THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by TONY SCHUMACHER JONES
2013 Churchill Fellow

THE MR and MRS GERALD FRANK NEW,
CHURCHILL FELLOWSHIP
to study person centred care for people with dementia - Netherlands, UK.

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Signed

Dated

Tuesday, 25 November 2014
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Introduction

If a traveller from a distant planet landed in Australia in 2014 and asked to be taken to the largest gathering of people living with mental and psychological problems then you would take them to an aged care facility. Since the deinstitutionalisation of the old psychiatric hospitals, which occurred from the 1960s to about the 1980s, their role has largely been taken over by the nursing home or the residential aged care facility, to give it the correct title. These are the new psychiatric hospitals where eighty to 94% of residents... have a major psychiatric illness.1

Within the walls of these modern and at times almost opulent structures live some of the most vulnerable Australians. And it is in the modern nursing home that our fictitious visitor will find a group of people characterised by a number of common variables; old age and associated cognitive decline, high rates of dementia, depression, delirium, anxiety and lesser but still fairly significant numbers of people with delusions, hallucinations and associated mood disorders. As if these burdens are not enough, our intrepid space traveller will find this group of elderly Australians further beset by numerous physical disabilities of which pain and reduced or impaired mobility are probably the most significant. And if they are particularly insightful they may also discover other aspects of this way of living, such as the over-use of psychiatric medication, problems of hydration and nourishment and more complex problems of loneliness, abandonment and powerlessness. And if they linger long enough to absorb something of the culture of such institutions they will find a work force that is poorly paid, poorly trained, sparsely present, overwhelmingly task oriented and, anecdotally at least, quite culturally and linguistically different from the people they care for. What will this traveller from a distant land make of us – we who place our elderly in such settings? Compassionate? Caring? Empathic? Or perhaps punitive? It may be that our alien friend will return to their own world with tales of how we, on earth, punish our elderly for some previous and unspoken of transgressions against perhaps our Gods or our fellow men. Such is how we live.

My Churchill Fellowship emerged against a backdrop of the previous ten years spent working in the area of older persons mental health and, in particular, the last seven years working for Alzheimer’s Australia in the Australian Capital Territory. As a clinician with Alzheimer’s Australia I visit aged care facilities nearly every day. My experiences are uniformly bleak. One colleague, an associate professor of psychiatry and a former Fulbright scholar, with whom I have collaborated professionally once described aged care in Australia to me as the forgotten caring for the abandoned. The more I work in this area the harder it is for me to disagree with him.

I wondered if it was indeed possible to treat those elderly Australians who have a dementia any differently. I had heard of places in Holland, notably de Hogevey, where a village had been constructed to care for the person with a dementia in surroundings that reflected typical communal living. I had also heard of an organisation called the Scottish
Dementia Working Group, a body established by and for the person with dementia. I found this idea both confronting and intriguing; a group of people with dementia running their own organisation, speaking for themselves, answering to their own aims, objectives and philosophies rather than having a set of prescribed polices thrust upon them. And so I hoped that through the Churchill experience I would find some way to challenge, perhaps my own beliefs and preconceptions as much of those of the society I live in.

I should make it clear that within the following pages voice is given to my experience both as a clinician and as a person. I do not speak for anyone else, least of all the person with dementia. I speak only for me and me alone. The observations are mine, the explanations are mine, the insights are mine. Make of them what you will.

There are many to thank. Nothing in life, it seems to me, is done without the support of others. Of course I thank the Winston Churchill Trust for giving me this opportunity. And within that body I especially thank my sponsors, Mr and Mrs New. Mr New died in 2000 after living with Alzheimer’s disease, the most common form of dementia. I often pondered whilst I was away on the curious fact that this man who I had never met and who died before I even knew there was such a thing as the Churchill Fellowship was playing such a major role in my life. I wondered who he was and what his life was like. And indeed I wondered what his experience of having Alzheimer’s disease was like. I often wondered what he would make of what I was doing. I hoped that he might approve of my research.

I thank too the CEO of Alzheimer’s Australia ACT, Ms Jane Allen and my direct manager, Petrea Messent. And I pay tribute to a colleague, Ms Charise Buckley, whose passion for dementia care is at least the equal of my own. All have been supportive and enthusiastically encouraging. I acknowledge their hard work and their efforts in the area of dementia care.

A special thank you to my partner who stayed at home. It was at times quite lonely without you. I consoled myself with the occasional single malt, outrageous quantities of English cheeses and Skyping you at often inappropriate times of the day or night.

But mostly thank you to Sir Winston Churchill, without whom none of this would have been possible. I feel honoured to have had at least some connection to such a great man no matter how tenuous.
**Project:**

To study person centred care for people with dementia with a particular focus on residential aged care facilities

**Executive Summary**

As the Australian population has aged, nursing homes have assumed an increasingly prominent role in caring for large numbers of elderly people with complex physical, psychological and emotional needs. It is here we find some of the most vulnerable members of our community; elderly people with high level physical care needs, high rates of various forms of cognitive impairment, most commonly Alzheimer’s disease, and associated mental health problems such as depression, anxiety, grief, loss and loneliness. Nursing homes have tended to become places of high density housing where a mix of people from quite disparate social, ethnic, religious and cultural backgrounds, reside. In this population challenging behaviours, or behavioural and psychological symptoms of dementia [BPSD], such as wandering, pacing, calling out and verbal and physical aggression are ubiquitous. The challenges of providing ‘person centred care’ in large scale nursing homes are many and varied and freely acknowledged by the industry. How have other societies responded to this challenge and what do we really mean by the term ‘person centred’?

My Churchill Fellowship was to explore notions of person centred care in residential aged care settings in Holland and Scotland. In particular the Dutch ‘dementia village’ of De Hogewey in the village of Weesp, about 20 minutes south of Amsterdam has attracted an international reputation for excellence in dementia care from a person centred perspective. I was keen to learn from their experience. Another centre of excellence is Stirling University in Scotland where innovative work is being done on the relationship between the built environment and a sensitivity to the needs of people with both cognitive impairment and issues of ageing. Finally I wanted to engage with groups of people with dementia in both Scotland and England who had formed their own interest groups to articulate their own special and unique needs free from advice or guidance or direction of those without a dementia.

What emerged from my Fellowship was a wider understanding of the impact of the physical and social environment on person centred care. But perhaps the most confronting aspect of my research was the recognition that the variety of clinical problems that we confront in aged care in Australia, problems that I face every day in my work as a clinician in the Dementia Behaviour Management Advisory Service [DBMAS] of Alzheimer’s Australia ACT, are better understood as an artefact of the way we organise aged care in this country. Whilst the problems of aged care certainly present as clinical in nature they are in fact social and political in solution. This was the overwhelming conclusion I was forced to face as a result of my Fellowship and this is the issue I hope to address in my future work.
## Outline of Visits Undertaken

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<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Visits – Aims - Contacts</th>
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| August 2014| The Netherlands| **Florence Centre for Specialized Care in Young Onset Dementia and Healthcare, Den Haag.** The care and treatment of the person with a dementia; community case management in dementia care; Dutch initiatives and innovations in dementia care; the work of the multidisciplinary team in institution and outreach. *Dr Christian Bakker.*  
**De Hogeweyk Dementia Village, Weesp.** Person centred care in an institutional setting; alternatives to traditional nursing homes; use of innovative design principles to foster normalised communal living. *Jorgos Arvanitis, Coordinator.*  
**Amstelring Care [Nursing] Home and Community Projects.** The multidisciplinary team; research in dementia care; independent community based projects as a way of normalising dementia care. *Dr Esther Helmich; Dr Vanusa Baroni Caramel.*  
**Centre for Evidence-Based Education at the Academic Medical Centre, University of Amsterdam.** Education and training for staff who work in the dementia setting. *Dr Esther Helmich.*  
**Over Singel Care Home – Weesp.** Adopting the Dutch ‘household’ model of care to the traditional nursing home design. *Jorgos Arvanitis.* |
| September 2014| Scotland       | **The Scottish Dementia Working Group, Executive Committee.** Speaking for ourselves – establishing a group for support of the person with dementia, by people with a dementia; empowering the individual; working with other government and non-government agencies. *Henry Rankin, Peter McLaughlin and David Mackenzie.*  
**The Scottish Dementia Working Group, Aberdeen Branch.** People with dementia managing their own lives; activities and discussions of the personal lived experience of dementia. *Sarah Geoghegan.* |
<table>
<thead>
<tr>
<th>Location</th>
<th>Event</th>
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<tbody>
<tr>
<td>Stirling</td>
<td>Various meetings with group members</td>
</tr>
<tr>
<td></td>
<td><strong>The Iris Murdoch Centre, Stirling University.</strong> Best practice</td>
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<td></td>
<td>design parameters for the built environment in dementia care; person</td>
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<td>centred care through managing the living space; being aware of the</td>
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<td></td>
<td>deficits of increasing age and cognitive impairment when designing</td>
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<td></td>
<td>accommodation for the elderly and the person with dementia.</td>
</tr>
<tr>
<td></td>
<td><em>Jilly Polson.</em></td>
</tr>
<tr>
<td>England</td>
<td><strong>The Dementia Action Alliance Conference.</strong> Working in collaboration</td>
</tr>
<tr>
<td>London</td>
<td>with diverse voices; the person with dementia as leader; hearing the</td>
</tr>
<tr>
<td></td>
<td>voice of the person with dementia.</td>
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<td></td>
<td><em>Rachel Litherland.</em></td>
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</table>
Structure Of The Report

In a sense all research is comparative; one compares what one finds with what one already knows. It is in this vein that I have written this report. The experiences in Holland in particular, but also in Scotland and London, have acted as a catalyst for me to re-assess not only my own approach to dementia care but also the way dementia care is practiced in my own country. Thus I begin this report with a discussion about dementia as a clinical syndrome and review how dementia affects Australia and Australians. I try to give some sense of residential aged care in this country and the many and varied challenges that confront it. From there I move on to talking about the Dutch approach to dementia, how it differs from traditional approaches in this country and what we can learn from them.

First I describe, albeit very briefly, the notion of person centred care. This philosophy is regularly cited as the inspiration and driving force directing the care relationship between the person with dementia and those others charged with providing care. I make only general statements due to limitations of space.

Second I outline the importance of dementia initially as a public health concern but more importantly as a disease of ageing that carries with it a range of cognitive, physical and mental health issues that increasingly compromises the health and wellbeing of the person who is diagnosed.

Third I briefly describe the residential aged care system in Australia wherein a large population of people who are diagnosed with dementia and are thus in need of specialist care and support typically spend the last months and years of their lives.

Fourth I describe my Churchill experience from the perspective of the insights and experiences gained by talking with people with a dementia, family and community carers and health care professionals in Holland, Scotland and London.

Fifth I make some suggestions based upon a review of the above.

Finally a brief comment about style. I have resisted the temptation to heavily reference this report. Although I have an academic background I did not want this report to be an academic exercise. It should not be judged by reference to academic standards of referencing and footnoting and other such conventions. I hope it will be judged purely on the ideas contained within. Only when I think it necessary do I quote, and cite, others. If anyone is interested in further references then they are welcome to contact me.
Person Centred Dementia Care

Introduction

This report is about the concept of person centred care and the application of this model of care to the individual with a dementia who lives in residential care in Australia. Thus it seems reasonable to begin with a brief discussion of what this approach implies.

The term ‘person centred care’ is one of those catchphrases, rather like ‘human rights’, that is used so freely in our society yet despite this seems frequently to defy clear and precise description and, indeed, application. It so often appears that whilst many may assert that they work from a person centred perspective, or from a human rights perspective for that matter, a disinterested observer might be forgiven for suggesting that they see no tangible difference in outcomes for the subject of such interventions. Both of these terms are proclaimed often as an underlying philosophy of care, indeed they are viewed as some form of a priori reasoning that is so ethically obvious that they require no further justification than to simply assert them. To deny a person’s human rights is to act in such a manner as to deny an individual’s actual humanity, to reduce the individual to a mere object, less than human. Similarly to behave toward the person with a dementia in anything other than a person centred approach is to also court charges of reducing the person to less than human status, a mere object of the whims or designs or plans of another.

Yet if we are to argue that person centred care is largely a stranger in residential aged care in Australia, as I wish to, then we are forced to make at least some brief attempt to define what people (say they) mean when they talk like this.

What is Person Centred Care?

The very least we can say is that person centred care places the person and our consideration of the person’s well-being at the centre of the care process. However this single statement alone does not tell us very much at all. The medical model of care, often contrasted with person centred care, would also claim to place the person and the person’s well-being at the centre of care, yet this model has come under much scrutiny in recent years and has attracted a good deal of criticism for its supposed failure to adequately identify and respond to the totality of needs that persons typically possess.

There are perhaps two perceived aspects of the medical model that have attracted censure. One is the focus on the bio-medical aspect of the person whilst tending to dismiss or ignore psycho-social aspects, and the other is a tendency to authoritarianism – in other words, the ‘doctor knows best’ approach.

There are of course other models of care that might be applied in the residential aged care setting. One might be a model that places the well-being of the facility at the centre of considerations. This might mean that whilst care of the person is indeed taken into account, still, the interests of the board, or a goal of fiscal responsibility, or the
reputation of the facility might trump any other concerns. Another might be one that places considerations of the family above all else. Another might be an overall sensitivity to the demands or requirements or expectations of society and government (however conceptualised or expressed) which might be the driving force behind the care process. All of these might recognise that persons ought be treated with respect and dignity and that persons are unique creatures with unique needs but the caveat might be that in a world of competing demands other considerations are simply more important.

Person centred care is unique in that, like the idea of human rights, person centred care trumps! That is, person centred care demands that persons and their well-being is, and always should be, the prime mover of action. In facilities that practice person centred care it is the needs of the person that are recognised and responded to. In facilities that practice person centred care, the person is recognised as a biopsychosocial being, an individual with a complexity of biological, social, spiritual, cultural, emotional and psychological aspects which are inherent in all individuals and which constitute being an individual and which, thus, are the centre, the focus and the driving force of the care process. Other considerations exist of course; the needs and interests of the board, the owners of facilities, families, society and government, but these organisations exist to promote, support and sustain the idea of person centred care. In a sense that is their raison d'être. When there is a conflict of interests, then the needs of the person who is referred to as ‘resident’ of the facility always trump.

A Brief History of the Concept of Person Centred Care

Person centred care has its genesis in the work of the psychologist Carl Rogers and his emphasis on the individual as the focal point of therapy rather than the expertise and knowledge of the therapist. Rogers emphasised the therapist as ‘person in a relationship with another’, that is being present as an equal rather than a notion of being elevated, aloof, knowledgeable or an external authority figure. Relationships we have with each other are recognised as moments among equals where each contributes their own unique personalities and shared experiences. Added to this context was the idea of a unconditional positive regard, an acceptance of the other person and their situation, and finally an empathic understanding of the validity of the other person’s experience and what it means for them, rather than the person’s experiences being described or interpreted by the therapist.²

Tom Kitwood adapted this approach to residential dementia care. He challenged previous approaches, which focused on viewing dementia as a medical condition where chemical control and physical restraint were the primary methods of intervention and the person with dementia was regarded as beyond any form of individual worth or agency. Kitwood proposed a model that at its core saw the person with dementia as a unique, valuable, and experiential human being. For Kitwood the person with a dementia mattered. In terms of moral worth they were no different to any other human person. Their well-being, needs, wants, desires, meanings, were as equally important
and valid as the person with no dementia. Their cognitive decline, an inevitable consequence of dementia, did not diminish their moral standing, rather it could be seen to have triggered a whole range of duties and obligations held by those who stood in relationship to them. And this identifies all others; not just carers, family members, facility owners, board members, managers and administrators, but also the rest of us in the wider society. We all have an obligation.³

Following on from Kitwood, Brooker has defined person-centred care in terms of four elements.

1. Valuing people with dementia and those who care for them;
2. Treating people as individuals;
3. Looking at the world from the perspective of the person with dementia;
4. A positive social environment in which the person living with dementia can experience relative wellbeing.⁴

For those of us who have a commitment to person centred care, whether in the aged care setting or beyond it, the above seems to be lacking. One may reasonably argue that the description of person centred care as expressed by Kitwood and Brooker does not appear to promote the person with dementia’s interests in any particular way, especially when they conflict with the interests of more powerful agents (family, facility, society). Yet person centred care as a philosophy has about it the assumption that the needs of the person with dementia are paramount and are not to be traded off against the needs of others. To overcome this deficit I suggest two further aspects. In putting these I acknowledge a Kantian approach to ethics.

"Act in such a way that you treat humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end."⁵

From Kant’s maxim, I assert we can propose three essential requirements of person centred care which may be stated thus:

1. All individuals are an end in themselves.
2. No individual should be treated as a means to the ends of others.
3. Primacy must be given to those individuals who cannot, by means of cognitive impairment, assert or realise or articulate their own ends.

The first states that, as suggested by Kitwood and others, the person with a dementia has worth, meaning and value inherently and needs no external justification. Their well-being is paramount. It cannot be traded off (by others on the person’s behalf) for benefits in other aspects of life, for other persons or agencies; neither facility owners, organisations, family members, staff and/or management, or bureaucratic or government policy.

The second states that no person with a dementia should be used to facilitate the ends of other people, agencies or organisations or indeed society at large.
The third suggests that as a person’s own particular ends are ends in themselves then it is logical to assume that those who claim to care for the person must seek to realise the person with dementia’s ends to the best of their ability.

The principles are those of ultimate worth and value and where we should direct our attentions but also, and more importantly, the overwhelming value of autonomy. This suggests that our *prima facie* position should be that the person with a dementia is able to pursue their own goals and should only be prevented from doing so if there is substantial risk of harm to themselves or to others. They also state that the well-being of the person with dementia (in bio-psychosocial terms) in residential care should be the benchmark for making judgements about how to proceed. All other expressions of interest, those of facility management, board members, owners, family and wider society are indeed valuable and recognised and have valid claims to be realised, yet must be considered only after the interests of the person with dementia have been assessed and attained.

If we cannot accept the above then I suggest that we do not accept the philosophy of person centred care.

**On Dementia**

**Introduction**

The term ‘dementia’ describes a syndrome within which we can identify over a hundred different types of individual disease processes. But despite the vast complexity of this syndrome, we can still make some generalisations. Dementia is characterised by a progressive neurodegeneration - in other words a gradual destruction in brain architecture and activity. Deficits emerge in the domains of memory, attention, concentration, abstract thought, insight and judgment, mental flexibility, speech and language comprehension and what are described as ‘activities of daily living’ [ADLs] – in effect the ability to physically care for oneself. Dementia is irreversible. Currently our efforts in treating the individual person with a dementia are focused on ensuring the person has the best possible quality of life given the cognitive and behavioural challenges they face, and on responding to the various symptoms that emerge at different stages of the disease process.

Common to all forms of the syndrome are both cognitive and personality changes and what are described as ‘behavioural and psychological symptoms of dementia’ otherwise referred to as BPSD. These symptoms are ubiquitous. Almost all people who have a dementia will, at some stage of the disease process, experience some form of BPSD. These symptoms contribute exponentially to the burden of the underlying disease process, are corrosive of the quality of life of both the person with dementia and those who care for them and for many provide a challenge to the very notion of moral personhood – or what it means to be a person. From a purely clinical perspective, behaviours indicative of BPSD typically include an overt behavioural element, such as
verbal and physical aggression, restlessness, agitation, wandering, pacing, sexual disinhibition, faecal smearing, screaming, rummaging and hoarding, intrusiveness and resistance to care, as well as more psychological symptoms such as anxiety, depression, delusions and hallucinations – although this distinction itself is problematic. Overt behaviours may be driven by intra-psychic events. Delusional ideas may inspire aggression, resistance to care, wandering and pacing for example. The dichotomy is not clear cut.

**Frequency**

Over 90 per cent of all cases of dementia are accounted for by the five most common forms of the syndrome; Alzheimer's disease is the most frequently diagnosed and accounts for about 60 per cent of all cases. Vascular dementia is the second most common with about 20 per cent, dementia with Lewy bodies accounts for about ten per cent whilst Fronto Temporal Lobar Degeneration and Alcohol related dementia make up between four and seven per cent of all cases.

There is some difficulty with making precise statements about the prevalence of dementia in the world population. A lack of methodological uniformity amongst studies, different diagnostic criteria and different mean population ages all compromise general authoritative global statements. Also, each form of dementia does not always present as a discrete entity. For example a mixed dementia, a combination of Alzheimer’s disease and vascular dementia, is thought to account for about ten per cent of cases. In addition it is not uncommon for a vascular dementia and Fronto temporal lobar degeneration to coexist. This may depend in part upon the location of the vascular insult in the brain. Further there is often confusion between Dementia with Lewy Bodies and Parkinson's disease dementia due to similar presenting clinical features.

Still there remains general agreement that Alzheimer’s disease presents as a major global challenge that cuts across national and international boundaries.

**The Impact of Dementia**

Dementia is overwhelmingly a disease of ageing despite the recent emphasis on young onset dementia, a variant of the syndrome which emerges before the age of 65 years. Indeed the greatest single risk factor for dementia is increasing age. This fact alone has major implications for both western countries, where longevity is now the norm, and for developing countries where growing economies are being reflected in better health outcomes for citizens. Thus we can certainly portray dementia as a major economic and social threat to local, regional, national and international economies worldwide [Table 1.1].

From this perspective Australia does not escape what is often referred to as the ‘burden of dementia’. As a highly developed post-industrial society Australia faces an increasing number of people living well into their 80s with a resultant increase in the numbers of people who will be diagnosed with a dementia. Already dementia is the leading single greatest cause of disability in Australians aged 65 years and older and the third leading
cause of the overall disability burden. In 2009-10 the cost to the health and aged care sector was estimated to be in the region of $4.9 billion and by the middle of the 21st century it is estimated that spending on dementia will reach about 11 per cent of total health and residential aged care sector spending.11 This has major implications for staffing of hospitals, residential care homes and community services, the building of new care homes and the pressure on hospital beds, as well as wider impacts on society as a result of those people who choose to leave the workforce to care for loved ones at home.

Table 1.1. Total population over 60 years; crude estimate prevalence of dementia (2010); estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010-2030 and 2010-2050) by Global Burden of Disease region. From: Dementia: A Public Health Priority. World Health Organisation. 2012

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<thead>
<tr>
<th>Region</th>
<th>Over 60 population (millions)</th>
<th>Crude estimate prevalence (%)</th>
<th>Number of people with dementia (millions)</th>
<th>Proportionate increase (%)</th>
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<td>North Africa/Middle East</td>
<td>31.11</td>
<td>3.7</td>
<td>1.15</td>
<td>2.59</td>
</tr>
<tr>
<td>Sub-Saharan Africa, Central</td>
<td>3.93</td>
<td>1.8</td>
<td>0.07</td>
<td>0.12</td>
</tr>
<tr>
<td>Sub-Saharan Africa, East</td>
<td>16.03</td>
<td>2.3</td>
<td>0.36</td>
<td>0.69</td>
</tr>
<tr>
<td>Sub-Saharan Africa, Southern</td>
<td>4.66</td>
<td>2.1</td>
<td>0.10</td>
<td>0.17</td>
</tr>
<tr>
<td>Sub-Saharan Africa, West</td>
<td>15.33</td>
<td>1.2</td>
<td>0.18</td>
<td>0.35</td>
</tr>
<tr>
<td>WORLD</td>
<td>758.54</td>
<td>4.7</td>
<td>35.56</td>
<td>65.69</td>
</tr>
</tbody>
</table>

**Dementia in Australia - key facts and statistics 2014**

In 2013, 322,000 Australians were estimated to have a dementia. This represented one in ten over the age of 65 years and three in ten over age 85 years. In addition, over 50
per cent of permanent residents in Australian Government-funded aged care facilities had a diagnosis of dementia. However this is likely to be an under estimation of actual numbers as not all people with a dementia, or behaviours that suggest a dementia, have an actual diagnosis. If current trends continue then Australia can expect almost one million people with dementia by the year 2050. The following is from an Alzheimer’s Australia fact sheet on dementia and presents the latest (2014) information on the syndrome.

- There are more than 332,000 Australians living with a dementia
- This number is expected to increase by one third to about 400,000 in less than ten years
- By 2050 over 900,000 Australians will have a dementia
- Each week there are approximately 1,700 new cases of dementia or approximately one every six minutes
- Three in ten people over the age of 85 and almost one in ten people over the age of 65 have a dementia
- An estimated 1.2 million people are involved in the care of the person with a dementia
- Dementia is the third leading cause of death in Australia and the second leading cause of death in women.
- There is no cure for dementia and no treatment that can enforce a remission

The chart below gives some idea of the scale of dementia in terms of raw numbers of individual cases by state and territory and also nationally.

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2012</th>
<th>2015</th>
<th>2020</th>
<th>2030</th>
<th>2040</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>91,038</td>
<td>95,028</td>
<td>107,037</td>
<td>128,238</td>
<td>182,331</td>
<td>248,139</td>
<td>303,673</td>
</tr>
<tr>
<td>VIC</td>
<td>68,397</td>
<td>71,544</td>
<td>81,117</td>
<td>98,123</td>
<td>141,161</td>
<td>195,459</td>
<td>245,813</td>
</tr>
<tr>
<td>QLD</td>
<td>48,674</td>
<td>51,005</td>
<td>58,509</td>
<td>73,470</td>
<td>114,800</td>
<td>166,032</td>
<td>215,272</td>
</tr>
<tr>
<td>SA</td>
<td>23,710</td>
<td>24,627</td>
<td>27,353</td>
<td>32,062</td>
<td>44,236</td>
<td>59,053</td>
<td>69,620</td>
</tr>
<tr>
<td>WA</td>
<td>23,931</td>
<td>25,177</td>
<td>29,041</td>
<td>36,500</td>
<td>46,332</td>
<td>57,781</td>
<td>68,708</td>
</tr>
<tr>
<td>TAS</td>
<td>6,732</td>
<td>7,003</td>
<td>7,818</td>
<td>9,362</td>
<td>13,544</td>
<td>18,043</td>
<td>20,653</td>
</tr>
<tr>
<td>NT</td>
<td>838</td>
<td>878</td>
<td>1,049</td>
<td>1,473</td>
<td>2,700</td>
<td>3,992</td>
<td>4,916</td>
</tr>
<tr>
<td>ACT</td>
<td>3,254</td>
<td>3,445</td>
<td>4,040</td>
<td>5,167</td>
<td>8,181</td>
<td>11,632</td>
<td>13,970</td>
</tr>
<tr>
<td>AUST</td>
<td>266,574</td>
<td>278,707</td>
<td>315,963</td>
<td>384,396</td>
<td>553,285</td>
<td>760,131</td>
<td>942,624</td>
</tr>
</tbody>
</table>

The Dementia Experience

We can of course portray dementia as an increasing economic challenge to the health sector and as a similar challenge to families, communities and the national economy. In both the professional literature and the popular press there is a tendency to describe dementia in terms of a social or economic ‘burden’ or ‘epidemic’ and discussion often centres on the ‘cost of dementia’, with this ‘cost’ being most often expressed in financial terms.
But dementia is, first and foremost, an intensely human experience. People get dementia. And dementia powerfully affects what it means to be a person. Framing dementia in this way leads us to appreciate the impact it has on a variety of individuals; the person diagnosed, their partner or spouse, their immediate families, their friends, colleagues and acquaintances. For the person with dementia it affects their very being; their sense of self, their identity, the meaning of their lives, the relationships they have with others, how they see themselves and how others see them.

This comment suggests that we can understand this thing called dementia in a variety of different ways. For example we can view it as a public health challenge, a medical diagnosis, an impairment in an individual’s cognitive capacity, a gradual decline in an individual’s functioning and ability to live an independent life, as a gradual dependency on others or perhaps as a narrative of increasing loss. The particular emphasis we place on explaining and understanding dementia will inspire different ways of conceptualizing the syndrome and different ways of responding to it.

Whilst we may suggest that there is no right or wrong way to explain dementia, my interest in this work and in fact throughout my professional life is in dementia as the human experience, as the experience of individuals and their families and loved ones who confront the constant challenges of dementia, and it is also in the way that we, as a society, respond to the needs of those with dementia and those who live with them and care for them. It was this philosophy that inspired my Churchill Fellowship.

**Clinical Notes**

Whilst there are many different types of dementia there are commonalities. All dementias present with similar impairments that affect thinking, planning, mental processing, memory, concentration, attention, abstract thought and task completion.

The following gives a sense of the degree of and process of impairment with particular reference to the most common form of dementia, Alzheimer’s disease.

1. **Overview**

Typically the early signs of dementia are subtle changes in a person’s memory, thinking, concentration or abstract thought. Such changes may not be initially noticed, as memory and concentration may alter somewhat with the normal aging process, with illness, feeling tired, run down or ‘out of sorts’, but once the usual run of life begins to be affected particularly by problems with the recall of very recent events, then concerns will emerge that it may be a dementia.

2. **Signs and Symptoms**

In general the early signs of dementia commonly include memory loss for recent events, confusion and becoming easily muddled, subtle changes in personality, a tendency to become apathetic and socially withdrawn and increased difficulty with completing everyday tasks
Alzheimer's Australia has listed ten warning signs that serve as a 'checklist of common problems with dementia'. These are:

i. **Recent memory loss that affects job skills** – whilst it is normal to occasionally forget meetings, the names of colleagues' or distant family members, telephone numbers or card PIN numbers, particular if we are busy or under stress, a person with dementia may not only forget things more often but also not be able to recall them when they are prompted or reminded.

ii. **Misplacing things** – putting something down, such as glasses, car keys and so on, and not being able to remember where they are is not uncommon in a world of competing demands and numerous distractions, however in dementia the person may increasingly lose items or put them in unusual or inappropriate places.

iii. **Difficulty performing familiar tasks** – whilst we can all be distracted at times, for example making a cup of coffee and forgetting to drink it, or forgetting to serve some part of a meal, still this is mostly a function of the busy lives people lead. A person with dementia might leave a bath running, or leave a pot boiling on the stove, or leave the gas on, or get so muddled they ‘forget’ how to be safe in the kitchen and so place themselves at risk of harm.

iv. **Language problems** – again, in times of stress or tiredness we can all occasionally have trouble finding the right words to use. Whilst this is not uncommon, a person with dementia may increasingly have these ‘word finding difficulties’ or they may forget simple words or substitute inappropriate words to name items, events or experiences.

v. **Disorientation** – this is not to be confused with momentary absent-mindedness regarding the day of the week or how to get to your destination, rather in dementia the person may forget the day or the month or where they live, or perhaps get lost whilst driving and have to ask for help in order to get home.

vi. **Impaired judgment** – this has to do not only with memory, attention skills and concentration but also the ability to make safe decisions about how to do tasks, such as driving a car or operating machinery or being safe in the home. In such cases a person may be at risk to self or others.

vii. **Loss of abstract thought** – similar to impaired judgment is a loss of ability to think abstractly or what we might call a degree of ‘mental flexibility’. On one level we may portray this as ‘if-then’ thinking, that is, if I drive my motorbike without a helmet then I will run the risk of at least getting a traffic ticket but also if I crash I may do myself serious injury. Again this can have a major impact on personal safety. But also there is a tendency to lose the ability to manage abstract concepts like organising our finances or understanding numbers and their significance.

viii. **Changes in mood and behaviour** – whilst everyone has changes in their mood and behaviour from time to time, these changes are usually mild, ranging from happy to sad and are typically congruent with the strength of external
events. The person with dementia however may increasingly experience mood swings that are dramatic and sudden and for no obvious or apparent reason.

ix. **Personality changes** – these can be most upsetting for those close to the person with a dementia. Whilst personalities may alter a little as we age, the person with dementia may over a fairly short space of time become suspicious or fearful, apathetic and uncommunicative or they may become dis-inhibited, over-familiar or challenge social rules of behaviour and etiquette. This can have a major impact on loved ones and indeed friends and colleagues who may be shocked at words and behaviours that are not consistent with their understanding of who the person was for most of their previous life.

x. **Apathetic and social withdrawal** - the apathy seen in dementia is more than just being tired or even feeling a bit lazy. In dementia apathy identifies a lack of motivation, interest and enthusiasm in formerly enjoyed activities and social engagement and as well it reveals a blunted emotional state and loss of insight.

3. **Behavioural and Psychological Symptoms of Dementia [BPSD]**

Dementia is a syndrome of gradual and inevitable mental impairment. As the disease progresses, abilities and skills disappear. Initially higher order abilities are compromised; abstract thinking, remembering, the capacity to do more complex and sophisticated tasks. Gradually, over time, the person with dementia loses the skills to do even the more basic day to day tasks that we take for granted and mostly do without thinking; tasks such as dressing, showering, combing our hair, brushing our teeth, getting dressed, going to the toilet – what we might call the most intimate tasks of human activity.

The degree to which the person with dementia relies on assistance from others increases. Roles are compromised. Husbands and wives become carers, parents to the spouse with dementia and in similar vein parents with dementia may now be forced to rely on their own children for intimate care such as toileting and changing clothes after periods of incontinence. And with this decline in functional ability and the worsening of dementia comes the emergence of a whole range of behaviours that are termed by professionals, BPSD, but are often described by those closest to the person as ‘challenging behaviours’, or ‘difficult behaviours’, or ‘behaviours of concern’. These descriptors probably reflect the degree of frustration, fear, anxiety or powerlessness that close family and carers experience as they see the person with dementia, perhaps the person they love, changing from someone they once knew to someone they can no longer recognise.

Most people with a dementia will experience BPSD at some stage of the illness. What sort of behaviours are indicated?

Behavioural symptoms include verbal and physical aggression, screaming, calling out
and/or repetitive vocalisations, restlessness, agitation, wandering, culturally inappropriate behaviours, sexual disinhibition, hoarding, shadowing and intrusiveness. Psychological aspects of BPSD include anxiety, depression, delusions and hallucinations. These behaviours are present in 60 to 90 per cent of people in residential aged care facilities who have a dementia and, in addition, the individual typically may display more than one BPSD both at one time and throughout the course of the dementia.  

<table>
<thead>
<tr>
<th>Psychological Symptoms</th>
<th>Behavioural Displays</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Agitation</td>
</tr>
<tr>
<td>Apathy</td>
<td>Calling out</td>
</tr>
<tr>
<td>Delusions</td>
<td>Crying</td>
</tr>
<tr>
<td>Depressed mood</td>
<td>Culturally inappropriate behaviour and disinhibition</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>Swearing</td>
</tr>
<tr>
<td>Misidentifications</td>
<td>Pacing</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>Physical aggression</td>
</tr>
<tr>
<td></td>
<td>Verbal abuse directed at another</td>
</tr>
<tr>
<td></td>
<td>Repetitive questioning</td>
</tr>
<tr>
<td></td>
<td>Restlessness</td>
</tr>
<tr>
<td></td>
<td>Screaming</td>
</tr>
<tr>
<td></td>
<td>Shadowing or stalking</td>
</tr>
<tr>
<td></td>
<td>Wandering</td>
</tr>
<tr>
<td></td>
<td>Hoarding</td>
</tr>
<tr>
<td></td>
<td>Intrusiveness</td>
</tr>
</tbody>
</table>

Taken from *A Nurses Guide to BPSD. 2007 International Psychogeriatric Association. Northfield, IL.*

4. **The Pathway of the Disease Process**

The common pathway for dementia is a gradual onset and insidious progression. This is the characteristic presentation of Alzheimer's disease. But to understand the individual's experience of dementia, and to place some context around what is happening to the person the literature often suggests we can describe dementia in terms of stages as outlined below.

The following diagram reflects the 'seven stages of Alzheimer's disease' as described by Alzheimer's Association USA.  

Whilst the stages are not precise sequential accounts of events relative to the progression of the illness still such descriptions give a sense of the gradual loss of abilities in the person diagnosed. These stages vary and it is often difficult to say which particular stage a person is in at any given point of time. The rate of decline is different for each individual and it may appear that a person moves into and out of different stages at different times of the day, still this does give us an important means of understanding the individual experience.
Dementia and Residential Aged Care in Australia

**Demographics**

How can we describe residential aged care in Australia? One way is by demographical information.

As of June 2013 there were 168,968 permanent and 4,126 respite residents living in residential aged care. Adopting a strictly demographic approach we can say that the residential aged care population in this country is characterised by the following:

<table>
<thead>
<tr>
<th>Stage 1: No impairment</th>
<th>There is no external evidence of any impairment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 2: Very mild cognitive decline</td>
<td>The individual may report some concerns with their memory or even some word finding difficulties. Losing items, forgetting names and so on may occur; but this may be due to tiredness, stress or normal age related changes. No symptoms of dementia are detected by family, friends or on medical examination.</td>
</tr>
<tr>
<td>Stage 3: Mild decline</td>
<td>People closest to the person begin to notice difficulties in remembering, thinking, concentration and attention to detail. The person has trouble using the correct name or words in a sentence; losing or misplacing things like glasses, car keys, mobile phones or credit cards. Performing tasks, especially complex ones, are impaired. Increasing difficulties with planning or organizing.</td>
</tr>
<tr>
<td>Stage 4: Moderate decline</td>
<td>Cognitive decline is clear to all and testing will suggest a dementia. Recall of recent events is clearly impaired. Complex tasks are increasingly too difficult for the person. Mistakes are made in areas such as paying bills, forgetting one's own personal history, finding the right word. The person may get lost in familiar environments. They may become moody, irritable, distressed and increasingly socially withdrawn.</td>
</tr>
<tr>
<td>Stage 5: Moderate-severe decline</td>
<td>General cognitive decline is evident. There is marked difficulty in remembering much of the recent past. They may not know the day, the month or the year. They forget the names of friends, some more distant family members, perhaps their address and phone number. Help is required in some day to day activities such as dressing appropriately. Complex tasks as using an ATM, managing money, using a computer are impossible.</td>
</tr>
<tr>
<td>Stage 6: Severe decline</td>
<td>Short term memory is very poor with medium term memory affected. Forgets the names of close family, perhaps spouse and children. Cannot name common everyday objects. Increasingly confused and disoriented. May think carers are stealing from them or spouse and children are intruders. Major personality changes. Changes in sleep/wake pattern. Emergence of multiple BPSD – delusions, hallucinations, wandering, confusion, screaming, aggression etc. Falls prominent. Pain an issue. Needs help dressing, eating, showering, toileting. Double incontinence.</td>
</tr>
<tr>
<td>Stage 7: Very severe decline</td>
<td>Little or no meaningful contact with environment. Totally dependent on others for all aspects of life. In the final stage of this disease individuals lose the ability to respond to their environment, to carry on a conversation and eventually to control movement. Loss of ability to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing impaired. Death from multiple systems failure or pneumonia.</td>
</tr>
</tbody>
</table>
• the population is largely female (79 per cent to 31 per cent males),
• and is primarily over 65 years of age, with only 3.7 per cent of residents under the age of 65 years,
• with 75 per cent of people aged 85 years or older,
• and 81 per cent of people rated as having high care needs,
• whilst over 50 per cent of people have a diagnosis of dementia
• and one in every two people require high level care to manage difficult or challenging behaviour.16

Systemic Issues of Care
Another way of describing residential aged care in Australia is to consider the sorts of problems that confront individuals within the aged care system and to think about how these impact on quality of life.

In the following I focus on five areas of residential aged care in Australia. I want to give a sense of the degree to which person centred care is absent from the aged care industry in this country and what this absence means for the person with a dementia. Further, I want to suggest that our current system of aged care management in Australia is institutionally and culturally constructed to actively prohibit the implementation of person centred care within residential aged care facilities.

1) Design and Space: The Aged Care Environment.
At a lecture at the Harvard Graduate School of Design held on the 26 February 2009, Mohsen Mostafavi, dean of the School suggested that architecture has shifted from object to atmosphere. The buildings we humans inhabit have to be designed in ways mindful of both the environment and human health. The relationship between lived environments and human experiences has a long and rich philosophical tradition. At the very least we can say that the spaces in which we live are emotionally constructed by us as much as they are physically constructed. The homes in which we work, play, sleep, relax, entertain, conceive our offspring and so often die, are intimate psychological spaces. We surely would regard this as axiomatic. Thus inherently we recognise the importance of the built environment.17

Yet the design of so many residential aged care facilities in Australia are, as Professor Henry Brodaty once put it, seemingly more akin to ‘warehousing’ the elderly person with a dementia than providing a space in which the person can find some degree of expression, meaning and emotional warmth.18 Aged care facilities in Australia tend to be large and impersonal buildings with plush entrances and exteriors and a décor with fixtures and fittings that often resemble a five star hotel complete with long corridors that lead to central eating spaces where as many as thirty, forty or even more people sit in a community dining room. This arrangement is so bizarrely juxtaposed to the normal way we humans live. The shape of the rooms, like the modern hotel, are formula built; bed, dresser, table, the ubiquitous television set and (hopefully) an ensuite. I say ‘hopefully’ as still in some of the older nursing homes the person with dementia may
have to share with others in a two, or four bedroom dormitory and be showered in a communal area distant from their room.

Certainly if you visit the more upmarket facilities then you will find each room designed largely the same, like an enormous hotel. They are modern, yes, and very fashionable looking, but as Richard Fleming once commented, those of us who travel quite a bit for work stay in hotel rooms regularly and the reality is that you grow to hate the clinical sameness modernity of them and long for your own, perhaps cluttered, disorganized, chaotic, yet distinctive and idiosyncratic homes, full of your memories and bric-a-brac, and ornaments meaningless to anyone but yourself.19

And the trend in nursing homes is to build fewer but larger facilities, according to AIHW spokesperson Mark Cooper-Stanbury, who pointed out that in the ten years to June 2013 the proportion of residential facilities that had 60 or more places rose from 20% to 48%.20

The table below shows the degree to which nursing homes in Australia are becoming larger in both size and population.

<table>
<thead>
<tr>
<th>Average number of places per aged care facility</th>
</tr>
</thead>
<tbody>
<tr>
<td>1998</td>
</tr>
<tr>
<td>2006</td>
</tr>
<tr>
<td>2008</td>
</tr>
<tr>
<td>2010</td>
</tr>
<tr>
<td>2012</td>
</tr>
<tr>
<td>2013</td>
</tr>
</tbody>
</table>


How does this sit with care that is person centred? There has been much research done into the designing of built environments for people who have a dementia. As Fleming has pointed out, the fewer people a resident with dementia has to deal with the less confused they will be.21 The Environmental Audit Tool has been designed by Fleming et al to evaluate the built environment to see to what extent it reflects best practice in dementia care.22 Ten essential principles of design are as follows:

i. Unobtrusively reduces risk
ii. Provide a human scale
iii. Allows people to see and be seen
iv. Reduce unhelpful stimulation
v. Optimize helpful stimulation
vi. Support movement and engagement
vii. Create a familiar space
viii. Provide opportunities to be alone or with others
2) **Culture and Staffing**

In Australia the modern nursing home resembles, to a lesser degree it must be acknowledged but still I think the comparison instructive, the total institution of Irving Goffman's work *Asylums*.

*A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life.*

Whereas in Western society in general *... the individual tends to sleep, play and work in different places with different co-participants under different authorities and without an overall rational plan*, within the walls of the total institution these arrangements do not apply. Within the total institution there is a distinct sense of order and control under a single authority, a predictability of the routine of daily life, an immediacy of the permanent (and inescapable) company of numerous others, a rigid scheduling of the day's activities and events, and various rules and regulations imposed on those inside the institution from authorities. There is also the idea of a 'rational plan', where the meaning of the institution itself is directed toward some single purpose.

Certainly the Australian nursing home is characterised by a task driven ethos, by a conformity to rules and practices, the routinisation of daily life, the collapsing of the social space with the eradication of any distinction between public activities and private, or intimate, moments. In this way there is a close interaction between staffing and culture, both of which combine to erode the possibility of person centred care.

First we actually know very little about the people who work in residential aged care in Australia. Whilst many other professions such as doctors, nurses, psychologists, pharmacists, social workers and occupational therapists are either required to be on a public register or have a professional body that regulates their clinical practice, those people who provide most of the face to face care for the person with a dementia in residential care, personal care attendants [PCAs], do not have to fulfill any such requirements.

Second, residential aged care is increasingly staffed by PCAs. Whilst workers in aged care may be referred to as 'nurses' they are in fact not nurses. Indeed residential aged care demonstrates a significant exodus in professional nursing staff, from 35.8 per cent in 2003 to 26.3 per cent in 2012.25 Nurses are typically not involved in the day to day care of the person with dementia. Personal care attendants are generally female, aged between 35 and 64, increasingly from non-English speaking backgrounds – 35 per cent of personal care attendants have been in Australia for 5 years or less – and are poorly trained.26 Whilst many may have a Certificate in Aged Care, or are undertaking Vocational Training, the question of relevance becomes crucial. How much time is
directed to dementia care and issues of mental illness in these programs? What do we know of the cultural attitudes of carers from Cultural and Linguistically Diverse [CALD] backgrounds? What do we know of their view of mental illness, of ageing, of dementia, of their attitudes toward sexuality, challenging behaviours and the highly specialized knowledge required to care for the person with a dementia? The Australian Nursing Federation has been unequivocal in their concern about the risk to the elderly person with a dementia from untrained or poorly trained staff and they point out that PCAs are not bound by the same professional frameworks as enrolled and registered nurses. They add that their skills are highly valued by care teams, and the ANF believes it is time to bring them into the realm of the professional boundaries that guide and protect licensed nurses and those they care for. Whilst I agree with the need to professionalize PCAs, I do not think the latter part of their comment reflects the real situation in aged care.

Third, the whole issue of staffing and the ratio of care staff to the person with dementia has been a constant concern in this country. The challenge is to ensure there are enough care staff to meet the needs of the person, and regular care staff at that. Agency staff are regularly employed in aged care facilities. The greater the reliance on agency staff the more person centred care is undermined and the more the focus is on task oriented care. This is an issue that has confronted the team in which I work, where we regularly attend dementia units and find it difficult to actually locate staff or the staff we do find say they are agency staff and do not actually know the resident in question! At one dementia unit at an aged care facility in Canberra, where there are ten people with moderate to severe dementia living, there is only one staff member on duty. On a recent visit to see a client at the unit I spent the entire visit with a staff member who was in tears, complaining that she was so exhausted that she could no longer do her job. Yet again one is reminded of Professor Brodaty’s comment about warehousing.

Benchmarks for staffing levels and skills mix need to be established which meet the need for quality outcomes for residents and clients, which meet the need for flexibility at a local service level, and which provide a safe and satisfying employment environment for staff.

3) Issues of clinical concern

Residential aged care in this country is beset by a whole range of clinical problems that not only effectively compromise any notion of person centred care but should give the wider society cause for serious concern. I will briefly outline them.

First is the issue of delirium.

A delirium is an acute disorder of mental functioning characterised by confusion, disorientation, an inability to pay attention and often presents with anxiety, agitation and restlessness, as well as accompanying perceptual disturbances such as hallucinations and delusional thinking. Deliriums typically have an organic cause, that is they can be triggered by an infectious disease such as a chest infection or urinary tract infection, a metabolic disorder, inflammation, pain, dehydration, malnutrition, falls and
fractures, sensory impairment or medications – actions and interactions. The importance of a delirium is that it must be regarded, particularly in the older person, as a life threatening event. In addition the symptoms can linger on for weeks or even months with increased levels of care needed. Delirium commonly involves hospitalisation and increased morbidity and mortality. A delirium is implicated in physical and mental decline, the emergence of a dementia and certainly makes a pre-existing dementia worse. It is a powerful challenge to quality of life of the older person in residential care.

Unfortunately delirium is common in residential aged care. Whilst the prevalence of delirium in the general community of people aged over 55 years is only one per cent, with up to 14 per cent in people aged over 85 years, the incidence in people in residential aged care facilities in Australia is over 60 per cent.30

Second is the issue of pain.

Like delirium pain is a common occurrence in residential care. Pain affects between 25 to 50 per cent of older people living in the community but between 27 to 80 per cent of those in residential care. The Australian and New Zealand Society for Geriatric Medicine write that pain in the older adult is commonly under-recognised, under assessed and undertreated, with this risk increasing with advancing age, cognitive impairment and for those in residential care.31 The effect of chronic pain can be catastrophic for the older person but for the person with dementia who cannot give voice to their pain the likelihood is that their pain will be ignored. Poorly controlled pain powerfully undermines quality of life and has been associated with depression, loss of weight and sleep disturbance. But perhaps of greater concern is that the person with a dementia is likely to have their pain misinterpreted by care staff as ‘challenging behaviours’ and run the risk of being prescribed antipsychotic medication.32

Third is the overuse of psychotropic medication.

There is a good deal of evidence that antipsychotic medication is overused in nursing homes, typically as a response to behaviours exhibited by the person with a dementia, and that such interventions have a limited efficacy. Antipsychotic medication is, as the name suggests, specifically designed to treat serious mental illnesses where the person has delusions, hallucinations and thought disorders. A side effect of this form of medication is its sedating ability, thus it is used in the person with a dementia primarily for this reason (unless of course the person has a current severe mental illness that requires such intervention). The danger is that restlessness, pacing, wandering, calling out, resisting care, all of which may be an artifact of; a strange or unusual environment; fearfulness; being showered by members of the opposite sex or by someone from a culturally different (to the person with dementia) background; confusion with respect to what is happening with the person, all of these may attract a diagnosis of BPSD, or challenging behaviours, and thus may result in an antipsychotic being prescribed. Yet such medication has no ability to reassure the lost and confused person, allay their fears, overcome the affront at being showered by a stranger let alone a member of the
opposite sex, or providing emotional comfort and consolation. Alzheimer's Australia write that:

.....the potential risks of antipsychotic medications are likely to outweigh potential clinical benefits for as many as 80% of the 50-100,000 people with dementia in Australia receiving antipsychotic medications. As a result, it is likely that there are a significant number of potentially avoidable deaths, strokes and serious side effects within this group.33

Fourth are recurrent problems with hydration and nutrition.

All people in residential care are at risk of poor nutrition and dehydration. Estimates of the rates of malnutrition are varied and depend upon the various measurement tools and criteria used. At the most extreme end it is suggested that up to 85% of residents are malnourished but most reports suggest the rate is somewhere between 15% - 60% although it has been reported in other studies as between 35% and 85%. A recent Australian study of fourteen low care facilities identified 34% of participants who were considered to be ‘protein malnourished’ and 62% having ‘deficits in energy intake’.34

Why does this situation exist? One reason is the paucity of staff to care for the frail elderly. There may simply not be enough staff to care and staff who are ‘run off their feet’ may simply forget. In the absence of required staff to resident ratios mistakes happen. Also, the use of agency staff, staff who may work on a unit for only one shift, increases the risk of mistakes. Another explanation might be lack of skills of staff in managing the person with dementia who might not accommodate normal eating and drinking patterns and at meal times might want to walk and wander or refuse food and fluids. Another might be that the person with dementia might want to eat and drink outside normal routine ‘task driven’ times and so might not receive food or fluids. The reasons are many but the problem remains.

Finally, residential aged care in this country is sadly beset by scandals of abuse and neglect. In the last few years for example we have seen numerous examples of abuse and neglect of the elder person in residential care, many of whom have a dementia. Their plight has been aired on a range of programs, from Late line to The Drum, to a whole variety of radio talkback programs. I will not go into the detail here, but in an attempt to answer the question of why such abuse happens, one website has, I believe, fairly accurately identified the causes.35

- Worker burnout - workers may be overworked, working long shift hours
- Untrained staff
- Staff underpaid or not enough benefits
- Staff may be frustrated with aggressive or rebellious clients
- Staff in a hurry to leave after a long day

On one level at least we can be sure, that such facts give lie to comments about the skills of PCAs being highly valued by care teams.
Caring for the person with a dementia, indeed delivering person centred care to the person with a dementia, is a highly skilled and sophisticated undertaking. One cannot abstract out factors such as design and use of space, facility culture, staffing ratios, knowledge and training of care staff, regular care staff who know the resident, the ability to discriminate between behaviours that might suggest pain, or depression, or psychotic behaviour, or infection causing a delirium, and still argue that one presents person centred care. The two positions are not compatible.

The above comment sets the scene for why I applied for the Churchill Fellowship and why I went to Holland and Scotland. The question now to be answered is; can person centred care really exist in residential aged care and if so, how?

**Dutch Initiatives in Dementia Care**

**Introduction**

At the interview for the Churchill Fellowship the most difficult question I was confronted with was; *how do you know that the different approaches to residential aged care are not a function of something we might call the Dutch Experience?* The assumption of course was that the way the Dutch care for the person with a dementia was so unique that it could not be translated to Australia.

In some senses this was in fact the case. At De Hogeweyk I found volunteers who had been volunteering for anywhere between a few weeks to over 20 years. One elderly lady had been volunteering for over thirty years and had recently received a citation from the Queen of the Netherlands at the village. I asked volunteers the obvious question; why do you give up your free time to work with people with dementia? The response was consistent. *Because it’s the right thing to do.* Teasing out their answer revealed a belief that society is a collective of individuals who have some form of obligation to help each other and to give back to a community that had given them so much. Yet Holland is not a collectivist society by any means. It is an advanced Western liberal democracy with a highly developed capitalist economy, like Australia. *But what if someone does not want to volunteer in any way, I asked?* Most responded in the same way. *We would look at them and think, what’s wrong with him?*

This section is titled ‘Dutch Initiatives’ for a good reason. It would be wrong to think that the Dutch response to dementia is uniform. Holland has its share of nursing homes like Australia; large, long corridors, task driven, an overtly medical focus, limited activities, a ‘one size fits all approach’ to care, poorly paid and poorly trained staff, the overuse of medication and so on. But in Holland it was clear that a new ethos was struggling to make itself heard and there were some people, Christian Baaker, Jorgos Arvanitis, Esther Helmich, Vanusa Baroni Caramel and others I met who were pioneering a new way of thinking about and responding to the person with a dementia.
**Principles of Care**

What are the principles that appear to be driving the innovative approach to dementia care in Holland?

1. **The built environment**

First there is an awareness of the built environment and its impact on the person. This begins with an understanding of environment-person interaction that transcends dementia care. Whilst there is a recognition that the individual’s environment is a personal and private intimate space into which we may invite others on certain occasions, there is an understanding that this privacy, this intimacy, is equally as important when the person has a diagnosis of dementia and is now in care. Perhaps it is in fact more important, for we in some way ‘anchor’ ourselves in our immediate environment. And if dementia is a sense of ‘disappearing self’; or at least the disappearing of the old self and being replaced with a new self, then what is familiar to us is precious.

Our homes are some sort of extension of ourselves emotionally and psychologically. But they are not stagnant. We change them, rearrange them, put our things on the walls, change the colours, design and redesign out spaces. Thus single rooms are crucial. How can we have person centred care when one is forced to share that most intimate of spaces, one’s bedroom and living room, with another whom one has not freely chosen to share it with? And how can we have person centred care when you are in a room that you cannot modify, alter, re-arrange to suit your own feeling?

Apart from sharing the intimate space, there is a recognition that dementia presents the person with a sense of being overwhelmed in larger spaces. Fleming urges us to ‘provide a human scale’. But this is a scale that the person with dementia who has impaired cognitions, can manage, can process, can understand, can make sense of. And so the Dutch have increasingly tended to introduce the notion of small cottages of between six to ten people, on average about eight people, living in close proximity to each other. Even in the traditional nursing home there has been a move to divide up the built spaces into smaller and more easily managed self-contained environments where a cluster of eight people may live, each with their own single rooms but with a communal kitchen, lounge area and dining area in each cluster. In this way the person with dementia has to manage just seven others and in a space that is both open and communal whilst at the same time providing opportunities to be alone and private. Again, as Fleming has so often pointed out, this reduces unwanted stimulation that threatens to overwhelm the person. It also creates a familiar space and as far as staff are concerned, it allows them to be aware at all times of the safety of the person with dementia. Without managing this reduced space and this person-environment dichotomy then person centred care is an illusion.

There is a recognition as well of a relationship between space and behaviour. Strange spaces, too open and large, like some cavernous dining rooms occupied by 30 or 40
people, tend to be overwhelming and confusing. We ‘make sense of space’ in our normal lives, that is we fashion it to our circumstances. In our own homes we do not build long corridors and have dining rooms 50 metres away from our bedroom. We do not have an activities room, another 50 metres away, and we do not have people who we have never met coming into and out of our rooms. As one physician in Holland said to me, when we are in our own space we first make it our own. The making it our own is a personal and emotional act and cannot be fashioned by an architect who we have never met.

The result of living in large and unfathomable spaces is fear and confusion. This can lead to wandering, looking for ways out, looking for people we have lost, looking for the room that is really ours, looking for a way home. The consequences of such wandering, such confusion and such fear and loss may be to be diagnosed as exhibiting the BPSDs of wandering, intrusiveness, shadowing people, resisting care, trying to abscond, being difficult to manage and the result of such diagnosis may be medication.

2. The individual as social being

Second is an understanding that the individual is a social being more than anything else. Dementia is of course a well-defined syndrome and as such occupies a central space in western medicine. Yet the person, person qua person, is fundamentally a social being whose nature embraces culture, language, meaning, spirituality, work, leisure, family, all of which are expressed through a variety of ways from laughter, to creativity, to song and music, to silence. And often expressed with intimate others. This suggests that activities and social engagements are crucial to the person. But not simply activities or engagements, rather meaningful, voluntary, planned activities that reflect the nuanced way of being that humans own as individuals. And in the same vein, social engagements with significant others with whom the person has a history of some sort of shared experiences rather than just another person in the next room or the next bed – some forced relationship based on the fact that two people are old and live under the same roof and thus it is assumed they will get on.

Unlike Australia where, as noted by Diversional Therapy Australia, *leisure and lifestyle care in the vast majority of aged care services, has seen a constant diminution in importance, clearly reflected in reduced staff hours for leisure and lifestyle programs*, in the facilities I visited in Holland there is a recognition of the importance of meaningful and targeted social activities as a part of specialist intervention. Activity programs I saw at the institutions I visited displayed a thoughtful assessment of the individual person’s needs and ranged from one to one music therapy with a trained therapist, to communal concerts featuring piano, violin and voice by professional musicians, to baking and cooking, to woodwork and all in well-equipped areas and not, as again described by Diversional Therapy Australia, *the present arrangement [which] allows ‘Lifestyle’ to be run by untrained staff who use activity calendars produced in yearly batches by off-site consultants*. Again, without a recognition of activity as an essential human enterprise, person centre care is an illusion.
There is another aspect of the recognition of the individual’s social being that appears to have been given scant attention in Australia. In de Hogeweyk in particular, the people who live there are grouped in the various cottages according to social class and social background – I discuss this later. This makes it more likely that people of similar background, status and upbringing will find things in common.

But another aspect is a noticeable homogeneity of carers. All the people I saw and spoke to in the institutions I visited spoke Dutch as their first language or were proficient in Dutch to a high degree. In other words the carers and volunteers could easily communicate with the people they cared for. Language and culture was not an obvious issue, unlike Australia where the profile of the carer has become increasingly one of a person who is from a vastly different cultural and ethnic background to the people they care for. Issues such as limited English skills, limited understanding of the culture and history of the person who is institutionalised, or simply the vastly different appearance of the carer, increasing numbers of whom are from parts of Africa, easily create suspicion, confusion, fear and thus resistance amongst the person with a dementia.

But there is a deeper and more uncomfortable issue here that is seldom dealt with. Culture is not simply equated with ethnicity. It is a social space in which the person inhabits. Thus the culture of the doctor or lawyer or accountant who has a dementia is vastly different from that of the urban disenfranchised, the housewife, the artist, the recluse. A particularly popular program on television recently was The Wire. How did the urban ghetto dwellers express their own culture? What language do they use? Yet their culture and frame of reference is much different to those who live in different circumstances. The challenge is how to reflect and respect their culture without objectifying it as pathology.36

3. The use of volunteers

De Hogeweyk exists as it does in no small way due to the work of Jorgos Arvanitis, and his over 150 volunteers. One of those volunteers was myself for just over four days. As I realised, my volunteering required no forms to fill out, no police checks, no Occupational Health and Safety course to attend, no Vulnerable Persons Certificate, none of which in any case will ensure that no unsavory characters become volunteers. That is not to say that there is no monitoring. Christian Bakker advised me that everyone who works at the Florence Centre for Specialized Care in Young Onset Dementia and Healthcare at Den Haag is interviewed by a psychologist. And at de Hogeweyk, Jorgos Arvanitis, maintains a powerful silent presence in the village, monitoring, checking, observing and is in constant communication with the staff who lead and direct the volunteers. In De Hogeweyk there is a sense of ‘ownership’ of the care of residents as a community responsibility, and not just as a clinical or work related responsibility. In Australia it seems we are committed to over regulating volunteering and making it so cumbersome and bureaucratic that one wonders why anyone would bother.

The use of volunteers is also an important way of connecting with the community at large. De Hogeweyk is not like the traditional nursing home that is frequented only by
staff, the people who live there and the families who visit their loved ones. It is in a real sense a part of the wider community. The numerous volunteers can be seen as a conduit by which community and facility come together. Thus the process of demystifying dementia and challenging stereotypes of ageing, dementia and what it means to live in a nursing home, is confronted. Unlike Australia, where nursing homes are places that old people and old people with dementia live and only specialist staff or immediate relatives get to see inside (thus ensuring the association with mystery and some concept of the unknown and threatening), De Hogeweyk is a place to be proud of, where innovation is the key. The people of Weesp, the nearby town, know of De Hogeweyk and they know its reputation and they take a degree of pride in volunteering there and in being associated with it. How many could say the same about traditional nursing homes in Australia?

4. Engagement with the community

In Australia, as in much of the West, dementia, like other forms of disability or illness – particularly mental illness – is associated with an overwhelming sense of stigma. Part of this stigma is institutional. For example in the jurisdiction where I work, mental health organisations do not want to be associated with dementia as they feel it compromises their focus on ‘mental illness’ and adds to the stigma their clients already face. Similarly dementia organisations do not want to be associated with mental health groups as they argue that dementia is not a mental illness. In a curious juxtaposition they do not want the added stigma of being associated with a mental illness. Both groups, thus, successfully encourage the continuation of stigma.

But part of stigma is social. In the facilities I went to in Holland there was an emphasis on an engagement with the community. This was expressed in two ways.

First, as stated above, was De Hogewyk, a small dementia village on the outskirts of the town of Weesp, some 25 minutes south of central Amsterdam. The village is about ten to 15 minutes’ walk from the centre of Weesp. The director of De Hogeweyk told me that as the person with dementia cannot go out of the village they have encouraged the village to come into De Hogeweyk. And so the village has, amongst its many services, a bar, a restaurant, coffee shops and a supermarket that are open to members of the public as well as to the person with dementia. The reality is that the restaurant is open for at least lunch and dinner to anyone who wants to go out for a meal. It has an impressive menu and a wine list. The aim is to ‘normalise’ the dementia experience, to erode the stigma that sadly confronts the person with dementia and those who love them and those who care for them.

Second is the work that Vanusa Baroni Caramel and others are doing at Amstelring, a care organization both for community and nursing home clients in the Amsterdam and Amstelland-Meerlanden region.

This project involved renting a block of flats and turning them into a series of apartment cottages for five, six or seven people with dementia. Again there was the home-like environment; people living together in communal setting; a sense of home as belonging
to a community quite distinct from the traditional nursing home style. To anyone walking by it was simply a block of units no different or in no way distinct from any other block of units where anyone might live. Of course there were problems. Because the units are not locked some people wander off and return to their original homes. Others have wandered and just got lost. This arrangement is really for people with early stage dementia whose illness perhaps develops whilst they are at the project so they can accept the project is their home. If people continue to leave then it may be that they cannot stay there and may be forced to re-locate to more secure units. But for the great majority this type of living enables the person with dementia to live amongst the wider community, without locks, without being cut off from the outside world, free from restrictions of closed institutional, task based living separated from other forms of human contact.

There is a recognition in these approaches that much stigma is actually reinforced by the very institutions and professionals who care for people. Arguments about where dementia fits clinically and where it does not fit are destructive, and indeed tiresome. Separating people with a dementia into ever larger facilities cut off from the rest of society merely supports and plays into fears people have about mental illness in general.

Now I want to turn to a discussion of the dementia village at De Hogeweyk to see how some of these principles have been put into action. Visiting the village was the prime interest as far as my Churchill Fellowship was concerned.
The Village at De Hogeweyk

The Dutch Dementia Village of De Hogeweyk is located in the small town of Weesp, on the outskirts of Amsterdam. It is home to about 150 people with dementia. De Hogeweyk is divided into 23 individual self-contained households, with each household having six bedrooms (one has seven), a dining area, lounge, kitchen, two bathrooms and an adjoining terrace that opens up onto a small garden area and a pathway that leads to the rest of the village.

There are seven lifestyles catered for at De Hogeweyk. These are described as:

i. **Traditional** – for people with a professional background

ii. **City** – for urban dwellers

iii. **‘Het Gooi’** – for people who may be described as ‘upper class’ and who may attach importance to etiquette and status

iv. **Cultural** – for people who have an appreciation or interest in the arts

v. **Christian** – for those who have a religion as part of their daily life

vi. **Indonesian** – for those who have a cultural connection to the former Dutch colony

vii. **Homey** – for those who cherish family life and domesticity

Of course the divisions are subjective to a degree but they do give people the best chance of finding others with similar backgrounds, rather than just lumping all people together as typically happens in the Australian nursing home. [Professor Brodaty’s comment about ‘warehousing’ comes to mind again].

There is an implicit (unstated) recognition in De Hogeweyk that culture and society are the essential building blocks of what constitutes the human life. In other words human life is seen as primarily social in its construction. Thus, it may be argued, disturbances in human life, as per a dementia, can be seen to some extent as a disruption of social being, rather than as primarily or even necessarily a medical issue. The implication is crucial. If we see dementia as a medical disease, as a clinical syndrome, then the temptation is of course to treat it in terms of diagnosis and disease, with signs, symptoms, medications, treatment regimes, nursing care plans and the like. But if we see dementia, as it appears De Hogeweyk does, as being a disruption of the person’s social existence, then our approach might be different, with an emphasis on social supports, a recognition of culture, of lifestyle, of relationships, of personal and social history, of the importance of past lives and so on. Thus in De Hogeweyk care is taken to ensure that, as much as possible, people from roughly similar backgrounds are placed in the same households. The assumption is to recognise the importance of shared pasts, the location of the person in certain social classes and of shared social experiences.

De Hogeweyk is a two story building which is built on a site that covers 3.78 acres or 15,310 square meters. There are households on both floors. Navigation around the village and from the ground floor to the first floor is unimpeded. There are no locked doors. To go to the first floor requires a lift which is sensor activated and so there is no
need to open the doors to enter or leave or to go up or down. Despite its size De Hogeweyk does not present difficulties for the person who is cognitively impaired as each individual household is self-contained and has a distinctly homelike environment to it. There are no vast open spaces in the Village. The streets, or walkways to give them a better description, are rather narrow. The person is not overburdened with unnecessary stimulation nor are they confronted with wide open spaces. The distance from the furthest household to the centre of the village is about a three to five minute walk for able bodied persons and perhaps ten to 15 minutes for a frail elderly person on a wheelie walker.

In the centre of the village are a variety of shops; a theatre, supermarket, hair and beauty salon, a café/bistro and a restaurant. Thus residents can maintain a normal life by engaging in practices they might have done prior to their going into care. In the supermarket the person with dementia can find a trolley and buy groceries, but no money changes hands. The lady behind the till ‘scans’ the items and they are placed into a trolley much like at any supermarket – a practice that does not extend to visitors however as I found out. Everyone else has to pay!

It is common to observe an elderly person with dementia walking about the Village with no-one [staff] in attendance. This is quite unlike traditional nursing homes when such behaviour might be defined as ‘wandering’. And if the behaviour of wandering was paired with going into someone else’s room, a reasonable enough thing to do when you are exploring your own environment, then the label of ‘intrusiveness’ might be applied as well. And if staff attempt to remove the intruder from the room of another resident and the resident resists, again a fairly common response to being re-directed elsewhere, then the label of ‘resisting’ might be added, and if the resisting is accompanied by verbal protests from the intruder then another label of ‘verbal aggression’ might be applied. And so there is often very little between an individual with dementia seeking out company, or looking for a lost relative or simply exploring their surroundings and a whole range of possible behaviours and subsequent diagnoses that might result in an antipsychotic being prescribed. Reflecting on this I wondered how often it might be that behaviour identified as BPSD was in effect the normal consequences of confused and cognitively impaired elderly people simply trying to make sense of an environment that was unusual, overwhelming, cluttered with strangers, noisy, busy and meaningless to them. The structure and design of De Hogeweyk mitigates against this.

It is also very common to see an elderly person walking with family members. The opportunity to do a normal activity with a loved one, go for a walk, go shopping, have a coffee and a cake in the village, perhaps attend a musical performance means that times spent with family can be interesting and restful. In many traditional nursing homes visiting family members might have the choice of either, taking the resident out for a drive some distance from the home, or simply sitting in their room, or in the dayroom. The former may involve transporting the resident to another part of the city with more time spent driving, parking and getting into and out of cars than time actually spent with the family member. The latter may involve competition from the ever present
television, from other family members, from residents who are calling out or the general noise and busyness of nursing home life intruding on intimate moments. In De Hogeweyk a visit to a relative in care can be both a normalising and a pleasant experience with a focus on the relationships and shared meaningful experiences rather than on extraneous tasks such as driving and parking.

The philosophy of care at De Hogeweyk appears to be based on a commitment to ensuring the person with dementia lives as independent a life as they can, given of course that increased dependence on others is a reality in any dementing illness. The environment is safe and reassuring, there is an opportunity to carry on a lifestyle that is as similar within the village as the person experienced outside the village and there is a subtle use of space that enables a large number of people to live in one setting yet, because of the design of each individual household, gives the feel of intimacy and seclusion. Partially this is because as each household is physically distinct from each other household by walls and pathways, there is a noticeable lack of noise. The traditional nursing home so often seems to be a place where noise is a constant. In De Hogeweyk it is quiet that is a constant – except of course in the music room and the café when there are activities! But to escape the boisterous singing that the Dutch excel at, one has only to take a few steps on a pathway to find a quiet bench. Whether or not this was an intentional design structure or not it is nevertheless effective at securing a reduction in stimuli and in fact has a powerful calming effect.

Inside each household, space is again maximised to ensure notions of community, yet give a sense of the intimate. Whilst there are single bedrooms there has been a tendency for some to share. This has often been encouraged by relatives who feel that their loved one would benefit from having company, but there is no compulsion to share a room. Because the households are self-contained, residents do not have to walk 20 or 30 metres, or in some cases further, to have meals. As in any home the dining room is an integral part of the living space. Only in hotels do you have to leave your room and walk to the large dining room. And also the eating spaces, as with sitting spaces, are small and shared by people the person with dementia knows, or at least has a chance to get to know. There is no large dining room that accommodates 40 or more people where one is allocated a table amongst others they might not know, or like, or choose to sit with in any other situation.

Perhaps an assessment of De Hogeweyk’s success or otherwise is best made by reflecting on the occurrence of BPSDs. When I met the director of activities, Jorgos Arvanitis, I asked him about instances of BPSD or challenging behaviours. He reported that we do not get any BPSD at De Hogeweyk. Naturally I was dubious about the veracity of such statements given that BPSDs are found eventually in all cases of dementia and in those with moderate to severe dementia BPSD is very common. Yet for the just over the four days that I worked at De Hogeweyk as an activities volunteer I saw no such behaviour. Both volunteer and paid staff said that BPSD does occur but it is very rare. Jorgos explained the absence of such challenging behaviours was a result of;
- the open environment,
- the frequent social activities,
- the absence of locked doors,
- the ability to walk around the Village in safety,
- an environment that was structured and reassuring and was not cluttered or overwhelming,
- the high ratio of paid and volunteer staff to the person with a dementia and
- the relationship that is built up between staff who have worked for so long at the facility that they know the people they care for very well.

Of course one might also add that an environment that was seeking to normalise life in a village context, rather than confining the person to a small room off a long corridor, isolated, alone and ignored or perhaps simply lined up with so many others in front of the every present television set, plays an important part in reducing potential behaviours of concern.

What is it that makes De Hogeweyk a Success?

- First, a recognition of the social nature of humans and the inherent social nature of dementia.

As suggested earlier in this essay, we can view dementia within a variety of paradigms; as medical disease, as functional impairment, as grief and loss, as reducing capacity, as a public health challenge. The view we take implicates our responses. If we see dementia as medical disease then we may focus our attentions on research, on diagnosis and early diagnosis, on treating aberrant behaviours. If we see it as a public health challenge then we may want to ensure we have the financial resources to care for people, or embark on public health programs that prioritise some notion of ‘healthy living’. But if we see dementia in terms of (i) the disruption of the person’s ability to live an independent and productive life, or (ii) the social consequences of being diagnosed with a dementia, then we will approach the person differently.

Neither denies dementia as being located within a biological substrate. The first recognises that individual people have dementia and that once the person diagnosed leaves the doctor’s surgery then the consequences are largely social: changes in roles, relationships, levels of dependency, loss of functioning, loss of rights, loss of autonomy, ability to perceive the world and so on. The second recognises that dementia itself carries with it a whole range of expectations held by other people, both professionals and the wider society, about how to categorise, respond to, classify, manage the syndrome and by implication each individual person with the diagnosis. Together they both prioritise the person and place the person at the centre of concerns about dementia. Defining dementia in terms of a person’s subjective being is vastly different to seeing it as an illness that requires treatment.
Second a recognition of the power of relationships

The village at De Hogeweyk is based on relationships. The relationships between each person in each individual household, where some form of social matching guides placement. The relationships between nursing staff and the person with dementia. The relationships between volunteers and the person with dementia. The relationships between the village itself and the wider community. I thought of De Hogeweyk as a form of web, each contact and each connection intricately balanced, sustaining and reinforcing the other. The strength lies in the relationships between these individual relationships.

Third a recognition of the influence of the past on the present.

The person as social creation is viewed in terms of the meaning of their lives. Understanding the person and who the person is and what the person's preferences are, are crucial in framing activities. There is choice. Also, the different households reflect the importance of past, but not just 'the past' rather the past as experienced by the person who is in the present. I saw no bare rooms at De Hogeweyk, or any of the other facilities I visited in Holland for that matter. It is an interesting and informative experience to go into a resident's room. In the course of my work I often visit aged care facilities and enter the rooms of residents. Some are bare, barren, devoid of anything that might suggest a life has been, and is being, lived. Some are like cells. No pictures or paintings on walls. No items of furniture that reflect the person. No special objects that we, as humans, collect through our lives. Part of the whole process of moving into care is 'downsizing', reducing the life of a person to four small walls, a bed and perhaps a chair. Not all facilities are like this, but many are. In De Hogeweyk, and the other facilities I visited, I was astounded at the lengths to which people had gone to fill their rooms with the accumulations of meaning from a life. But this is how we, as humans, live. Our rooms are full of reflections and representations of our past and our present. Of who we were and who we are.

This has important implications for the well-being of the person. How much wandering is the result of the person, upon finding nothing familiar in their surroundings and then nothing familiar in their little room goes looking for 'home' – whatever that means to them. And the wandering risks being defined as BPSD and risks being treated with medication. People in care cannot return to their homes, but that is no reason why their homes cannot come to them. De Hogeweyk was the most developed example of the person's home coming with them to their new home.

Fourth a recognition of the relationship between space and being.

This is perhaps De Hogeweyk’s greatest achievement. The recognition that the space that we humans occupy is as much emotional and psychological as it is physical or, to be more accurate, that one cannot divorce the emotional elements of space from the physical.
Finally a management team that is proactive and philosophically focused.

In any organisation it is management that sets the tone. In De Hogeweyk that tone, to me at least, was set by two people who have a powerful presence in the village, Yvonne van Amerongen, the Manager and co-founder of De Hogeweyk, and Jorgos Arvanitis, who is in charge of activities. It is their expectations and philosophies that guide the direction that De Hogeweyk takes.

The Scottish Dementia Working Group

One of the central problems that all societies have when engaging vulnerable or disenfranchised people is that it is so easy for others to usurp the role of spokesperson. Harding sums this up nicely when she writes that

\[.... we have heard entirely too much from men about women and gender, from whites about blacks and race, from heterosexuals about lesbians gays and sexual preference, and from the economically powerful about workers and about why the poor are poor. Claiming to adopt the critical persona of the Other in the name of her emancipation is unlikely to earn the applause of the Other.\]

Harding wrote this comment in the early 1990s, yet it is so prescient today and indeed could easily have been the inspiration for the Scottish Dementia Working Group.

In the ongoing hustle and bustle of the process of dementia it appears that the person whose voice is most important is so often the person who is not heard. In Australia the dementia pathway appears to blur clinical with socio-legal moments. The person begins to show early signs of cognitive impairment. After a period the GP is consulted. Memory and other lapses are beginning to cause concern to the person, family and friends. The GP makes a referral to a specialist, perhaps a neurologist, neuropsychologist or a geriatrician. Dementia is diagnosed. Affairs are required to be put in order. Perhaps an Enduring Power of Attorney is drafted whereby the person with dementia gives another authority over their own decision making when they can no longer do so. Later an Aged Care Assessment Team does a functional assessment of the person and assigns them an ACAT level, thereby enabling them to get access to various care packages that reflect their level of incapacity. Perhaps, along the way, the person – still reeling from the shock of being diagnosed with a life ending illness - is encouraged to make an Advanced Care Directive whereby they state, in effect, how and when and in what manner they want to die. A nursing home may be considered for respite or, later, for permanent care.

The above includes some confronting and very difficult decisions. Consultations happen with families, friends, doctors, aged care facilities, government assessment teams and so on. Amongst all this is the person with dementia, one lonely and often misheard or perhaps even forgotten voice amongst many. It may seem that everyone is speaking for the person with dementia; doctors, bureaucrats, assessors, family, community agencies,
spouses even, and despite a whole range of good intentions one may be entitled to ask, who listens to the voice of the person?

The main purpose of my Churchill Fellowship was to look at the concept of person centred care primarily through the prism of the residential care facility – what we might refer to as institutional living. But person centred care transcends institutional life. When we use the word ‘care’ we often think that it is something one person does to another person. I care for you. I am the deliverer of care and you, by reluctant implication (often), are the recipient. This is not a relationship of equals. Should you be grateful to me for example? And it is surely the case that one cannot parachute person centred care into a relationship. The relationship itself must be based on it. And a part of being person centred and indeed of having a relationship that is meaningful and equal is hearing the voice of the person, however faint that voice is.

I first heard about the Scottish Dementia Working Group by speaking with Rachael Litherland on her recent tour of Australia. She spoke of an organisation formed by people with a diagnosis of dementia in the Aberdeen and Aberdeenshire area of Scotland whose purpose was to

*give people with dementia the chance to influence, inform and improve health, social care and voluntary services that impact on the lives of people with dementia.*

This was in 2004 and since then the group has developed to become an influential voice for the person with dementia. The aims of the group are broadly;

- To help the person with a dementia to maintain a fulfilling personal and social life;
- To reduce the stigma associated with dementia and thus to encourage positive social attitudes toward the person with the disease;
- To provide a forum whereby the person with a dementia can talk and interact with others who share the diagnosis;
- To influence public policy in relation to dementia care.

These aims are realised by providing consultations, giving public talks and lectures, sharing information, working closely with local health and social care services, in particular Alzheimer’s Scotland, and organising group visits and social events.

The groups website documents some of their achievements.

- Helping Alzheimer’s Scotland secure £500,000 from the Primetime Lottery Fund;
- Hosted five Theatre Forum performances of a play exploring the diagnosis of dementia in the last 18 months;
- Involvement in discussing issues of concern such as the NHS Smoking Policy, counselling for people with dementia, Aberdeen City Council’s Commissioning Strategy and respite and the National Dementia Strategy;
- Taken part in a local workshop on the ‘Reshaping Care for Older People’ agenda;
- Contributed to reviews of the Scottish Dementia Working Group;
- Given presentations to hospital chaplains, social work students, junior doctors and mental health officers in training;
- given presentations at World Alzheimer Conferences (one in Berlin, one in Singapore) on their experience of dementia.40

**Dementia, Voice and Vulnerability**

When we use terminology such as ‘vulnerable’ we typically identify those groups and individuals who have a reduced capacity for both articulating their needs and securing access to resources in order to achieve those needs. Thus under such headings we usually place the elderly, the poor, those with a disability or chronic illness and, of course, the person with a dementia. This idea of an impaired ability to access resources (social, political, economic) is often linked with notions of stigma. Thus the vulnerable person is doubly challenged.41

A particular challenge is how to frame our relationship to the person with dementia. It could be argued that many institutions have contented themselves with discussion *about* dementia rather than *with* the person who has a dementia. Thus it has been the voices of specialists who have been heard. Because we typically frame dementia in the context of illness then it becomes easy to assume the ‘experts’ on dementia are in fact medical professionals and then, following them, various other professional groups. Only in recent times have we appeared to have given a space for immediate family members to be heard. We have, even then, assumed that immediate family members have the ability to speak for the person. Just as we assume that parents speak for their children, we have expected that the person who cares for the person with a dementia is able to speak for both themselves and their loved one.

The reasons for this are complex and need not be addressed here. But certainly we have traditionally viewed people with a dementia as being ‘less than persons’, that is less than a rational, autonomous moral individual who can conceptualise and articulate their own preferences. Thus we have ignored them and all too frequently consigned them to some outer world where their needs are both formed and articulated by others.

When I met members of the Executive in Glasgow I learnt of their struggle to both retain their individuality as persons, that is to not be defined by an illness they were living with, and at the same time to be accepted as an organisation that, in their own right, had the authority to speak for themselves. A challenge is certainly to resist definitions and explanations being imposed on the person from the outside. Similarly with the members I met in the trips I undertook to Aberdeen. One group member said to me that the importance of the Working Group was that they could meet with other people who also had a dementia.
This seeking others of like circumstance is what we do as humans. We look for commonalities in our lives. And so this lady of 64 years with a diagnosis of Alzheimer’s type dementia explained that as everyone in the group had a dementia, finally she could meet and talk with others of her kind.

*Carers do not know dementia. Neither do doctors. And neither can our families. My partner knows what it is like to be a person who is married to a person with dementia and I can never know what that is like. But he can never know what it is like to be me, who has a dementia. But the people here know what dementia is really like. How it is with you all the time. How you can never get away from it. How it gradually takes you over. And meeting with each other is so important for me.*

The innovation of the Scottish Dementia Working Group is that the concept of voice has been not given, but taken. That is, there is in the literature a discussion that asserts how and when the voice of the person can be heard and what we can do to enable this voice to be heard. Again this is a disguised form of paternalism. *We enable the vulnerable to have their voice heard. We, by our efforts, have given the vulnerable a space in which to talk. The implication is that the vulnerable, the person with dementia, could not assert their own voice without us. Yet what the Scottish Dementia Working Group have done, and what is now beginning here in Australia due in part to the efforts of Alzheimer’s Australia, is to show that they are the ones who have chosen to speak and they do so without our help, without our guidance and without our permission. This group of people have carved a space in an environment that is all too often hostile to their actions. Perhaps through their actions we might be led to re-frame how we think of the person with a dementia and how we think about ourselves in relation to them.*

### The Challenge to Australia

Person centred care is generally regarded as the driving philosophy underpinning care of the person with a dementia. If asked, almost all residential aged care facilities would admit a commitment to the principles and practices of this model of care. Yet the reality is that, in the Australian Capital Territory at least, where I live and work as Senior Behavioural Consultant with the Dementia Behaviour Management Advisory Service, a program managed and administered by Alzheimer’s Australia ACT, person centred care is non-existent.

The reasons for this are many and varied.

First it is surely the case that like most all-encompassing slogans, human rights being another, it appears as if no-one is quite sure what they mean by person centred care. There is a belief amongst some, perhaps many, that person centred care describes only the relationships between carer and cared for. It does not. To take an extreme example, one cannot deliver person centred care to a person confined in a small cage no matter how empathic or caring they are. This suggests that the environment is crucial. Person
Person centred residential aged care must take into account the environment in which the person with dementia lives. This environment is both physical and social.

We currently know how to design physical environments that are sensitive to the deficits the person with dementia has. Dr Richard Fleming has done a great deal of work in this area for many years. The Iris Murdoch Centre at the University of Stirling is an authority on the relationship between design and dementia. We need to learn from them and also to put that knowledge into practice. Yet we continue to build environments that are hostile to the person with dementia, and thus as a result we continue to have problems with challenging behaviours.

With respect to the social environment within aged care facilities, it is essential that care staff are valued, are fluent in English, have a deep understanding of dementia care, of mental illness and of specific clinical conditions such as delirium, depression, dementia, pain management and hydration, to mention the most obvious. We also need to be confident that staff are culturally aware of not only the influence of their own culture on their attitudes but also the validity and meaning of the culture of the person they are caring for.

Second, there are powerful political forces who act in a manner that successfully undermine person centre care. In our refusal to demand that carers are registered, trained and skilled to a definite and settled clinical standard, are paid a reasonable living wage – not given less than a person working at a check out in a supermarket – and that facilities do not have to abide by clinically approved ratios of professional carer to the person with dementia, then we have made person centred care an impossibility. The current rates of delirium, depression, overuse of antipsychotic medication, dehydration, problems with nutrition and the effective treatment of pain in our residential aged care facilities are a disgrace. Until we professionalise the workforce this will not change and person centred care will remain an illusion.

Third, there are economic forces that mitigate against person centred care. Building facilities to specific cottage or household-like designs, as occurs in some parts of Holland, may enable person centred care to grow and develop, but the question of cost may prohibit this, at least in the minds of developers. It often appears that the driving force behind the construction of ever larger residential aged care facilities is not so much the desire to facilitate person centred care as it is to secure financial returns. These modern and often rather opulent facilities are more than occasionally the subject of black humour by clinicians who suggest, perhaps unkindly, that the facilities are really designed to appeal to the children of the people who will live there rather than the actual inhabitants themselves.

The building of large facilities that can house up to and over 100 residents does not, in and of itself, prevent person centred care. Most facilities can be internally redesigned to reflect a household style of accommodation. And large facilities can still be created with adherence to space and design principles that enable self-contained household style living amongst a group of people of backgrounds that may approach some form of social
and cultural similarity. The examples of De Hogeweyk and other institutions dotted around the world are there for us to see and to learn from.

The achievement of person centred care, if that is indeed what we as a society want, is too important to be left to chance. Whilst we cannot regulate that each individual person will act out of respect, compassion, tolerance, understanding and from a highly developed clinical knowledge base towards the person with dementia, we can create the environment that gives such a viewpoint the best chance of succeeding. But of course this begs the question. Are we really committed to person centred care or not?

**Conclusions and Recommendations**

In the following I have included some suggestions for achieving person centred care in residential aged care facilities.

1. **Design of the physical environment.** All new residential aged care facilities should conform to dementia best practice design parameters. Such parameters should be required for facilities in order for them to be accredited.
2. **Existing aged care facilities who specialise in dementia care** should be modified in order to facilitate smaller, cottage style household living in keeping with current best practice design parameters in order for them to be accredited.
3. **All care staff, and not simply those who work in residential aged care or dementia care** should be required to be on a national register of carers.
4. **All care staff and not simply those who work in residential aged care or dementia care** should be required to have approved educational qualifications in dementia care.
5. **There needs to be a legally binding set ratio of personal care staff to residents in all aged care facilities.**
6. **All aged care facilities should have a full time diversional therapist and occupational therapist** employed in a staff to resident ratio to be determined.
7. **Wages and conditions for nursing staff in residential aged care** should correspond to wages and conditions enjoyed by nursing staff in the public sector.
8. **Wages and conditions for all non-nursing care staff need to reflect the value of the work they do.**
Notes and References


8 All information on dementia data in Australia can be found on the Alzheimer's Australia website at: https://fightdementia.org.au/research-and-publications/reports-and-publications


15 Alzheimer’s Association of the USA. Information accessed through their website at: http://www.alz.org/
16 Australian Institute of Health and Welfare.  


18 This comment was made by Professor Brodaty on the video promoting and describing the Smile Study; using humour therapy for the person with a dementia.

19 Personal conversation.


22 Fleming, R. (2010). 'The use of environmental assessment tools for the evaluation of Australian residential facilities for people with dementia'. This tool can be downloaded from the following website.  

At the time of production of this assessment tool Dr Fleming was Director, Dementia Services Development Centre Hammond Care and Clinical Associate Professor, Faculty of Health and Behavioural Science, University of Wollongong, NSW.


24 Ibid


26 Ibid.

27 Ibid.

28 Ibid.


33 Alzheimer’s Australia (2014). Antipsychotic medications and dementia. Alzheimer’s Australia Position Statement. This can be accessed through the Alzheimer’s Australia website.

34 Beattie, E. et al. (2013). How much do residential aged care staff members know about the nutritional needs of residents? International Journal of Older People Nursing. 9. 54-64.

35 http://www.agedcarecrisis.com/

36 https://www.youtube.com/watch?v=SFpovfkzYRs
The Wire is a powerful reminder of the differences in culture expressed through language. Would such dialogue, perfectly acceptable on the streets of the inner city (in fact required) be acceptable in an aged care facility? And if not, is that denying the culture of the people?


38 http://www.innovationsindementia.org.uk/rachael.htm


40 Ibid.


42 Personal communication.