSITIVES AND NEGATIVES OF THE PROGRAM FOR THE FOUR RESIDENTS

3.1. Joan

| Positives       | The program gave an opportunity for social activity in a smaller group than in the general leisure program. |
|                | It gave Joan a place to go and something to do. |
|                | Some staff offered her positive interactions, treating her warmly and with respect. |
| Negatives      | The smallness of the room forced her to be close to people with (to her) frightening behaviours. |
|                | There remained a lack of opportunity and of environment for one-to-one communication. |
|                | The actions of some staff both in and outside the program tended to disempower by reinforcing Joan’s passivity and anxieties. |

3.2. Anna

| Positives | The program gave Anna a place to be where she was perhaps more accepted than in the mainstream areas. |
|           | She seemed to gain pleasure in some of the activities, and particularly if these involved singing and music. |
She benefited from the warm one-to-one contact with certain staff members. (Much of this however came through a carer privately employed by Anna’s son, who was not involved in the program.)

**Negatives**  
The environment was too noisy and fragmented and increased her confusion and anxiety.  
There was a lack of recognition of her abilities by some staff who attempted to control and manipulate her.  
Things specifically identified as actions which would help fulfil Anna’s needs were not carried out, such as providing her with a doll and having finger food available in order to meet her nutritional needs while avoiding confrontations.

### 3.3. Eva

**Positives**  
Bringing Eva out of her room meant a change of scene and an opportunity to be among other people and activity.  
Occasional inclusion in the group (for instance for flower arranging) or one-to-one interaction (for example, hand massage) offered recognition of Eva’s ongoing awareness and personhood.

**Negatives**  
Her physical disabilities meant that staff did not acknowledge her as an aware being. Staff lacked the skills or empathy (or both) to work with someone so disabled.  
Her emotional needs were not addressed. Even her physical needs were not always adequately dealt with because of lack of communication among staff.  
While physically present, she often remained excluded from the group.  
There was overall a lack of positive experiences for Eva.
3.4. Sara

| Positives | She had freedom to move in and out of the room if she chose and enjoyment in participating at such times.  
She had good relationships with staff who by and large accepted her as she was. |
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<tr>
<td>Negatives</td>
<td>There were some attempts to control Sara, particularly by Marie (although by and large Sara seemed able to shrug these off).</td>
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4. SUMMARY

It would seem that the assessment of the program at Star of David is a mixed one. Organisationaly, there were not the structures needed to support the program and while the program did offer some benefits to residents in terms of giving them somewhere to go, something to do and a degree of socialisation, it only partially achieved its aims for them. Its major deficit, I would suggest, was its lack of focus on the residents with dementia as individual and unique people, which of course is at the heart of person-centred care. Having looked at the dementia program in relation to its own aims, it is appropriate now to compare the program at Star of David with the model which had originally inspired it, namely person-centred care. This will be discussed in the next chapter.

For this discussion I will draw on the relevant literature, the matrix (Appendix A) and my external interviews. I begin each section with the relevant principles of person-centred care from the matrix and expand on their implications for person-centred practice. This then will be compared and contrasted with actual practice at Star of David during the period of the study. I have used different fonts to differentiate the description of the model of person-centred care from that of the care practice at Star of David.

1. AN ETHIC AND AN UNDERSTANDING OF DEMENTIA

1.1. Person-Centred Model

- Person with dementia is viewed as a human being with a life history, culture and identity, who should be treated with respect.
- Many factors are seen to influence the course of and experience of dementia. Staff input therefore can make a considerable impact.
- Staff see behaviour as a response which is meaningful in terms of internal and/or external influences. They therefore try to understand and work with it.

The understanding at the basis of person-centred care is that the experience of dementia cannot be explained solely in terms of brain pathology. The person with dementia needs to be viewed not simply as a bearer of pathology,
but rather as a whole person with a history and situated in a certain cultural, social and environmental context.

In regard to the behaviour of the person with dementia, Moore (2002) suggests an adapted version of Kitwood’s equation (1997) thus: \( D = NI + PH + P + BH + PE + SE \). Behavioural responses in dementia (\( D \)) equal Neurological Impairment plus the effects of: Physical Health, Personality, Background History, Physical Environment and Social Environment. There are many factors, then, which may influence behaviour, only one of which relates to brain pathology. Indeed, in some instances, neurological impairment (the “disease”) may not be a factor at all. Garratt and Hamilton-Smith (1995) found in their study of residents in an aged care facility that much so-called “abnormal” behaviour could equally well be understood as a natural response to an unnatural situation.

Behaviour should not be viewed as meaningless. Garratt and Hamilton-Smith (1995) suggest that behaviour represents the adaptive response of the person as he or she tries to make sense of and cope with the impact of neurological impairment. Cecchin and Jarrad (2002) note that in homes offering good quality care “behavioural responses showed staff viewing behaviour as indicative of need rather than a ‘problem’ and responding creatively” (p.2).

1.2. Star of David Program

While the training program my supervisor and I offered stressed a person-centred view of dementia, it was clear that this had not been truly integrated by many of the staff who by and large subscribed to a biomedical view in their practice. Thus behaviour was seen as a symptom of dementia, something to be managed and controlled. Sometimes challenging behaviour was viewed not even as a symptom but as an expression of ill will, aggression or nastiness on the part of the person with dementia, that is, it became a personal affront to the staff member.
So I try to do my best for her, but she not appreciate this, so this make me unhappy. I told her many times – I understand that she is a sick woman – I told her many times: “Joan, I don’t want anything from you. I’m just coming to help you and you should be happy for this. You should be helpful, yes? Tell me thank you, but you’re never happy”.

(Maria/8/14-20)

Neither the clinical nor the personal perspective validated the experience of the person. There was also insufficient attention paid to the impact – for good or ill – of the staff’s own behaviour and the impact of the environment.

2. PRIORITIES/FOCUS OF CARE

2.1. Person-Centred Model

- The person with dementia is at the centre of care. Establishing and maintaining warm and supportive relationships and communication with residents are most important.
- Choice is built into every aspect of the person’s life in the institution.
- Flexibility of institution and staff. The needs of the residents are paramount and the focus of care.
- Care planning looks at the whole person (past and present).

The focus is on the person, not as a patient but as a full human being with a life history, a psychology, personal preferences, from a particular family, time and culture. The aim is to maintain the personhood of people with dementia, by affirming who they are (and who they have been), valuing them as persons and creating warm relationships which are supportive and empowering. Cecchin and Jarrad (2002) note that a common theme of the nursing homes they studied was that “maintaining identity and dignity was viewed as the cornerstone of quality care…with a requirement to reduce ‘busyness’ around
tasks to a listening and enabling approach” (p.1). Institution and staff are at the service of the resident, are flexible and not wedded to institutional routine. They need to fit in with the resident rather than the resident become a “good patient” and fit in with them.

Underlying this whole person approach is the requirement to know the person well, past and present, desires as well as needs. Care plans need to be living and regularly used documents. In homes offering quality care, “information gathering and assessment about the individual was continuous and contributed to regular review of care and activity planning” Cecchin & Jarrad (2002, p.1). The care plan must also go beyond what is required by government, to include information other than the purely physical and medical.

(Care plans) should tell a “person story” (Coker 1998). These stories should relate what the people wanted to achieve, what they did achieve, what they value, where they lived, how they earned a living, who and what they cherished, their interests and their hobbies. (Schulz-Robinson, 2004, p.49)

It also needs to be a workable, accessible document which staff will use, and management need to encourage staff to use it.

Louise, the Director of Nursing at an aged care facility, developed a series of assessment pages covering not just the physical but many other aspects of the person. This was reduced to a working document of one sheet – a snapshot – and time was provided for staff to read it every day. Her care plans then included:
“not just only toileting and feeding and all those very important issues but issues like – and there is a section for family processes – please make sure you talk to the son every day he comes in. And I think items like grooming become very important. You know, Mrs. S has never ever gone without her stockings so that’s an important alert for the nursing staff, never ever to dress Mrs. S without her stockings on. So that is dignity and self-esteem are very important, so that goes on the care plan as well. The care plan’s a living document. What I try to capture is that this is a snapshot of this person’s life – I mean it’s very inadequate when you look at the totality, but it’s workable. (Louise/12/10-21)

Care is not dependent on the knowledge or whim of individual staff members. There needs to be consistency of care.

So this (the care plan system) I believe does work because it has the opportunity to write little snippets like, Mr. S. always likes an avocado with his breakfast, so then it’s not left up to the whim of the particular nurse who might happen to know that. So that when she’s on one day, he gets his avocado for breakfast and the daughter will bring in seven avocados for the week, so you reduce that problem then of the daughter coming back in and finding six still there at the end of the week. If it’s on the care plan, then it should be done. (Louise/12/22-13/2)

2.2. Star of David Program

Physical care was the major focus at Star of David, and the sheer mass of physical tasks needing to be done was cited as a reason for not having enough time to spend with residents. Particularly in the mornings PCAs had a busy schedule of personal care tasks. Even in the dementia activities room, the PCA on duty might be running back and forth taking people to the toilets, organising lunches, cleaning up.
Therefore, she at times would be absent for long periods as she attended to residents needing assistance. One of the strong feelings I had, whilst sitting with residents in the activities room waiting for the PCA to come back was a feeling of being peripheral to the action. Everyone seemed so busy around us while we sat there seemingly invisible. Several of the PCAs spoke of the need to have another PCA working in the room with them, so that one would be able to “hold” the group and continue with the activity, while the other attended to individual needs. Management did not seem to view this as a possibility, presumably because of the resourcing implications.

Care plans, even the new care plans upgraded to meet government accreditation requirements, seemed inadequate in terms of the kind of social, psychological and familial information of Louise’s care plans noted above. There was some more personal and social information, but this seemed swamped by medical and physical data, was fairly superficial and not always accurate. The care plans were not easily accessible, and while senior staff and management agreed it was unsatisfactory, they had not been able to find a way around the problem. Even if they became accessible, it was acknowledged there was still the problem of ensuring that staff read them. The difficulty surrounding adequacy and availability of care plans, and the lack of motivation to read them, suggests that knowing the person beyond his or her physical and medical needs was not a priority.

The idea of having family help create the social profile for the care plans was excellent and those staff present at the joint meetings had found them informative, especially in giving a sense of the person. However, after about three of these sessions, the process was put on hold, supposedly for a short time only, so that staff could get through the practical issues. By the end of my study, the sessions were yet to recommence. When I tried to find the notes on Anna made during the session with her son, I was unable to find
them although Yael assured me that they were supposed to be with the care plan. There was also talk of creating life story books with the help of families, but this too came to nothing during the period of the study.

It had been suggested that the record keeping in the dementia activities room itself should be of the kind which would help build up a picture of the residents, who they were, their interests, likes and dislikes. However, these notes were sketchy, if done at all, and usually only listed those present, with a comment on the activity and if the resident participated.

Physical and medical care then seemed to have priority, and the knowledge needed to carry out these tasks was of the physical and medical issues. Residents were viewed mainly in terms of these tasks, and knowing the whole person was regarded as a necessity for carrying out the task of care.

3. MANAGEMENT/LEADERSHIP

3.1. Person-Centred Model

- There is agreement on a clear and positive vision for care, based on an understanding of dementia and an ethic as outlined above. Good leadership is required.

- Provision of appropriate training and supervision is a priority in staff management and relations.

It is management who hold and communicate the vision, spell out pathways to achieve the vision, encourage and support staff and are present to facilitate and reinforce new practices. Skene (2004) distinguishes between the concepts of “management” and “leadership”, suggesting that leadership “is not only about meeting goals and objectives but also encompasses how this is achieved. It includes such issues as how a team is developed, shaped, refined,
and motivated. Leadership is thus about how management achieves its goals and objectives (p.2).

Cecchin and Jarrad (2002) note that “leadership was identified as a key factor in all settings with different leadership styles evident but with the common element (of) sharing the vision and empowering staff to create change” (p.1). Flett (2002) also puts vision and leadership at the top of her organisational hierarchy, for this “draws all this effort (the “lower” levels of the hierarchy) in a single direction” (p.5).

Resourcing very much depends on priorities of care, which in turn depend on the vision and commitment of management. Staff selection, in the first instance, is paramount. Adequate numbers and quality of staff are important as well as training and ongoing support and supervision. Allocating time (a precious resource) to staff to do the things necessary for person-centred care (such as reading care plans) is also important. However, resources by themselves are insufficient if deployed in an unhealthy organisation.

Adequate resources are clearly needed for staff to feel valued and supported, and for there to be sufficient staff to provide individualised care. However, resources alone are not enough; there needs to be clarity of communication and an effective use of resources to achieve the desired quality of care. More staff is not the answer if the extra staff are, for example, reinforcing dependence or interacting in an unhelpful manner. Those in management positions have a crucial role to play if the new culture is to become a reality. (Woods, 1995, p.22)

An organisation which endeavours to offer person-centred care to its residents, must be person-centred in relation to the people working for it, the organisation’s “human” resources. “An organisation which is truly viable, is one which values and enables its people…job enrichment, being part of a true
team, a real quality culture, which asks for people’s intelligence and their hearts” (Flett, 2002, p.5). One of the principles underlying the philosophy of the “domus” special care units, for instance, is “that the needs of staff should be considered equally with those of residents” (Woods, 1995, p.22).

Management should therefore be present within all levels of the organisational functioning, specifically in terms of leadership in relation to an overall vision, selection of staff, support of staff, organisational aspects such as channels of communication, documentation and, above all, keeping the vision alive and dynamic. It also requires an ongoing process of quality assurance. It will require “quality control, systematic and regular checks on performance” (Woods, 1995, p.22). It is not something which is set up and left, but requires ongoing effort. It is a “never-ending story” (Flett, 2002, p.5).

3.2. Star of David Program

While there was enthusiasm for and a stated commitment to person-centred care, management appeared vague about what should be happening in the program, what was actually happening, and the best ways to achieve their objective of a person-centred approach to care. This lack of management certainty and input left staff feeling unsupported and divided. Furthermore, management gave conflicting messages, expressing enthusiasm for the program – and I should add, demonstrating it through some of their actions – while showing that ultimately their expectations about the work of care still lay with a task orientation.

Management at Star of David did not persist in ensuring that directives were followed, nor consistently monitor that changes were being implemented. Instructions and requests were repeatedly given and repeatedly ignored. The coordinator selected for the program, Yael, was a volunteer and did not have the power to enforce directives. Ultimately, the quality of the program was dependent on the individual staff, their skills, interests and motivation.
There was also a lack of formal evaluation of the work. There was a trial and error approach to implementing the program, not necessarily a bad idea, if error was reflected upon and learnt from. Yet at Star of David, I was often frustrated at being unable to elicit why certain actions were viewed as having positive or negative outcomes. There seemed a lack of ongoing evaluation of what did and did not work, and reflection on the means to improve.

*Why are for instance staff more positive – is it because they are seeing improvements...or has there been specific managerial input or some training - what factors have contributed to improvement and can these therefore be used to promote further improvement. I feel that often the word “hopefully” occurs and that the power seems to lie with staff in the lower levels (although in hierarchical terms they are the underdog) whose preferences and prejudices so often seem to form the type of care people will receive.* (Anmem3/1/20-28)

While the Executive Director and the Director of Nursing sounded fairly optimistic about the program, the PCAs were much less so. This was rarely expressed to management, but even when PCAs raised difficulties (the oft-mentioned issue of having a second PCA in the room), this was waved aside without management truly hearing that the PCAs experienced this as a very real difficulty. There was a feeling among staff that once the dementia activities room was set up, they were left by management to get on with it. After the first six months, the PCAs were already feeling bogged down. They seemed to be biding their time till one or another thing was going to happen, for example for Yael to take over as coordinator or new funding to be received. There was no sense of a dynamic to the program, an ongoing process of development and improvement.
There were communication difficulties which were not addressed by management. While there were mechanisms in place such as meetings and minutes, these opportunities were not used. Staff did not share openly their feelings and their difficulties in meetings, preferring to focus on practical issues; only a few staff attended; and those not attending did not appear to read the minutes. Yael, did her best to put in place channels of communication, but her efforts were either ignored or circumvented by staff and not supported fully by management.

Communication often took place at an informal level among members of the same staff grouping or alliance, so was not very efficient. The difficulties were compounded by cultural and language misunderstandings among staff and had an impact at many levels: management communication with staff and vice versa, sharing of information about residents, teamwork. It meant considerable frustration for both management and staff and impacted on the care of residents.

4. NATURE OF CARE/PROGRAM

4.1. Person-Centred Model

- Person with dementia has a variety of activity, social interaction and relaxation throughout the day – a satisfying lifestyle.
- People mostly feel safe and secure and have people to reassure them when distressed.
- Programs are tailored to meet the needs of the individual. This results in a variety of programs – one to one, small group and large group.
- Activity programs are integrated into an overall care program which aims to offer a satisfying and meaningful life-style to the person with dementia.
The focus of care is on the person not the task nor the needs of the institution. It is on being, well-being, communication and relationship, not doing and activity, although activity can certainly be part of care.

Activity is fitted around the individual’s interests, rather than a perception of what older people “usually” like, a “one size fits all” approach. Nor is there an assumption that old interests are necessarily current interests. In other words, staff members are flexible and sensitive to the individual person as he or she is now and ready to change activities as the person changes. Most importantly, there is a broad understanding of activity, which may be in a group, or in a one-to-one situation, active or as inactive.

Activity is only a part of person-centred care and not the total answer to taking care of the social and emotional needs of the person, nor is the activities person the only staff member to address these needs. All staff are responsible for the “spirit” of the person with dementia. Thus relationship and communication are of utmost importance, and this is reflected in the kind of training offered to staff and the culture of care created in the home.

A person-centred culture of care therefore is a flexible, sensitive and listening culture, with a readiness to respond authentically in the moment with authentic rather than with pre-digested formulae.

Person-centred care is not mechanical. We cannot diagnose a particular problem of dementia, and thus prescribe a certain action to treat the problem. It is more of an art, requiring imagination and creativity. (Buckland, 1995, p.33)

4.2. Star of David Program

The dementia program at Star of David was almost totally defined in terms of activity, and staff efforts were channelled into finding activities rather than finding the person. This unnecessarily narrowed the scope of the
program and its ability to meet the needs of the person with dementia. Furthermore, even as an activity program, it was quite inadequate in terms of variety and the “fit” of the activities to individuals in the group.

The focus on activity and on the dementia activities room itself meant that staff outside the room, and therefore outside of the program, had little involvement. The registered nurse, Janet, considered that her only responsibility in relation to the program was to allocate PCAs to the room; otherwise she had little to do with it beyond what she saw through the windows when she passed by. As far as I know, Mary was the only senior staff member who actually had spent some time in the room trying to do activities with residents. While in theory the program was not supposed to be limited to the activity room, nor support for the program limited to the PCAs in the room, this was the reality. Janet pointed out that even the PCAs working in the room had trouble connecting what happened in the activities room with what happened outside. The PCAs would think, it’s alright in here because they’re (the residents) here, but they’re not supposed to do things like that out there (Janet/13/7-8).

5. STAFF

5.1. Person-Centred Model

- Staff exhibit an understanding of the care needs of residents and are flexible in their efforts to meet those needs.
- Staff attitude is positive, with focus on remaining abilities and skills.

Good staff are vital to the achievement of person-centred care and require a combination of personal qualities – flexibility, sensitivity, empathy and warmth – positive attitudes toward the person with dementia, an understanding of dementia which is not limited to the biomedical, and appropriate skills and training. Of these, probably personal qualities and
attitudes are of prime importance. Deficits in training can always be compensated for, whereas ingrained personal characteristics and attitudes developed over a lifetime and within a certain culture of care are extremely difficult, if not impossible, to change (Kitwood, 1997).

In the first place therefore, there need to be good selection procedures, with staff being selected in relation to their suitability for a person-centred approach. “Getting the selection right in the first place had become a major priority as senior staff believed it was very difficult to change inappropriate attitudes to people with dementia with education and training” (Rosewarne et al., 1997, p.85). Garratt and Hamilton-Smith (1995) go so far as to suggest that people without previous experience in aged care be employed, so that they do not bring the wrong attitudes and culture with them.

Once employed, staff need to be supported by means of ongoing and appropriate training and supervision from management and senior staff. Role models are important. Louise observed that good attitudes are “caught rather than taught” (Louise/17/1), thus emphasising the need for good role models which can positively influence the staff culture. Teamwork is of utmost importance in that staff can then support each other and create a culture of care which is person-centred. Garratt and Hamilton-Smith (1995) note that while there needs to be recognition and acknowledgment of the particular skills different professionals bring, there also needs to be a blurring of boundaries among professionals. Specifically, “differences in staff roles do not need to be emphasised in relating to residents” (1995, p.87), for this becomes confusing and disturbing to residents with dementia. All staff need to be involved and have as their focus the “agreed care plan for each resident”. (p.87). The focus therefore is on the resident rather than the role of individual professionals.
5.2. Star of David Program

Like many other aged care facilities, Star of David had difficulties finding and keeping staff. The staff who worked in the program had undertaken a course of study for personal care. However, as was pointed out by Iris, PCA training was unregulated and varied in quality and it is doubtful that this training equipped them for the kind of work they were to do with the residents with dementia, which required many more skills than the carrying out of physical care tasks. Paula had chosen not to work in the dementia activities room for this very reason, namely that she felt she did not have the training to run group activities. There had been initial training workshops given by my supervisor and me, but not all the relevant staff had attended. Some staff were subsequently sent to an external training workshop and Yael offered in-house training. However, the latter was usually the first thing to be sacrificed to the pressure of other work. Training was piecemeal and not necessarily focussed on a person-centred approach. The PCAs then were expected to do things which were beyond what they were trained for. Some PCAs were simply unsuited through personality and attitude, yet ended up working in the dementia activities room simply because there was no one else.

The different alliances among staff were never really addressed and this made for interpersonal conflict and a lack of teamwork, in the midst of which residents’ needs could be forgotten. The home retained a hierarchical framework; everyone had his or her job, his or her territory. Iris commented on her difficulties getting the registered nurses to understand and be involved and support the staff in there. It’s been something like, oh we have to allocate staff to it and that’s that (Iris/14/5-7). This did not support teamwork nor a whole person approach to resident care.
6. INTERPERSONAL

6.1. Person-Centred Model

- Staff interact positively and meaningfully with the person with dementia.
- Staff endeavour to spend time listening to the person with dementia.

Staff take care of relationship and consider this and communication as major foci for their work. Effort is put into listening to the person with dementia and finding ways for satisfactory communication, whether verbally or non-verbally. The relationship is one of I/Thou rather than I/It, to use Buber’s terms (1965).

Whereas I-It is the ideal in the clinical, “professional” style of the traditional (biomedical) model of care, I-Thou – a meeting of persons – is the kind of relationship fostered in person-centred care. Here are my reflections on my efforts to “meet” the person with dementia:

I’ve also experienced very clearly the truth of seizing the moment, and that in order to hear the voices of residents, not only must I listen with my whole being, but I need to choose the right moments, the right physical space… and the right psychological moment for the resident.

(anmemo 2/2/14-18)

This openness to the resident does not deny the need for psychological boundaries, to protect both resident and staff member. Nor does it deny the additional skills and additional role the staff member needs to have in order to engage in a relationship which will be beneficial to the person with dementia. However, clinical distance which allows staff to ignore their own humanity and relate to symptoms rather than to persons, is counter-productive in caring for residents struggling to maintain their fractured selves.
6.2. Star of David Program

Staff members at Star of David spoke of how busy they were and how they had no time to talk to residents. Their busyness was a barrier I believe to residents having themselves heard. Staff members seemed so busy with important work, that it took confidence and assertiveness to speak up for oneself I noted in an analytic memo: *I’ve also learnt how difficult it is for residents to have their voices heard – for I have found it difficult to even speak up on their behalf* (anmemo2/2/25-26). It was significant that in the afternoons, when the PCAs appeared to have a little free time, they would sit and chat, not with the residents, but with the PCA on duty in the dementia activities room. It was an ongoing battle for the Yael, coordinator, to try to get the PCAs to spend time interacting with residents in the afternoons.

Generally, attention to task seemed to dominate. When carrying out some task for or with a resident, the staff member seemed more focussed on the task than on the quality of the interaction. Thus Maria refused help from a resident because she could do it much better or faster alone. Those staff who were naturally inclined to interact personally with the residents found it hard to do so in an environment where the physical tasks were identified as the real work.

Staff would at times call on certain techniques, for example, singing to Anna, but usually this was in order to achieve their aim of taking her to the toilet without fuss or getting her to eat. Thus it had much to do with control and little to do with relationship. Also there was an assumption that such techniques would always work in a kind of Pavlovian stimulus-response way, but of course they did not. For instance, I observed that application at the wrong moment of the “technique” of singing to Anna in order to get her to do something or simply quieten down, would
infuriate her and further inflame the situation. The measure of care lay with the physical task, rather than the quality (and quantity) of interaction. It was the physical care which was monitored by management, not the quality of the interpersonal.

7. ENVIRONMENT

7.1. Person-Centred Model

- There is flexibility in space use, including varying degrees of privacy.
- Attention is paid to the quality of the social, emotional and physical environment.
- Staff seek to create a homelike atmosphere.

Care facilities need to pay attention to the environment, physical and emotional and social, the latter two being the more important in terms of their influence on the wellbeing of the person with dementia. The physical environment should be flexible, and guided by two principles – orientation in space (that is have a single, unambiguous use) and personal mastery/control (Garratt and Hamilton-Smith, 1995). Goldsmith’s (1996) study notes the influence of various environmental factors such as noise on communication with people with dementia.

7.2. Star of David Program

The dementia room offered dual benefits: For the residents without dementia, it was a break from those who might have disturbing behaviours. For the residents with dementia, it was a (usually) supervised space where special attention was given and where there was some acceptance of the people as they were.

The space itself was too small and too inflexible to adequately accommodate the residents who were in the program. The priority given to medical and physical tasks
in the space meant that not enough attention was paid to social and emotional aspects. The multiple functions taking place in the room, the noise and frequent interruptions all served to create an environment which was confusing (that is not orienting) and threatening, an environment where residents did not have a sense of personal control and safety. Paul pointed out how the moment of relationship between him and a resident would just be lost when interruptions occurred. These were not seen to have value in comparison to the carrying out of tasks. The focus on physical and medical tasks also cut across the aim of having a homelike environment instead of an institutional environment, for instance having the podiatrist do a resident’s feet just a metre or so away from where the other residents were having lunch.

8. FAMILY

8.1. Person-Centred Model

- Families are encouraged to be involved and to work with the facility to create the best possible care for the person with dementia. (Matrix)

Families are viewed as a positive resource in the care of the person with dementia and should be included in the care team, allowing of course for those families who do not wish to be involved. Families too need care and support and the more happy their relationship is with their relative with dementia, the better for their relative. Louise saw one of the challenges for nurses as being, “how do we make a hospitable environment for the family members who feel cut off from the person that they felt that they knew and is no longer that person?” (Louise/6/6). For instance staff can help families have more satisfying visits with their family member. Louise however notes that this is difficult because they are not funded to fulfil this role, yet it is a much needed one. The relationship between staff members and families is also important and has significant impact on the care of the person with dementia.
8.2. Star of David Program

At Star of David, families were regarded, by some staff members at least, as being very demanding of staff. This was attributed in part to Jewish cultural attitudes to geriatric nurses (which were negative) as well as the over-protectiveness of families towards their ageing parents who had suffered through the Holocaust. Some staff resented this as interference and a questioning of their professionalism. Among the families in this study, there was great variety in the quality of relationship with staff and the home generally. Anna’s son seemed to have a positive relationship with staff and with many of the residents who knew him from the past. He was able to offer valuable input, both from his role as a son but also as a professional with added knowledge and skills. Possibly the fact he was a doctor made his contribution more acceptable. Other families did not see a role for themselves in the care situation, perhaps because there was not an obvious role apart from visiting and being there during crises. Esther had an uncomfortable role in relation to the staff. Below is an extract from the research log and my reflections on it:
After we parted, Esther went in to see her mother. I had to go into the nurses’ station to ring my husband and Esther came up and asked (the) PCA for tweezers, which were given to her, she then had to ask for some tissues. I’m not sure if I was influenced by her comments (on the staff) or not, but it did seem that there was little generosity on the part of the staff and she had to draw out from them what she wanted. Reflection: Is there a kind of vicious cycle here. Eva is “hard” to deal with, which makes staff uncomfortable and maybe avoiding, which makes their relationships to Esther hard (they have no good news to tell) and Esther’s own “guilt” makes her more demanding, which in turn turns the staff off even more, which in turn leads to more dissatisfaction from Esther and overall worse care for Eva. (RL1/47/19-23)

It seems that a complex of resentments, guilt, helplessness on both sides (staff and family) worked against optimal care for Eva who, unable to communicate herself, depended totally on the communication of others.

The two interconnected aspects referred to in the ideal above - of using families as a resource and offering support to families - were not sufficiently addressed.

9. CULTURE

9.1. Person-Centred Model

While the matrix does not list a separate principle for culture, it is clear that culture is a part of what makes the person who he or she is and impacts on the experience of dementia, relationships to others, perception of meaning, and preferred ways of living and being (for example, refer Garratt and
Hamilton-Smith, 1995). Cultural factors therefore need to be taken into account in planning care for individuals.

A Greek aged care facility I visited with staff from Star of David set up its dementia specific unit in a way which recreated much of Greek village life. Residents would assist with making breakfast, making up the beds, washing. Rather than activities, an alien concept to Greeks from predominantly village backgrounds, their day consisted of the daily round of household chores, with singing and dancing in the afternoons, and regular taverna nights. Paul at Star of David noted from his experience with Italian residents that they were happy to sit together outside, just as they would have done back home, rather than engage in “activities” such as bingo.

Where there is a history of trauma, there are additional factors to be considered. This need not be restricted to the Jewish context of this study, which is of course an extreme case, but may also apply to other of Australia’s immigrants. Many residents at the Greek facility discussed above had experienced and witnessed atrocities during the last war, and they behaved in some of the same ways as the Jewish residents (stealing and hoarding food for instance).

Joffe, Joffe and Brodaty (1996) write:

Many Holocaust survivors have had post-traumatic symptoms, including chronic states of anxiety, depression, guilt about having survived, nightmares, flashbacks, isolation loneliness and social withdrawal. Curiously, these problems developed years, even decades, after the Holocaust ended. (p.517)

They further note that old age “has the capacity to retraumatise” because of loss of friends, dislocation (from home to nursing home) and the prospect of dying. Cohen (1991) writes that “stressful events…in the present can
reactivate difficult situations from the past” (p.226). Dementia, by its very nature, places great stress on the individual and therefore may exacerbate unresolved traumatic feelings. Cohen points to the destruction of basic trust in many survivors. “Distrust may have been the only thing that led to survival; such feelings resurface at a time when they are no longer productive (p.229). The promotion of a feeling of safety is important for all people with dementia, but would appear even more so for people who have survived the Holocaust.

Culture, therefore, needs to be taken into account when trying to meet the needs of people with dementia and help them live in a manner they feel comfortable with. The effects of trauma and its revisiting of people when they have dementia should be addressed in terms of safety, trust and comfort needs of residents. With Jewish people, this may require sensitivity to fears around showering and anything which might mirror traumatic actions of the past. Staff knowledge of a resident’s first language is an advantage, but needs to be accompanied by sensitivity.

Whilst acknowledging the role of culture, one must take care not to view culture as totally defining the person, who is shaped by many factors such as personal qualities, history and experience, generational factors and family. Furthermore a culture cannot be viewed as a global entity but may contain many micro-cultures which reflect quite different ways of being.

9.2. Star of David Program

The home was set up to meet the needs of Jewish elderly. These were of the generation affected by the Holocaust and there was an awareness of issues to do with safety. Indeed a major motivation for the establishment of a separate dementia activities room was to offer a safe space, both physically and emotionally. Yet the confined and busy environment in the activities room itself created anxiety in some of the residents with dementia. At an interpersonal
level, some staff behaviour increased feelings of disempowerment and fear (for example, doing things to the person without explaining).

The activities in the dementia room itself did not appear to reflect much of the Jewish culture except superficially, for example playing Jewish dominoes). Paul had raised the question of the appropriateness of games within a Jewish culture. Some of the residents with dementia could still participate in Jewish rituals with the other residents, but others were unable to. Staff agreed it would be good to arrange for someone to come and do the Shabbath rituals in the dementia room. I am unsure if this ever happened.

10. SUMMARY

It would seem that the program at Star of David fell short of the model of person-centred care: in terms of a vision which was not clearly articulated and promoted by management and carried by all in the institution; its priorities of care which placed emphasis on physical and medical tasks; inadequate care plans; its attention to the physical and inattention to the environment and interpersonal; and staff who were lacking in their personal qualities and attitudes and training. These deficiencies, individually and in interaction with each other, made it difficult to focus on the whole person. Most significant is that management attempted to implement person-centred practice in a piecemeal fashion, where the focus was on some staff, a particular space, and activity as opposed to the overall care. Without these procedural aspects in place, it was impossible to implement a program which focussed on the whole person and which viewed communication and relationship, the emotional and the social, as equally important alongside the physical care. Thus, in the first instance, one may say that at Star of David a significant barrier to care was the lack of appropriate person-centred procedures and practices.
While some of these difficulties may be said to be particular to Star of David, the literature on dementia and aged care, and my external interviews suggest that most of these present to some degree in other aged care facilities. Another issue, which was raised at Star of David and is commonly identified by aged care facilities, relates to the constraints imposed by government regulation and funding. In the next chapter, I will look at how very similar procedural barriers occur at other aged care facilities. I will also address policy barriers to person-centred care.
Chapter 7

PROCEDURAL AND POLICY BARRIERS TO PERSON-CENTRED CARE

In this chapter, I will develop my argument that the difficulties encountered at Star of David are not dissimilar to those encountered by many other aged care facilities. The discussion will be framed by themes and issues which have been raised in the previous chapter in relation to the experience at Star of David.

1. PROCEDURAL BARRIERS ENCOUNTERED BY MANY INSTITUTIONS

1.1. Physical Care has Priority

The medical model continues to be the major influence on practice within aged care facilities, despite increasing talk of the person and the availability of activities. Those things which feed the spirit and nourish personhood are still considered “extras” rather than the core of the work. Lintern, Woods & Phair (2000a) observed that:

interaction between staff and residents was limited with a focus primarily on the physical care of residents to the exclusion of their psychological needs. Residents frequently expressed anxiety or distress to which staff did not respond. Interviews indicated that this was because staff attributed symptoms of anxiety and distress to the resident’s medical condition which therefore could not be helped. (p.16)
Louise notes how difficult it can be to change this focus of attention to physical task.

*It’s been a huge culture change…to say you are not to get up from your chair and race out and do four showers before breakfast. You are not to move from the chair until you have read the care plan of the people you are caring for today. Even if you cared for them yesterday, something might have changed last night. So that is happening, but it’s taken a huge amount of culture change because there’s still this great thing to get the work done. The work is seen to be the physical showering and so on.* (Louise/13/15-23)

### 1.2. Activities/Life Enhancement are not Real Work of Care

In recent years, activities have become very much part of the services offered by aged care facilities. Indeed it is written into the aged care legislation. However, Lintern et al. (2000a) noted in their study that there was a culture which saw activity as separate rather than a culture “where purposeful activity is considered part of the daily care” (p.16). By and large, the activities program in their study was run by outside agencies, not mainstream staff. However, when staff

were observed providing some stimulation for residents, … their approach was not personalised, in terms of the individual resident’s background, preferences or abilities. For example, they may have been handed a book to read or look at alone, taken for a short walk around the garden, or encouraged to watch television. (p.16)

Activities are often those which in a general sense are seen as good for people, or appropriate for old people, rather than being tailored for the individual. Furthermore, while the benefits of activities programs may be
acknowledged, it is often in terms of improved behaviour and putting less
demand on staff, than in terms of benefits for the resident.

Direct care staff inevitably see their work as the real work of care and
activities as extras which annoyingly interfere at times with the fulfilment of
their tasks. In my training sessions, activities staff often complain of the
obstructiveness of the care staff who believe that only physical care is the real
work.

Sally, a lifestyle/recreation nurse I interviewed at another aged care facility,
observed the difficulties in having her program recognised as real work.

I think it’s always going to be an uphill battle with task-oriented
nursing staff, I really do. It’s taken four years with the program and
we have a minority of staff who think the life enhancement program is
nonsense, whereas in the start it was the majority where they view the
staff doing life enhancement as a waste of resources. It would be far
more important for you to go and make a bed, than like an activity,
we just call it TLC, it might just be sitting with someone holding their
hand, rubbing their knee, just chatting to them and that’s just – do
something else, you’re doing nothing. (Sally/7/23-8/9)

As well as a division between activity and care, there is also a division between
those who deal with the emotional side of care and those who get on with the
physical care. Nolan, Grant and Nolan (1995) observed the absence of activity
in the facilities they studied. “Nurses were aware of the lack of suitable
stimulation and saw this as important but did not perceive providing activity
as a legitimate part of their role” (p.535).

Care staff often have ambivalent feelings towards such programs. Sally
comments:
The rest of the nursing staff, they’ll say (the lifestyle/recreation program) is really, really important but we don’t want to have anything to do with it, or they all say, we want to have a go, we want to have a go and when you invite them, they don’t want to because it’s easier to make a bed and toilet people and then they can sit down and have a cup of coffee. Whereas (the lifestyle/recreation program, it’s the harder slog. Because…you go home more physically and emotionally tired from doing (the lifestyle/recreation program) than working in the unit. (Sally/13/23-14/6)

1.3. Lack of Quality Person-Centred Documentation

Many homes struggle simply to have the documentation fulfilling medical/clinical and government requirements. The additional “whole person” information appears just too much both to write and to read and, given the task-oriented priorities of care, must appear as an optional extra. Furthermore, staff members do not necessarily know how to write such documentation.

1.4. Staffing

1.4.1. Level of Staff Education and Training in Dementia is Insufficient

Deficits in training in Australia vary according to the level of staff. For instance, there is yet to be a nationally accredited training course for Personal Care Attendants. Division 2 nurses (formerly referred to as state-enrolled) do have a developed training program, which focusses on aged care and dementia. Division 1 (registered) nurses believed “that their undergraduate programs did not have a high enough aged care content and that there was little or no focus on dementia care issues (Rosewarne et al, 1997, p.85).

A lack of understanding of dementia meant that staff might interpret behaviour as wilful. Nicholson (2002), a master trainer in quality management systems and an aged care adviser, notes:
Staff submitted complaints and incidents describing sexual harassment by male residents with diagnosed dementia, other reports included physical and verbal attacks by residents. The wording of the incidents suggested that residents were capable of controlling their own behaviour. This belief was verified through a focus group where staff described the behaviours of the residents and blamed them for the stress, they the staff were experiencing. (p.2)

1.4.2. Roles, Hierarchies and Staff Divisions
Briggs (1997), an educator with the Behaviour Advisory Unit of Alzheimer’s Association of South Australia, comments that in all the time she has spent in aged care facilities talking to staff, no matter who is telling their story, there is always a “they” who are the stumbling block to improvements. Staff in her training groups agree “all these suggestions are ok, but not everyone will do them– THEY won’t”.

“They” are the registered nurses, who have no idea what personal care staff have to cope with – “They are always writing”.

“They” are the personal careworkers who go their own way and never read or follow the care plans.

“They” are the kitchen staff who have to get the meal cleared away so “they” can be off on time.

“They” are activity staff who don’t lift a finger to do anything. “They” play all day.
“They” are the directors of nursing or directors of care who can’t manage the budget, understand the care needs of people with dementia, appoint decent staff, or organise a roster.

“They” are administrators who are more protective of the money than if it were their own.

“They” are the standards” who veto absolutely everything.

(p.1)

Nursing homes and hostels, she explains, bring together professionals from different industries with their own tasks and roles. In the traditional model, professionals remain within their roles and are quite protective of role boundaries. Briggs points out that the frustration staff feel is a result of this dominance of task role over the needs of residents.

The tasks controlled by certain professions are also seen to be more important than those carried out by others, and this can lead to conflict about whose task has priority in a given situation, with the focus on professional role rather than patient or resident need. An incident from my own experience as a dance therapist in an aged care facility, written up as a vignette, illustrates how in the midst of professional disputes, the person with dementia is lost.
It had been a session of much warmth and laughter – hugs and teasing. I had just told everyone I would put on some music for us to go around to finish (and for a last hug or whatever interaction would occur). The door opened and A. appeared. I think I asked her if she could just wait a couple of minutes but she said “I need to take G. for his insulin”. I nearly let it go but then thought, wait a minute, surely one minute will not make a difference so I said, “can’t you just wait one minute so we can finish off”. “No”, she said, “the HEAD NURSE is waiting to give G. his INSULIN.” (Note the emotional blackmail – head nurse – pulling rank, you will be in trouble with the authorities; it’s not me who’s saying this, I’m the spokesperson for the powers that be; insulin – we all know that missing insulin can be potentially life threatening – do you want this person to die? And of course – what I’m dealing with are matters of life and death, that is, what’s important. You’re just a diversion). I shrugged my shoulders and moved away – I must have been feeling so angry because I didn’t even do my usual going to a resident who is taken out early and saying a goodbye to him or her. As she went out the door, I thought I overheard her saying “This is more important” – “Not necessarily,” I said loud enough to be heard….(great communication there eh – with us both with our backs “facing” each other?)

Of course, the moment was lost, so my colleague and I had a quieter farewell to everyone.
Later I spoke to the “Head Nurse” – who’s no other than B. – well known and not “head nursery” at all. I asked her if it really would have been a problem to wait one minute – no, she said. I told her about the incident and that really I felt that staff should think critically about whether something really was that necessary at that moment. She suggested that it might be easier to have G in the first session just to avoid any difficulties. It’s o.k. but really why should G be moved around just because we can’t communicate or indulge in power plays.

I’m also struck how this becomes so much a power play. I’ve worked there 5 years and yet a nurse who’s known me for much of that time, still has to play the heavy and can’t actually just work cooperatively rather than insisting on playing such games. I’m also struck by how hard it seems for managers to control these staff. They seem to go merrily on their own way. It’s obvious I’m still angry! The thing is of course that in all this, G has got lost. He was enjoying an experience and was abruptly removed for an insulin shot (to become a patient again) and of course as we staff “fought” over him, lost was the fact that he missed out on a chance to finish off the process in a satisfying way – and nobody asked him! I like to feel I was advocating for him seeing as it is hard for him to say things. Maybe the nurse thinks the same, but maybe she just doggedly follows through on task and obeys the commandment that the medical will rule all.

1.4.3. Poor Staff Communication

This relates in part to hierarchical issues where staff are informed on the basis of role status.

Lintern et al. (2000a) describe communication processes observed during their action research:
The organisation of staff was clearly hierarchical, with care assistants given little opportunity to contribute their opinions or experiences, or be involved in decision making. Staff meetings occurred infrequently, were problem-focused and did not appear to facilitate an open exchange of views and ideas between all levels of staff. Shift handovers occurred between the two qualified members of staff in charge, while care assistants immediately began direct care work. Therefore little information about previous shifts, the well-being of the residents or information about any new residents admitted was communicated to care assistants coming on duty. (p.16)

1.5. Lack of Management Leadership and Support

Lintern et al. (2000a) observed that many care assistants in the home they studied “were concerned about the absence of any induction training and the lack of feedback received about their work and progress. They conveyed the impression of a group which was somewhat uncertain about the direction and appropriateness of its work” (p.16).

There are now much higher expectations of what staff should achieve, and management often seem to have little understanding of what is being asked of care staff and offer insufficient support and training. Packer (2000c) points out that the needs of care workers themselves are being “subjugated in the face of overwhelming demands from the environment in which they work”. Further,
our expectations of the abilities of people with dementia have moved forwards, and yet this changing knowledge base does not seem to have been accompanied by a parallel change in provision for suitable resources, facilities, training and support mechanisms. Care workers, it seems, are expected to deliver much more complex care packages and meet considerable psychological demands upon their own personhood within the same service provision as 10 years ago. (p.29)

1.6. The Institutional Culture of Care

This is an elusive aspect to pin down, yet there is no doubting its reality and its impact, as the vignette below shows. Organisational cultures have a tangible quality which pervades every aspect of organisational activity and can be benign or malignant. The vignette below shows the difficulty one person faced in her attempts to change an institutional culture without management and structural support. It also shows the dead weight of routine, and the need to do things as they have always been done.
The Chair

Christina is a highly trained registered nurse whom I first met at Star of David. She subsequently moved to another aged care facility to become unit manager. By the time I came to interview her, she had resigned from that position. Not only was she highly trained but, from my observations of her at Star of David, she appeared to have a warm, caring relationship with residents. Her experience as unit manager very much illustrates the difficulties in bringing about change and the power of the grass roots staff. On starting this job, she early on encountered some very rigid and obstructive care staff whom she had tried to include in the process of much needed change on the unit—without much success. She told me the story of the chair which had been placed in the office by the previous unit manager. One of the residents came to associate this chair with a toilet, with consequent expected and unpleasant results. The staff were naturally unhappy with this and tended to blame the resident. However, Christina undertook to change the situation by removing the chair to another part of the nursing home and creating a pleasant semi-private space where the resident could sit. Within a short time, the behaviour had more or less stopped. Christina also undertook other things to enhance the life of this resident. Staff thought she was wasting her time and management finally moved her to another ward, probably as a result of staff complaint about this and other changes she attempted to make in resident care. The previous unit manager returned and the chair was returned to its place in the office!

This example shows again how easily the person with dementia gets lost in the midst of institutional and staff conflict.
1.7. **Lack of Importance Attached to the Interpersonal (Relationship and Communication)**

1.7.1. **A Culture of Busyness Around Tasks**

Packer (2000b) talks of the “no-time environment” (p.18), in other words an environment which has time for the physical, visible tasks of care, but not for the less quantifiable, visible aspects of emotional care.

Burgio et al (2001):

Observation of certified nursing assistants’ (CNA’s) work behavior in nursing homes revealed that 53% of observation time was spent in a broader category of resident care, with 11.8% of observation time engaged in staff-resident verbal interaction. (p.449)

They comment furthermore on the quality of staff-resident interactions:

Sadly, positive verbal interactions appear to be as rare as negative verbal interactions in nursing homes (Burgio et al., 1990), where neutral interactions appear to be the norm (Carstensen, Fisher, & Malloy, 1995). (p.449)

What then happens for the person with dementia unable to express his or her needs or to be heard?

The emotional needs of the person with dementia can and do eventually “spill over in an unpleasant way – through incontinence, anger, disruption, sexual disinhibition, or repetitive actions. Ironically, it is only then, when the task has become really unpleasant, that the needs of a person with dementia may be considered “more important” than some other task. (Packer, 2000b, p.18)
Even then, Packer notes, “it is only the physical manifestation of this need that is addressed and not the emotional one” (p.18).

Goyder (2001), whose experience with Joe awakens her to the stories of people with dementia, observes of her nursing practice: “I had always cared for these patients’ physical needs and given comfort where I could in instances of emotional distress, but it had never occurred to me to take seriously what they actually said” (p.16).

Nolan et al. (1995) conclude from their review of the literature on nurse/elderly patient interactions:

A depressing picture emerges in which activity within care environments for elderly patients is extremely limited, with staff-patient interactions being minimal. Such interactions as do occur are predominantly staff initiated, treatment orientated and of short duration. The language used is often of a “controlling” nature (Lanceley 1985), thereby inhibiting patient response. (p.529)

1.7.2. Care Which Controls and Does Things for Residents

Lintern et al. (2000a) note how residents’ efforts to do things for themselves were often “thwarted by carers offering to do it for them”(p.16). However, this was not done out of ill will but rather because staff “perceived that their role was to ‘look after’ the home and the residents and were clearly trying to be helpful (p.16). Residents are under constant surveillance and control. Goyder (2001) writes:
The fat patient is not allowed too much food, the lethargic patient is not allowed an afternoon nap, the restless patient is not allowed to wander and is often restrained in a chair, the lazy patient is not allowed to use a wheelchair but must walk, the incontinent patient is put on the toilet every two hours to avoid “accidents”, the patient who is too loud and boisterous is confined to his or her room, the unsociable patient is not allowed to stay in his or her room and is encouraged to mingle, the smoking patient’s cigarettes are rationed, the dying patient is guarded and the behaviour of the demonstrative patient is curbed…(patients) get used to a lack of choice about anything. Under the watchful eyes of their…carers, patients succumb or submit to a disciplinary control. (p.42)

1.7.3. The Unliked or the Uncommunicative Highly Disabled Receive the Least Attention from Staff

Nolan et al. (1995) note the issue of popularity of patients or residents.

Patients (who) seem to be more popular in continuing care environments are those demonstrating behaviours which are the opposite of those the staff are supposed to be encouraging. Nurses appear to value compliant, cooperative and less demanding elderly patients (Gilliard & Brunston 1984, Robb 1984, Lanceley 1985, Fielding 1986). Furthermore, the socially adept and appreciative patient gets more attention (Gilliard & Brunston 1984, Fielding 1986), whilst those who complain, are unappreciative, “know it all” or lack communication skills, are the least popular (Gilliard & Brunston 1984, Fielding 1986). (p.530)
Parallels can be drawn here with the situation of Joan and of Eva at Star of David (refer Chapter 4).

1.8. Lack of Attention to the Care Environment

Little importance appears to be attached to the care environment as a whole – physical, emotional and social – such that staff will actively undermine efforts to improve it, again probably viewing this as not central to the business of care. Teresi, Holmes and Ory (2000) describe how a study of the impact of an intervention to reduce noise and light at night was effectively sabotaged by staff. Teresi et al. conclude: “These findings, showing the difficulty in implementing the most basic of interventions, highlight the need for sharpened awareness on the part of administrators and regulators regarding the importance of the environment” (p.418).

Where there is attention to the environment, Teresi et al (2000) note that this may be focussed on simple, often technical strategies, as demonstrated in the oft asked question as to which colour is best for people with dementia. “Such questions point to a broader problem – the failure to consider the environment as a part of the big picture that includes both the physical and social environment in a model of person-environment fit” (p.420).

1.9. Exclusion of Families from Involvement in Care

Rosewarne et al (1997) reported that very few aged care facilities involved families in care plan reviews in a formal way, and only 70% involved families informally (during visits). Dementia-specific facilities “were no more likely compared with mainstream accommodation areas to involve relatives directly in either initial care plan development or ongoing care plan reviews” (p.83). The fact that there has been little research into the involvement of families in the care of their relative after entry to a nursing home (Hertzberg & Ekman, 2000) suggests a lack of attention to any possible role for them. Traditionally, families are seen “as a backcloth rather than a part of the nursing process” (Hertzberg & Ekman, p.615).
Louise was aware of the complex web of family interactions which could impact on their relationship to the resident and the home and saw the need to support and encourage families. However, she noted that this was difficult given the pressure staff members were already under in carrying out the day to day care of the resident. *And often those things are sadly overlooked. And there’s no easy way around that and sadly, again, we are not funded for the kind of support, to provide support programs for families which is so important* (Louise/6/22-24).

She noted too, that lack of contact with families meant that staff at times had judgmental attitudes towards them.

### 2. POLICY BARRIERS TO PERSON-CENTRED CARE

All aged care facilities function within a certain regulatory and funding context and they often cite the mandatory requirements of government as a major barrier to developing person-centred care practice. In the following, I will limit the discussion to government policy in the Australian context.

In Australia, aged care facilities are regulated and funded in the main by the Federal Government, so I will focus the discussion on Federal legislation with brief mention of relevant state legislation.

#### 2.1. The Aged Care Act 1997

The current regulatory and funding system was set up by the Aged Care Act 1997, which introduced substantial reforms to the aged care sector. Some of the key changes introduced, described in Angus (2000), were:

- the unification of hostels and nursing homes into a single system referred to as “Residential Aged Care Facilities”
- the development of a single classification system - Residential Classification Scale (RCS) - to replace the Residential Classification Instrument (RCI) and Personal Care Assessment Instrument (PCAI)
• the introduction of accommodation bonds for incoming residents
• the introduction of an accreditation system (The Accreditation Standards Framework) covering the following areas: management systems, staffing and organisational development; health and personal care; resident lifestyle; physical environment and safety systems, but with no requirement for particular staffing levels, skills mix or qualification
• the removal of the mandatory requirement for 24-hour nursing care by registered nurses in nursing homes which “effectively removed the legislative and regulatory requirements for professionally qualified staffing in nursing homes” (Angus, 2000, p.220).

Angus (2000) points out that rather than maintain current funding and have fees for nursing home admission as an extra, the government in fact planned to remove more than half a billion dollars from aged care and substitute this loss of funding with admission fees. She views government practice as very much within “economic market discourse” and as a move “towards a regime of market rationality, incorporating self-regulation through competition, contracts, new systems of accreditation and codes of practice. Part of this process was the distancing of government as the provider and regulator of services” (p.161). This is in line with government’s overall philosophy of withdrawing from social interventionist policies to policies which celebrate the free market and competition as the ultimate form of regulation. “It is a political culture divorced from traditional beliefs in government intervention and egalitarianism” (p.160).

The above provides a broad overview of the act. Its implications for the care of people with dementia I discuss below.

2.1.1. Provision for People with Dementia
At present the special needs of people with dementia are not recognised within the Act, nor is there recognition of the concept of person-centred care. In contrast, the National Service Framework for Older People in the U.K.
(Department of Health, 2001) has a standard on person-centred care (Standard 2) and the Alzheimer’s Society U.K. (2001) has formulated standards for quality dementia, although these have yet to be integrated within government regulations. Thus, the provisions of the Act do not directly address the special needs of people with dementia. Cecchin and Jarrad (2002) highlight one example:

For those who are significantly impaired physically and mentally, “encouragement to participate” (3.7 Leisure interests and activities) is irrelevant. For this seriously impaired group, pleasurable activities that are person-centred could be identified and integrated into care and relationship activities. One example is that of classical music played to soothe a resident who has always loved this music before the onset of dementia. (p.18)

2.1.2. Care Policy Predominantly Guided by Economics

Aged care facilities work within an economy-driven framework. Angus (2000) points out the conflict between economic and nursing practice considerations.

The language of care is displaced with measures of time for “interventions” which assumes that nurses always intervene. What is not factored in the economic discourse is the critical role of watching, waiting, intervening/not intervening. Funding interventions which ignore this important clinical and practical space have consequences for economic, medical and social discourse. Quality of life and care begins here. Ignoring these so called softer non-rational issues is what is expensive to the public purse. (p.236)

At present it is the physical, measurable task or intervention which is recognised and funded. In effect, this means that the medical (defined in
narrow, technical terms) and physical tasks are the recognised work of care. The less tangible, feeling and relationship aspects of care do not exist as far as the legislation is concerned.

Hudson (personal communication, February 2, 2003) takes issue with the focus of the RCS (resident classification scale) which “is about numbers and weightings that depersonalise the resident in order to fulfil funding criteria”. What’s more, it emphasises deficits. Hudson (2000) writes in her doctoral thesis:

> It is the intention of this thesis to hear from within the nursing home community the voices of those who are calling to be known for who they are as persons rather than what they represent as the “institutionalised aged”, defined by their deficits. This kind of knowledge is the obverse of Cartesian objectivism that apprehends reality through reductionist descriptions, leaving no room for transcendence, self-reflection, mystery or ambiguity. (p.17)

It does not pay – literally – to see beyond deficits. Institutions are funded not for enabling residents, but for managing their deficits.

Hudson (personal communication, 2 February, 2003) also points out that at the time of death of a resident, facilities are under pressure to fill the bed immediately, allowing little time for “appropriate respect to be paid to the deceased”.

### 2.1.3. Documentation

There are lengthy requirements for documentation to meet the Accreditation Standards, and this raises two issues. First is the inordinate amount of time staff members are required to spend writing up material in order to ensure funding, time which could have been spent with residents. The second issue relates to the quality of the documentation required which is more about
accountability than a focus on knowing the person with dementia. Documentation which only fulfils government requirements is inadequate from a person-centred perspective.

2.1.4. Quality Assurance
Cecchin and Jarrad (2002) specifically discuss the links between accreditation and quality of care and conclude that accreditation as it stands does not sufficiently guarantee person-centred care. They recommend that a new standard for person-centred care should be added, which “has a focus on knowing the person and applying this knowledge in a meaningful individualised way in every aspect of care” (p.19).

2.1.5. Staff
The legislation talks of appropriately trained staff and does not specify qualifications or training. Through lack of funding and lack of valuing of the work, the staff are poorly paid and with little training. Financial pressures mean that aged care facilities cannot attract better-trained staff, nor do they have the finances to offer much training. “In a market-driven industry, poor wages and hard, heavy, boring distasteful work ensures job “burnout” and a high turnover of staff” (Angus, 2000, p.233). Stressed, overworked staff, who are themselves not treated as persons, will find it difficult to offer person-centred care.

2.1.6. Amalgamation of Nursing Homes/Hostels
With the Aged Care Act 1997 it became possible, if aged care facilities wished, to adopt an Ageing in Place policy such that residents could remain within the same care facility. This is the policy Star of David adopted, a policy which is more complicated than it may at first appear. Sach (2001) argues that Ageing in Place is more than just keeping people in the same room, or same institution, but involves dealing with interpersonal relationships (staff and residents, and residents with and without dementia), financial issues (buying of necessary equipment such as special beds), facilities (separate dementia
unit), care provision which meets complex and differing needs. There are professional issues too, regarding numbers of qualified staff to care for increasing numbers of frail elderly. Ageing in Place, despite benefits (such as avoiding the dislocation of moving to a nursing home), also creates new challenges at the level of physical care and in the social, interpersonal realm. Sach suggests that attention needs to be given to balancing the needs of residents with dementia and those without. According to his research, “if you are to introduce an Ageing in Place strategy into a residential care setting, then the development of a dementia specific unit is highly desirable. Some would suggest it is pre-requisite” (p.37).

3. **SUMMARY OF PROCEDURAL AND POLICY BARRIERS**

It would seem that the implementation of person-centred care in aged care facilities is hindered by a number of procedural and policy issues. At the procedural level there are common issues surrounding priorities of care, and organisational issues to do with leadership, appropriate staffing, teamwork, communication and documentation. Government regulatory and funding practices appear to give little recognition to person centred care practices and are concerned with observable and measurable care, care being defined in terms of services and efficiency in delivering them. Institutions are therefore under pressure to provide the basic physical and medical care, and associated documentation, to meet government requirements. Anything over and above the basics adds to the load and is necessarily the first to go when institutions are under pressure (which is most of the time).

4. **LOOKING BEYOND PROCEDURES AND GOVERNMENT POLICY**

There is no doubt that procedural and policy issues pose significant barriers to the implementation of person-centred care. However, as I reflected on the
experience at Star of David and in other aged care facilities, there seemed to be some other process at work, some other level of barrier. For instance at Star of David, I found myself puzzled at the intransigence of old practices. Even seemingly small changes appeared much too difficult. I felt perplexed and frustrated by the apparent “splits” I observed. Management for example, expressed support and enthusiasm for the new program, without proper support in practice, and at times, they actively undermined the program by requiring that different priorities be met. Some of the appropriate mechanisms or frameworks were in place (meetings, care plans), but were inadequate or were not used for one reason or another. Through my interviews I saw that management and senior staff were aware of much of what was needed, but did not follow through on it. Finally, despite considerable effort at change in the early stages of the program, ultimately much remained unchanged.

It is well known in psychotherapy that splits in perceived reality are the stuff of madness and these splits were certainly maddening and mad-making to me as a researcher trying to understand where the difficulties lay and why all the good will was not translated into an effective program. I constantly moved between excitement at being part of a trailblazing program, and despair at the lack of any real or significant change. Similar paradoxes have been noted by others. Flett (2002) has pointed out how institutions may invest in staff training, but no lasting change may occur in care practice. Nolan et al. (1995) in their study of nurse-patient communication note the contradiction between stated values and action. “The results of the study suggest a paradoxical situation… in that nursing staff report a high commitment to the importance and value of communicating with patients, but in practice accord it relatively little priority” (p.535). While lack of staff is often cited as a difficulty, Kitwood (1997) has written that even where there is more generous staffing, staff do not necessarily spend more time with residents. “Here, where all the conditions are advantageous, it is still common to find that interactions are
brief and superficial; when staff have done their essential duties they tend to chat with each other or find something ‘practical’ to do” (p.87).

Interestingly, even in institutions such as the one where Louise was Director of Nursing and which had gone quite a lot further than Star of David in implementing person-centred care, it required ongoing perseverance and persistence to keep from falling back into old care practices. The intransigence of old ways of practice, that is practice based on the biomedical model, suggests that there are more to the difficulties than mere organisational procedures or government constraints. Despite great enthusiasm for person-centred care in the last 15 years and the plethora of writing on theories and models of person-centred care, facilities where person-centred care is happening remain the minority even in Britain, the hub of the person-centred movement. In her article, Packer (2000a) is moved to ask: “Does person-centred care exist?”

A parallel to this situation may be found in the writings of Plamping (1998) who expresses puzzlement in relation to the lack of real change within the National Health Service in Britain. There is a paper mountain of advice on reforms, restructuring, and managing change. Yet many behaviours do not change. The puzzle is why the NHS has been so unchanging, given the barrage of attempts to ‘reform’ it” (p.69).

Plamping (1998) concludes that the National Health Service remains essentially unchanged because “most insiders have not come to want the NHS to be different” (p.69). She proposes that:

In this anniversary year it may not be enough simply to restate values and purpose. A more fruitful approach may be to focus on the behaviour of this complex system and to try to understand what creates the internal dynamics and maintains enduring patterns of order and behaviour. (p.69)
The roots of resistance to change in the National Health Service, she believes, lie within its guiding principles and assumptions.

I would suggest therefore that procedural and policy issues represent only a partial explanation of the difficulties of adopting person-centred care practices and that a more complete explanation must include the frameworks of thought and belief which underlie current practice and which often sabotage efforts to change it. An exploration of these “values” barriers, and the interface with procedural and policy barriers, will I believe account for the resistance to change and explain why the model of person-centred care remains an ideal outside the scope of many aged care facilities.
VALUES AS BARRIERS TO PERSON-CENTRED CARE

In this chapter, I will discuss the values, thinking and beliefs, which I have suggested represent another level of barrier to person-centred care in dementia, and their influence on care practice. However it is important in the first instance to understand the power of society’s accepted values and their role in maintaining “enduring patterns of order and behaviour” (Plamping, 1998, p.69). As a preface therefore to this discussion, I will introduce two concepts from the writings of Bauman (2001), namely society as a factory of meanings, and ideological hegemony.

1. SOCIETY AS A FACTORY OF MEANINGS

All societies, in their endeavour to make sense of the world, create certain understandings of the world and attribute certain meanings to it. Society “is another name for agreeing and sharing, but also the power which makes what has been agreed and is shared dignified” (Bauman, 2001, p.2). That understanding then becomes “reality”. Cunliffe and Jun (2002) note that such understandings have substantial power over intellectual and social practice because they form the basis for defining, judging, and valuing others; what is “good” practice; who are “good” performers; and what and who will be included and excluded because they do or do not fit the generally accepted norm of “rational standard”. (p.4)
2. IDEOLOGICAL HEGEMONY

These agreed understandings or shared meanings may become dominant, to the exclusion of other ways of understanding. Bauman (1997) calls this “ideological hegemony”. While we are free to make choices, these choices are within the circumscribed limits of what is agreed upon in society. The dominant ideology requires “conformity, passivity and inevitability” (Saul, 1997, p.39). Only some will be prepared to criticise; the rest will feel the inevitability of the dominant ways of thinking and doing. Fleck (1935/1979) observes: “Whatever is known has always seemed systematic, proven, applicable, and evident to the knower. Every alien system of knowledge has likewise seemed contradictory, unproven, inapplicable, fanciful, or mystical” (p.22). Attempts to step outside the accepted limits of the dominant ideology will be greeted with “it can’t be done”, “it’s too hard”, “it’s unrealistic in our present climate” or “it’s mad to try it”. As Bauman points out, “‘Mad’ are only the unshared meanings. Madness is no madness when shared” (p.2).

Thus the ideology which is embraced by a society is powerful in its feeling of inevitability and “truth” and thereby excludes other ideologies or value systems. It becomes “self-sealing” (Cunliffe and Jun, 2002, p.4). Furthermore, “once a structurally complete and closed system of opinions consisting of many details and relations has been formed, it offers constant resistance to anything that contradicts it” (Fleck, 1935/1979, p.27).

Merton (1957) takes the argument further by pointing out that hegemonic beliefs become “self-fulfilling prophecies”, which have very real, practical impact. He reminds that
men respond not only to the objective features of a situation, but also, and at times primarily, to the meaning this situation has for them. And once they have assigned some meaning to the situation, their consequent behaviour and some of the consequences of that behaviour are determined by the ascribed meaning. (p.421)

Merton gives as an example the assumption that “negroes” (in the terminology of the 1940s) were not as intelligent as “whites” and not educable. This resulted in educational opportunities being withheld, thereby reinforcing the original prejudice. What was in essence a prejudice and a myth in fact created reality. It is easy to see the connection here to the assumptions made about the behaviour of people with dementia. In these situations, belief “father(s) the reality” (p.424).

All societies are blinkered in the sense of preferring certain explanations of the world to others. However, Saul (1997) declares that our present day society is particularly addicted to ideologies and has foreclosed on questioning and conscious living. We are the “unconscious civilization”. “The overall effects on the individual are passivity and conformity in those areas which matter and non-conformism in those which don’t” (p.3). That Western cultural norms have become all pervasive and exert global dominance adds to persuasiveness and inevitability.

The concept of ideological hegemony therefore suggests that society’s meanings have solidified into an unquestioning acceptance, passivity and a bending to the inevitability of the status quo. Difficulties and contradictions within the accepted system are rarely scrutinised, while difficulties implementing change which goes against the accepted system are seen as proof that such change is not possible in the “real” world.

I would suggest that the old care practices are maintained by a number of hegemonies of thought and belief which have come to define a reality of what
is and is not possible in the care of people with dementia. It will be important therefore to understand the nature of this thinking and belief.

3. WESTERN MODES OF THOUGHT
In order to identify those thoughts and beliefs which are hegemonic in our society, it will be necessary to look briefly at key points in the development of Western philosophy, namely the philosophy of the ancient Greeks and the Enlightenment. The ways of thinking which developed have in turn framed the key structures in European society – legal, medical, political and economic – and influenced how we as individuals and communities think and what we do.

3.1. The Greeks
The roots of Western philosophical thought may be found in Greek philosophy.

In spite of dramatic transformations over the millennia, such core conceptions as truth, reality, certainty, cause, particularity, and self and other have shaped the way we human beings think, talk, and even dream about thinking, speaking, dreaming, and the infinity of other things we do and experience. (Newman and Holzman, 1996, p.14)

It is a system of thought grounded in dualisms. Plato, in positing man as epistemological perceiver and the world as perceived, suggests a “fundamentally dualistic world view that, together with varying forms of mediating between the duals, has dominated Western thought as ideology ever since” (Newman and Holzman, 1996, p.20). They see this dualism as not just accidental, but as “structurally necessary” (p.20) within Western philosophy. This “gave rise to systems of thought that contain their own particular dualities and that, although born in the West, have come (for better or worse) to rule the world: religion, politics, science and technology, and
psychology. (Newman and Holzman, p.2). The centrality of dualism was not just accidental but “structurally necessary”. Within this dualism, man as epistemological perceiver (Newman and Holzman point out that women were not even considered) took on ever-increasing importance, the beginnings of the peculiarly Western emphasis on the individual. Western religion – Christianity – focussed also on the individual in relation to God and on individual salvation and survival. The cult of the individual is very much a child of the West.

For the purpose of this discussion, the next historically significant date comes with the Enlightenment where most of these ideas came together in a powerful tidal wave of reason. While the Enlightenment is rightly seen as a turning point in Western cultural history, most of the ideas were already present in the philosophy of ancient Greece.

3.2. The Age of Enlightenment

The Enlightenment (end of the 17th Century to the end of the 18th Century) represented a turning away from thinking and action governed by religious beliefs and superstition, towards reason and a conviction of the power of human beings, through reason, to control their world (Lupton, 1995). Science based on objectivity, reason, and empirical fact was the sole means to real knowledge. “The uncovering of truth using rational thought, scientific method, experiment and calculation was believed to be the key to human progress” (Lupton, p.21). The change in the constitution of knowledge may be summed up as representing a shift:

From the Oral to the Written: formal logic was in; rhetoric was out.

From the Particular to the Universal: general principles were in; particular cases were out.
From the Local to the General: abstract axioms were in; concrete diversity was out.

From the Timely to the Timeless: the permanent was in; the transitory was out. (Toulmin, 1990, p.30)

Reason also became the defining characteristic of human beings; it was what made us distinctly human. “Je pense, donc je suis” – “I think therefore I am” – was the ultimate conclusion of Descartes as he tried to find what was above doubt, thereby asserting the primacy of reason in our knowing and in our being. “And since reality – our physical existence – can only undermine that certainty, we define reason and thought as something above the corporeal” (Saul, 2001, p.286). Reason was indeed a symbol of the human being’s rise from the darkness of superstition and ignorance, to supremacy and the ability to control his or her environment. To be human was to be a rational being who could rise above the frailty of body and the messiness of life.

At the core of the Enlightenment then were the primacy of reason as defining human beings and the civilised society; the scientific method as the method of choice to gain knowledge; the emphasis on the autonomous individual; and a dualist view, separating mind and body, reason and emotion, subjectivity and objectivity.

These remain at the heart of Western culture today and indeed have been taken to extremes, such extremes that Saul (1992) declares that Enlightenment ideals have in fact been deformed.

3.3. Modern Deformations of Enlightenment Ideals

Enlightenment thinkers saw reason as giving birth to a new “enlightened” and humane society. However our attachment to reason has become ever more encompassing, far beyond what those early philosophers would have imagined or even possibly agreed with. It has far outstripped other ways of knowing.
Reason began, abruptly, to separate itself from and to outdistance the other more or less recognized human characteristics – spirit, appetite, faith and emotion, but also intuition, will and, most important, experience. This gradual encroachment on the foreground continues today. It has reached a degree of imbalance so extreme that the mythological importance of reason obscures all else and has driven the other elements into the marginal frontiers of doubtful respectability. (Saul, 1992, p.15)

Saul is right, I believe, to invoke the power of myth because reason, narrowly defined as logic, has indeed assumed a mythological importance and status. As a society we have elevated reason as the sole means of knowledge. This ultimately is a weakness. “What seems to be missing are the mechanisms to reach out easily to find what other qualities have to offer” (Saul, 2001, p.286), other qualities such as intuition, imagination, common-sense. Reason by itself tends to simplification and delusions of certainty. “It has produced a system determined to apply a kind of clean, unemotional logic to every decision and this to the point where the dictatorship of the absolute monarchs has been replaced by that of absolute reason. The development and control of intricate systems for example has become the key to power” (Saul, 1992, p.20). What was to lead to a more humane, just society has instead created a mechanistic and anti-human society.

Rationality exists in a linear, causal, reductionist universe. “Deformed rationality has become a life-preserver for those afraid of reality and complexity “ (Saul, 2001, p.287). Our society has a quite pathological need for certainty, answers and above all control. We seem unable to look critically at the kinds of actions based on so-called rational thinking. “Our society contains no method of serious self-criticism for the simple reason that it is now a self-justifying system which generates its own logic” (Saul, 1992, p.21). As Saul points out, reason working in isolation itself becomes irrational,
a view shared by Damasio (1994), who has studied the relation of reason and feeling from a neuroscientific perspective.

The Western focus on the individual has also been deformed. Western thought and culture, in contrast to Eastern thought, has long emphasised the individual, but in the past this did not exclude notions of the individual within supportive networks of family and community. However, in the last century the emphasis on the individual, autonomous and in control, or to quote Saul (1997), “a single, ambulatory centre of selfishness” (p.2), has been raised almost to a religion. The very concept of society itself has been rejected (by former British Prime Minister Thatcher, for instance). Thus, “user pays” means we contribute only to what we ourselves need or want without any concept of contributing to the communal good. Saul (2001) considers it a delusion

that we can exist outside the whole. We convince ourselves of this in spite of being begot by others, begetting others, living thanks to the consideration of others, the self-control of others, the bridges built by, bread baked by, words written by others. By the other. (p.297)

This emphasis on autonomy means, as Bauman (2001) points out, we now have unprecedented freedoms, though these are not in fact accompanied by the power to control the resources we need to exercise these freedoms. If we fail, we alone are to blame. To be dependent – whether unemployed, ill or disabled – is to be dysfunctional and an affront to a society of independent, autonomous individuals. Whereas in some cultures the concept of an individual apart from the community is inconceivable, in Western society the mark of a functional individual is independence and having control over one’s life choices, without recognizing that not all have the personal or material
resources to exercise such control. Individualism, control and choice are some of the watchwords of our culture.

These ways of thinking are embedded in formal structures of society and in common societal and individual attitudes, so to complete this examination of the meanings within which dementia care practice is carried out, I will look at some of the bearers of societal meaning relevant to it, namely the biomedical model and the more recent development of neo-liberalism.

4. **THE BIOMEDICAL MODEL**

4.1. **Theoretical and Philosophical Bases**

“Our diagnostic and therapeutic method, the structure of our profession, and the structure of the health care system are products of the Enlightenment” (McWhinney, 1995, p.1).

The success of the biomedical model can be attributed in large part to its alignment with science, scientific knowledge being knowledge which is

  instrumental, defined, and valued as a means to produce certain ends….Knowledge that matters is impersonal, public, productive, and empirically verifiable. Knowledge that is personal, tacit, experiential, or intuitive is hardly recognized as knowledge. (McWhinney, 1995, p.7)

Nettleton (1995, p.3) has listed five assumptions underlying the medical model, and it is easy to see how these have grown out of rationalist, Enlightenment thinking: “mind/body dualism”, “mechanical metaphor” (the body can be repaired like a machine), “technological imperative” (an over-emphasis on technological interventions), “reductionist” (explanations of disease focus on biological changes to the relative neglect of social and psychological factors), “doctrine of specific aetiology” (influenced by the germ
theory of disease which assumes that every disease is caused by a specific, identifiable agent).

Just as the dualisms referred to by Newman and Holzman (1996) pervade Western thinking, so are they evident at many levels of the biomedical model. The dualistic split of human beings allows for different functions to be addressed separately such that “our world is now dominated by these ‘puny boundaries’ between mind and body, biological and psychosocial, fact and value, subject and object, observer and observed” (McWhinney, 1995, p.8). The person can be divided into physical (the measurable and observable – the “real”) and psychosocial (which may be acknowledged but is not considered crucial). Buber (1965) talks of the impact of this kind of thinking on how one looks at or views the other person:

This look is analytical, or rather pseudo analytical, since it treats the whole being as put together and therefore able to be taken apart....This look is a reductive one because it tries to contract the manifold person, who is nourished by the microcosmic richness of the possible, to some schematically surveyable and recurrent structures. And this look is a deriving one because it supposes it can grasp what a man has become, or even is becoming, in genetic formulae, and it thinks that even the dynamic central principle of the individual in this becoming can be represented by a general concept. An effort is being made today radically to destroy the mystery between man and man. The personal life, the ever near mystery, once the source of the stillest enthusiasms, is levelled down. (p.80)

Within the biomedical model there is the further dualism of the professional and the patient. The professional must be objective and keep a distance from the patient. The professional has the answers; the patient does not. The
patient’s only role is to be passive and compliant while the professional takes
to charge and effects the cure. A disease view of illness supports this stance,
since emotional issues, the patient’s experience of illness and his or her
relationships and social environment are deemed irrelevant or at least much
less relevant than the physical aspects. The language of medicine, with
consequent labelling of pathology, also serves to distance the professional
from the patient and tends to a view of the patient not as a whole person but
as a carrier of pathology. The clinical method has moved “towards increasing
levels of abstraction and an increasing distance from the experience of illness”
(McWhinney, 1995, p.8). Within the institutional context, routine represents
another mode of professional control. “Elaborate rituals have been devised
in order to distance the nurse from the emotional life of the patients;
detachment from the job is achieved through routinization of simple self-care
tasks” (Kitson, 1987, p.323). Good patients are compliant and play their part
in the smooth running of the institution.

Mitchell (1990) in documenting her change from the medical model of
nursing practice to a more person-oriented model (Parse’s theory of human
becoming) notes: “I changed in practice from being a diagnostician, informer
and environmental manipulator to offering self as a true presence” (p.173).
The concept of offering one’s self in a professional encounter is alien – not to
mention unprofessional – within a strictly biomedical paradigm.

Neuwirth (2002, a Professor of Medicine, believes that traditionally, medicine
has included more humanistic strands, but that modern medicine had moved
away from this tradition. He remarks how the humanistic attitudes and
behaviours he was teaching students were not finding their way into the
hospitals or clinics. “It seems as if these compassionate behaviours are being
extinguished by a lack of incentive or reward in the system. Valued and
rewarded instead are academic acumen, technical knowledge and skill,
business savvy and financial success” (p.77). He goes on to say:
We have forgotten that medicine is a healing profession, not a technological one, and that the contribution of a doctor adds up to more than the sum of his or her knowledge and skill. We have forgotten that the patient, as a person, is far more important than the illness; that the illness is far more than the presence of a disease; and that when the cure of disease is not possible, as is so often the case, the humanistic care of patient and family fosters hope and healing. Our society has become myopic in its focus on technical treatment to the exclusion of how we might treat each other as sublime human beings. (pp.77-78)

Neuwirth rightly points to the increasing dominance of technological rather than humanistic approaches to medical practice. However, my earlier description of the biomedical model would suggest that its underlying principles and assumptions (mind-body dualism, labelling, professionalism) mediate against whole person approaches.

4.2. The Hegemony of the Biomedical Model in Health Care

The biomedical model, in aligning itself to scientific knowledge, early on staked its hegemony over other forms of healing. “Medicine thus claims to offer the only valid response to the understanding of disease and illness” (Nettleton, 1995, p.3). The health system as a whole is hierarchical “Occupations are organised into an hierarchical structure entailing huge disparities in power, status and ultimately rewards for their labours” (Willis, 1994, p.12). It is a system where everyone should know and keep to his or her place and professional boundaries are passionately defended. Doctors are at the top of the hierarchy, which gives them levels of authority and autonomy unknown at the lower levels. Kitson (1987) discusses how the status of nursing has suffered in comparison with that of the medical profession because it is viewed as not wholly scientific. She notes that the more intuitive
aspects of nursing have been dismissed, “being viewed with suspicion, reckoned to be unimportant, unscientific, unreliable” (p.323). Non-medical health professionals are seen as “allied” or complementary. To raise the status of one's “allied” profession requires that one becomes more “scientific” in language, theoretical basis and practice. For example in my own field of dance therapy, which is grounded in a holistic understanding of human beings and a rejection of mind-body dualism, some dance therapists describe the dance therapy process as treatment, and many dance therapy researchers continue to use a natural sciences model of research in order to prove the efficacy of the work (though there are some using qualitative methods –Hill, 1995 – and developing “artistic inquiry” – Hervey, 2000). Science remains the gold standard of knowledge, and the biomedical model the gold standard of health care.

After initially dismissing alternative therapies, medicine has seen that it is in its own best interests to open up to some of these alternatives and has begun to encourage research into their efficacy, the research of course being within medical parameters. Nettleton (1995) describes this change as “a shift from open hostility to one of reluctant co-option” (p.210). This clearly is an attempt to control by making its rivals conform to its standards, and probably fall short of them.

Of course, doctors are beginning to recognise other aspects – social and environmental influences for instance – but “these non-specific elements of health care are, nonetheless, according to the medical model, optional extras, fringe benefits to the central scientific agenda of medicine” (Fulford, 1996, p.4). While it may be denied, “yet it is evident, for example, in the still hierarchical organisation of medical practice around doctors, in the almost exclusively scientific basis of medical training, and in the priorities of medical research funding” (p.4).
Despite the challenges of alternative therapies, the constraints of the more recent economic intrusion into the autonomy of the medical profession and rumblings within the profession itself, in practice the medical model retains its hegemony as the ultimate authority on health. There would indeed appear to be an increasing medicalisation of every aspect of life. What was once viewed as normal though perhaps eccentric, strange or different is now given a medical label, for example the epidemic in recent years of Attention Deficit Disorder (Breggin, 2001). Another example is the labelling of senility, at one time considered a natural part of ageing, as Alzheimer’s. This spread of the medical to more and more aspects of life also meets some of the needs of our society, namely the security offered by a model which can contain the complexities and messiness of human suffering. It is deeply entrenched in our thinking that finding a medical label somehow offers us reassurance that we are in control, or at least our doctors are, even if the label does not point to the means of cure. Even when the medical system does not have the answers, they offer the security of “managing” the problem. The medical establishment has promoted the myth of having all the answers – certainly – but the community itself has colluded in this. As a society we look to doctors to provide the answers, and these are inevitably medical answers.

4.3. Changes Within the Profession

In recent years an interest has developed in patient-focused care by general practitioners and individualised nursing care. Not all advocates of these approaches would appear necessarily to be offering necessarily a serious challenge to the biomedical model. At one level, it may simply mean a growing awareness of consumer power and the requirement to give “customers” the service they want. Medical practitioners are starting to take lifestyle factors into account and some more emphasis is being placed on interpersonal skills and techniques for doctors. However, none of this seriously questions the underlying assumptions of the medical model. McWhinney (1995) in talking of person-centred medicine suggests that to
significantly change the medical model of practice requires a major shift in values and ways of thinking: to remove the emphasis on cure, and respond to suffering; to switch “attention from the linear notions of cause and cure to the holistic notions of function, care, context, support and healing” (p.14); and to give up the dualistic language which gives the impression of people divided into compartments. Therefore,

it is not simply a matter of learning some new techniques…nor is it only a question of adding courses in interviewing and behavioral science to the curriculum. The change goes much deeper than that. It requires nothing less than a change in what it means to be a physician, a different way of thinking about health and disease, and a redefinition of medical knowledge. (p.15)

McWhinney (1995) recognises that what is required is a fundamental shift in the assumptions and values underlying the biomedical model. However, as earlier discussion has shown there is much which continues to support the dominant assumptions underlying the biomedical model, both within the medical community and within society as a whole.

The biomedical model however is no longer the sole determinant of health care, and has had to contend with the rise of the market-driven economy and increasing intervention by non-medical people in the management of health and aged care services. This brings us to the other dominant ideology of our society and the values it brings to health and aged care.

5. **NEO-LIBERALISM**

In chapter 7, I discussed the Aged Care Act and the constraints it imposes on institutions attempting to implement person-centred care. This legislation must be seen within the context of the global rise of neo-liberalism in the West from the 1980s onwards and the assumptions inherent within it. Turner
(1995) describes it as a “new right-wing economic doctrine of radical marketization, deregulation and devolution of responsibilities” (p.219) and points out the paradox of a system promoting the withdrawal of government from many of its social welfare functions, while in practice increasing government regulation and control.

According to Hancock (1999, p.57), there are three core assumptions within this neo-liberal ideology:

- first, the commitment to a limited role for government in creating the legal and institutional setting for the efficient functioning of the laissez-faire economy – what Campbell (1997:93) refers to as the “build-down” of government;
- second is the freedom of individuals from government coercion except when individual rights are under threat and, relatedly, the assumption of individual rationality and the centrality of public (rational) choice theory to this rationality (Emy and Hughes, 1991:385); third is the assumed benefits of unregulated voluntary market transactions to optimal wealth creation, distribution and efficiency.

In essence this has meant a progressive withdrawal of government from its previous role of ensuring equity in society and a move towards dependence on market forces, whose role as an independent and “just” regulator of society appears to be an unquestioned tenet of this belief system. Interestingly, while in Britain this change was brought about by the conservative Prime Minister Thatcher, in Australia it was the Labour Party that engineered these changes (Hancock, 1999). It has been an ideology therefore adopted by both liberal and conservative governments.

I will discuss its impact on health services in terms of the new managerialism consumerism and the closely related area of risk management.
5.1. The New Managerialism

The term “new managerialism” (Nettleton, 1995) arose in the 1980s, with this neo-liberal culture based on the principles of business and the rise of managers. Nettleton describes its effect within the National Health Service in Britain, where a more interventionist, active style of management was brought about and the autonomy of doctors in making health care decisions was challenged:

> With this new type of management the structures of control in the Health Service have shifted and managers have tackled head-on the Government’s crucial dilemma, that is, “how to impose its political priorities on an organization where professional judgement determined the local delivery of services” (Cousins, 1988, p.211). (Nettleton, 1995, p.219)

The emphasis therefore has shifted to efficiency in delivering services. In order to do this, there needed to be measures of “activities and outputs” (Nettleton, 1995, p.219). Note the business language. Thus came into being performance indicators (PIs), quality assurance (QA), quality adjusted life years (QALYs), the aim being “to increase productivity and efficiency of clinicians by encouraging them to consider factors other than their clinical judgement when making decisions” (p.219). The emphasis in the health care field is on “evidence-based” practice, practice which can justify itself on the basis of proven outcomes. A similar process has happened in Australia. Hancock (1999, p.53) cites the five key principles for public sector reform, outlined in the Victorian Management Improvement Initiative (1993):

- clear accountability for results
- empowering consumers of public services (through service commitments and choice, by funding consumers where possible)
• minimising government bureaucracy for consumers (through defining government’s core functions and separating policy from service delivery)
• preference for market mechanisms in the provision of public services
• professional and business-like management of public agencies (through devolution, risk management, performance incentives and improved financial management and reporting systems).

This business imperative has reached not only into the health care system, but into disability services and the education system, requiring essentially social service organisations to function as businesses with a high priority on efficiency and cost-saving. It has meant that practitioners and clinicians have had to reduce their work to simple measurable “interventions” which can be documented in “input /output” terms and assigned a dollar figure, patients now being “commodified ‘revenue-earning units’” (Hancock, 1995, p.56). In relation to welfare practice, but with equal application to the care context, Bauman (2001, p.79) quotes van der Laan: “moral assessment has been replaced by the procedural execution of rules”. It has also changed relationships within care. Senior nurses are now unit managers; patients or residents and their families are stakeholders.

The business model does not sit comfortably within a health nor indeed a social welfare framework. In an article in the Melbourne Age, Father Peter Norden, policy director of Jesuit Social Services, is quoted concerning bureaucratic requirements and the actual work of a centre which helps young offenders:
You don’t measure your success on the numbers, but by what you’re actually communicating to this person; a sense of care and respect and belonging. And out of that, potentially, would come a change in behaviour. (Bureacrats) would say ‘you’ve been working with this person too long. Why have you got so many people who are still hanging around after two years?’ And we say ‘Well, it’s a bit like family, you know?’ (Kissane, 2003, p.4)

In the same article, Jan Carter of Meals on Wheels describes the conflict between government requirements and the core work of welfare:

People were paid to deliver in the shortest possible time. They were leaving meals on old people’s doorsteps but part of the point of it all was the chat between the person delivering and the old person. So much of what community agencies do is hard to specify; the whole relationship-building and relationship-maintenance aspect of agencies’ work was completely ignored. (Kissane, 2003, p.4)

The central concerns of the new managerialism may be summarised, then, as: “audit, accountability, organizational rationality and efficiency” (Nettleton, 1995, p.221). This is grounded in a value system based on money and where arguments for humanistic values have no place. While the person has little standing, it may seem that the “consumer” has experienced an increased visibility in the market economy, and this is discussed below.

5.2. Consumerism

If a business model sets the agenda for healthcare, then it follows that people who receive health services are considered consumers of services – customers – who are able to have choice of services offered by competing interests. In
the past few decades, there has been a move towards consumerism and away from paternalism. “Patients are increasingly being treated as consumers who make demands and have needs which the Health Service must strive to meet” (Nettleton, 1995, p.248). She goes on to identify what this means in practice:

- the maximization of patient choice; the provision of adequate information; raising the standards of health care;
- ensuring the quality of services by taking into account the views of consumers; carrying out surveys to ensure consumer satisfaction; developing tools for the assessment of needs; reducing waiting times for treatment and encouraging consumers to complain if they are not satisfied with the service they receive…It is about the rights of the individual consumers rather than collective representation and participation. (Nettleton, 1995, p.249)

This can sound very positive for consumers, but “indeed, the emphasis is more on customer care than on ensuring that people receive adequate health services as of right” (Nettleton, 1995, p.249). Achieving customer satisfaction is not necessarily the same as offering good and equitable health care.

It is also questionable, just how real the choices are and how widely available (for example, for those who cannot pay). Winkler (1987) describes this approach to consumerism as the “supermarket model” of consumerism, which allows choice over superficial matters but not over the essentials of health care. Consumers may be consulted through multiple surveys, but there are few mechanisms to ensure managers act on them. “In sum, consumers may be consulted but they cannot participate, that is, they can express their views but they cannot in themselves influence decision-making” (Nettleton, 1995, p.250). Winkler concludes that “this model is a ‘harmless version’ of consumerism – it requires little serious change, but much public visibility. It is about the appearance, not substance, of change” (p.1).
The mantra of the consumer’s right to choose also assumes the consumer has the means, skills, abilities and, importantly, a context wherein they can take advantage of the choices offered. The kind of consumer focus inherent in this ideology “shies away from structural explanations (based on class, gender or race/ethnicity) which would point out how particular individuals or groups are better positioned to maximise outcomes for themselves” (Hancock, 1999, p.59).

This is an especially relevant point for people with dementia. As Goldsmith (1996) has shown, it is certainly possible for some people with dementia to give feedback on the care they receive. However, given the unequal power ratio, it is questionable how effectively “consumer pressure” can be applied either by the person with dementia or his or her spouse. Real, as opposed to apparent, participation and choice need be facilitated in the context of relationship. Talking about people with dementia in care facilities as “consumers”, I believe, grossly misrepresents their position and their power.

It is not hard to see the relationship, albeit a much deformed one, of the neo-liberal ideology to Western reductionist models of thinking described earlier with their emphasis on reason, the individual and a lack of recognition of the complexity of human action. Hancock (1995) notes the “continuing dominance of beliefs in the ‘rationality’ of the biomedical model and of beliefs in the ‘rationality’ of the market, driving health reforms, policy development and service delivery” (p.56). In other words, the biomedical and neo-liberal ideologies set the priorities for health services, with the result as Hancock further notes of “continuing dominance of acute care and fears of further marginalisation of health promotion, illness prevention and traditional community health programs” (p.56). While at one level neo-liberalism has challenged the autonomy of the medical establishment, at another it serves to reinforce medical hegemony in health service provision. If anything, the neo-liberal agenda has emphasised the worst aspects of the medical model, removing the humanistic strands which in practice have been part of a
biomedical approach, even if rarely overtly celebrated. Together these ideologies and their associated values represent a huge barrier to person-centred approaches.

6. THE RISK SOCIETY

As a society, we have become more and more obsessed with risk and the minimization of risk (Beck, 1992). Yet it is no longer about specific dangers to individuals, but rather an amorphous abstraction of a number of factors rather than a specific danger (Turner, 1995, p.227). Nettleton (1995, p.57) cites Douglas (1986), who “notes, risks ‘clamour for attention; probable dangers crowd from all sides, in every mouthful and at every step’”. The response to this lies in increasing control and regulation, and attempts to minimize risk. In the health field this involves increased surveillance of health behaviours, as well as increasing requirements to document and to protect against any possible risk to or comeback from consumers. Risk is no longer seen as a potentially constructive part of life, which indeed is part of being a person (“the dignity of risk). Rather it is to be avoided at all cost, even at the cost of the person’s sense of wellbeing. Hudson (2003) notes that the emphasis on risk “focusses on the deficits of people while ignoring their potential”. Moreover, she asks:

Why is there no discussion of risk in relation to emotional, psychosocial, and spiritual matters? What if this person dies without her wishes and dreams ever being explored? What if that person dies without his deepest religious longings ever being articulated? (p.218)

She goes on (p.219) to quote Nay (2002): “Overzealous risk management may protect a physical body from bruising but it may also damage irreparably the already vulnerable human soul.”
It seems that our concern for risk is limited to the physical, and at times at the expense of the emotional, psychological and spiritual realms.

7. COMMUNITY ATTITUDES
The description of the Western mind-set above suggests that the valued person in society is autonomous, rational and productive.

This clearly presents then a problem for those who do not measure up. It is no surprise therefore that the elderly have increasingly been marginalised in society. While ageism is merely another manifestation of Western thinking rather than a separate ideology, its impact on the care of older people and particularly those with dementia, warrants separate discussion.

7.1. Ageism
It was only in the 19th Century that aged people came to be seen as a discrete group characterised as needy and dependent, in other words, a problem (Hockey, 1990). With the ageing of the baby boomers, countless articles now warn of the bulge in the ageing populations accompanied by an increase of epidemic proportions of Alzheimer’s disease. Apart from better off retirees who can be consumers of “lifestyle”, older people are rarely seen to offer anything to society. In the main, the ageing population represents a potential burden and a threat to the economic wellbeing of the community.

Perceptions of ageing and aged people tend towards stereotypes, most of them negative, and these are evident already in children (Thomas, 1992). Minichiello, Browning and Aroni (1992) list some of the common stereotypes:

- All older people are sick
- Most older people live in institutions
- Old age is a time of helplessness and hopelessness
- Older people behave like children
• Older people have little to offer society
• All older people are depressed
• Older people live alone and are lonely
• Older people are all alike
• If we live long enough we will all become senile. (p.2)

The elderly are seen as being “conservative, passive, weak, dependent and lacking personal acceptability” (Thomas, 1992, p.84). The greatest negative about older people is simply that they are old, and ours is a society which puts youth above all else. Youth is, after all, a time when one can live with the illusion of invincibility. Once we ourselves age, our response is either to give in to the stereotype of ageing, or to fight against it by starting a busy schedule of gym sessions, physical makeovers and plastic surgery. Oberg (1996) points out that even seemingly optimistic perspectives on ageing – he cites Kaufman’s “ageless self” concept – deny the reality of ageing, which must include an ageing body. Thus older people will talk of the spirit remaining young despite the bodily ravages of ageing, which ultimately reinforces the negativity associated with ageing.

Either way then “the optimistic and pessimistic views (of ageing) share a premise that “old age is affliction” (Hillman, 1999, p.xviii). On occasion one reads of the “odd” older person who amazes everyone by going bungee jumping. This is celebrated – albeit somewhat patronisingly – but mainly as the exception which proves the rule. Hudson (2002) has pointed out that while it is important to acknowledge those older people who are still active and achieving, this can have the effect of further distancing those who are dependent from mainstream society. The elderly themselves fear dependency, which is understandable as there is no positive image of dependency. To be dependent in this society is absolutely to be feared.

There is then a stigma associated with being old, and people with dementia who have the stigma of that condition, are doubly stigmatised. Goffman
(1965) notes that, where people are stigmatised, whatever they do is
considered a symptom or function of their disability. They get talked to
differently (infantilising, bullying, talked about) and they are treated
differently, for example having everything done for them so that the abilities
they do have fall into disrepair. When they do something “normal”, the
actions “excite the same kind of wonderment inspired by a magician who

Ageing stereotypes also permeate the attitudes of health professionals.
Minichiello, Browne and Kendig (2000) observe in their study of ageism that
health professionals are “a major source of ageist treatment” (p.253). “For
example, staff in hospitals often raise their voices in normal conversation with
older patients because they assume that, being older, they are probably hard
of hearing and ‘going a bit silly’” (Minichiello et al., 1992, p.2). Minichiello et
al. (1992) also note that doctors, paramedics and so forth are likely to make
more heroic efforts to save the young than the old (p.2).

Ageing has also become increasingly associated with death. (In previous
centuries, death was more likely to be associated with the very young.) We all
die and many or most of us will age, and these are uncomfortable realities in a
society which is uncomfortable with death, associates ageing with death and
puts youth on a pedestal. Death is a challenge to our notions of autonomy
and control. The aged, the dying, therefore need to be kept separate. Hockey
(1990), in talking of the distancing of death in our society, describes her
experience when her grandfather died, “Closer and more consistently
accessible than either parent, he made a rapid, invisible and emotionally
unremarked departure” (p.1). For a society which is so open about much of
the intimate details of human living, we are remarkably coy about death.

Walter (1994) notes “that the impact of death on society is usually reduced by
reducing the social importance of those who die” (p.50). Social death
therefore occurs before physical death. Since death is now associated more
with ageing, “most of our own society’s dying members are elderly, and it is no surprise that we treat them in as cavalier a fashion as our ancestors treated their infants” (p.51). It is little wonder that if one is old and is labelled “demented”, it will be easy for one’s personhood to be lost.

These then are some of the meanings which have been created within Western Society, meanings which are implicit in thinking and action in our society, including key institutional structures such as politics and health, as well as contributing to individual psychology and professional attitudes. They are not necessarily and always conscious, but they do have a profound influence because they developed in response to society’s attempts to make sense of life and they have long been a part of the Western mind-set. As such, they are promoted, reinforced and rewarded at all levels of society.

8. IMPACT OF THESE HEGEMONIC BELIEFS ON THE CARE OF THE PERSON WITH DEMENTIA

It may seem a long way from philosophy to the practical field of dementia care, but in fact these beliefs and values are very much present in dementia care, impacting upon perceptions within the institution of the practicality and value of certain practices, staff motivation and attitudes towards the person with dementia. What appears unrealistic, too difficult or inefficient in practice, may simply be so because of perceptions formed by dominant beliefs and values. Furthermore, these assumptions are embodied in action and reinforced by it. It is little wonder, therefore, that even the best intentions to implement person-centred care are inevitably scuppered by “reality”; for changing care practice is not just about substituting new practices but about challenging very entrenched ways of thinking and being. It may be useful to consider here some examples of the impact of hegemonic beliefs on practice in dementia care. The examples are framed in terms of key areas which have been discussed throughout this thesis.
8.1. **Priorities of Care**

8.1.1. **Care is Defined by Biomedical Priorities as Physical, Treating Disease which is Separate from the Person**

Relationship and communication are not a care priority in the medical management of dementia. This does not mean that persons and relationship are necessarily missing, but by its very nature, the biomedical model can only regard the social and emotional aspects as additional to – and not absolutely necessary to – the real work of care. Thus at Star of David, the dementia activities program and associate training were the first to be sacrificed.

8.1.2. **The Economic Imperative cannot Accommodate the Nature of Care in Dementia**

The marketplace ideology reinforces the focus on physical (and measurable) care, which puts great pressure on institutions and staff who try to offer care which is based on relationship. Staff members spend time on documentation which focuses on deficits, which in turn reinforces a focus on pathology rather than the person. It also takes away time staff could spend with residents. The requirements of documentation, together with busyness around task and the lack of motivation of staff (who cannot see the point of “knowing” the resident beyond the needs of physical care), discourages spending time relating to residents in other than purely functional terms. Institutions are not funded for sufficient staff to offer the kind of care which focuses on the person.

8.2. **Staff Perceptions of the Person with Dementia**

8.2.1. **Rationality Defines Personhood; the Person is Somehow Less if the Brain is not Intact**

Care staff more often than not may like their residents, but their actions suggest that they do see them as “different”. Care staff feel free to talk about the person while he or she is present, the assumption being that he or she is not really aware, or as the quote from Goffman demonstrated, they are astonished when the person appears to say or do something “normal”. Thus
an otherwise apparently kind and caring staff member such as E at Star of
David can describe a resident with dementia as “Level 2”.

It may also partly explain (along with the “biomedical loss of self” view) why
behaviour is attributed to symptoms rather than an expression of need. If
people with dementia are no longer persons, it follows that they will not have
the same feelings as “normal” people, feelings such as sadness, or pain.
Instead they have “behaviours”. If behaviour is merely a symptom of
dementia, then there is no need to understand it, but simply to manage it.

If one assumes people with dementia are not really persons, then it is hard to
feel motivated to get to know them or spend time trying to understand and
communicate. Without in any way dismissing the difficulties of
communicating with people with dementia or the time constraints on staff, I
believe that part of reason staff do not spend communication time with
people with dementia lies in the assumption that essentially it is an exercise in
futility, that these people have neither understanding nor anything to say.
Goyder (2001), whose experience with Joe awakens her to the stories of
people with dementia, observes of her nursing practice: “I had always cared
for these patients’ physical needs and given comfort where I could in
instances of emotional distress, but it had never occurred to me to take
seriously what they actually said” (p.16).

8.2.2. The Biomedical Model Focuses on the Problem Belonging to
an Individual

Bird et al. (2002) indicate that many of the approaches he and his colleagues
used with challenging behaviour involved tackling staff attitudes. Yet, as I
observed at Star of David, little attention is given to the impact of staff
behaviour and attitudes in the day to day care.
8.3. The Care Relationship

8.3.1. Professional Distance is Core to Professional Practice

The relationship with the person with dementia is, in the first place, influenced by how the person is perceived (as discussed previously), but it is also influenced by considerations of what constitutes appropriate professional behaviour. In the biomedical model, there is emphasis on professional distance, objectivity and the professional as the one who knows and treats, in contrast to the patient who is passive and receives treatment. There is of course also a deep-seated psychological need on the part of staff members ("normal" people) to keep themselves separate from the dysfunctional. Dementia is a possibility too close to home to all of us and is hugely threatening to the very essence of our humanity (the mind). A unit manager in one nursing home commented on the horror expressed by care staff at the idea of submitting themselves to be residents for a couple of days as an awareness raising exercise. “But we’re not residents, we’re nurses” (Personal communication, 2001). A relationship of I/Thou – an open, equal and sharing relationship – is seen as neither professionally nor personally desirable.

8.3.2. Professional Knowledge and Control

The need and indeed the right of medical staff to control the care of patients, together with increased attention (enforced by government) to risk management, has meant that residents or patients are under constant surveillance and control. The quotation from Goyder (2001) in chapter 7, page 205 of this thesis, gives a vivid depiction of this.

Finally, in a society which collectively and individually emphasises autonomy, control, risk minimisation, certainty and rational (linear) thinking, the hardest thing is to establish an institutional culture which encourages staff to be flexible and creative, to accept and work with chaos, rather than attempt to control it, and to accept their own humanity, both weaknesses and strengths. Person-centred care demands a leap into uncertainty and doubt, acceptance of
our personal and professional limitations and a recognition of the bonds which join us as human beings rather than the labels which separate us.

9. CONCLUSION

In this chapter I have identified the values and beliefs which are hegemonic in our society and underpin traditional (that is, biomedical) care practice in dementia. I have also given examples of their impact at the practical level of care. From this discussion, it would appear that the core values and beliefs of society – and which underpin dementia care – are by and large inimical to the philosophy and practice of person-centred care. In implementing significant and lasting change it will indeed be necessary to address beliefs and values, not instead of, but as part of a strategy which addresses all levels of barrier (procedural, policy and values) and at the individual, institutional, government and community levels (Figure 1, p.246). My discussion and recommendations for change are presented in the next and final chapter.
Figure 1 – Barriers to Person-Centred Care in Dementia
DISCUSSION AND RECOMMENDATIONS

In the previous chapter, I concluded that a major barrier to person-centred care in dementia lies with the beliefs and values hegemonic in our society and that the process of change cannot be limited to practices and procedures but must engage with the beliefs and values which underlie them. Nor can it be limited to changing individuals, but must take in the whole institution and indeed reach beyond the institution to the wider context of government and community. The following discussion will deal with each of these – institution, government and community – in turn. I will also give separate discussion to the issues of training and health services research.

1. CHANGE IN THE INSTITUTION

Having identified hegemonic beliefs as the basis for resistance to changing care practice, I am not proposing another dualism, for I believe the procedural and values barriers are integrally connected and must be addressed as a whole. In attempting to understand how this may be done, it will be helpful to recapitulate the qualities of hegemonic beliefs.

1.1. The Power of Hegemonic Beliefs

Hegemonic beliefs define a reality which has evolved over time, appeals to common-sense and is unquestioned. Practice confirming to these beliefs is rewarded. Hegemonic beliefs fulfill a variety of societal and individual needs and are consciously or unconsciously held. They underwrite how we are in the world, and their “truth” is in turn constantly reinforced by the action and practice of others. Indeed, these beliefs can become self-fulfilling prophecies. Merton (1961, p.421) quotes the dean of American sociologists, W.I. Thomas:
“If men define situations as real, they are real in their consequences”. Finally, hegemonic beliefs are perpetuated in and sustained through institutional structures within society. Such beliefs can be “helped over the threshold of oblivion, not by insisting that it is unreasonable and unworthy of them to survive, but by cutting off the sustenance now provided them by certain institutions of our society” (Merton, 1961, p.437). Hegemonic beliefs then are very powerful and need to be met through many different dimensions: thought and action, reason and emotion, conscious and unconscious, individual and societal.

1.2. Implications for Changes in Practice

Essentially, models such as ELTOS have provided the “what” of person-centred care, the framework for the practices and procedures which make person-care possible. I would suggest that what remains a barrier to full implementation of person-centre care and what we now need to pay attention to is the “how”, in particular, questions such as whether person-centred care needs to be introduced as a totality or whether it can work when just parts of it are applied; what are the non-negotiable aspects of a person-centred care model. It is in dealing with the how that I believe we engage with values and beliefs, and I will therefore discuss this in terms of the key aspects of hegemonies noted above.

1.2.1. Commonsense/Unquestioned Reality

There needs to be a vision alternative to “common-sense” and “reality”. This is where management has a particularly important role to play since management has the position and the authority to implement change throughout the organisation. Management needs the understanding of and commitment to an alternative vision, the ability to articulate it unambiguously and the authority, together with the human and organisational skills, to bring about change. Good management is of course important if any organisation is to run well, but even more so when the organisation is trying to change the accepted and unquestioned practices of care.
1.2.2. Fulfils Psychological, Social and Cultural Needs of Individuals and Societies

It is important to be aware of what keeps certain practices of individuals or groups in place. Until such issues are acknowledged and addressed, staff members will easily fall back into old practices. For instance, staff are unlikely to open themselves to residents if this opens them to guilt about not having time to talk with them (because of task pressures) or if they feel unsupported in doing so. Understanding who the staff are as professionals and as people, supervising, supporting and offering appropriate training (the emphasis being on appropriate) are all important. Support from other staff is also important when undertaking actions which may appear unrealistic according to traditional practices of caring.

1.2.3. Its Truth is Reinforced in Action

Seeing person-centred care in practice can help reinforce that it is indeed possible. Good role models are necessary therefore, as well as involvement of all in the institution so that each supports the other to use person-centred practices. There should be support, encouragement and reward from management for thinking the “unthinkable” and doing the “impossible”. Management and senior staff have an important role in showing that person-centred practices are possible. This leads to another crucial aspect, which is that it is not just about changing individual staff members, but that all need to be involved in the changes.

1.2.4. Belief Creates Reality – “Self-Fulfilling”

The biomedical model offers a whole system of belief and values, along with the actions arising from them. Similarly the person-centred care model represents a system from which certain types of practices flow. It is therefore a system which needs to be implemented in its entirety, rather than implemented in isolated fragments. It is the model as a whole which creates a care environment which is person-centred, and it is this environment which
will give strength to a culture of care which is alien to current hegemonic beliefs and practices.

1.2.5. **Supported by Societal Structures**

So long as government and the larger community do not support person-centred approaches to dementia, institutions will find it difficult, though not impossible, to change care practice. Opening out to include family and the wider community network can fulfil an educative role and assist in advocacy to government.

The major conclusion from the above is that the path to overcoming barriers to person-centred care requires in the first place, a focussing on the whole institution (an ecological approach) rather than focussing on individuals, together with implementation of a person-centred care model as a whole, rather than individual parts. It will also require that all within the institution address the values, the old messages, which prevent them from taking on person-centred approaches. To do this does indeed mean that relationships within the institution and the valuing of staff as persons become of prime importance.

Hegemonic beliefs have great power and durability, and it will require persistence, ongoing reinforcement and reward on the part of management, and strong supportive relationships among all within the institution, to bring about and maintain change.
2. **RECOMMENDATIONS FOR CHANGE IN PRACTICE IN AGED CARE FACILITIES SUCH AS STAR OF DAVID**

1. Leadership

   - **Authority.** Because of the power of the belief system and the longevity of the care practice which has grown out of it, leadership from management is of the utmost importance, for management have the power and authority to implement change. Through the organisational structures (documentation, communication, supervision), selection of staff and setting and rewarding the appropriate priorities of care, management is central to the task of changing institutional practice.

   - **Vision/skills.** It is important that management own the vision of person centred care and has the human and organisational skills to bring the whole organisation along with them.

   - **Consistency.** Management must be unambiguous in their acceptance and promotion of a new culture of care. Every decision and action must be informed by person-centred priorities.

   - **Support/troubleshooting.** Management need to show that person-centred care is possible, by providing resources, listening to and supporting staff and helping remove barriers, real or imagined.

   - **Advocacy.** Securing the support of the Board of Management. Networking with other facilities and joint advocacy to government.

2. Relationship

   - Relationship is crucial to the implementation of person-centred care. All relationships in the home need to be taken care of: resident and staff, resident and family, management and staff, staff member and staff member, family and the staff and management. Individuals and relationships need to be nurtured.
3. Programming for Person-Centred Care

- Person-centred care is about every aspect of care, carried out by every staff member, therefore it should not be restricted to a program (for example, activity program) nor to specific individual staff. It should not be an add-on to care, but an integral part of the total care.

4. Organisational structures

- Organisational structures need to reflect the priorities of person-centred care.
- In particular, communication and relationship need to be nurtured within working relationships.
- A form of care plan needs to be developed which addresses the whole person and staff must be given time to read it. Indeed the reading of care plans must be considered part of the job description and every encouragement given to read them.
- Staff need to learn to write up documentation which goes beyond the physical and medical and helped to understand the rationale behind it.

5. Staffing

- Selection of new staff should reflect the requirements of person-centred care. Skills are only part of the criteria; flexibility, empathy and positive attitudes are equally important components. Employing staff just to fill the gap can adversely affect the overall culture of care.
- All staff need training in person-centred care. (This is discussed in depth in the next section).
- Volunteers, private carers, casual staff, all need to be oriented to a culture of person-centred care.

6. Family Involvement
• Families necessarily impact on care whether they are included or not. Where they are willing, they should be encouraged to be involved in developing care plans.
• Families should be supported and encouraged to remain involved in the care of their relative.

7. The Environment
• Attention should be paid to the physical environment, in terms of noise, confinement and any other aspects which impact on the social and emotional wellbeing of residents.
• While there may be some design features which appear to be generally more suited to the needs of people with dementia, there is no ideal environment which suits everyone. Therefore, it is best to have an environment which is flexible and can be adapted to meet different needs as necessary. Garratt and Hamilton-Smith’s suggestion of creating environments with a view to orientation and spatial mastery for the person with dementia would seem to be useful general guidelines.

3. TRAINING FOR PERSON-CENTRED CHANGE WITHIN INSTITUTIONS
Training is rightly seen as a key tool in bringing about change within institutions yet, as Flett (2001) notes, training seems rarely to survive long in the institution or create ongoing change in practice. Lintern, Woods and Phair (2000a, b) have further shown that there is no direct, linear connection between training and improvements in the wellbeing and subjective experience of care of the person with dementia. If one recognises the power of hegemonic beliefs and values, it will be clear that training which merely provides facts and some skills to individual care staff is not enough to change how individuals work, let alone make significant changes to the institutional culture and the residents’ experience of care. Training for person-centred
care will need to start from completely different premises from a biomedical model and will need, in training care staff and management, to engage not just with the professional but with the person. The discussion below reflects this perspective.

3.1. Who Needs to be Trained?
Training needs to be institution-wide, not just of direct care staff. This is important at the practice level but also important in the message it gives, namely that this is not a change which rests on the shoulders of a few staff members, but is change which needs to be taken up throughout the institution.

All within the institution – management, nursing, direct care, cleaners, kitchen staff – need training in person-centred care, although the content and mode of training will necessarily vary depending on the staff. It may even be that qualified staff will need to be de-trained to an extent, in order to let go of some of their professional assumptions. Management and senior staff have to learn about the kinds of support staff working in a person-centred way will need. They need to become aware of what person-centred work entails and the personal and professional challenges this sets, so that they hire appropriate staff in the first place and offer appropriate training, ongoing support and appropriate organisational structures. In the evaluation of the National Residential Dementia Training Initiative (Ageing and Aged Care Division, 1998), it was noted that proprietors and senior organisational managers often did not attend information sessions provided by this Initiative. One project manager noted the importance of management’s understanding dementia care: “Sometimes management’s knowledge of aged care is still almost custodial ….they want people to be secure” (section 5.4).

Recommendation 3 (section 5.4) states: “That additional strategies be implemented to continue to raise awareness among facility managers, proprietors and Boards of Management members of the benefits of ongoing dementia care training for all staff in residential aged care facilities”.

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It is interesting that even within as comprehensive a program as Hammond care, Geeves and Tulloch (2002) note the challenges in obtaining the input from corporate leadership and management, as well as having time allocated for training and for the dementia champions to fulfil their role.

3.2. Content of Training

It is important that institutions are selective about training courses to ensure they do indeed cater for the training needs of staff and the institution. This is where management’s understanding of person-centred care is crucial so that they can identify the kinds of training relevant for their institution. Some of the relevant content areas are discussed below:

3.2.1. Information

Information needs to be given on a person-centred understanding of dementia and person-centred care.

3.2.2. Skills Development

Additional and different skills need to be taught based on care priorities in person-centred work. These would include, for example, communication skills, group skills and empathy training.

One of the difficulties at Star of David was a lack of recognition of the very real skills needed by staff in order to offer care which focussed on the person with dementia. For instance in running the group activities, the PCAs needed not so much “activity ideas”, but skills in working with groups and in identifying appropriate and meaningful activities for each resident. Formal “activity” is of course only a part of person-centred care and in this wider realm, the most important area of skill lies within the interpersonal realm. Killick & Allan (2001) have done excellent work in addressing both the verbal and non-verbal components of communication. Buckland (1995) notes that “careful attention to another’s actions can guide our understanding of how they make sense of the world around them. For many of us, however, our
main experience is of seeing our point of view. The move from imposing our views to successfully gauging those of another is a difficult and necessary skill” (p.32). While there are skills to be learnt to practise empathy, there are also elements of awareness and growth in personal experience. Approaches to empathy which address these will be discussed in the later section on intersubjectivity.

3.2.3. Reflective Practice – Encouraging Questioning and Positive Doubt

Staff members and indeed management also need to take a reflective approach to their work, developing an awareness of what they think they’re doing and what they are actually doing, that is between espoused theories or values and practice. At Star of David, management and senior staff listened to and seemingly took in the facts presented to them, yet their actions were not consistent with a person-centred approach. Fook’s (1996) writings on reflective practice are of relevance here.

A reflective approach acknowledges that, contrary to the idea that formal theorising precedes action in a linear (from cause to effect) and deductive relationship, theory is typically implicit in a person’s actions and may or may not be congruent with the theoretical assumptions that the person believes themselves to be acting upon. (p.4)

Fook notes that espoused theory does not imply particular actions. Rather it is embodied in action that one observes the actual (as opposed to the espoused) theory. Knowing the theory or indeed even approving of it, does not necessarily mean that it is integrated into the functioning and action of the individual. Fook suggests that in examining “critical incidents” in one’s practice, one may see what is in fact driving one’s practice rather what one thinks is driving practice. This kind of awareness is important for the
individual, as well as the institutional team, if they are to effectively change practice.

A reflective approach in this sense recognises that ‘reality’ merely consists of the extent and ways in which the different players share an understanding of the situation. It becomes important, then, as researchers and practitioners, to appreciate the situation in ways which are congruent with the perspectives of the players we believe are important, be they marginal or ostensibly dominant groups.” (p.4)

Another important element of the reflective approach is that of positive doubt. Whereas society generally, and the professions in particular, have tended to give value to certainty, the reflective practitioner model encourages questioning and an embracing of doubt and complexity. Trainers need to encourage a questioning approach to the work, and part of this will come from their own refusal to offer easy remedies or firm solutions and to show their acceptance that there are some things they do not or cannot know. In the field of professional education, Professor Brian Simon (1967) of Leicester University spoke of how in teaching and social work – and this certainly applies also to dementia –

there are few easy and tidy solutions which can readily be applied in standard situations. It is no service to the student to present him with what purports to be universal nostrums, or neatly packaged remedies, so that when he faces the hard facts with this equipment, and they do not respond, he suffers acute disillusion. The student who is equipped to doubt and question is a much better prepared and oriented professional worker – more open to further development and creative achievement – than the one who
depends on the crutches of received opinions, painfully recorded in his notebook as facts. (p.12)

Another area where I think staff need to take a more reflective approach is in the interpersonal realm. Too little attention is paid to how staff interact with residents, and there is little realization on the part of staff of the impact they can have on residents. Of particular importance is the aspect of their physical being and presence, always a significant part of any human interaction but even more so with people with dementia who may be even more sensitised to the non-verbal.

Training needs to raise awareness and develop students’ ability to question, rather than supply them with ready made answers for every situation.

3.2.4. Intersubjectivity/Empathy

Relationship, communication and empathy are at the core of person-centred care. Therefore training needs to reflect this. It is important to break down the barriers of professional distance (while not compromising the safety of the person with dementia nor the professional carer), by helping staff members to bridge the gap between themselves and the person with dementia. To do this, facts, skills even, are not enough. Sheard (2002), in his article, “Beyond Mechanistic Dementia Care Training are Real Feelings and Real Life”, aptly describes some of the directions in which training should go. He emphasises “us” rather than “them”, connecting the experience of the person with dementia to that of the staff member. Trainers need to translate the language of person-centred care in a way which will enable care staff to make connections to their own lives, for instance looking at when they have felt confused or abandoned. This approach allows staff to have their own humanity recognised.

How can we expect care staff to practice person-centred care when they have not had the opportunity to focus on these issues themselves in their own lives? There is an
urgent need to bridge what I term “the sophistication gap”. The skills promoted in person-centred dementia care demand a level of reflection on, and connection with, people with dementia. This can be too big a gap to jump unless you begin the same parallel journey in your own life so as to bridge the gap. (Sheard, 2002, p.11)

If care staff have rarely experienced themselves being treated as persons, then they cannot translate this into their work. The personhood of all must be honoured.

What this kind of approach highlights is the need to meet the staff member as a fully human being – a person – and the centrality of working towards developing empathy in care staff, arising from an experience of self and connecting one’s own experience to that of the person with dementia. Sheard (2002) concludes: “People with dementia will truly receive person centred care when each of us can demonstrate real respect for another” (p.12).

Like Sheard, Parse emphasises that a process of personal growth is required (Mitchell, 1993). I would also suggest that both in training and supervision, the emotional and psychological issues which arise in working with people with dementia need to be addressed, in order that staff may find positive ways to deal with them. At present, too many staff survive through emotional distancing, negative behaviour towards their residents, or simply through experiencing burnout and leaving the field.

This kind of learning of course takes time and that is why training needs to go beyond the one-off training programs to be incorporated in a variety of ways into the working environment of the care staff.
3.3. Mode of Teaching

Training needs to employ different modalities to appeal to mind and feeling; it needs to balance theory and practical application and offer different teaching situations. These are discussed below.

3.3.1. Different Modalities

Training should encompass a variety of knowledge, not only factual, and take into account different learning styles.

I would point to a neglected aspect in training, namely body learning. It seems extraordinary that staff, working with people who are acutely sensitive to non-verbal messages and interactions, are not themselves sensitised to this area. They need to become aware of the negative impact of insensitive physical presence as well as the possibilities for communication and positive interaction. The unique contribution of body learning is that it addresses feeling, and it is feeling which so often sabotages the best and most intellectual learnings. However, it also addresses the whole – embodied – person and therefore offers the opportunity for a learning which integrates thinking and feeling and physicality. Through body and movement experiences, care staff may develop increased empathy and come to a greater understanding of the experience of the person with dementia. For instance, within their own bodies, they can experience the unequal power dynamic between staff and resident and the feeling of powerlessness of the person with dementia when treated as a “dementia patient”. Through their bodies, they may also experience a different, more positive way of being with people with dementia, that is, they can take the intellectual and emotional learning into embodied action.

Such experiences may also go beyond the individual experience to the experience of self as part of a society. In Butoh dance, a form of movement developed in Japan as a reaction to Western culture and political dominance, it is considered that the body contains not only the personal and individual,
but also that societal structures are embedded within it (Nakamura, 2003). By working with movement and reflection therefore, Butoh practitioners believe that significant change may impact on the socially formed value system. It is interesting therefore to speculate whether these deeper societal values which affect the practice of care may be addressed in some way through movement and body learning.

3.3.2. Theory and Practice

Fook has noted the need to blur the distinction between theory and practice. In a sense this is another dualism inherited from western ways of thinking. In talking of professional education, and this may also be applied to the training situation, McWhinney (1995) refers to Whitehead’s criticism of professional education as being too full of abstractions.

What we need is not more abstractions, but an education in which the necessary abstractions are balanced by concrete experiences, an education that feeds both the intellect and the imagination. (McWhinney, p.15)

One possible model for training, which would appear to address some of the issues raised above, is that given by Adkins (1974, p.517) in relation to problem-centred life skills learning. His four stages comprise: stimulus – “to motivate the student”; evocation – “to dignify what he already knows about the problem-task”; objective inquiry “to add what he needs to know through various means to master the problem-task”; application – “to give him experience in translating his knowledge into action”.

This model addresses the integration of theory and practice in the learning process, but also importantly offers affirmation to the learner, in terms of his or her prior knowledge and skills, as well as his or her ability to find and take on new knowledge. All of this contributes to the necessary process of owning knowledge and embracing change.
3.3.3. Different Teaching Situations
Settings for learning can be formal or informal, external workshops or onsite, peer group learning, case presentations. Much informal training occurs on the job through the role modelling of individuals and the influence of context and therefore should be taken into account in planning the training.

3.4. Extending into the Institution
It has been noted before that the effects of training very quickly slip away once the staff member has returned to the institution. Part of this reflects the difficulties of changing practice which is grounded in the entrenched beliefs and values of the individual care worker. However, equally if not more significantly, is the effect of returning from training to the same context of work. Only the strongest and most committed have much chance of changing their own practice let alone those of their co-workers and managers. Without the support and promotion of new practices by the on-site supervisor, the individual worker will be unable to significantly change practice, their own or others. Some interesting approaches to this aspect have been developed by the Hammond Care Group and I will refer to them in this discussion.

3.4.1. Building in Peer Support
The Hammond Care Group in Sydney have integrated within their training a system of “dementia champions” who would be “a guide, supporter, inspirer, monitor, mentor, change agent and educator/trainer” (Geeves & Tulloch, 2002, p.6), and have developed a network of dementia champions to support individual champions. Part of the dementia champion role is eventually to take over some of the training function within the institution. This approach would seem to recognise the need to have people with particular commitment within the institution, who can keep the ideas alive and encourage and support other staff. It further recognises the power of whatever culture dominates a particular institution and the fact that good practice (and bad practice) is caught rather than taught. This is what Bowe and Loveday (1995)
call “informal training” (p.76). A nurse educator colleague (personal communication, March 2003) has commented on how her young nursing graduates leave with all the right ideals, but appear to lose them quickly on entering the workforce. We pick up the culture within a particular context by picking up on how others behave. An example of this appears in Hockey (1990). She describes how she had difficulty dealing with an elderly resident. Another staff member is able to take over and get the elderly resident to do what she wants. This care aid was

new to the home, but six months voluntary work with elderly patients in the nearby hospital had been sufficient for her to absorb the assertively familiar style of low-ranking NHS employees when dealing with less-esteemed categories of patients. For those employed in this way, making people do what is required of them is frequently understood through metaphors such as “it’s for your own good, “sometimes you have to be cruel to be kind” and “we all have to go through it”. Such metaphors highlight areas of the experience such as bodily welfare and the inevitability of pain or discomfort. They also conceal or downplay other areas such as loss of privacy and loss of adult status. The power of these metaphors is reflected in the effectively assertive style of the care aid. They preclude any hesitancy or diffidence which might diffuse her authority or complicate the manoeuvre she was attempting” (p.24).

This example shows how staff develop their own professional “toolkit” (Wright, 1988, p.814) by picking up on the dominant culture and modelling the behaviour within it. “Training therefore, broadly understood, occurs every day in the institution. Much learning, if not most learning, does happen
on the job and it is important to make use of this to encourage positive role modelling of care.

3.4.2. Individualising the Training

Often staff cannot make the connection between the training and their own situation. A valuable feature of the Hammond Care approach is that they make training site-specific through practical case studies from staff and in-house training by dementia champions.

3.4.3. Involving the Whole Institution

It is also important that the institution as a whole takes ownership of the training, seeing it as an ongoing, day to day aspect of institutional life rather than an external, one-off event for individual care staff. Geeves and Tulloch (2002) concluded that where the corporate body (in charge of several institutions) takes on the championing of the champions, that is, supports and underwrites the work with resources and “muscle”, the system works best. Training involves the whole organisation.

3.5. Making the Connection from Improved Practice to Improved Resident Experience

Lintern, Woods and Phair (2000a, b) discovered in their action research project in a nursing home that while a first round of training brought changes in staff attitudes and behaviour, it took several years and several intervention phases to translate this into improved resident wellbeing. Their interventions comprised a variety of approaches, some of which were practical, for instance having staff spend more time with those residents who were more withdrawn or unable to express their needs. However, much had to do with addressing the organisational aspects of leadership and support, and issues to do with communication and teamwork.

From this research Lintern et al. (2000b) conclude that: “Training alone did not lead to improved outcomes for residents, although it did appear to be
related to changes in staff attitudes and behaviour that may underpin such outcomes later” (p.17).

This research shows there is not a simple linear connection between training and improvement in care, nor training and improved resident wellbeing. Training is not a panacea which automatically improves care. Even the best of training will be insufficient if the organisation itself does not support the process of change. Lintern et al. (2000b) note:

There is, in our view, little purpose to be served in sending staff on training courses and/or organising inhouse training sessions, if there is not the determination and will at a management and organisational level to overcome barriers to individualized, person-centred care. (p.17).

The Ageing and Aged Care Division Dementia Training Initiative evaluation report (1998), point 4.6, concludes that training did not carry over into workplace practices where management, organisational practices and peer support were not present.

4. RECOMMENDATIONS ON TRAINING

1. Institutions need to be selective in their choice of training.

2. The content of training should include not only facts and techniques, but also the development of understanding and empathy, awareness-raising and encouragement of reflective practice. It needs to work with persons, not just professionals.

3. Teaching modalities should incorporate different ways of knowing – cognitive/intellectual, body knowledge, practical – and different formats – formal lecture, case presentations, peer group learning.
4. Trainers should encourage a questioning approach to practice rather than offer ready-made answers, and tap into the skills and knowledge people already have.

5. Trainers should offer opportunities to apply learning in the workplace.

6. The understanding of training should extend to in-house learning within the institution and role modelling.

7. Learning must be at many levels: individual employee, managers, corporate body. The larger the system supporting the same values, the better chance of their being maintained.

8. While continuing to train individuals, consider the individual as a worker in context. Develop ways that their learning can be reinforced and maintained in situ by co-workers and the organisation as a whole. Training needs to be an endeavour of the institutional community rather than a means to improve individuals.

9. Help organisations and their staff to make what has been learnt their own.

10. Approach training with a view to the whole system or organisation, rather than expect that the training of individual staff can bring about individual and organisational change.

11. Training alone, in the absence of management support and structural change, will not bring about lasting or significant change in care practice.

5. **CHANGE IN THE WIDER CONTEXT**

5.1. **Advocacy to Government**

While institutions may still accomplish a good deal within the current context, there is no doubt that the current regulatory and funding climate puts great stress upon institutions and their staff. At the moment, the implementation
of person-centred care often depends on a considerable degree of
determination and commitment from management and self-sacrifice from
individual staff members. Ultimately, for person-centred practice to thrive,
changes need to come in the aged care policy of government itself, and this
will require advocacy from all who work in aged care and dementia.

At present in Australia, unlike in the United Kingdom where there is already a
person-centred standard (Standard 2) as part of the National Service
Framework (Department of Health, 2001), there is no specific mention of
person-centred care within the aged care legislation. This means that the
concept itself has no formal recognition within the field. Accreditation
standards for institutions similarly have no standard relating to person-
centredness. Cecchin and Jarrad (2000) have recommended rewording of the
accreditation standards to meet dementia care needs. They conclude that a
person-centred standard should be incorporated with “a focus on knowing the
person and applying this knowledge in a meaningful individualised way in every
aspect of care” (p.19). This at least would be a step in the direction of
recognising at a statutory level, and therefore as an institutional requirement,
that care has the person as its focus.

The accreditation process also is a forum for communication between
institutions and government, and therefore offers an opportunity for
institutions to advocate for the realities of caring for people with dementia.
This is not easy, especially in a market-driven society, because care appears so
“unproductive”. Indeed, care may be invisible.

Caring is inconspicuous. As such it is devalued and
threatened. The power of caring has been obscured in a
society which gapes at its absence and glances over its
presence. As an expression of the human heart, caring has
no neon lights, and it does not seek attention. Modern
scientific, technological and bureaucratic systems dwarf
manifestations of caring from the heart. Still, caring lives and reveals itself to those who cut through the noise and glare. Caring comes to life in human relationships; there it is formed, displayed and given definition. (Gramling, 1997, p.85)

Given the value attached to monetary efficiency and patient turnover, it is not surprising that there is no room for caring within market discourse. The task for those involved in dementia care is to make person-centred care visible. Those working in aged care need to advocate for the messy reality of care in every forum within which they meet government, be it through the accreditation process, or through direct lobbying. This, therefore, is a task of education but also political action and advocacy and will be greatly aided if families, the community and community advocacy groups like the Alzheimer’s Association can work together to support these efforts.

For person-centred care to be sustainable, institutions need a regulatory and funding context which recognises person-centred care so that the focus of policy moves from funding deficits to funding the empowerment of people with dementia and the care relationships involved.

6. RECOMMENDATIONS FOR ADVOCACY TO GOVERNMENT

1. Aged care facilities, Alzheimer’s Associations and other organisations involved in the aged care field must take on an advocacy role in relation to government, bringing to government’s attention the reality of caring for people with dementia and the implications for resourcing and funding.

2. Part of the advocacy should be for recognition of person-centred care in dementia within the aged care legislation and the inclusion of a person-centred standard in the accreditation standards.
3. Support from families and the general community should be sought as they will greatly aid these efforts.

7. COMMUNITY AND THE PERSON WITH DEMENTIA

However much the concept (though not always the practice) of person-centred care has permeated the “consciousness” of institutions, practitioners and theorists in dementia care, it is doubtful whether it has pervaded the consciousness of the community. The general public would appear still to be very much in thrall to the biomedical view of dementia. Thus the experience of the person with dementia even while living in the community is a predominantly medical one.

The process of diagnosis itself can be an extremely disempowering experience. This is evident in the nature of the assessments, how they are carried out and how the person is involved in what is happening to him or her after diagnosis (Cheston and Bender, 1999). From the moment of diagnosis, the person becomes a sick person whose illness dictates his or her present and future life. Bryden and Friedell (2001) have spoken of the experience of receiving a diagnosis of dementia as akin to the Aboriginal notion of “pointing the bone” where “the terrorised victim sickens and eventually dies” (p.144). They ask why the moment of diagnosis should render them immediately incapable victims. Families too have a new role thrust upon them. “After diagnosis, a couple may leave a doctor’s surgery with new identifying labels of ‘person with dementia’ and ‘carer’, roles that neither may be ready or willing to assume” (Eayrs, 2002, p.46). The caring role within a medicalised framework “is inevitably associated with ‘burden’” (Downs, 2000, p.372).
The view of the total incapacity of the person with dementia spreads to every aspect of life.

On diagnosis, many people with dementia and their family carers are forced – or feel obliged – to curtail many of their previous activities. If still in the work force, people with dementia may be asked to leave their employment or be sacked if their work performance is below standard. (Eayrs, 2002, p.44)

Bond and Corner (2001) observe that

people experiencing mild symptoms of the condition are often aware they have dementia but there is a strongly held belief that people with dementia are unable to communicate what they are really experiencing. As with death, with a few exceptions (Lorimer 1990), no one has “returned” to tell us what it is like to have dementia. (p.96)

It seems therefore that long before institutional care is entered, the person with dementia has difficulties being treated as a person and has entered a process of disempowerment and loss of self. “The two big issues (for the person with dementia) are sense of isolation and disenfranchisement” (Eayrs, 2002, p.45).

I noted in the previous chapter that, as a society, we tend to look for medical solutions to the different, the deviant and the incomprehensible, and in so doing, often separate such people from their community. Sacks (1996) gives an example of this in comparing the experience of chronic illness of people with motor neurone disease (ALS) in New York and among the Chamorros people of Guam. He describes how relatives in the village will take the best food they have to the sick person and will continue till the person gets better or dies.
This acceptance of the sick person as a person, a living part of the community, extends to those with chronic and incurable illness…who may have years of invalidism. I thought of my own patients with advanced ALS in New York, all in hospitals or nursing homes, with nasogastric tubes, suction apparatus, sometimes respirators, every sort of technical support – but very much alone, deliberately or unconsciously avoided by their relatives, who cannot bear to see them in this state, and almost prefer to think of them (as the hospital does) not as human beings, but as terminal medical cases on full “life support”, getting the best of modern medical care. Such patients are often avoided by doctors too, written, even by them, out of the book of life. (p.155)

Sacks’ description vividly illustrates that medical care can be the best and the most technologically advanced, but somehow miss the person’s needs as a whole human being, one of which is a need to be included in a community of other human beings.

However, it is not just a matter of changing society’s attitudes to people with dementia, but of actively enabling people with dementia to remain part of society. This requires a recognition of and a willingness to deal with those obstacles society itself puts in the way of ongoing participation. People with dementia themselves (Alzheimer’s Association, 2003b) state that “the creation of environments that are friendly to people with dementia is very important in maintaining personhood as a person with dementia” (p.2).

In talking of change in the community, it may be useful to consider the experience of the Alzheimer’s Association Australia which has been going through some significant changes in its own relationship to people with dementia. Alzheimer’s Associations grew out of the identification of
Alzheimer’s as a disease and were set up principally to support carers and to advocate for more funding and research into Alzheimer’s disease. Their focus has gradually expanded to include support for people with dementia themselves. At the 2000 and 2002 Alzheimer’s conferences, people with dementia were included as delegates and keynote speakers, and the Alzheimer’s Association has committed itself to a process of working towards the inclusion of people with dementia at all levels of the organisation itself. It has been interesting to see the kinds of issues which have arisen as this has been discussed and workshopped with staff, carers, people with dementia and volunteers, showing that despite the organisation’s evolving focus, there are difficulties breaking away from medical models of pathology and incapacity. For example, in considering the election of people with dementia to the Board, some have suggested that a special capacity assessment should be done for people with dementia. Others pointed out that this could be seen as discriminatory. Some also rejected the notion that there should be special arrangements to facilitate participation of people with dementia.

During the State consultations, a minority queried why people with dementia should be supported in their participation by special arrangements.

The response must be that like other people with a disability, people experiencing cognitive and other dysfunction as a result of their disease can, with appropriate assistance, make a valuable contribution to Association activities, as well as have a positive impact on their own well-being. (Eayrs, 2002, p.60)

The report lists some of the special arrangements which are these days accepted to accommodate people with disabilities such as special access arrangements for the physically disabled, or provision of special large print
documents for visually impaired. It concludes: “These types of support are accepted as appropriate and a worthwhile use of resources” (p.60).

These discussions above reflect the overall prejudice in our community which equates dementia from its earliest stages with incapacity, and, as has been discussed in the previous chapter, these prejudices lie in a number of deep-seated, long-held societal beliefs.

In arguing for inclusion in the general community, I am not placing community in opposition to institutional care. Indeed, so-called community care is often a synonym for the government’s relinquishing of its role and leaving the work of care to struggling family carers, the majority being women. It is rather about keeping the person as part of society – firstly within the community for as long as possible, but even when institutionalized, retaining links within the community. It means discarding a purely medical view and its disempowering and stigmatising effects (even if this is not the intention). In the AIDS area, people are now considered people “living with HIV/AIDS” and this perhaps is a more positive model for dementia, placing the disease to the side of rather than in place of the person. Indeed Alzheimer’s Victoria have named their newsletter “Living with Dementia”. Within this concept of “living with”, there is the notion of wellbeing, and “health within illness” (Lindsay, 1996), in that the physical pathology or deficits do not necessarily inhibit one’s ability to live an enjoyable life and experience feelings of wellbeing and health.

At the same time, it is important in emphasising remaining abilities and possibilities for ongoing active participation in the community, not to sell short those people who become severely disabled in the later stages of dementia – in the way that sky-diving elderly are raised up as models to range against ageism, approval being dependent on their measuring up to standards of activity or productivity. We need to find a way to accommodate the so-
called “unproductive” and continue to treat them as persons who are still part of the community.

8. RECOMMENDATIONS AT THE COMMUNITY LEVEL

1. There must be ongoing advocacy and education by organisations such as the Alzheimer’s Association which emphasise the ongoing personhood of the person with dementia, their remaining abilities and how their needs may best be met. This involves advocacy to government (for funding and resources), to the general community and to professionals.

2. Organisations such as the Alzheimer’s Association should continue on the path of including people with dementia at all levels of the organisation, thus making them visible and showing that people with dementia are still able to participate in life. Such organisations should also encourage local government and community organisations to accommodate people with dementia, and offer advice as to how this may be done.

3. There should be advocacy by people who themselves have dementia. The advocacy of strong individuals with dementia, such as Christine Bryden in Australia, has meant that people with dementia are being seen and, importantly, being heard. They are beginning to emerge from being “victims” to being people living with dementia.

4. Institutions need to encourage families and communities to retain links with the person after he or she comes into an aged care facility. Organisations such as the Alzheimer’s Association can offer education and support as noted in 3 above.
9. HEALTH SERVICES RESEARCH IN DEMENTIA

The majority of research studies in dementia continue to focus on understanding the biological aspects of dementia and developing appropriate drugs with the gold standard methodology being that of the randomised controlled clinical drug trial. In health services research, researchers feel constrained to fit their research studies into a clinical model with its key tenets of objectivity and focus on the physically observable and measurable. Research funding is also an important consideration since governments fund research on those issues which are of interest to them – those dealing with effective and efficient service or those which deal with mainstream and accepted health goals (as in drug research). Thus the research questions and methodologies employed are not just those dictated by health researchers and medical priorities, but by considerations of what kind of research will be funded. In other words, research too is subject to the hegemonic ideologies within society.

9.1. The Framing of Research Questions in Dementia

In health services research in dementia, the research questions continue to be framed very much within a biomedical model and address issues important in that context. This means that many of the significant questions from a person-centred care perspective remain unasked because they are not viewed as important or because they are not even conceptualised. In particular should be noted the absence of the perspective of the person with dementia in research questions. Research questions often appear to reflect concerns of the institution and its carers rather than those of the person who has dementia. Even where, as in the 2001 study of Bird et al., it is explicitly stated that psycho-social approaches are qualitatively different from drug interventions and require different methodologies, the framing of the research question “Psychosocial Approaches to Challenging Behaviour in Dementia:
A Controlled Trial”, would seem to place it still within a biomedical framework and subject to the focus and standards of that framework.

Changing this situation will require tackling hegemonic ideas about what is relevant to research in dementia and the current political (neo-liberal) ideology.

9.2. Methodology

“For almost 30 years the randomised controlled clinical trial has remained the method of health services research, other approaches being sidelined by those disciplines for which experimental method is the only way to ‘do science’” (Bond and Corner, 2001, p.97). Bond and Corner note that this is not just an issue for dementia research but for all research in the social/psychological area. It is a sign of the hegemony of science, that, despite the substantial work already carried out in post-positivist research and the shortcomings of the scientific methods in the psychosocial area, there are still many who argue for the “rigour” of the scientific method.

Bird et al. (2002) in their study reject the notion that psycho-social approaches in dementia can be researched in ways similar to clinical drug trials.

This is a fundamental misrepresentation of the nature of psychosocial approaches. It also trivialises the important insights these and similar proprietary approaches contain and is contrary to their main thrust, which is more about changing attitudes and providing a consistent humane empathic approach to distressed people with dementia.

(p.2)

In order to answer questions which are of relevance to person-centred care, more appropriate methodologies must be adopted. Rather than seeking single solutions which can be generalised over large populations, research needs to
address complex questions involving individualised and multi-faceted answers.

Researchers may also need to question the standard scales and tools of measurement, which again reflect hegemonic ideas of objectivity and which disguise the subjectivity involved in creating the scales in the first place. Methods, for instance, of evaluating care and its impact on the person are needed but will need to be framed in ways which are relevant to a different paradigm. Dementia Care Mapping (DCM) is one such evaluation tool (Younger and Martin, 2000; Brooker, 1995; Moore, 2003, Fossey, Lee and Ballard, 2002) which has been developed on the basis of Kitwood’s work. However, it is not universally accepted and still needs much work to delineate what it can and cannot do.

Finally, people with dementia tend to be marginalized in much of the current research on dementia. Dewing (2002) notes that researchers with a person-centred orientation are beginning to espouse research methodologies which are more inclusive of people with dementia. “With this there is accompanying debate around what inclusion in research means and the level to which it can be achieved while not cognitively and emotionally out-pacing the person with dementia”(p.158). Her discussion focuses in particular on the area of consent and the need for meaningful involvement of the person with dementia in the consent process, which necessarily includes relationship and a recognition of the personhood of the person with dementia. Furthermore, Dewing notes that experience as a research participant – as opposed to research subject – can have a positive effect on the person with dementia. (Similar observations were made in my own research, Hill, 1995). This has implications for the choice of methodology. Dewing suggests: “Inclusionary ethics and the methods suggested here clearly have implications in that they will tend to be suitable for certain research methodologies, they have time implications and they require particular skills in relating with older people who have dementia” (p.168).
Apart from the fact that it makes good sense to choose a methodology appropriate to the questions being asked, it would be both more consistent and ethical to choose a methodology which is consonant with a person-centred philosophy. The words of Junge & Linesch (1993), written in connection with research into the creative arts therapies, are equally valid for research into the humanistically based person-centred approaches to dementia care: “As we develop research more integral to and synchronous with our proclivities, we may contribute important research about the human condition in our own voices and from our own ways of being and knowing” (p.66).

The task of researchers is therefore broad and encompasses the methodological (developing appropriate methodologies), the theoretical (creating a knowledge base) and practical (promoting good person-centred care). There is also the larger political dimension where health services research in general, and person-centred care in particular, receive comparatively little support. This is a political issue which needs to be addressed as part of overall action and advocacy in the field as recommended earlier in the chapter. Part of this advocacy lies also in the undertaking of good person-centred research which unashamedly addresses questions and uses methodologies which are consistent with person-centred values.

10. RECOMMENDATIONS FOR RESEARCH

1. Researchers need to develop research questions for dementia care services which reflect issues important in person-centred practice:
   - Research what it means in practice to be person-centred (for example, Zingmark, Sandman and Norberg, 2002). Marshall (2001) notes that it still has to permeate the consciousness of many professional carers that people with dementia “need to be more than clean, warm, and comfortable” (p.410).
• Study those care facilities where person-centred care is working. The work of Cecchin & Jarrad (2002), for example, points to ways in which person-centred care can be put into practice “in the real world”. “More is learned from the single success than from the multiple failures. A single success proves it can be done” (Merton, 1957, p.436).

• Clarify key concepts in person-centred care such as wellbeing, personhood and the nature of the care relationship in dementia. Ask questions such as how personhood may be maintained, how the good life may be fostered, the nature of wellbeing for people with dementia and its relationship to quality of life (see for instance Jennings, 2000; Whitehouse, 2000)

• Frame research questions about specific therapies or activities in ways which reflect the individualistic nature of their effectiveness. Emphasise meaning for the individual rather than efficacy as a general tool.

• Study the role of families. Hertzberg and Ekman’s (2000) study on the relationships between family and care staff suggests that an important and neglected area of study is how families may be positively integrated into the care of their relative.

• Explore other cultures where dementia is not viewed as a medical condition, to learn about “contexts which promote quality of life” (Downs, 2000, p.372).

• Explore the relationship of training to the improvement of care and also to the enhanced subjective wellbeing of people with dementia...

2. Appropriate methodologies need to be developed:

• Develop ways to critically evaluate practice in person-centred, not medical, terms.

• Related to the previous point, develop methods for evaluating person-centred care, for instance developing and refining tools such as Dementia Care Mapping.
• Actively seek ways to develop methodologies which are inclusive of people with dementia.

3. It is important to narrow the gap between research and practice. Earlier I have noted the interplay of thought and practice and this seems very relevant for research, for instance, action research (Younger and Martin, 2000) may fulfil the dual role of studying practice and shaping it, through awareness raising and exploration of new ways of practice. It is also a way in which staff may be helped to “own” the changes.

4. The person with dementia should be included in a meaningful way although this does not imply that the person’s subjective experience is the sole element of research study.

11. BEYOND PERSON-CENTRED CARE

Person-centred care has certainly sought to humanize the care offered to the person with dementia, addressing the whole person rather than the disease and recognising individual history and psychology, as well as cultural, social and environmental influences. However, Nolan, Ryan, Enderby and Reid (2002) suggest that the expression person-centred care “does not fully capture the interdependencies and reciprocities that underpin caring relationships” (p.203) and that it might be more useful to talk of relationship-centred care, a model which recognises the inter-relationship of the person with dementia, family carers and professionals. This is a model wherein the professional is no longer viewed as expert, suggesting “that meaningful triadic relationships are based on mutual appreciation of each other’s knowledge, recognition of its equal worth, and its sharing in a symbiotic way to enhance and facilitate joint understanding” (p.104). Nolan et al. rightly shift the focus from the individual to the relational context but in defining the relational context in terms of individual, family and the professionals’ negotiation around services, they have perhaps not gone far enough.
In the area of palliative care, which has parallels to dementia care in its person-centredness, Kellehear (in press) offers a more radical agenda by challenging the very focus on services and service provision.

In hospice and palliative care we frequently speak about ‘whole person care’ – the care devoted to the physical, psychological, social and spiritual dimensions of an individual life. But within the narrow confines of a health service so much of the attention to these aspects of a person is translated into occupational responses. We have doctors, nurses, social workers and counsellors. But sometimes these professions are viewed as inadequate to the complex needs of a person or their family so yet more professions are recruited – massage therapists, aromatherapists, music therapists, pet therapists, occupational therapists, or physiotherapists. And it doesn’t end here either.

Every year more ‘needs’ of the dying person or their families are identified, analysed, debated or discussed in the academic and professional palliative care literature. This is followed by suggestions for yet other professionals to meet those needs.

In this framework, needs are translated into professional categories, and Kellehear (in press) asks “Can we afford to keep assembling – should we keep assembling – an occupational response to one person’s life every time they do something as simple as enter a health service such as a hospice or palliative care program?” He suggests that it is ultimately self-defeating – and indeed undesirable – to continue adding more and more professionals to address the needs of the whole person. Rather, a radically different approach is required. In his book “Compassionate Cities”, he offers an alternative vision to the
hegemony of professionalised care at the end of life, an approach which I believe may be of equal relevance to dementia care. I will therefore discuss some of the key aspects of Kellehear’s Compassionate Cities approach.

11.1. Compassionate Cities

Kellehear draws on the World Health Organisation’s public health framework of “Healthy Cities” to create his end-of-life approach, “Compassionate Cities”. Compassion he describes as “commiseration – a joint journey of sharing with another”. Central to Compassionate Cities are the following concepts:

- Compassion is an ethical imperative for health.
- Health is a positive concept even in the presence of disease, disability or loss.
- Compassion is a holistic/ ecological idea.
- Compassion implies a concern with the universality of loss. (Kellehear, in press)

The Compassionate Cities approach represents a departure from current palliative care and Kellehear addresses the tensions between them in the following terms:

11.1.1. Patienthood versus Citizenship

“A patient-centred approach – however admirable and crucial this idea might be in institutional settings – will not be adequate nor workable in a public health scenario” (Kellehear, in press). A Compassionate Cities approach is about citizens not patients. “In this framework and language health becomes an entitlement and not simply a service.” Furthermore, it recognises the person as part of the community. Rather than services, it is about “partnerships with citizens and learning from communities”.

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11.1.2. Health Services versus Social Capital
Kellehear (in press) emphasises the importance of developing social capital which covers “valued social activities such as co-operation for mutual benefit, community participation and support, levels of community trust and respect, and the degree to which communities interact with one another”. Rather than a focus on services, the focus should be on “build(ing) social capital in the community so that these communities are better able to support themselves in death and loss”.

11.1.3. Family versus Community
Palliative care has tended to focus on patients and their families, dismissing “community” as an abstract and possibly romantic notion. However, Kellehear (in press) believes community can be conceived in terms of specific networks people actually use in their lives. Community is therefore a more useful term than family in that it captures the “complexity of direct support”. He suggests that a community framework “not only extends the idea of family but underpins and supports it”.

11.1.4. Palliative Care Holism versus Public Health Holism
This is a move from viewing “the whole person as individual” to “the whole person-in-community”. The difference is that “ ‘whole person’ care is disembodied care – the body and mind of the person is disconnected from his usual physical place at the work desk, the bar, the club, the church or the theatre. The whole person is really the whole patient”. Whole care of the person needs to move out to the wider world in which he or she lives.

11.1.5. Occupational Capacity versus Community Capacity Building
Palliative care, in recognising the whole person needs of the dying person, has focussed on a multi-disciplinary approach to dealing with multi-dimensional needs. Kellehear argues that the focus should be on community capacity building – community development – rather than simply adding another professional occupation.
11.1.6. **Palliative Care versus Palliative Approach**

Compassionate cities “recognises the need to employ early intervention strategies and in the matter of social contexts and relationships” (Kellehear in press).

Palliative care has already recognised that its focus is not simply on care in the last few days of a person’s life, and that much can be done to maintain quality of life much earlier. However, Kellehear (in press) notes it will be difficult for palliative care to move to a palliative (public health) approach.

The fact is that palliative care has an occupational profile best fitting an institutional model of care – doctors, nurses, social workers with casework interests, and psychologists. The employment of community development workers, health educators, social workers specialising in community work, pastoral care workers who see their role as community members more than counselors, all these occupations and epistemological assumptions are uncommon in contemporary palliative care. Although the palliative approach and commitment is present the current occupational and funding infrastructure is wanting and insufficient to the challenge.

11.1.7. **Cancer Care versus End-of-Life Care**

Palliative care has mainly focussed on cancer patients. Kellehear suggests that end of life issues go beyond a specific disease and are relevant to the wider population, that is it is not restricted to a medical issue, but is a social issue.

Kellehear (in press) offers nine vision policies and several associated operational policies for implementation of a Compassionate Cities approach to end of life. These policies include a recognition of compassion as an ethical imperative, acceptance of difference and integration of end of life issues within education, government and the community.
Kellehear (in press) is at pains to point out that he does not intend to devalue the work of professionals, but to remind his readers that community care preceded professional care and that “although modern professional care in these areas improves every day that care remains unsupported, fragmented and incomplete without community involvement before, during and after these experiences.”

A Compassionate Cities approach suggests, then, widening the focus beyond the individual person to the person in community, beyond families to the larger networks around them, beyond a focus on providing services for individuals to enabling communities and working in partnership with them. Kellehear has chosen the term compassion rather than caring, and this seems an appropriate choice, for while many writings on care do stress the reciprocity and equality of the care relationship (Mayeroff, 1971; Noddings, 1984), care often becomes fused with notions of professional care and the individual as patient. Compassion, on the other hand, is “founded on the principle of social interdependencies” (Kellehear, in press), which takes it beyond the “care relationship” between professional and patient. Kellehear’s Compassionate Cities vision does not set community in opposition to clinical care. Rather,

a compassionate society is one that has an end-of-life care that recognises and values both clinical and public health approaches to health care and end-of-life care and one where clinicians and community workers work together for the mutual benefit of each other and the community they serve. Their mutual role is to provide care when the community cannot and at all times to enhance the inherent abilities of a community to perform that care within the political and social constraints of its resources and vision.
Valuable as the person-centred movement has been in offering a more positive view of people with dementia and the care relationship, its prime focus has remained in the context of professional care. Kellehear’s Compassionate Cities framework may be a framework within which to build an alternative vision for dementia, one which views professional services not as a substitute for but as part of the community caring for its own people.

12. RECOMMENDATIONS

1. We need to rethink the viability and desirability of care in dementia which is limited to professional service provision.

2. Kellehear’s Compassionate Cities – his vision and operational policies – may serve as a useful model for a public health approach to dementia. In particular the focus should move from the patient to citizen or person in community, from professional services in isolation to professional partnerships with community, from separating from community to enabling communities to accommodate its members, from family to community network, from an inner-focused institutional model to an outward looking public health and community model.

3. Research could be carried out on a public health approach to dementia, along similar lines to the Compassionate Cities’ vision policies and operational policies.

13. CONCLUSION

In this study I started with my own practitioner prejudices which inclined me to see barriers to person-centred care in terms of staff behaviour and, to a degree, in the institutional environment. However, in tracking the barriers to person-centred care, I have had to move beyond the individual, beyond the institution, and beyond government, to the over-riding values and beliefs of the society in which I live, at the same time recognising the revolving
interconnections between them or “the vicious circle of the system” (Macdonald, 2000). In seeking ways to overcome these barriers, I have recognised that it is not a matter merely of improving individual staff or of improving organisational structures or of changing government policy or of making communities more tolerant. It is about all of these; all must be involved in the process of change.

I have also come to recognise that I may need to broaden my own vision of dementia care beyond person-centred care itself. Ironically, this study of the barriers to person-centred care has led me away from a strict focus on the person and a realisation – quite contrary to Western individualistic ideas – that ultimately the person’s needs are met by being part of a community. Person-centred care has offered a more positive and validating perspective on the person with dementia and philosophy of practice. However, much more radical change is required if the work is to be truly person-centred. Indeed, contradictory as it may sound, I would suggest that in order to work in a truly person-centred way, one must widen the focus beyond the individual person to the community as a whole. I return to Kellehear’s central concepts of compassion as they relate to dementia. There is the ethical imperative; there is the belief that people can feel well even with dementia; there is the realisation that actions need to occur at many levels, that is an ecological perspective; and finally a realisation that people with dementia are not so very different from the rest of the human race. All of this brings people with dementia back into society and returns them to the fold as human beings. This is a vision I believe we all should embrace.
APPENDICES

Appendix A

MATRIX OF PERSON-CENTRED AND NON-PERSON-CENTRED PRACTICES IN DEMENTIA CARE

This matrix contrasts practices which mediate against person-centred care (presented in italics) with key principles of person-centred care practice. It was developed through personal reflection on the relevant literature, in particular the work of Garratt and Hamilton-Smith and Kitwood, and my practical experience in the field.

1. UNDERSTANDING OF DEMENTIA

- Dementia is viewed as a degenerative illness involving loss of personality and identity, the course of which is shaped by neural damage and is not amenable to change or improvement.
  - Many factors are seen to influence the course of and experience of dementia. Staff input therefore can make a considerable impact.
- Staff see behaviour as a symptom of the disease and something therefore to be managed.
  - Staff see behaviour as a response which is meaningful in terms of internal and/or external influences. They therefore try to understand and work with it.
- Person with dementia is viewed as a recipient of care, a “patient”, who is different and therefore does not need to be treated with the same respect for their dignity.
  - Person with dementia is viewed as a human being with a life history, culture and identity, who should be treated with respect.
2. PRIORITY/FOCUS OF CARE

- Physical aspects of care and associated practical tasks are central to dementia care.
  - The person with dementia is at the centre of care. Establishing and maintaining warm and supportive relationships and communication with residents are most important.
- Care planning focuses on the physical/medical.
  - Care planning looks at the whole person (past and present).
- Person with dementia has no choices concerning food, showers, general activities, where they sit etc.
  - Choice is built into every aspect of the person’s life in the institution.
- Routine rules. Care is determined by the needs of the organisation and or staff.
  - Flexibility of institution and staff. The needs of the residents are paramount and the focus of care.

3. MANAGEMENT

- There is no common agreement between staff and management on the focus for care.
  - There is agreement on a clear and positive vision for care, based on an understanding of dementia and ethic as outlined above.
- Staff feel unsupported and undervalued.
  - Provision of appropriate training and supervision is a priority in staff management and relations. Good leadership is required.

4. STAFF

- Staff work very much within their own professional discipline and according to their own profession-specific and personal routines.
  - Staff exhibit an understanding of the care needs of residents and are flexible in their efforts to meet those needs.
- Staff attitude to resident’s situation is pessimistic, focusing on the negative, on deficits.
  - Staff attitude is positive, with a focus on remaining abilities and skills.
5. **NATURE OF CARE/PROGRAM**

- Person with dementia spends most of the day with little or no meaningful activity.
  - Person with dementia has variety of activity, social interaction and relaxation throughout the day – a satisfying lifestyle.
- There is much evidence of negative behaviour, restlessness, distress in residents with dementia.
  - People mostly feel safe and secure, and have people to reassure them when distressed.
- Programs are generic and in large groups.
  - Programs are tailored to meet the needs of the individual. This results in a variety of programs – one to one, small group and large group.
- Activity programs are quite separate from the rest of the care.
  - Activity programs are integrated into an overall care program which aims to offer a satisfying and meaningful life-style to the person with dementia.

6. **INTERPERSONAL**

- Staff have only superficial or functional interaction with resident. Staff should not form relationships with residents.
  - Staff interact positively and meaningfully with the person with dementia.
- Staff do not listen to the person with dementia (for a number of reasons – because of their understanding of dementia, or lack of time or of communication skills.)
  - Staff endeavour to spend time listening to person with dementia.

7. **FAMILY**

- Family involvement is not encouraged. Institution often makes the family feel they’re in the way.
  - Families are encouraged to be involved and to work with the facility to create the best possible care for the person with dementia.
8. **ENVIRONMENT**

- *Space is either public or private.*
  - There is flexibility in space use, including varying degrees of privacy.

- *Little attention is given to the impact of the environment (noise, activity, and so forth)*
  - Attention is paid to the quality of the social, emotional and physical environment

- *Institutional imperatives dominate.*
  - Staff seek to create a homelike atmosphere.
1. RESIDENTS

(Most of these were answered through spontaneous comments and my observations)

- Describe your life.
- How would you describe yourself? What kind of a person are you – interests, passions, beliefs, philosophy of life?
- What sort of life did you lead prior to coming to Star of David?
- What sort of things do you do now?
- What do you enjoy doing now?
- What would you like to be able to do?
- What do you like about Star of David?
- Are there things you do, or which happen to you which you don’t like?
- Who do you like to spend time with?
- In an ideal world, how would you like to live?
- Tell me about your family?
- Do you have a favourite staff member – who and why?
- How do you feel about your life overall?
- How do you feel about your life now?
- What makes you happy?
- What makes you sad?
- Do you ever feel lonely?
- Do you feel others treat you well?
- Are there people around you can talk to? Who?
2. FAMILIES

Can you tell me about your parent’s life – main events. What kind of person was your parent before dementia?
What were her lifestyle, interests, hobbies?
What were her passions?
What do you think was the most important thing in your parent’s life? What is central to who she is?
What led to your parent coming to Star of David?
What is your parent like now – personality – what is her lifestyle now?
What do you see as the positives and the negatives of her life at Star of David?
Are you happy with the care provided in terms of physical health and emotional and psychological wellbeing?
What are your concerns? What would you like to see improved?
What are your impressions of the dementia program and its impact on your parent?
Do you feel included by the Home in the process of providing care for your parent?
Is there anything you feel could be done to make your parent’s life more enjoyable, meaningful?
## PERSONAL CARE ATTENDANTS (PCA’S)

What work (paid & unpaid) have you done in the past?
What have you learnt from it?
What skills do you think you bring to your present work?
What additional skills and knowledge do you feel you need to acquire in your present job?
Can you tell me what you do in your present work. What are your major tasks?
How do you decide what to do with residents in the dementia activity program?
What are the special demands, challenges of working with people with dementia?
What do you enjoy about your work? What don’t you enjoy?
Describe some of the difficulties of the job.
How do you work in with other staff in the dementia program? What do you do if there’s a situation you don’t know how to deal with?
Do you feel supported by other staff and/or supervisors – what support would you like? (Staff meetings?)
Which residents do you relate to most easily?
Which residents do you find harder to work with? Why?
What are the issues which arise in trying to meet the needs of individual residents?
What contact/involvement of families is there?
What sort of use do you make of the care plans?
What do you understand to be the aims of the dementia program?
In what ways do you see the program working, in what ways is it not yet achieving its goals (as you perceive them) (morning/afternoon program?)
How do you find the physical environment? What sort of improvements should there be?
In your ideal world, what would you like to be able to do in the program, what resources, what support, etc.?
4. SUPERVISORS/SENIOR STAFF

Can you tell me briefly about your professional background?

Can you give me your understanding of the aims /objectives of the dementia program?

What is your role in relation to the program, the dementia program staff and residents attending the program? How do you perceive the program to be functioning? How would you like to see it functioning?

What have you observed to be the positives for residents of the program?

What aspects do you feel remain to be improved, put into effect etc.?

In what way are the care plans being used in relation to participants in the dementia program? How do you think ideally they should be used?

How is communication re care maintained currently among staff in the program? How would you like to see communication functioning?

Do you feel staff understand the aims of the program?

Do you feel more training is needed for staff to more effectively implement the program?

Describe, ideally, the kind of person who would be most suited to this sort of work.

What are your impressions of the needs of individual residents? Are they being met?

Can you give an example of a resident who you feel offers particular challenges to the program, to staff? In what ways?

What aspects of the current organisational structure either support or impede effective implementation of the program?

Are there cultural aspects which affect the program (negatively or positively)?

How does the program fit into the overall care at Star of David?

What do you see as the positives of the program overall? Any negatives?

In an ideal world, what sort of care would you like to be able to offer residents with dementia?
5. **EXECUTIVE DIRECTOR**

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>What is your position at Star of David? Can you give me a brief history of the events/ideas leading to the establishment?</td>
</tr>
<tr>
<td>Can you explain the philosophy underlying the program and its aims/objectives?</td>
</tr>
<tr>
<td>What is your “vision” for the program?</td>
</tr>
<tr>
<td>What is your current role in relation to the dementia program?</td>
</tr>
<tr>
<td>How do you view the roles of supervisory level and personal care staff (PCAs) working on the floor in the program?</td>
</tr>
<tr>
<td>Does the dementia program have full support from Council?</td>
</tr>
<tr>
<td>What sorts of issues have arisen from the Ageing-in-place policy?</td>
</tr>
<tr>
<td>From your perspective, what issues have arisen in implementing the dementia program?</td>
</tr>
<tr>
<td>What are the positives so far?</td>
</tr>
<tr>
<td>What difficulties have arisen – expected, or unexpected?</td>
</tr>
<tr>
<td>How do you see the dementia program fitting in with the overall care at Star of David?</td>
</tr>
<tr>
<td>How much are policies at Star of David constrained by federal and state government legislation?</td>
</tr>
<tr>
<td>How would you like to see the program develop in the future?</td>
</tr>
</tbody>
</table>
### 6. OTHER AGED CARE FACILITIES

#### 6.1. Interview with Sally, Leisure/Activities Nurse

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>Can you just give me an indication of your training and how long you’ve been working here?</td>
</tr>
<tr>
<td>Can you describe how the Leisure/Activities program came to be set up and the vision underlying it?</td>
</tr>
<tr>
<td>Can you describe the program? How have you seen it develop over time?</td>
</tr>
<tr>
<td>What benefits have you observed for residents?</td>
</tr>
<tr>
<td>Where do you see the Leisure/Activities program fitting in with the overall care?</td>
</tr>
<tr>
<td>What have been the difficulties, issues, challenges with the program e.g. resources, support from management or other staff?</td>
</tr>
<tr>
<td>What personal or skill qualities should staff in life enhancement ideally have?</td>
</tr>
<tr>
<td>Could you comment on the nature of care for people with dementia generally at the home?</td>
</tr>
<tr>
<td>What would you like to be able to offer your residents with dementia (in a global sense)?</td>
</tr>
<tr>
<td>What should be the role of staff who work with people with dementia – aims, etc.?</td>
</tr>
</tbody>
</table>
6.2. Interview with Louise, Director of Nursing/Christina, Unit Manager

What is your vision of dementia care for your residents?
Can you describe the kind of program of dementia care you offer here?
Can you talk about the following in relation to your program of dementia care:

- **VISION** – how do you get your vision to percolate the whole establishment/translate into practical terms?
- **PHYSICAL RESOURCES** – environment, materials etc. What has been important here?
- **QUALITY OF STAFF** – personal qualities, type of training? What sort of staff have you found to be best suited to this sort of work? How difficult has it been to get the right staff?
- **STAFF NUMBERS/NATURE OF PROGRAMS** – activity and lifestyle? Group, individual, etc. How do you feel you cater for the individual? How do you and your staff get to know the individual (use of care plans? involvement of families? talking/interacting with residents?)

What support is in place for staff working with people with dementia?
What are the issues, challenges, difficulties in implementing a good program of dementia care?
What would be the kind of program you would like to offer in your ideal world?
EXAMPLES OF DATA ANALYSIS SUMMARY AND REFLECTION ON INITIAL CATEGORIES

1. CONTROL

The motive behind this is not necessarily unkind or malevolent, though its results often are. It is rather to do with:

- a belief that the residents with dementia don’t know what’s best for them
- a belief that the institution determines the needs and that the role of staff is to ensure this is carried out. Thus feeding, keeping busy/entertained etc. – these are the focus of staff.
- residents need to be managed, need to be “manipulated” even, in order to get them to do or be as the institution dictates.
- a good staff member gets the jobs done and keeps residents “happy”.
- residents who resist or don’t do what they’re told or are unhappy are difficult and further attempts need to be made to get them to fall into line.

- One of the tools of control and also one of the results of control is that staff do not listen. This is tied up with:
  - simply being insensitive
  - not seeing any need to listen, because he or she knows what is best anyway
  - erroneously assuming that people with dementia have nothing meaningful to say
  - and are incapable of knowing what they want and need. If resident is more able, they are more likely to be listened to.
• a desire not to hear anything that might get in the way of your smooth achieving of tasks – this can be related to pragmatism but also to fear/uncertainty/lack of skill to deal with anything outside your narrow range of tasks. Staff style therefore is rigid, inflexible and impenetrable.

Another aspect of this type of controlling care is lack of humility – assuming you know best, that you understand the resident and what he or she needs more than she does, so you don’t need to ask permission, or ask what that person wants. That person better receive – and be duly grateful.

This model of care seems best represented by the STERN MOTHER. She knows best, she loves her child and manages her. Beware the child who steps out of line – see how Maria talked to one resident, K.

In terms of the experience of this sort of care, the image best suited is that of the iron corset – it’s meant to be good for you, it’s meant to support, but it also stops you moving and breathing freely. The effect on someone like Joan, who is pretty passive, is to render her even more powerless. The effect on the staff is for them to miss out on the abilities of people, their remaining skills, perceptiveness, humour etc.

2. LISTENING/NOT LISTENING

This is closely tied to control – consciously or unconsciously, it helps to prop up control and indeed it’s a natural outcome if you believe that you (and/or the organisation) know best, are the ones to dictate what the needs are and what the tasks are. Listening can simply be an inconvenience and cause for doubt if you heard what you don’t want to.

Also, not listening can be an aspect of personal insensitivity and lack of training to deal with complex situations and issues. Thus, I saw evidence of people asking questions which they didn’t wait to hear the answers for or which really were inappropriate since the resident could not really answer
such a question. Also instead of observing the person and the situation, they
tended to use a Pavlov’s dog approach – press the same button and you get
the same response (eg using singing with Anna)

Listening (or lack of it) relates to observing the overall situation, the person in
the situation, the person’s non-verbal and verbal responses, having skills to
“read” these, asking the kind of questions which genuinely promote
communication.

Lack of listening means the resident feels discounted. In the cup of tea
situation, the resident missed out on a decent cup of tea but also on the
opportunity to feel valuable, to feel she could use her past experience to teach
the staff member something.

Lack of listening also occurred within the organisation – management not
listening to the concerns of staff, but hiding behind – well, so and so is
supposed to do it. Interesting that even staff are daunted by the busyness of
other staff – imagine what it’s like for residents faced with this busyness).
Staff in the dementia program felt they could not ask other staff for help.

I noted the difficulties I felt even given time in understanding residents, and
this is obviously a difficulty staff who did try to hear (eg Janice trying to find
out what men liked) found too. Maybe we just ask the wrong questions;
maybe we just need to try out things. In terms of finding out what’s
meaningful for people, we need to look beyond activities and find the
questions that really tap into what is meaningful (See interview with Louise,
Director of Nursing).

I also note the difficulties residents have in getting themselves
heard...busyness, staff assuming they know what residents need/want etc. –
“the daunting task of standing in the path of that huge juggernaut of routine,
tasks and your place in the scheme of things”
2.1. **Listening Involves:**

1. Sensitivity
2. Understanding of dementia and ways to communicate
3. Understanding the background of the person and how s/he functions – familiarity.
4. A commitment to hearing the person and relinquish control
5. Picking up the verbal and the non-verbal
6. Asking the right questions
7. Flexibility and ability to respond in the moment to the mood, situation, etc. of that moment.
Appendix D

VIGNETTE OF JOAN

The writing of vignettes was part of the process of reflection on and analysis of the data. They represent my intersubjective response to the observational and interview material and an attempt to imaginatively enter the experience of the individuals participating in this study.

To most people, I just look an old, and rather uninteresting old, woman sitting for hours on end without companionship. I know I’m not the easiest person to be with but I’m like everyone else – I like a bit of friendly talk and an acknowledgement that I’m worthwhile too.

People don’t know what’s happening inside. For a start, there’s this pain in my legs – sometimes it feels there’s pain everywhere. People tell me I’ve had a pill already, but I’d never know. I get dark feelings. I’ve always had them – who wouldn’t when most of your family’s been wiped out – of course I’m bitter about that. I get scared too. People want to do things to me and there are some really strange and infuriating people around. That woman who moans and rocks drives me crazy. And to think I have to be in the same room, at the same dining table even, as she is. I get angry – angry at everything, angry at being pushed around. What do they want with me?

I know I’m not easy to talk to. These days the clouds of confusion get in the way and I try not to let that show. I’d be so embarrassed – after all I’m known for my sharp, precise thinking.

I know people need patience and persistence to talk with me, but you know, a kind word, an acknowledgment, can warm the coldest reaches of a heart. Don’t pass me by.
Feedback was given to Star of David three months after completion of the data collection. This took the form of a verbal presentation to staff and management and a written report to management consisting of the following:

- text of the verbal presentation
- text of overheads
- supporting data mainly summarising staff-management interviews but including some of my observations
- description of the four residents and my impressions of needs to be met.

1. **VERBAL PRESENTATION**

I’ve been privileged to be part of Star of David for quite some time now and to be able to observe the daily working of the Dementia program. And I’d like first to thank staff for having me around and also for giving me their time for interviews.

The purpose of this session is to feed back to you what I have learned based on my interviews and observations. What follows will include the good and the bad – and this would be the case for all nursing homes. Nowhere is perfect...not possible in the extraordinarily complex and human area we work in.

Where Star of David is different is that you have allowed someone like me to scrutinise closely what you’re doing, and hopefully what I report back to you may assist you in further developing your program for people with dementia. I am reporting on the positives to affirm and acknowledge the good work that
is already being done...and you should congratulate yourselves on that. The negatives on the other hand represent the growing edge of your work – the areas you can work through and find ways to improve.

And that’s why, after giving the positives and the negatives, I want to address the “where to next”.

1.1. Background to the Program

I just want to briefly recap on the beginnings of the dementia program. The dementia program started almost two years ago in response to a perceived need in relation to people with dementia. The mainstream program did not seem to cater for those people who had dementia. There was also a safety issue – people wandering out of the home. And there was also the issue of the conflicts arising between those people with and without dementia. The dementia program therefore was intended: a) to provide a safe space; b) an activity program; c) as a support within the overall program of care.

Several new and permanent staff joined some of the established staff to run the dementia program room – and they are to be congratulated for their bravery! Although they attended some training, they were very much in new territory.

People without dementia do attend – and it was seen that some of them also had special needs – however, the program last year while not discouraging (them), had to reorient itself to its original population, namely those with dementia.

The program started in the morning, expanded into the afternoon, but as yet has not expanded further to the evening hours which was in the original plan.

In February L (new staff member) started as coordinator of the Leisure and the Dementia programs – and a new stage in the program is beginning. So this is a good time to report back to you all on what I learnt about the
program so far. It is clear that management have recognised already some of the difficult areas and are already addressing them. So....

1.2. **Let’s Start with the Positives: (Mainly Based on Staff and Family Comments)**

1.2.1. **Improvement in Residents’ Emotional, Social and Physical Well-Being**

- Safe, non-judgmental environment. Environment where people don’t need to conform to the “normal” behaviour, where they can be themselves. Also physical safety – in one place.

- Improvement in physical well-being in terms of nutritional needs. Quieter environment and more individual staff attention helped encourage people to eat. Also more able to keep an eye on whether they were getting adequate food or not.

- More individual attention.

- Activity, occupation – something to do. I observed that residents seemed a bit lost without the program.

- Social opportunities – an opportunity to interact with others – over a cup of tea, or playing ball.

- Residents with dementia get less negative interaction with other residents. Some residents without dementia are choosing to come into the dementia activities room. Residents with dementia seemed to get less negative attention from other residents – perhaps people with dementia more settled, happier, perhaps also that they are somewhere else for part of the day and this lessens pressure on people. Interesting that despite lack of tolerance, people without dementia have wanted to come into the room.

- Residents seem happier (they look at a loss when the program is cancelled), less disturbed, less disoriented.

- Offers opportunities to express self and respond in different ways (eg one staff member commented on how often she would be surprised at what a person did).
• Families by and large seem happy with the care – particularly now there is a little more continuity of staff in the home generally.

1.2.2. Staff
• Increased their understanding of dementia
• Get to know these residents better and residents get to know them better
• Increase in confidence
• Sense of achievement.

1.2.3. Star of David
• Residents with dementia more settled but also because they are away for some of the time, other residents get less angry or agitated by their behaviour.
• Diversifies the space.

1.3. The Negatives
1.3.1. No Clear Agreement Re. Vision and the Process for Achieving that Vision
• Staff at different levels and within levels seemed to have different ideas of the WHO (people with dementia or all), the WHERE (only in the dementia activities room or in the rest of the home, the WHAT (activity program, more global program, where does it fit in overall care at Star of David).
• Not clear on the process – HOW to support people with dementia, how to truly personalise, individualise the care.
• What does meaningful/enjoyable activity mean (activity at all?, being busy? being happy, building confidence/self-esteem, something which relates to who you are, your interests, or simply lifestyle)?
• Is activity a means to an end such as building self esteem or is it the activity itself which is important to keep people busy. How do you select suitable activities, role of care plans?
• Is the program only about activity or is it more generally about support for people with dementia within the overall context of individualised care?
• Is the program confined to the room – or does it move beyond?

1.3.2. Communication of the Vision
• Vision needed to be more clearly articulated at higher levels and the process clarified and then communicated to staff.

1.3.3. Use of Care Plans
• This area needs work in terms of creating care plans which are truly useful tools, and then using these to individualise the care.

1.3.4. Issue of Activity
• Activity idea still dominates. For some activity was an end in itself, for others a means to an end.
• Difficulty in contradiction between a safe space and an activity space.

1.3.5. Training and Support
• Needs to be linked to the vision.

1.3.6. Non-Verbal Component
• How to deal with the non-verbal clients – indeed skills in non-verbal communication important even with people who are better able to express themselves verbally.

1.3.7. Status of the Program
• Supposed to be equally important but inevitably sacrificed.

1.4. Where to Next?
• Clarify the vision and the process by which it can be achieved
Be able to spell out the process in practical terms, e.g. look at people in terms of care plans and not just on the activity the staff member decides to do on a particular day.

- Communication of the vision (aided by translating vision into practical terms)
  This too relates to support in a real sense for staff.

- Resources

- Training
  Consider training once the vision and the process are clarified.

- Support
  Left this till last because basically it is defined by what I’ve talked of above. There was no doubt that management were keen to support staff. Also staff did talk of support given by management. However, perhaps it is useful to think of support in terms of the above:

  - SUPPORT in terms of a clear vision coming from above
  
  - SUPPORT in terms of communicating that vision, of having that vision permeate the home as a whole
  
  - SUPPORT in terms of management’s communicating the process – i.e. the practical steps which staff can take to achieve this vision
  
  - SUPPORT in terms of resources (human and material), training etc.

It might be a good idea for management to spend a morning in the dementia activities room one time.

- Status of the program
Create a culture where the emotional and social have equal status with the physical.

VISION – PROCESS – COMMUNICATION – SUPPORT – STATUS OF THE PROGRAM (clarifying how the program should work i.e. care plans etc, resources – staffing, space, material; and training education where appropriate).

2. OVERHEADS

2.1. The Positives

2.1.1. Improvement in Residents’ Emotional, Social and Physical Wellbeing

- safe, non-judgmental environment
- improvement in physical well-being in terms of nutritional needs, physical safety
- more individual attention
- activity, occupation
- social opportunities
- residents with dementia get less negative interaction with other residents
- residents seem happier (they look at a loss when the program is cancelled), less disturbed, less disoriented
- offers opportunities to express self and respond in different ways
- families by and large seem happy with the care – particularly now there is a little more continuity of staff in the home generally.

2.1.2. Staff

- increased their understanding of dementia
- get to know these residents better and residents get to know them better
- increase in confidence
- sense of achievement.
2.1.3. **Star of David**

- residents with dementia more settled
- other residents coping better with people with dementia
- diversifies the space.

2.2. **The Negatives**

- no clear agreement re vision and the process for achieving that vision
- communication of the vision
- use of care plans
- issue of activity
- training and support
- the non-verbal
- status of the program

2.3. **Where to Next?**

- clarify the vision and the process by which it can be achieved
- spell out the process in practical terms
- communication of the vision
- resources.
- training
- support
- status of the program
3. SUMMARY OF STAFF/MANAGEMENT INPUT  
(PCA’S, SUPERVISORS, EXECUTIVE DIRECTOR)

3.1. The Nature of the Dementia Program

3.1.1. What is the Dementia Program?

- a safe space – physically (in terms of wandering behaviour) and psychologically (acceptance, feeling of safety etc.). – a home-like environment
- an activity program
- a place to keep people with dementia away from others (for the benefit of those with and without dementia
- a program which aims to support people with dementia and provide a more enjoyable and meaningful lifestyle as more of the overall care
- originally to go till 8pm (this is not happening).

3.1.2. Who is it For?

In the original vision it seemed that it was for people with dementia. In practice, other people without dementia came in and for a while the vision broadened to include people such as these who might have other unmet needs. However, there were difficulties with the more able people taking over, and the program is being refocussed on people with dementia, though other people still come in. There were mixed staff views on the presence of others – some thought it good to be open, others were aware of difficulties (taking over, etc.)

3.1.3. Relationship to Overall Care

Management believed that the dementia program was part of the overall care at Star of David and that the program could go out to meet people. However, at ground level, the focus of the program seemed very much on activity. Problems with afternoon program where less structured activities seemed appropriate.
3.1.4. **Aims of Dementia Program**

Aims varied along the spectrum of keep people busy, diverted, “happy”, to increasing self-esteem, motivating residents, offering opportunity for communication (one person expressed the view that the activities were merely the means to achieve such goals), to making life more meaningful for residents. One staff member mentioned rehabilitation (e.g. keeping people walking). The opportunity for smaller staff/resident ratio and more one to one was mentioned by a couple of management/supervisory staff.

HH (researcher): Staff comments reflected very much a personal view developed because of their personal and professional qualities and lack perhaps of a common view concerning crucial issues such as the nature of the program (activity or more ?), kind of activity (what is meaningful?), purpose of activity, relationship to overall lifestyle. One staff member pointed out that whereas staff could work with behaviours in the dementia activities room, outside of the dementia activities room they had a different attitude. Seemed some disagreement among PCAs about leaving people to rest (some felt people should be allowed to do nothing – as indeed some supervisors had suggested.) Another PCA who was very much into motivating felt it was reasonable to rouse people to participate because of the benefits they got on doing so.

3.2. **Positives of the Dementia Program**

3.2.1. **For the Person with Dementia**

- get more individual attention
- kept busy, not bored, doing something purposeful
- less disturbed, less disoriented
- kept safe
- feel safe, not judged
- physical needs, eg nutrition being met. Provides some exercise (via games)
• enjoy life more
• opportunities to express self, can respond in unexpected ways
• interaction with other residents.

3.2.2. For Other Residents
• they are choosing to come into DEMENTIA PROGRAM – maybe teach tolerance
• better for residents without dementia that residents with dementia in a separate room.
• residents without dementia less anxious/angry about the residents with dementia.

3.2.3. For Staff
• get to know residents better (and residents get to know them)
• staff beginning to become aware of just how challenging this work is
• increase in staff confidence and understanding. Sense of achievement (These comments from supervisors/management).

3.3. Negatives/Difficulties in Implementing the Program

3.3.1. Staff Aspects
• supervisors aware that staff do not understand the dementia activities program in context of whole program, focus on activity. Also issues of communication, not using care plans
• difficulties recruiting staff, partly due to financial constraints. Also staff not keen to do the dementia activities job, prefer to stick with personal care.
• insufficient training – made staff task quite impossible
• not enough staff, not enough time, increase in work in dementia activities room (due to feeding), staff stress
• language and cultural issues amongst staff.
3.3.2. Organisational Aspects

- Dementia program is always the first to be sacrificed – this suggests lower priority to a program dealing with emotional and social needs of residents.

3.3.3. Practical Aspects

- Diversity of resident needs
- Intolerance of behaviour (or even just the presence) of others.
- Some difficult behaviours in a group context (e.g., crying out)
- Lack of games (One PCA)
- Lack of creativity (Management/Supervisor view)
- Size of group – more participants now
- Only one staff on duty – difficulties with interruptions when toileting etc.
- Support from supervisors
- Lack of time
- Staff divisions – “not my job”. But also influenced by being too busy.
- Domination of those without dementia in the dementia program
- Negative aspects of program
- Too much repetition of games
- Focus on activity
- Afternoon program – still difficulties.

3.4. Suggestions for Improvement

3.4.1. Physical Resources

- More money!
- Games, foot massager, foot spa, music, more variety of fruit, having plates of finger food permanently available.

3.4.2. Environment

- Need more space, nicer furnishings.
3.4.3. General

- expanding on range of activities – sensory, outings
- a space that is not necessarily one that residents have to do activities in. Also, home-like. I’ve found that the notion of the dementia activities room as a safe space and a place to do activities can create conflict, in that people who might just like to be there are expected to do.
- tuning in more to the residents – what they need, who they are, their life stories, past interests etc.
- more education of staff. More staff
- need to address men’s needs
- need transition from PCA work to dementia activities room work
- integrity of time and space in dementia activities should be respected
- sensitivity to cultural issues
- would have been better to have structures in place before plunging into this sort of program
- use of care plans, better communication
- a separate unit for people with dementia would probably be better.

3.5. Staffing

3.5.1. General

- would like more continuity of staff
- need more training. One PCA, however, felt she had enough training for the job
- would like more support from reg nurses
- because only some staff suited, registered nurse felt she probably overloaded them
- staff benefit from dementia program experience.
- some staff more suited to the dementia program work than others, but registered nurse didn’t always have a choice about whom she assigned to the room.
3.5.2. Ideal Qualities

- Emotional energy, patience, tolerance, sense of humour, able to relate to/communicate with person with dementia, sensitive, listens plus understanding of dementia and normal ageing, common sense, intelligence, kindness, joy, articulate, empathy, gentleness, personality, empowering, creative, able to work with several people at once, love the people, understand purpose of the work, want to work in the dementia program.

- One staff member (Jewish) thought staff should be Jewish. Non-Jewish staff were aware of cultural differences – one felt he needed to learn more, the other felt she could use that ignorance as a tool – getting residents to teach her.

- One staff member (PCA) said she thought it should be an activities person, not a nurse.

3.5.3. Staff Attitudes to the Dementia Program

- Staff attitudes varied. Some were scared of the work, preferring to stick with personal care. Others, particularly in the early months of the program, thought the staff in the dementia activities room had the easy option.

3.5.4. Staff Roles (As Seen by Individual Staff Members)

- Supervisory staff see themselves as support people. Only one specifically said she thought she should sometimes spend time in the room as a practical support (reg. nurse).

- Two of the PCAs mentioned the importance of teamwork.
4. SUMMARY OF FAMILY/RESIDENT INPUT

4.1. Family Input

4.1.1. Overall Care

- Three of the family carers were satisfied overall with the care at Star of David. One (of these) commented that the nursing situation had improved greatly in the last 2-3 years. Prior to that it had been “drastically hopeless”.

- The family member who was dissatisfied raised, I felt, issues which are important to look at. There were clearly issues of the family member’s feelings of guilt and personal difficulties dealing with her mother’s situation which influenced her perceptions. However, her concerns do highlight the extra attention needed in caring for the most disabled residents – residents who no longer can communicate, residents who are “unattractive” because of this lack of communication and no longer being able to express much obvious personality, as well as because of their immobility and need for total care. They can literally go in the too hard basket.

4.1.2. Family Involvement in Care

- variety of attitudes: feeling you couldn’t be involved once parent transferred to nursing home; feeling that maybe you didn’t want to know necessarily what was going on all the time

- mixed staff responses to family involvement (some positive, some negative); families not really aware of day to day, nor of parent’s condition or changing medication.

4.1.3. Dementia Program

- Not very much seemed to be known of the dementia program in particular, though they all knew there were activities of some kind. They were unsure what activities their parent participated in if any. One family
member was unaware of the dementia program until I wrote to him about my research.

4.1.4. Environment

- One family member commented that it was homely. Not nursing-home or prison-like.

4.1.5. The good

- good to see parent participating in activities
- knows how hard it is working in this area. Thought staff “wonderful” dealing with everything
- staff seem very attentive
- freedom to come and go for families
- saw improvement in parent’s physical well-being since being at Star of David.

4.1.6. Concerns/Suggestions for Improvement

- hygiene and/or appearance. The issue of hygiene/cleanliness for incontinent residents was raised but also two members commented about facial hair. Both parents hated having facial hair – would be good to remove it.
- issue of private carers and where they fit in within the overall care at Star of David. This was raised by one family member. How many hours do you employ someone for? If you have someone the whole time, then will the Star of David staff leave the caring to the private carer? Should the carer not be integrated into the service and into the care plan.
- changing staff an issue, though less than it used to be
- one family member commented on the level of heat – puts people to sleep. Also need to get outdoors more.
- one mentioned some missing jewellery. Would be better to remove valuables?
• why not use cups for soup instead of bowls?
• psycho-geriatrician consulting at Star of David would be good
• suggestion that Star of David staff might also learn from external carers
• attitude to people who make complaints.
• security features should be improved. On the other hand, don’t want it to become like a prison.
• would like some information on mother’s condition and on medication in particular. A six-monthly note?
• all felt the staff had a difficult job.

4.2. Resident Input (Based on Informal Talks)
Three of the four residents I studied made positive comments about the dementia program or their life at Star of David, the fourth resident being unable to communicate verbally. I observed that several residents looked quite lost on the days the program was not running.

5. NOTES ON THE FOUR RESIDENTS: ANNA, EVA, JOAN AND SARA
Below are “cameos” of each of the four residents – my impressions of each person based on staff/family interviews and my conversations with and observations of the residents. It seems clear to me that much of the person, the character and coping skills remains and that it is really helpful to have access to this background, in order to better understand and better meet the person’s present needs.

5.1. Anna
According to her son, Anna was and is a very much loved person – a sort of counsellor to the Melbourne Holocaust survivors and “God” to him. Family was central to her life. She had no real hobbies except that she did a lot of walking with friends. She was not one for trivialities, liked the simple life and
was not a great socialiser. As a mother of her young family she always made an effort to provide healthy food. Her son describes her as strong and sensible, as someone who had no enemies, but yet who was quite clear in what and whom she liked (those she didn't like she avoided). She focussed on priorities. This ability to focus had probably helped her survive her wartime experiences. Despite losing everyone, she had never shown any bitterness.

With dementia have come agitation and anxiety. At times she gets extremely agitated, starting to pull her hair and nothing would appear to help. At other times, she appears simply sleepy, or a little unhappy and moaning. However, on the positive side of the scales, I have the impression that she is still in many ways self-sufficient and can cope with some of these ups and downs herself. For instance, I wonder if the moaning or humming is a bit of self-comforting. Sometimes when she is just sitting quietly, I have the impression she may well be doing what she used to do on her walks “turning the pages of her life”. One senses a strength (despite the agitation) and a great warmth and wisdom. She is very affectionate and enjoys physical contact.

In my observation of her interactions with staff, it is clear that staff need to listen to what she is saying (verbally and non-verbally) – at times when she’s agitated, singing, or massage etc. will help, but at other times leaving her, giving her space is the best approach – and this she quite clearly indicates. She obviously digs her heels in when people try to get her to do something she doesn’t want to and it is quite useless, as some staff do, to think that she will always respond to singing or music etc. When she really doesn’t want something, she does not want it. When staff don’t listen, she finally lashes out. I wondered if perhaps the fact that on one occasion, every person who passed her said “Anna, you haven’t eaten your food yet” served to make her more stubborn than ever about eating!
Given her real interest in and concern about healthy cooking, it’s interesting that much of the conflict revolves around eating times, when she refuses to come to the table, or just even to eat. One staff member tries to force, the other insists on encouraging her but giving her time to eat.

Relationship makes a huge difference, as even in situations where she displays anxiety, she will allow herself to be led if it’s one of the staff she likes.

While many of the games seemed inappropriate for Anna, she made a favourable comment about it being bad if they didn’t have games (This was on one morning that the dementia program was cancelled) so perhaps even if she dozes through much of it, she gets something from the environment. On days when the dementia program has been cancelled, she has certainly looked quite lost.

At good moments, for instance the day that she and I sat outside the office observing people, she was very aware and made very perceptive comments. She also initiated most of our talking. She has also shown herself to be very aware of and negatively affected by the interruptions of people moving in and out of the dementia activities room.

She responds to music and is able to relate to it – copying changes in rhythm, being conscious of the pauses in the music, etc. Singing with others seems a wonderful way to interact with other people and a good counterbalance to some of the negative responses she evokes because of behaviour such as moaning, or taking other people’s biscuits, etc.

In many ways, despite the dementia, I think Anna remains a very strong person who may often give us the best clue as to what she needs at any given moment. I think she in fact demands to be taken seriously (ie no means no) and I suspect she does not suffer fools (or people who say foolish things) gladly. She can often see right through staff who are trying to “manipulate” her to do what they want.
There are no easy solutions to the agitation nor to the conflict over food and toilet, but it would seem like paying more attention to what she is “saying” and tapping into the positive aspects of relationship (touch, etc.) and music. She certainly needs people, but at times she might just need a space (such as the one she had during her walks in the past).

5.2. Eva

Eva is also a Holocaust survivor losing two parents and one of her two sisters. She came to Australia with her husband and 10 year old daughter in 1957. Her daughter said when she (the daughter) was really young, her parents wanted to tell her about their experiences but she wasn’t interested. When she did get interested, her mother no longer wanted to talk about it.

Eva seemed to have been a hard worker all her life – even worked at home into her 70s and helped look after Esther’s baby when he was first born (when Esther was physically unable to care for him). She was extremely tidy – always cleaning the house – and in personal care was very fastidious. She always made sure she got rid of her facial hair. Liked a daily shower. She liked dancing and would dance with friends as her husband was not a dancer. Indeed my impression from some of what Esther said is that her husband essentially held her back from things she might really have enjoyed doing (like travel). They fought a lot too. Esther saw her as pretty dependent on him, allowing herself to do or not do as he wanted. It’s interesting that he now cannot cope with Eva as she is – as soon as she starts crying, he goes and leaves them for the rest of the visit.

In contrast, Eva had a very close relationship with Esther who would tell her everything. They’d go shopping together and so on.

Eva liked TV and liked to play games like bingo, but otherwise no hobbies as such. She loved her home and loved cooking.
Eva had begun with dementia already at Star of David and had had a first, not too incapacitating stroke when in there. However, the next stroke had completely taken away her ability to communicate. It seemed that only in the last year or so had staff considered bringing her out of her room to have a change of scene. Her days are spent partly (or sometimes wholly) in her room – often with the TV on. Staff take her into the dementia activities room, but often leave her with her back to the group (though she does look out the window onto the courtyard)

It can be easy for Eva to be forgotten or at least not be acknowledged. Her inability to communicate verbally – even if it’s a somewhat confused verbalising (like Sara for instance) – makes communication difficult for her and for staff. Her main means of communicating is through moaning and crying and some staff are aware that this may mean anything from an expression of physical pain (she’s had quite a few physical ailments), to emotional pain, to possibly just a response to another person being there. It is tempting to avoid interaction because of the discomfort staff feel when she communicates in a way that generally is associated with pain (but may not be so with her). Her inability to communicate conventionally also means that her awareness and intelligence can be underestimated. In fact, she seems to understand quite a lot and if brought into a situation where something interesting is happening, will watch and follow whatever is happening with her eyes.

As it is, with little stimulation, she tends to lie in her chair or bed, drifting in and out of sleep. I think she’s lonely and bored and needs stimulating things to watch, as well as being included in human interaction (just even acknowledging her within the group, but also massaging, etc.)

I feel there may also be physical issues to address – her daughter has talked of hygiene, etc. and while one needs to be aware of the daughter’s perspective, it is clear that for a number of reasons it would be easy to “forget” about Eva
since she cannot voice her requests. Her daughter cited how her mother was taken to hospital where it was discovered that she was dehydrated and had a urinary tract infection but no one had picked it up. She also commented how no one had noticed a bruise on her mother’s face – the person feeding her had not noticed it because it was on the other side of her face.

5.2.1. **Areas Which are Important for Eva**

- physical hygiene – given her concern for cleanliness, tidiness – this must be an important area for her, affecting her sense of well-being. Regular facials, manicures
- this may show my biases – though one of the staff also suggested this – but I believe some passive exercises, done sensitively, could also contribute to more physical comfort
- it would be good (and this is already in the care plans) for staff to acknowledge Eva in every situation and context whether doing her personal care, or bringing her somewhere etc.
- having someone with her – even just stroking her hand – would ease sense of isolation
- providing sensory stimulation – things to see, listen to etc.
- could be related to the previous point. – include her (actively) in a group. Watching what others do is also beneficial and acknowledging her can also ease isolation.

Eva’s situation demonstrates the difficulties of residents who are unable to communicate their needs or even to communicate much of their personality. Sara, by contrast, though confused is still verbal and has much of her personality which she can communicate (e.g. her humour). Hence she is quite a favourite of most of the staff. Eva is much less attractive because it’s hard to know who she was or is. Not only is she hard to understand but also her sole means of communication is one which is very distressing to others and tends to make them go away rather than remain.
I don’t think Joan was ever a life and soul of the party type. She certainly, according to her son, had a circle of friends, liked to cook and have friends in, but as he said she was not “aggressively social”. For much of her life she struggled with depression and was preoccupied with various aches and pains. She felt bitter about the loss of her family in the Holocaust, felt bitter about
being put in Star of David. (She herself had come as a young married woman to Australia in 1939). Her main joy in life was her sons whom she lived through. She was intimately tied up with their lives, trying to guide them in the right directions, caring for them, interested in what they were doing etc. The only other interest was music, mainly Jewish music, which she loved to sing along with. She was a “sharp” woman with a good brain for maths and a good memory and I presume a hard worker as she worked alongside her husband in his tailoring shop. For her son his mother’s dementia has meant that she has become harder to communicate with and apart from the grandchildren and the dog (or perhaps the dog and the grandchildren), there is little that really gets a response from her. The positives of dementia were that his mother had lost her bitterness, her depression and much of her preoccupation with her bodily aches and pains.

My impression based on what was said, and my impression of her son Adam as a person, make me think that Joan has never been a very outgoing person, though she did have a circle of friends and did socialise. There is a contradictoriness in the message Joan sends out (and I wonder if this is how she has always been) – a desire for engagement (she wants someone to talk to her), but also a guardedness (note how she always shrugs off things relating to her in particular and says, oh everyone does that, it’s not hard etc.). Yael. (psychologist) commented she always felt intrusive when asking Joan anything about herself. Certainly now, she is passive in the interaction – her son, like me, find one needs to push and push to keep the communication going. How much of this is her character and how much a compensating for or hiding of the deficits she’s experiencing through dementia?

I do feel she seeks the warmth of human contact – even though she is not able to foster it in the interaction. In our conversations, she has been able to move beyond herself to expressive concern for my well-being and even offered compliments. Her warmest reactions seem to come when she can
take on this “mothering” role (eg. make sure you go to bed with your flu), or when responding to my mothering experience with my daughter.

I can’t help feeling some of the passivity has always been there. She almost invites people to take on the active role (which disempowers her) and while at times resenting it, basically lies down to it.

Key words – passive – ambiguity: desiring interaction but not fostering it.

I’m trying to think whether the goal of social interaction is just my goal or if she genuinely would welcome it. My feelings (at an intuitive level) are that she is inviting and desirous of interaction but not necessarily all the time (she indicated this – in reslog3 I think). And she is certainly not always tolerant in the social situation (with people like Anna) and in fact, such interactions tend to make her withdraw from and reject others. It also increases her anxiety (“What do you want from me”). I think she is one who needs “diversion” – to be diverted from thinking about her aches and pains. Because of her difficulties maintaining “conversation” in a one-to-one situation, she needs much support – tapping into her mothering qualities can elicit positive response and interaction. Also, having something to talk about – a kind of “transitional object” which may be a focus of talk but also allows one just to be beside her without talking eg the fish tank. I think a group activity could play a positive role in offering a structured activity where she can be involved in something outside herself and with the right facilitation be in a positive interaction with others. She needs support to maintain interaction, and a group activity could offer this. In addition, I think it should encourage her to become more visible (good for her self esteem).

Anxiety – this relates in part to her personality, but it would be worthwhile for staff to look at their ways of relating to her – I’ve seen them take her over in ways that feed into her anxiety and sense of powerlessness.
It’s been interesting to hear conflicting staff views of her – demanding/undemanding; pleasant, cooperative, appreciative of help/lack of joy, inflexible.

5.3.1. Needs

- interaction in a structured situation which supports and maintains for a while positive interaction with others. She wants human contact but a combination of her personality and the effects of dementia make this difficult without support
- anxiety – critically look to see if there are some aspects of staff interaction which contribute
- Jewish music, singing
- emphasis on her individuality – staff should not foster passivity.

5.4. Sara

A Holocaust survivor who lost her whole family during the war. After the war, married and moved first to Germany and then Australia in 1950 (by this time with two sons). Her husband developed uncontrolled diabetes and therefore Sara. effectively took over as head of the family, and also running the family business. Her son, Jacob, her favourite, had a close relationship with her and remembers her as a calm and coping sort of person who never seemed overly stressed and who had a good sense of humour. Even with later problems such as when husband was put in a nursing home and subsequently died, she seemed to adjust fairly well. She liked to socialise but never developed really strong relationships with other people. Indeed, her son suggested maybe not even with her husband, whom she regarded perhaps more as a patient than a husband. In retirement, she kept pretty much to herself. Except for the odd card game with friends, her life was focussed on her family. The first signs of dementia related to episodes of paranoia and wandering/confusion.
Much of what the son says of his mother in the past seems to place Mrs. Sara’s present state very much in context. My impression of her has been of a strong presence, someone with a good sense of humour, someone nice, someone likeable, but also someone unattached. This translates very much in physical terms in that she moves around the home and sometimes right outside of it! Yael (psychologist) spoke of her as flowing in and out and I noted her as being “in transit” and “on the move”. She moves around the home, occasionally staying in the dementia activities room for an activity, but often in the general lounge, or going to her room, changing her clothes and moving back into the lounge. In the lounge, she may be seen sitting with someone but not connecting. She seems a benign and self-sufficient presence, who can be quite conversational if approached, but whom one senses always stays one step back. Having said that, I would also add that this does not diminish the warmth and pleasure one has in talking to her and especially, enjoyment of her humour.

The staff as a whole tend to find her “gorgeous” and likeable, though some commented that she could be stubborn and that at times she could be aggressive when it came to shower time. I found that perhaps depending on the day or how one approached her, she could become suspicious and feel threatened. This happened one day when I approached her too quickly and she was unsure of my intentions.

Speaking and understanding present difficulties to her, but there is still much evidence of understanding and awareness and that sense of humour. One staff member commented that she observes and takes things in without your knowing – she had found her one day teaching other residents the door access code! I too have found her a keen observer of people. On one occasion when one of the vocal residents was stridently stating her opinions, it was clear that Sara was finding it all quite amusing.
Is she happy at Star of David? Is she fulfilled? Sara herself says she is happy, but also (in the same conversation) will indicate that she misses home and family. However, she is aware that her family feel this is the best for her – they think she’ll become a genius – Sara’s comment! Her son seemed to say that in fact, apart from family, she didn’t ever do much in her retirement and he feels she’s happy. Other staff have suggested that she’s bored and needs to be occupied, so she won’t try to wander out of the home. My impression was on the one hand that most times she seems to be moving about in a contented way and that it works well for her to have the occasional activity she can drop in on. I had noted in reslog 2 that she seemed in transit and lacking purpose and place, but I wonder if this demonstrates a bias in myself (and I imagine other people in the field) to have people purposefully or meaningfully engaged. Perhaps for Sara, meaning does lie in this flowing, shifting and moving lifestyle, with opportunities to float into, plug into some activities, but be free to move on. And obviously the contact with family is important.

Her son pointed out that one of the positive aspects of dementia was that Sara had forgotten the war and now seemed to only remember the nice and the good and those things which are important to her, viz. him, his brother and to some extent their children. She certainly seems most times to appear on an even keel and living in a benign world, though I understand she does suffer from migraines.

One staff member commented that Sara at times gets anxious. Although she gets confused at times about where her room is or loses her handbag, she hasn’t appeared to be particularly upset about this and seems to be able to approach someone to help her. Iris has said that Sara knows who to go to for help. A big plus in terms of environment is that Sara’s family seem to find the nursing home a very comfortable environment. They would very much hate high fences etc. and feel that when they visit their mother at Star of David, it’s just like visiting her at her flat. This must make family contact more
pleasurable for all. Perhaps what Star of David does best for Sara is to provide this home-like environment where she can just be, one where she can drift in, sample, participate, move on and where she knows there is always someone there to approach for help if necessary.

Heather Hill

March 2000
Appendix F

ETHICS COMMITTEE APPROVAL

La Trobe University
MEMORANDUM

TO: Professor Elery Hamilton-Smith

SUBJECT: Reference: FHEC98/169
    Student's Name: Heather Hill
    Title: The self in dementia

DATE: 5 November 1998

The Faculty Human Ethics Committee (FHEC) has considered and approved the above project. You may proceed.

Please ensure that each participant retains a copy of the Form of Disclosure and Informed Consent.

Please note that you are required to provide an annual report (where applicable) and/or a final report on completion of the project. Would you please return the completed form to Mr David Williams, Secretary, FHEC, Faculty Office, Faculty of Health Sciences, La Trobe University, Bendigo, Victoria, 3550.

David Williams
Secretary
Faculty Human Ethics Committee
Faculty of Health Sciences
### Appendix G

**INFORMATION AND CONSENT FORMS**

1. **RESIDENTS (CONSENT FROM FAMILIES):**

   **INFORMATION FOR RELATIVES ON RESEARCH PROGRAM AT STAR OF DAVID HOME FOR THE AGED**

   **PROJECT TITLE:**  THE SELF IN DEMENTIA

   **SENIOR INVESTIGATOR:**  PROFESSOR ELERY HAMILTON-SMITH  
   HONORARY RESEARCH FELLOW  
   LINCOLN GERONTOLOGY CENTRE  
   LATROBE UNIVERSITY

   **RESEARCHER:**  HEATHER HILL  
   POSTGRADUATE STUDENT (PHD)  
   SCHOOL OF PUBLIC HEALTH  
   LATROBE UNIVERSITY

   **INTRODUCTION:**  
   The dementia activities program was set up at Star of David in order to better meet the needs of those residents who have dementia. The program has been running for almost 6 months. As a result of the positive environment created through this program other residents, without dementia, have also begun to participate.

   **AIMS OF THE RESEARCH STUDY:**  
   Through study of the program and its benefits for those residents with dementia, this project aims to increase understanding of how the self may be maintained in dementia and ways in which this understanding may contribute to the achievement of a more satisfying and meaningful lifestyle for people with dementia.

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6 This was the initial title of the research at the time consent was sought (prior to the reconnaissance phase of the study).
This research is being conducted in fulfilment of the requirements for Ms Heather Hill's Phd in Public Health. Ms Hill will be supervised by Professor Elery Hamilton-Smith.

**PARTICIPANTS:**
Since the researcher will be studying the program as a whole, consent will be sought from all residents who take part in the program. However, the major focus, in terms of the research, will be on those residents who have dementia.

**RESEARCH PROCEDURES:**
Research procedures will be relatively unobtrusive. Apart from normal participation in the dementia activities program, there may be some informal interviews with residents, family and care staff and occasional videotaping during the program. The researcher will also draw on care plans and social history to assist in formulating new strategies for the program.

It is expected the research study will last for up to three years.

**CONFIDENTIALITY:**
Data will consist of written material and some audio- and video-taped material. In the written data, initials will be used instead of names. All data will be kept in a locked filing cabinet during the study, and after the study, will be stored at the office of Professor Hamilton-Smith, Latrobe University.

The results of this study will appear in Ms Hill's thesis, in journal articles and in presentations to professional groups. At all times confidentiality will be maintained. In printed journal articles, participant identity will not be revealed. Where video material is shown outside Star of David, identities of residents and the institution will not be disclosed.

**BENEFITS OF THE RESEARCH:**

**Residents:**
Residents with dementia will benefit as the program develops and is refined through the research in order to help achieve a more satisfying lifestyle. It will also benefit many other residents who in time may develop dementia.

**Staff:**
Staff in the dementia activities program require encouragement and support in finding new and creative ways of working with residents in the dementia activities program. They will therefore benefit from external input, new ideas and an opportunity for support in developing and improving the program.

**Star of David:**
It is hoped that the program at Star of David may serve as a model for other organisations wishing to have a more effective and more positive program of care for people with dementia.
Dementia Care:
It is hoped that what is learned through study of the program at Star of David may contribute to the field of dementia care in general, in offering a more positive approach to working with people with dementia.

NON-PARTICIPATION IN THE RESEARCH:
A resident has the right to withdraw from the project at any time and to have all traces of participation removed from the project records provided that this right is exercised within 2 months after the completion of participation. Non-participation in, or later withdrawal from the research, will in no way affect your relative's participation in the dementia activities program.

FURTHER INFORMATION/QUERIES:
Any questions regarding this project may be directed to Professor Elery Hamilton-Smith, Senior Investigator (tel.) or Heather Hill (tel.). If you have any complaints or queries that the Senior Investigator is unable to answer, you may contact the Secretary of the Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University, Bundoora 3083, telephone 9479 3574.

Elery Hamilton Smith          October 1999

Heather Hill
THE SELF IN DEMENTIA
A Research Program of the Lincoln Gerontology Centre of La Trobe University, based at the Star of David

Senior Investigator: Prof. E. Hamilton-Smith
Researcher: Ms. Heather Hill

I/We* ________________________________ (Print name(s))
give consent to the following:

1. Participation in the above research program being carried out by Prof. E. Hamilton-Smith and Ms. Heather Hill at Star of David.

Signed: _______________________________________

2. Use of videotape or photography, both as a research tool and for future educational use under the conditions outline in the attached Information Sheet. I/we also consent to Ms. Hill having access to nursing records, only in order to gain information on physical health.

Signed: _______________________________________

3. We recognise that the results of this study will be published in the professional literature and consent to this on the basis that personal identity is not revealed.

Signed: _______________________________________

*If signing on behalf of relative, please give:

Name of person taking part in research ..........................................................
His/her age ..........................................................
Your relationship to him/her ..........................................................
Reason(s) why he/she cannot give consent ..........................................................
............................................................................................................................................
............................................................................................................................................

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2. FAMILIES (UPDATE ON STUDY AND REQUEST FOR THEIR PARTICIPATION):

25th October 1999

Dear

STUDY AT STAR OF DAVID OF THE DEMENTIA ACTIVITIES PROGRAM

In October last year, I asked families of residents participating in the dementia activities program to give permission for their family member to be part of a study being carried out on the program at Star of David. The study aims to gain insight into the issues and challenges involved in setting up a program of dementia care which truly caters for the needs of each individual resident. This study will eventually form part of a PhD thesis, but is also intended to contribute to ongoing efforts of staff and management to provide an effective program for residents with dementia.

As the study has evolved over time, I have chosen to focus on a limited number of staff and residents - using both interview and observation to gain an understanding of the program from multiple perspectives. Obviously, what residents themselves think is of prime importance and while I am making every attempt to talk with and spend time with the residents, it is clear that families, if willing, could give very useful input.

Your mother ----- is one of the residents I have selected for particular focus. The possibility of informal interviews with family had already been mooted in the initial information sheet and I would now like to ask if you would be willing to be interviewed. Questions would relate to your mother's life pre-dementia, how she is at present, your thoughts regarding her present care and how it might be improved. The interview would last between 3/4 hour to 1 hour, at any time which suits you, at Star of David or any place convenient to you.

I would like to ask permission to tape the interview. The tape is only for my use and will not be played to anyone else. It is merely a matter of making sure I do not miss any valuable points and have an accurate record of what you say, so it may be incorporated within the total data collected. I enclose a consent form together with a stamped addressed envelope for its return. Should you have any questions, please do not hesitate to contact me at home on tel.

I will contact you shortly to find out your response and hopefully arrange a time to meet.
Your help in this is very much appreciated. The information you provide, along with all the other material I have collected, will I'm sure be of great value in assisting staff in their efforts to provide the best care possible to residents at Star of David.

Yours sincerely,

Heather Hill

CONSENT FORM

FAMILY PARTICIPATION IN

THE RESEARCH STUDY ON THE DEMENTIA ACTIVITIES PROGRAM AT STAR OF DAVID 1999

I agree to be interviewed by Heather Hill, PhD student, Latrobe University, for the above research study at Star of David.

I understand that the interview will be taped for data collection purposes only and will not be played to anyone other than the researcher.

I understand that in any subsequent writing on this study, comments will not be attributed directly to me and my personal identity will remain confidential.

.............................................................................(Signature)

..............................................................................(Please print name)

Relative of:............................................................................
<table>
<thead>
<tr>
<th>3. STAFF MEMBERS:</th>
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<td>3rd August 1999</td>
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Dear

**RE: RESEARCH STUDY OF DEMENTIA ACTIVITIES PROGRAM AT STAR OF DAVID**

Over the past 18 months, you may have seen me around Star of David. I am a PhD student from Latrobe University and, with management's permission, I have been doing some preliminary studies of the dementia activities program. I am now about to embark on the research study proper and am writing to ask formally for your assistance.

The aim of the study is to come to an understanding of the issues, the successes and the difficulties which arise when implementing a program like the dementia activities program which aims to improve the overall lifestyle of your residents who have dementia. I have decided to look at these issues by selecting four residents, four supervisory staff and four PCAs to interview. In consultation with management, I have tried to choose a variety of staff and residents in order to get many different perspectives.

I will be at Star of David two days a week from August till December this year, making general observations around the Home with particular focus on the dementia activities program and its effect on residents.

Your involvement would consist of an interview of between 45-60 minutes, as well as some informal talks in the course of your work. To facilitate data collection and analysis, the interview will be taped. Interviews will take place within the next two months.

Some time, probably around November, I will report back to staff my preliminary findings and ask for feedback.

In any reporting, you will not be identified as an individual and pseudonyms will be used, so you may be assured of confidentiality.

Management have been most supportive of this project, realising that it will provide useful information to further improve the program. I hope you will therefore be happy to contribute as outlined above.

Please sign the slip below as indication of your willingness to participate. If you have any questions concerning the above, please feel free to ask me.
Thanking you in anticipation for your help.

Sincerely,

Heather Hill

CONSENT FORM

STAFF PARTICIPATION
in

RESEARCH STUDY ON DEMENTIA ACTIVITIES PROGRAM AT
STAR OF DAVID — August – December 1999

I agree to be interviewed by Heather Hill, PhD student, Latrobe University, for the above research study at Star of David. I understand that the interview will be taped.

I understand that in any subsequent reporting my name and personal identity will remain confidential.

Signed: ..............................................................

Position: ...........................................................

Date: ..............................................................
4. OTHER INSTITUTIONS:

CONSENT FORM
FOR INTERVIEWEES FROM OTHER INSTITUTIONS/ORGANISATIONS

PHD RESEARCH STUDY ON ISSUES INVOLVED IN AND IMPEDIMENTS TO THE IMPLEMENTATION OF A PERSON-CENTRED PROGRAM OF DEMENTIA CARE

I agree to be interviewed by Heather Hill, PhD student, Latrobe University for the above research study.

I understand the interview will be taped for data collection purposes only and will not be played to anyone other than the researcher.

I understand that in any subsequent discussion of or writing on this study, comments will not be attributed directly to me. Further, both my personal identity and that of my employing organisation will remain confidential.

....................................................................... (Signature)

............................................................................... (Please print name)

............................................................................... (Position, eg. D.O.N.)
BIBLIOGRAPHY


Goyder, J. (2001). We’ll be married in Fremantle. Fremantle, Australia: Fremantle Arts Centre Press.


Sheard, D. (2002). Beyond mechanistic dementia care training are real feelings and real life. Signpost to older people and mental health matters, 7 (2), 10-12.


