Exploring the Needs of Younger People with Dementia in Australia

Alzheimer's Australia

Report to Australian Government
Department of Health and Ageing

March 2007
# Table of contents

**Executive Summary**

**Acknowledgements**

**Abbreviations**

**Chapter 1 – Introduction**

<table>
<thead>
<tr>
<th>Subsection</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background</td>
<td>10</td>
</tr>
<tr>
<td>Project methodology</td>
<td>11</td>
</tr>
<tr>
<td>Terminology used in the report</td>
<td>12</td>
</tr>
<tr>
<td>What is dementia and who does it affect?</td>
<td>12</td>
</tr>
<tr>
<td>General issues for people with dementia regardless of age</td>
<td>13</td>
</tr>
<tr>
<td>Specific issues for younger people with dementia</td>
<td>14</td>
</tr>
</tbody>
</table>

**Chapter 2 – Delays in Diagnosis**

<table>
<thead>
<tr>
<th>Subsection</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>The process of diagnosing dementia</td>
<td>16</td>
</tr>
<tr>
<td>Referral to specialist services</td>
<td>17</td>
</tr>
<tr>
<td>Tests</td>
<td>18</td>
</tr>
<tr>
<td>Conduct of health professionals</td>
<td>18</td>
</tr>
<tr>
<td>The value of early diagnosis and counselling</td>
<td>19</td>
</tr>
<tr>
<td>The need for raised public awareness</td>
<td>20</td>
</tr>
</tbody>
</table>

**Chapter 3 – Access to Services**

<table>
<thead>
<tr>
<th>Subsection</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gaps in services</td>
<td>21</td>
</tr>
<tr>
<td>Acute care setting</td>
<td>22</td>
</tr>
<tr>
<td>Services at point of diagnosis</td>
<td>22</td>
</tr>
<tr>
<td>The Living with Memory Loss Program (LWML)</td>
<td>22</td>
</tr>
<tr>
<td>Respite, day care and in-home services</td>
<td>24</td>
</tr>
<tr>
<td>The need for respite, day care and in-home services</td>
<td>24</td>
</tr>
<tr>
<td>Activities with people of similar age</td>
<td>25</td>
</tr>
<tr>
<td>Appropriate and interesting social activities</td>
<td>25</td>
</tr>
<tr>
<td>The difficulties for staff caring for people with younger onset dementia</td>
<td>26</td>
</tr>
<tr>
<td>Individual responses</td>
<td>27</td>
</tr>
<tr>
<td>Funding issues</td>
<td>27</td>
</tr>
<tr>
<td>Reluctance to access respite services</td>
<td>28</td>
</tr>
<tr>
<td>Mobile Respite Response Team (MRRT)</td>
<td>29</td>
</tr>
<tr>
<td>The Sundowner Club</td>
<td>30</td>
</tr>
<tr>
<td>Residential care</td>
<td>30</td>
</tr>
<tr>
<td>Design of premises</td>
<td>31</td>
</tr>
<tr>
<td>The Ritz Nursing Home, Blue Mountains NSW</td>
<td>31</td>
</tr>
<tr>
<td>The aged care system</td>
<td>32</td>
</tr>
<tr>
<td>Involvement of the Aged Care Assessment Team</td>
<td>33</td>
</tr>
<tr>
<td>Young People in Nursing Homes Campaign</td>
<td>33</td>
</tr>
</tbody>
</table>
Attachment 1  Alzheimer’s Society UK.  *Charter for Younger People with Dementia and their Carers*  81

Attachment 2  Alzheimer’s Association US.  Recommendations from  

   *Early Onset Dementia – A national challenge, a future crisis*  82

Attachment 3  Alzheimer’s Association.  Recommendations from  

   *A Young Mind – Issues in relation to younger people with dementia*  83

Attachment 4  Alzheimer’s Australia and Parliamentary Friends of Dementia  

   *National Consumer Summit. Seven Action Point Plan for Change*  88
Executive Summary

In its 2004/05 budget, the Australian Government pledged to support dementia as a National Health Priority with a $320.6 million package over five years, targeting better prevention, treatment and care. Alzheimer’s Australia has been funded to undertake a national project to identify and map the needs of younger people with dementia and develop recommendations for future initiatives in this area.

Although most people with dementia are over 65, younger people are diagnosed with dementia. The term ‘younger onset dementia’ is used to describe any form of dementia in a person under 65 years. The age and stage of life of a person at the onset of dementia influences its effect on that person, their family and their needs. Age also affects the type of dementia a person may have and consequently, the sort of behavioural change in that individual.

This study explores the main differences between the impact of dementia on younger people and older people and the resultant unique needs of people with younger onset dementia. It incorporates information from a number of sources including a literature review and a wide-ranging consultation of people with younger onset dementia, primary family carers, other family members, Alzheimer’s Australia service providers, other service providers and special interest groups.

All people with dementia and their family carers want timely, quality and accessible services that meet their individual and holistic needs throughout all stages of the disease process. There are unique and complex issues faced by younger people with dementia and their family members, in terms of finding appropriate services. These are reported in literature from Australia and overseas, and confirmed through the national consultations.

The issues younger people may face include:

- Difficulty and/or delays in getting an accurate diagnosis;
- Family responsibilities including still actively raising a family;
- Currently working or being only recently retired;
- Having significant financial commitments based on previous earnings;
- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others;
- Future plans that are affected at an earlier stage in life;
- Being more likely to have a rarer form of dementia than Alzheimer’s disease or a genetically-based cause; and
- Experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.

Policy changes to better equip Australia’s system to service younger people with dementia should take into account the following key factors:

Minority group

- Since people with dementia under 65 are in the minority, they therefore form a hidden or small sector of the dementia-specific or general care service client base in most areas. As dementia is typically associated with old age, it is usually considered in the realms of the aged care sector, rather than the disability or health sector. Consequently, many younger people with dementia have reported not fitting into current services appropriately more particularly in rural and remote areas where even mainstream services may be scarce or lacking altogether.
• Relatively low numbers should not mean that services should not be equitably provided. There is a unique mix of issues and needs that a younger person has by virtue of their age and circumstances which should be taken into account in providing services.

Access to services
• It is apparent that young people with dementia attempt to access a variety of services in the health, aged care and disability sectors, but few have reported finding anything appropriate to meet their needs, and it is often left to the goodwill of providers to provide services. This may be at the end of a frustrating and long process, and so the younger person’s dementia may have progressed markedly by that stage. The emotions of the younger person and their families may also be heightened because of frustration at not being catered for adequately by any service or being denied a service because they are deemed to be not eligible. The situation may be exacerbated as their condition progresses and their care needs increase.

• Residential care facilities may be reluctant to offer long-term respite to younger people. There may also be longer waiting times for permanent and appropriate residential placement.

Social circle
• A younger person is more likely to have a different immediate circle than an older person (typically in their 70s, 80s or 90s), including children still living at home, a husband or wife, and friends who still work. A younger person is usually surrounded by friends at pre-retirement age who are more likely to be divorced, remarried, single or have complex family arrangements than the older generation. They may also have elderly parents with dementia, putting pressure on their role as carers. Therefore, in providing services for these clients, a holistic approach is needed to take in the additional needs, demands or pressures of the wider circle. This includes the provision of social support services for children of those with dementia, such as counselling.

• People under 65 seem less likely to be already involved in social clubs, groups or communities than older people who have retired. This means they may not have immediate access to engaging in appropriate activities and will need to be specifically referred to such services, if available.

Financial commitments
• In the families of the under 65s, their financial commitments may have been dependent on the earnings of that person and their carer. A significant financial burden on the family can evolve as the person with dementia is forced to give up work, and the spouse and/or children juggle the role of breadwinner for the family and carer. Continuing in the workforce may become impossible for some carers, particularly as they become more reliant on accessing suitable respite services.

• In some cases, people are still paying off mortgages and some have to additionally manage the costs of their children’s education and upbringing. These people worry about the prospect of financing residential care while maintaining a family home, being too young to qualify for an aged pension but having an undersized superannuation because they were forced to retire early.

• In light of the complicated financial pressures placed on the family of a younger person with dementia, there is a need to establish good referral pathways to appropriate bodies for advice and/or financial assistance. Legal and other planning needs to be urgently addressed as younger people may be less likely to have an up-to-date will or enduring power of attorney or health and care plans in place. The role of Centrelink and other welfare services and the need for a more consistent information process nationally also should be investigated.
Diagnosis

• Considering the immense value of an early and correct diagnosis, delays in the diagnosis of dementia have emerged as a huge issue among younger people. This is for a number of reasons, e.g. a lack of awareness about dementia among the public and general practitioners to which the individuals first present; and the large number of tests and scans needed in determining the correct diagnosis. Many younger people have also reported that the reason for the large number of tests isn’t clearly explained.

• Dementia under 65 years is uncommon and therefore often misdiagnosed as depression or another mental health disorder, resulting in considerable delays in obtaining a diagnosis and inappropriate use of anti-depressant or other medication.

• Delays in diagnosis and lack of referral from that point on can lead to grievances and feelings of dissatisfaction about treatment by health professionals, in turn contributing to the huge emotional impact on the younger person and their family.

• Delays in diagnosis can have serious implications in terms of legal issues like getting wills and enduring powers of attorney in place.

Huge emotional impact

• Those with younger onset dementia and their families have reported having to deal with feelings of shock, grief, relief and denial on initial diagnosis. Depression is common.

• As the onset of dementia is largely unexpected for younger people, they are less likely to have had the opportunity to achieve lifelong goals and wishes for the future. As a result, counselling and support may be necessary, especially in helping the younger person establish what plans they can still realistically achieve.

• Many younger people need to revise their expectations of everyday life, as they gradually lose the ability to carry out activities in the way they did previously. Many people conveyed dismay at changes to relationships, both socially with friends and family, and intimately with their partner.

Reluctance to access respite services

• Some carers of younger people reported they were reluctant to access respite services because firstly, the younger person with dementia might feel isolated in that they feel that they will not fit in with much older clients. Secondly, they felt guilty about not looking after their loved one, a feeling common among carers of all ages, and thirdly, they might not trust the services to be appropriate for an active, younger person.

Engaging activities

• Most younger people with dementia conveyed concerns about the lack of engaging activities in respite and residential facilities, and for those at home. The provision of engaging activities for younger people allows them to use existing skills and increase self esteem. Going for walks, visits to museums and art galleries, or having lunch out with a group could be appropriate, although this may require a higher staff-client ratio than for older, frailer clients. Transport has also been highlighted as an issue, especially for those who have given up driving.

• Some service providers indicated that caring for a younger person could be more demanding than caring for an older person because they generally had more energy and would rather get ‘out and about’ than be involved in sedentary activities. It is difficult to find staff capable of caring for younger people, especially those willing to put in the extra effort needed. Younger people may require a higher staff/client ratio which is expensive unless volunteer staff are accessed.
• As women have a greater life expectancy than men, aged care facilities are generally more designed for females and can pose problems for younger, agile men receiving services.

• There are some good programs for younger people around the country and examples of these are described.

Range of causes of dementia among younger people

• As causes of dementia are different among younger people, there is a higher proportion of rarer dementias in this group. Different causes of dementia give rise to different patterns of symptoms and behaviour changes, reflecting the dissemination of pathological changes in the brain.

• For example, among younger, physically healthy and active people with fronto-temporal dementia, some behaviours may be of concern, including aggression, anger, rudeness and loss of sexual inhibition. They may pose an emotional and physical threat to those around them and their behaviour can become confronting and intimidating. Services need to take this into account and provide the most appropriate methods to deal with this behaviour. Extra support services for carers are necessary to reduce the risk of burnout, fatigue and grief. Many services may be less willing to offer this additional support as behaviours change, perhaps due to the staffing and cost implications.

• There are causes of dementia more common among younger people than older people. These include alcohol related dementia, HIV/AIDS related dementia and dementia among those with Down syndrome, Huntington’s or Multiple Sclerosis. The unique needs of and services available for these people are also explored.

This report highlights the unique and often complex needs of younger people with dementia. It provides evidence for an individualised approach to improving services for this group of people and their families, with recommendations for increased research into prevalence, service models and more innovative and creative approaches to service a group with distinctly different needs to the majority of those with dementia, who tend to be older. Incremental steps are advocated as there is a long way to go in improving the haphazard and inadequate service framework in which this sits. With increased government attention to the needs of this population group, there is potential for vast improvements in this area.
Acknowledgements

Many thanks go to all the people who have contributed to the various stages of this report’s development.

A very special thank you to all those who were interviewed as part of the research, including:

- people with dementia;
- carers and family members of people with dementia;
- service providers, policy makers and others who work in this field.

Your willingness to share your experiences so openly has been invaluable.

To all those who provided feedback, comment and editing advice on the report - your assistance is much appreciated.

This report was prepared for Alzheimer’s Australia by Marguerite Tyson, Policy Officer, Alzheimer's Australia NSW.
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
</tr>
<tr>
<td>ADAHPT</td>
<td>Aids Dementia and HIV Psychiatry Team</td>
</tr>
<tr>
<td>AHMC</td>
<td>Australian Health Ministers’ Conference</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
</tr>
<tr>
<td>DAC</td>
<td>Disability, Ageing and Carers</td>
</tr>
<tr>
<td>DASNI</td>
<td>Dementia Advocacy Support Network International</td>
</tr>
<tr>
<td>FAD</td>
<td>Familial Alzheimer’s disease</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HRS</td>
<td>Health and Retirement Study (USA)</td>
</tr>
<tr>
<td>LWML</td>
<td>Living with Memory Loss</td>
</tr>
<tr>
<td>MRRT</td>
<td>Mobile Respite Response Team</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service (UK)</td>
</tr>
<tr>
<td>SSDI</td>
<td>Social Security Disability Insurance (US)</td>
</tr>
<tr>
<td>SSI</td>
<td>Supplemental Security Income (US)</td>
</tr>
<tr>
<td>YPINHNA</td>
<td>Young People in Nursing Homes National Alliance</td>
</tr>
<tr>
<td>YPWD</td>
<td>Young Person with Dementia</td>
</tr>
</tbody>
</table>
Chapter 1 – Introduction

Younger onset people are often the forgotten people with dementia; facing challenges that are often different and, perhaps, more difficult than those with older onset. – younger woman with dementia

Background

In the 2005 Budget the Australian Government announced support for dementia as a National Health Priority with a $320.6 million package over five years, targeting better prevention, treatment and care. This recognised the current and future social and economic cost of dementia on the Australian community. It was a landmark for people with dementia and their family carers, who have strongly advocated for this cause over a number of years.

Alzheimer’s Australia has been funded to undertake a national project to identify and map the needs of younger people with dementia and develop recommendations for future initiatives in this area.

Although most people with dementia are over 65, younger people are diagnosed with dementia. Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

The term ‘younger onset dementia’ is used to describe any form of dementia in a person under 65 years. The age and stage of life of a person at the onset of dementia influences its effect on that person, their family and their needs. Age also affects the type of dementia a person may have and consequently, the sort of behavioural change in the individual.

This study explores the main differences between the impact of dementia on younger people and older people and the resultant unique needs of people with younger onset dementia. It incorporates information from a number of sources, including a literature review and a wide-ranging consultation of people with younger onset dementia, primary family carers, other family members, Alzheimer’s Australia service providers, other service providers and special interest groups.

The report is structured according to the main issues found to affect younger people with dementia and their families and carers. It provides a brief background to dementia before discussing its nature and prevalence among those under 65. An extensive review of literature about younger onset dementia is provided as an appendix. Individual and/or group interviews were conducted with over seventy younger people with dementia and/or their spouses and children. Interviews were also conducted with service providers, policy makers, counsellors and special interest groups. Feedback was received via email and through online chat discussion with younger people with dementia from Australia and overseas.

Throughout the report, verbatim excerpts are used to provide an accurate picture of individual views. All statements provided are used with permission, but names have been withheld to respect privacy. These anecdotal comments support the range of issues facing all involved.

Every individual’s situation and experience with dementia are different. While not all younger people experience the same problems and some people over 65 may experience them too, the report focuses on the distinct areas of need that emerged from the consultations and literature review.
Project methodology

The project was conducted in 2006 under the direction of a policy officer employed by Alzheimer’s Australia NSW. The project involved several steps:

a) Literature review
A review was conducted of literature from Australia and overseas regarding the needs and services for people with dementia and their family carers. It noted direct services available for younger people with dementia in the United Kingdom, the United States and other countries. The Appendix describes the outcomes of this review.

b) Consultation phase
A multi-pronged consultation phase was designed to cover as many sectors affected by or related to younger onset dementia as possible. Avenues for consultation included:

- Appeals for feedback through Alzheimer’s Australia State and Territory members’ magazines, and the National website at www.alzheimers.org.au (The information provided for the magazines and website is included at Attachment A);
- Interviews at Alzheimer’s Australia member organisations in all States and Territories including with client service providers and consumer reference committees;
- Face-to-face and telephone interviews with 30 younger people with dementia and over 30 carers;
- Interviews with independent service providers in NSW, Victoria, ACT and SA; and
- Interviews with special interest groups who experience similar issues to those with younger onset dementia (for example, the Brain Foundation of Victoria and the MS Society).

All interviews were conducted sensitively and in a casual format, each lasting from thirty minutes to an hour, generally following a set of questions prepared to investigate the needs of people with younger onset dementia and their family carers. (The list of questions is at Attachment B).

An information sheet was given to participants detailing the purpose of the project and their right to privacy in compliance with Alzheimer’s Australia NSW Policy and Procedures, 2005. (The information sheet is at Attachment C). A consent form was signed by the individuals met in person, while consent was obtained verbally from those interviewed over the phone. (A copy of the consent form is at Attachment D).

A list of all those involved through direct consultation is at Attachment E.

c) Data Analysis and Interim Report
The policy officer documented all information from interviews, phone conversations and written input provided. An analysis of this information led to a summary in the form of a written report, outlining the key issues raised in relation to the questions asked, as well as the broader information found. The draft report was circulated among the State and Territory offices of Alzheimer’s Australia and to its National Consumer Committee. The subsequent feedback was incorporated into the editing process of the final report.

d) Final Report
This Final Report was submitted to the Australian Government Department of Health and Ageing in March 2007.
**Terminology used in the report**

There are a number of terms that may be ambiguous or confusing, especially where meaning and common practice has changed over time. Other terms for younger onset dementia have been used in the past, including 'early onset dementia' and 'pre-senile dementia'. To prevent confusion with early stages of dementia, the term ‘younger onset dementia’ is preferred to ‘early onset dementia’. Any references to ‘early onset’ and ‘pre-senile dementia’ have been taken to mean younger onset dementia and the report reflects this assumption.

**What is dementia and who does it affect?**

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

The condition is described as progressing through a number of identifiable stages, increasing in the severity of symptoms. During the early stages, the individual usually experiences some loss in memory with a reduction of coordination and reasoning skills (Robertson, 1996:3). Early symptoms may include difficulties with remembering (particularly recent events), making decisions, expressing thoughts, understanding what others are saying, finding one’s way around, performing more complex tasks and managing finances (Alzheimer’s Australia, 2005). By the final stages, the condition impacts on daily life more intensely, with common symptoms such as near-total memory loss, lack of recognition of familiar objects and family members, disorientation in space and time, huge loss of weight, severe language impairment, incontinence and difficulty in performing basic tasks of washing, eating and dressing (Robertson, 1996:3). At this stage, the individual may need full time care.

The prevalence of dementia has been estimated to double every 5.1 years of age after 65 years, affecting one in four over 85 years (AIHW, 2004: xi). While the risk and prevalence of dementia is highest among those who are over 85 years old, in some cases it affects people in their thirties, forties and fifties.

There are over 100 different types of dementia. Each cause can affect different parts of the brain, producing different symptoms and affecting behaviour differently. Generally the most common causes of dementia among people under 65 are different to those affecting older people. This difference will be examined in more detail later in this report.

The most common type of dementia among people in both age groups is Alzheimer’s disease, accounting for approximately 70% of all dementia cases (Australia Institute of Health and Welfare, 2004: xi).

While Alzheimer’s Disease is still the most common cause of dementia among younger people, other causes of dementia, such as vascular dementia, dementia with Lewy Bodies, frontal lobe dementia (which includes Pick’s disease), alcohol related dementia, HIV/AIDS related dementia and dementia among those with Down Syndrome, occur more regularly than among those over 65 years (Baldwin and Murray, 2003: 4).
Alzheimer’s disease can be sporadic or familial. The sporadic form is the most common and can affect adults of any age, but usually occurs after 65 years (Alzheimer’s Australia, 2005). Familial onset is very rare (probably affecting no more than 100 people at any given time in the whole Australian population), and runs in a few families where a gene on chromosome 1, 14 or 21 is mutated. It is an autosomal dominant condition, meaning that if a parent has the mutation, each child has a 50% chance of inheriting it (Duncan, 1998:28). The presence of the gene means the person will eventually develop Alzheimer’s disease with the symptoms manifesting earlier in life, usually in their forties or fifties but sometimes as early as their thirties. Therefore, almost all those with familial Alzheimer’s disease are under 65 at the time of onset.

There are a number of difficulties in identifying people with mild or moderate dementia and as a result, in estimating the prevalence of those with dementia in Australia (AIHW, 2004: xi). For example, methodological differences such as definition of dementia or sample characteristics, have substantial effects on the levels reported (Jorm et al, 1987, cited in Wancata et al, 2003).

Access Economics estimated that there would be 212,500 cases of dementia in Australia in 2006. This included 53,780 new cases during the year. Using prevalence data from the United Kingdom, it is estimated that 3% of those with dementia are under 65 – that is, approximately 6,400 currently in Australia.

The ABS Survey of Disability, Ageing and Carers (DAC) data provide the only estimate of prevalence of dementia among younger people in Australia, showing an estimated 1,700 Australians under 60, but with a high standard error (Access Economics, 2005: 4).

Using DAC data and the latest meta-analyses, Access Economics estimated that 10,500 of the 212,000 people with dementia in 2006 were aged under 65. This represents 0.01% of Australians under 60, and 0.6% of women and 1.2% of men between the ages of 60 and 64 (Access Economics, 2005:4).

There are limited data about the distribution of younger onset dementia in Australia. The rarity of the condition among people under 65 makes it less likely to be specifically recognised or addressed by medical practitioners or other services. In addition to the difficulties dementia generally, recognition and accurate diagnosis for those under 65 with rarer types of dementia (e.g. HIV/AIDS related dementia or alcohol related dementia) may be problematic. This report will explore the implications of these issues.

**General issues for people with dementia regardless of age**

The onset of dementia in someone of any age can bring many changes to the life of the individual and those around them. The areas that are significantly affected in most cases include emotional, financial, legal and service issues.

Firstly, a diagnosis of dementia and the changes to memory and behaviour of the person affected can impact on the emotional wellbeing of the individual and their family. Feelings of shock, sadness, frustration, embarrassment, anger and loss are common. There may be an impact on relationships in the family and externally, with issues of grief, loss and role reversal. The family’s financial future is usually significantly affected, including the loss of employment, changes to who manages financial matters, and focusing finances on services and medication rather than activities for pleasure. Other legal issues become important, such as establishing an enduring power of attorney and planning ahead. There are also issues related to the person with dementia giving up driving.
All people with dementia and their families are interested in accessing quality, timely services that are appropriate to their needs, that respect their dignity and individuality, and that empower them and take into account the needs of those around them in a holistic sense. Increased awareness among the public and health professions about dementia and its impact will provide improvements on many levels for all people with dementia and their families, no matter what their age.

**Specific issues for younger people with dementia**

Some of the abovementioned issues that people with dementia and their families might face are exacerbated for younger people. Younger people and their families also have unique needs that should be considered. In comparison to older people with dementia, younger people with dementia may experience specific and perhaps greater problems due to their stage of life, medical condition and other circumstances such as:

- Difficulty and/or delays in getting an accurate diagnosis;
- Family responsibilities including still actively raising a family;
- Currently working or being only recently retired;
- Having significant financial commitments based on previous earnings;
- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others;
- Future plans that are affected at an earlier stage in life;
- Being more likely to have a rarer form of dementia than Alzheimer’s disease or a genetically-based cause; and
- Experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.

This report explores those issues through the personal experiences of younger people with dementia and their family carers. In keeping with recent work that has drawn attention to the rights of those with dementia to convey their feelings and views about services (Kitwood and Benson 1995; Goldsmith, 1996), this report presents a consumer-driven set of views that takes into account the current policy context. This is also consistent with the views expressed at the National Consumer Summit on Dementia at Parliament House in October 2005, particularly the fundamental principle that ‘people with dementia and their carers need to be recognised as partners in decision making about care options. Care must be person-centred, planned and involve people with dementia (as far as is possible) along with their carers and family’ (Alzheimer’s Australia, 2005:67).
Chapter 2 – Delays in Diagnosis

Getting a correct and early diagnosis is critical – this enables the correct medication to be diagnosed to slow down the progression, which in turn allows families/people to lead manageable lifestyles. Diagnosis in younger people can be neglected as specialists/doctors believe young people are too young for dementia. A lot of times it gets put down to depression. Once the diagnosis [has been made], it is essential to have the best ongoing medical support, advice and checkups. To maintain optimum health is important – 60 year old man with dementia

As described in Chapter 1, dementia is characterised by a number of changes in the brain, some degenerative – resulting from intrinsic changes to brain neurons, others extrinsic, where the dementia may be secondary to vascular disease (Neary & Snowden, 2003:7).

Differentiation between the diverse conditions that cause dementia is important, as different therapies have been developed based on differing causes, symptoms and behaviours. Because of the nature of the syndrome, a degree of uncertainty exists at the onset of dementia and adds to the overall sense of confusion for all involved at the time. For these reasons, the diagnosis of dementia may pose difficulties for health professionals, the person with dementia and family members. Even then, a completely accurate and definite diagnosis of the cause may only be confirmed after death through an autopsy or in very rare occasions, through a brain biopsy (Alzheimer’s Society UK, 2000).

A diagnosis that is as early and as accurate as possible has undisputed value for someone of any age. For a younger person, it is likely that the onset and diagnosis of dementia will bring about a great number of lifestyle and expectation changes, so early diagnosis is especially important. An early diagnosis is essential to:

- Eliminate the possibility of other conditions that may have symptoms similar to dementia and may be treatable, including depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours;
- Eliminate other possible causes of confusion, such as poor sight or hearing, emotional changes, bereavement and loss, or side-effects of or interactions between certain drugs;
- Allow early access to advice, information and support from social services, voluntary agencies and support groups;
- Allow the prescription of drugs that are effective in slowing the progression of certain types of dementia (e.g. Alzheimer’s disease) in the early to middle stages, but are ineffective for other dementia types. An accurate diagnosis of the type of dementia is also important because drugs prescribed for other conditions could be detrimental to those with dementia (e.g. prescribing neuroleptics for mental health problems has very dangerous side effects for those with dementia with Lewy bodies);
- Allow the person with dementia and their family to plan and make arrangements for the future such as writing a will, establishing an enduring Power of Attorney, writing advanced care directives (a living will) and planning for financial management (Alzheimer’s Society UK, 2000; Alzheimer’s Society, 2003).

A group of younger people consulted as part of this project agreed that early diagnosis is important as it means the person with dementia is ‘more likely to still be articulate…can help professionals …[and] can plan for the future’.

One 62 year old man with dementia claims he was ‘fortunate to be able to be diagnosed at an early stage and still be coherent’, but there were many other less positive stories. For a woman caring for her ‘young’ mother with frontotemporal dementia, finding the correct diagnosis was extremely difficult and put the whole family under extreme stress for a number of years before the correct diagnosis was given.
Improved diagnostic techniques in recent years means that increasingly, dementia is being diagnosed at an early stage of the illness. However, such improvements do not appear to have extended to the population of younger people with dementia. There are still many reports of misdiagnoses of depression, stress related disorders and other mental health conditions.

**The process of diagnosing dementia**

The process of diagnosing dementia involves a number of health professionals, usually starting with the general practitioner (GP) who will refer the person to a specialist for further assessment.

This step of first presenting to the GP can be problematic for a number of reasons. Firstly, many younger people experience a delay in noticing changes in their behaviour and often it is their partner or work colleagues who notice the changes. In the case of fronto-temporal dementia or other non-Alzheimer’s disease types of dementia, many younger people attribute the difficulty in noticing changes due to only limited memory loss in the early stages. Some admitted that even after noticing changes in behaviour or their ability to carry out everyday activities, they attributed it to stress, other crises in their lives, or slight depression.

One 46 year old woman with frontotemporal dementia noted that at this very early stage ‘every symptom...could have been also caused by stress, fatigue and many other more common causes... I just thought I was tired, overworked and stressed. I had an excuse for everything’.

There was a consensus among those consulted that dementia was never or very rarely considered as a reason for the changes experienced, which could contribute to delayed presentation at the GP or other health professional. Most people’s perception of dementia reflected the public’s perception and the epidemiology of the syndrome – it is more likely to occur among older people. This issue of public awareness of younger onset dementia is discussed on page 20.

In some cases, the person with dementia may be reluctant to see the GP for fear of being diagnosed with a condition they would rather not have. Also at this stage, symptoms are more obscure and social skills may be able to disguise problems. One woman whose husband was diagnosed with Alzheimer’s disease at 55 said ‘in the years preceding diagnosis, I noticed changes in (my husband) which he refused to acknowledge. In fact, he went out of his way to cover up his failing memory and more frequent bouts of confusion’.

Some carers reported frustration at not being able to convince the younger person to present to the GP and when they finally attended, some GPs felt there was nothing wrong because the younger person with dementia looked and acted healthy. Many of these carers expressed disappointment at GPs not listening to their point of view as the person who knew the patient best.

For most of those who presented to the GP willingly hoping for an explanation for the changes they had noticed, it was a disappointing result. Many reported that when they first presented to their GP, the GP did not acknowledge the changes as key indicators of an illness. One woman whose husband was diagnosed with Alzheimer’s at 55 years, stated that ‘GP had no idea at all ... GPs are not aware – they don’t detect it for under 65s ... there were delays in diagnosis and a lot of time wasted’. She felt that had her GP been able to pick up the dementia earlier on, there might have been more understanding of her husband’s behavioural changes, instead of her children putting it down to their father ‘just being nasty’.
Many younger people and their carers reported difficulty in convincing their GP that the changes exhibited were out of the ordinary and that a referral might be needed. Some were initially told that nothing was wrong with them, some to change their lifestyle, others to not exaggerate, or that the changes were fabricated.

On the other hand, there were GPs who were unsure of what the changes indicated and appropriately referred the patient for more testing. Overall, there were wide variations reported in the way that GPs responded to the legitimate initial memory and/or behaviour concerns of younger people with dementia.

This raises the issue of the lack of awareness of younger onset dementia among GPs due to the relative rarity of such cases. While most younger people consulted recognised the limitations of and strains on GPs, particularly in needing to be knowledgeable about a wide variety of disorders and having only limited time for consultations, such difficulties exacerbated delays in diagnosing dementia. GPs might be more concerned about tending to life threatening illnesses such as heart disease or diabetes and so looking out for dementia became a lesser priority. Some service providers mentioned that ‘dementia can sometimes be overlooked in favour of other medical conditions or situations’ as they had seen this occur not only in the diagnostic phase, but also through the full spectrum of the disease.

If GPs are provided with adequate dementia education throughout the course of their medical training and continuing professional development, it is hoped that they will develop a good level of understanding of dementia, and better recognise indicators in a patient, even when performing under extreme stress or pressure.

**Referral to specialist services**

When a person over 65 years presents to their GP with symptoms of dementia, referral to a geriatrician is the obvious choice as they specialise in conditions common among older people, such as dementia. However for those under 65, GPs may be confused as to which specialist is the most appropriate for the patient to be referred to. Many of the younger people consulted acknowledged that the GP could probably not diagnose dementia, but as one younger woman with dementia said, ‘if the doctor doesn’t know, they should refer us to a more appropriate expert service’.

Some people voiced strong concerns about being referred to geriatric services because they would be among other patients who were up to thirty or forty years older than them. This was found to be confronting and difficult to deal with by those who felt they did not fit into this clientele group. One man diagnosed with dementia at 55 years old claimed he found the word geriatrician ‘offensive’. People such as this man recommended that younger people not be referred to geriatricians, but instead to neurologists or psychiatrists. The dilemma is that geriatricians are familiar with dementia due to its higher prevalence among older people, highlighting confusion regarding which specialty or specialties should be responsible for younger people with dementia.

In the UK, many younger people feel that GPs refer to a neurologist, geriatrician or psychiatrist in a haphazard manner, with no clear, standard path of referral to follow. The individual GP decides on the most appropriate specialist, leading to widespread variability in referral paths across the country. Many younger persons with dementia have reported this to be confusing and frustrating, as even individuals in the same local area may receive very different levels of support from doctors and professionals (Alzheimer’s Society UK, 2005b).
**Tests**

Once referred to a specialist, the younger person must undergo a series of tests to determine the specific type of dementia. It is at this stage of identifying the variety of dementia that some younger people reported conflict between the opinions of specialists.

Although it is important for clinicians to be thorough in diagnosing dementia, many younger people reported they were not clearly told what the tests were for, what the results meant or why they needed so many tests. One younger woman with dementia said her neurologist ‘never mentioned dementia or the word Frontotemporal, or Alzheimer’s to me, he simply wrote me a prescription for some pills that we said would ‘help my memory’’. These pills were Aricept which the woman later found out from the internet were for Alzheimer’s disease. Other younger people mentioned problems with re-diagnosis of the dementia, for example someone diagnosed with Alzheimer’s disease who was later re-diagnosed with fronto-temporal dementia. While most understood the importance of getting the diagnosis correct, they were aggrieved by the small alterations in the path to diagnosis without any explanation.

Throughout the many tests, the younger person is often passed between a number of different specialists, such as neurologist, psychiatrist or geriatrician. Many spoke of the financial costs involved at this stage. One woman whose husband was diagnosed at 44 with dementia claimed that diagnosis took ‘a couple of years, with lots of tests, six specialists, expensive medications and a huge cost to us overall … we got to a point where we were begging the specialist for a diagnosis … there was no explanation of what the specialists were looking for … the diagnosis took about three years’.

This woman clearly articulated that in her husband’s situation, there was need for more assistance for the person with dementia and their carer in navigating the system, so that unnecessary expenses were not incurred and they were helped to understand the importance of the many specialties involved in the diagnostic process. This was summarised by one woman whose husband was diagnosed with dementia at 55: ‘we need more continuity of care in the health services’.

**Conduct of health professionals**

There were mixed reports regarding the conduct of health professionals throughout the diagnostic process. Most reported agitation when clinicians did not fully explain the reason for the thorough process of diagnosis, as though the younger person and their family ‘did not have a right to know about the workings of the exclusive field of medicine’.

There were a number of reports of health professionals being cold, unsupportive, patronising, rude, dismissive of symptoms and even evasive of the truth. One younger man with dementia claimed, ‘they could give more thought as to what they’re saying and who they’re saying it to … we had no explanation and no understanding of what was going on.’

While less frequent, there were also reports of health professionals being caring, honest, informative, cognisant of the uncertainties surrounding diagnosis and keen to refer the individual and their family members to other social supports or groups, such as Alzheimer’s Australia. These younger people referred to themselves as ‘very lucky compared to lots of other people’, commenting that ‘doctors who are pleasant and helpful make life easier’.

Family members commented that many health professionals did not take into account the experience of those around the person with dementia – the spouses and children who were the primary carers. Some carers expressed dismay at the way dementia was seen in a medical model, rather than a holistic model that incorporated the social circumstances of the person.
They reported ‘it’s frustrating that the family has a silent voice and is not seen as important’, ‘listening to the carer is important’, and ‘we need more general awareness by specialists as to the impact on the patient’s partner’. Another woman called for ‘more people to believe the carers’ as it was her opinion that they were often left out of any consultation during the diagnostic and later stages.

Another woman whose husband had younger onset Alzheimer’s disease felt that ‘privacy laws are a big problem … my husband’s psychologist asked my husband’s permission to double check with me – she was the only one who enabled me to have a say which was vital due to his good public presentation. GPs need to be able to get a better picture of the person from other social sources – privacy laws make this difficult.’

It appears that health professionals are also frustrated at the process of diagnosing dementia among younger people. They expressed difficulties in finding appropriate tools for diagnostic processes and collecting evidence of changing symptoms over a period of time. Most acknowledged that early diagnosis was important for anyone with dementia, and even more important for a younger person because of the huge life changes set to occur for them.

Clinicians expressed dissatisfaction with diagnostic services, with specialists sometimes seeing a person up to three or four years after they noticed the first symptoms and were turned away by their GP. Among medical professionals, there are different referral patterns for younger onset dementia to neurologists, geriatricians and psychiatrists. This may be exacerbated in regional areas where choice of specialist may be limited. To date, there appears to be no clear consensus about which speciality is best placed to support people with younger onset dementia. In the meantime, the younger person has suffered by falling through the gaps in diagnostic services.

**The value of early diagnosis and counselling**

There is evidence that familial Alzheimer’s disease (genetically related) is more common among younger people (Duncan, 1998; Alzheimer’s Australia, 2005). (More of this will be discussed in Chapter 6 – Various Types of Dementia). As such, one would expect diagnosis to be made earlier, provided there is an awareness of the genetic disposition in the family.

However, of those younger people consulted with familial Alzheimer’s, there were still comments such as ‘there were delays in diagnosis … a lot of time lapsed before anyone knew anything about the disease’ or reports of ‘general ignorance and denial even in families who ought to have expert knowledge’ (of familial dementia). Early diagnosis in these cases may be even more pertinent as genetic counselling may be necessary for the person and their family. As one health professional emphasised, ‘diagnosis of dementia is more complicated among younger people and needs to be discussed accurately and sensitively, with counselling offered particularly when the dementia is familial’.

The offer of counselling at the point of diagnosis is something that many younger people have called for, regardless of the type of dementia. This is even more valuable where the person with dementia still has insight. However, it appears from the interviews that it does not happen as often as it should. (The value of counselling will be explored in more detail in Chapter 4 – Emotional Impact.) A 46 year old woman with frontotemporal dementia stressed that ‘if you are a medical professional we ask that you provide us with information as soon as possible after diagnosis. We want to learn about the nature of our disease and that it is as individual as we are.’
The need for raised public awareness

A general issue that has been raised by almost every person consulted is the need for increased awareness among the public about younger onset dementia. An increased awareness of the existence of dementia in younger people would mean that individuals themselves notice changes more readily and in turn, GPs and other specialists would also be aware of such changes.

There was also an overwhelming call for more promotion of the needs of younger people with dementia and the unique issues that they faced. One younger man with frontotemporal dementia mentioned that in his wish list, he would ask for ‘more publicity about younger onset dementia – what to look for and where to go for help when you see the early signs’.

A counsellor with Alzheimer’s Australia stressed that ‘increased public awareness will allow individuals to know what to expect from their health professional and to at least get a second opinion when they are at that point’. Increased public awareness also empowers the consumer in decisions regarding their own health care.

Increased public awareness is particularly significant, as many reported that those around them doubted the existence or level of impact of their dementia. Comments such as ‘people can’t see the problem so they don’t understand’ and ‘no one believes it’ were common; reflecting that these people had been active and looked healthy on the outside.

As one 60 year old man with dementia said ‘no one expects it, you’re too young’ – it is the public’s perception that dementia, particularly Alzheimer’s disease, is a disease of the aged. Changes in a younger person due to dementia are less likely to be noticed or attributed to dementia. This has a huge bearing on the individual as later presentation to their GP or memory clinic means a later diagnosis.

While it is true that the prevalence of dementia increases with age and the majority are over 65 years old, the public needs to be aware of its presence among younger people. A woman who has lost many family members in their mid to late forties with familial Alzheimer’s disease recommended: ‘governments should address early onset Alzheimer’s and not advertise this as only an old person’s disease’.
Chapter 3 – Access to Services

Services for the younger onset dementia sufferer are sadly lacking – woman whose daughter was diagnosed with Alzheimer’s disease at 43 years

There are no day care facilities to place them safely during work hours. If we had day care places we would not have to leave work or disrupt our work and family life. It would create less stress for all concerned – woman who has lost many younger family members with familial Alzheimer’s disease

We need to take up issues for younger people and try to make changes in the policy setting … I’m not interested in hanging around people who are 80-85 years old – man diagnosed with dementia at 59

Our local government has some very good day centres and day centre programmes, however, once more these are all directed at the geriatric end of the community … It’s pretty uncomfortable sitting there with people 20-30 years older than oneself. There really isn’t any common ground that you can get your teeth into, as you do when you’re around people of your own age. The types of things that the centres offer are excellent, but special days for the younger person are desperately needed – younger man with dementia

The literature review (see Appendix) and the outcomes of discussions with younger people with dementia and their families confirm that compared to older people, these people experience far more difficulty in accessing services appropriate to their needs. This chapter explores the issues relating to access to services, by discussing the divide between disability, health and aged care services, and looking at examples of specific types of services for in the home, day care and residential care settings.

Gaps in services
Dementia is ‘an evolving concept, whose definition has changed over time’ (Clarke, 1999:6). While in the eighteenth century, dementia was not perceived as a distinct condition or associated with any age group (Berrios, 1997), since then the term dementia has been known to encompass a set of disease causes, with epidemiological studies showing that incidence increases with age (Reed et al, 2002:96). This supports current popular perception that dementia is an old person’s disease marked by changes beyond those of the normal ageing process. As a result, studies of dementia prevalence as well as dementia specific services are focused on older people and services are provided principally within the aged care sector.

The National Framework for Action on Dementia underscores the complexity of the Australian service system in providing care and support activities for people with dementia and their families, through specialised and mainstream health, aged and community care. The Framework notes that at times the maze of options presents risks of service duplication and service gaps that go unnoticed (AHMC, 2006:1). Younger people with dementia and their families fall into one of these service gaps.

The services needed by a person of any age with dementia depend on different factors, e.g. the stage of dementia, social circumstances, existing support networks and the needs of their family and significant others. There is a unique mix of issues and needs that a younger person with dementia has by virtue of their age and circumstances, which should be taken into account in providing services. Although younger people represent a small number of those with dementia, equitable service means the specific needs of this group should not be ignored.
**Acute care setting**

As part of this project, health professionals were invited to highlight the difficulties in providing services for younger people who do not have a full time family carer or other social support in place. Some health professionals working in inpatient units in health care facilities experienced trouble in finding an appropriate place for younger onset clients to move to, which meant that they often blocked inpatient units when they were meant to be outpatients. This not only increased waiting times, but it could also be difficult for non-dementia specific staff in inpatient units to cope effectively with behaviour such as confusion, yelling and afternoon agitation.

A woman who trains hospital staff working with people with dementia observed staff concern that there was nowhere for these clients to go. She felt that ‘the system cannot cope with them … some clients with fronto-temporal dementia are of risk to themselves and to others … but there is no option for them to go once they are ready to be admitted.’

She also identified huge difficulties in caring for someone with dementia in the acute care setting as the staff did not get a sufficient opportunity to get to know the person. As the staff/client ratio was low, staff often felt unable to cope with difficult behaviour of younger, stronger patients, and sedation was extremely common. A number of health professionals suggested that there was little understanding about younger onset dementia in the acute care setting and with improved training of staff about the issue, issues could be anticipated early (e.g. through inclusion of the family in the social history) and dealt with appropriately.

**Services at point of diagnosis**

A group of counsellors from Alzheimer’s Australia confirmed, ‘there are very few support services for younger people with dementia’. Younger people seeking services beyond diagnosis were often at the end of a frustrating and long process, in which their dementia might have progressed markedly. Throughout discussions, they unanimously called for a suite of service options to be offered at the point of diagnosis, including counselling and information. (Counselling services will be discussed in more detail in Chapter 4.)

A suite of options would take into account the different social circle of a younger person compared to an older person. Their social circle is more likely to be pre-retirement age, and include children still living at home, and a husband or wife and friends who still work. A holistic suite of services offered to these clients is more likely to be able to meet the needs, demands or pressures of this wide range of people.

**The Living with Memory Loss Program (LWML)**

The Living with Memory Loss Program (LWML) is a psycho-educational program which aims to maximise the health and well-being of people living with early stage dementia and their family carers.

Research (Bird et al 2005) has shown that the benefits of this type of program in providing early intervention and ongoing support for people of any age. The program is provided free of charge to clients and usually runs over six weekly two-hour sessions at the same time each week (some programs are run over a weekend in rural areas). Sessions are held concurrently for individuals and their family, and ongoing support is available to provide social contact and further educational opportunities. In a group format, participants are given the opportunity to:

- Tell their story of memory loss and behaviour change;
- Reflect on the impact of their diagnosis;
- Develop an understanding of the importance of self-care;
- Enhance their skills for communicating with others;
- Learn techniques for problem solving; and
- Extend their knowledge about legal and financial issues.

(Alzheimer’s Australia, 2006)

Almost all people consulted who had attended a LWML Program provided positive feedback about the impact it had on them. Most of them had attended a Program specifically for younger people.

A diagnosis of dementia can leave a person of any age and their family feeling extremely isolated, and many younger people consulted had been sent home to get on with life with little or no information about dementia and support options. Although these people set about coping as best as they could, it was not until they met other people in the same situation that they began to recognise how shocked, anxious and alone they had been feeling. These participants were deeply grateful to meet others who, like them, were facing the daily challenges of living with dementia at such a young age.

Many marvelled at the tangible benefits they gained from being together in a group environment where they could share their experiences, questions and problems. Comments from those consulted included: ‘it was very helpful’, ‘social interaction with the carers and the clients is very uplifting’, ‘they taught us how to form routines to free our minds from stress and worry’, ‘it reduced our isolation as we met people with the same problem’, ‘it was very supportive … you leave feeling positive but then your partner leaves feeling upset as it can scare them … but for those with little social support it can have a strong impact’, and ‘it provided more support in coming to terms with it all’.

The LWML Program is one means to reducing the stigma of the diagnosis of dementia on individuals as it helps them feel less isolated and part of a group experiencing similar problems. This was particularly pertinent for those who attended a Program designated for younger onset dementia.

One woman and her husband diagnosed with fronto-temporal dementia at 55 years were involved in a LWML Program that was not run for younger people. The woman stated that ‘while it was very good to know there were other people in similar situations to us, we were the youngest people by about 15-20 years. It was very confronting at the time but I made lots of contacts and networks that I didn’t think I’d need to call on but now, it’s helping me a few years down the track’. This reinforced the view that younger people benefit from the LWML Program, particularly when other participants are in the same age bracket as themselves.

One of the strengths of the LWML Program is its ability to provide information and support for people who are in the early stages of dementia and still have the insight to understand and apply what they have learned. It is generally not offered to people who have progressed past this early stage of dementia as convenors feel they lack the insight needed for the Program’s success. Hence, some people who are not diagnosed early enough or informed early about the services Alzheimer’s Australia has to offer, may miss out on the valuable opportunity of participating in a LWML Program. It is anticipated that implementing successful policies to reduce delays in diagnosis and to promote services early to younger people will impact on the numbers eligible to participate and benefit from the LWML Program.
After the initial LWML program, participants have the opportunity to participate in follow up sessions and many of the younger people consulted were still involved in social activities as a consequence. In general, people under 65 are less likely have immediate access to engaging in activities, and so social groups (such as those organised by Alzheimer’s Australia and other service providers) are very important. The sense of isolation for a younger person with dementia accessing a service for the first time is intensified if they are with clients who are up to forty years older than them. This is why many younger people spoke so highly of LWML programs specifically for those with younger onset dementia.

**Respite, day care and in-home services**

It would be helpful at this stage to consider what an appropriate service system would look like. Generally those consulted favoured a service that provided a number of options to meet the range of needs among younger people with dementia. These included:

- Options acknowledging that the needs of the younger person are different from older people in aged care facilities;
- More support in the home so the younger person can be cared for longer in the home; and
- Separate premises or a section of a facility to be designated specifically for younger people with dementia.

Some supported the idea of a separate wing of an aged care facility that was specifically for younger people, which could also be used as a day centre. One woman with many younger family members with familial Alzheimer’s disease stated ‘I ask not for a facility to be built specifically for them, but a normal house with a lockable fence, where they could go during the day while I worked’.

Another man whose wife was diagnosed with Alzheimer’s disease at 54 said ‘there is a need to have hostels, or units in hostels, that are set aside for young onset sufferers. Placing them together with the elderly is morale destroying and their needs are different. A younger person’s hostel could cover people with a range of issues and conditions … it doesn’t have to be an entire nursing home.’

He also believed, as did many others, that there was definite benefit in placing younger people with dementia with other younger people with neurological disorders or acquired brain injuries. Overall there were differences in the specific type of model people felt should be implemented, yet all agreed that an individualised response was needed that took into account the specific needs of the younger person with dementia.

**The need for respite, day care and in-home services**

Younger people with dementia are more likely than older people to be in full time work at the time of diagnosis. Given the level of activity a younger person is used to, it is even more crucial for them to be involved in a range of interesting activities after diagnosis. For those younger people recently diagnosed and being forced to leave employment, there may be a huge reduction in activity in their lives, and an increased risk of boredom and lack of motivation.

A 60 year old man with dementia said ‘it would be good to have some employment of some sort’ but admitted that if he could not work it would be ‘helpful to be involved in some way’ leading to an interest in volunteer work to suit his capabilities.

A man whose mother was diagnosed with dementia in her mid fifties explained how both he and his mother became heavily involved in voluntary work with Alzheimer’s Australia, providing a valuable way to keep involved in the community. This is important because dementia can cause people to lose interest in and withdraw from normal activities including family relationships (McLennan, 1999:18). Keeping them involved can help to alleviate this problem.
Most younger people and family carers also raised the need for improved and more specific services in the home. One woman whose husband was diagnosed with dementia at 44 stated: ‘carers were not well trained at all … they were brokered out as contractors … we had a different carer each week … one carer was on drugs … some weeks the carer wouldn’t turn up at all’.

Many people spoke of the need for consistency in services offered, which would promote better behaviour by the person with dementia who felt more comfortable in a familiar and steady environment.

One man whose wife was diagnosed with Alzheimer’s disease at 54 felt he was in a classic ‘catch 22’ situation. Able to earn a good income working four days a week allowed him to pay for carers, yet he found there were too few programs for his wife during the day that allowed him to stay at work. The few good programs in his area were only run once a week or for a half-day, meaning he had to organise rosters of volunteers and friends to fill the rest of the day. He explained, ‘more day programs – that actually go for a full day and are designed for younger onset – are greatly needed’. He felt that if he stopped working he would become a greater drain on public funds and would no longer be able to afford private carers.

Activities with people of similar age

In general, younger people have called for social activities with other people their own age, as they feel more comfortable among their own age group. There are also differences between the physical capacities of a young, fit person compared to a more frail, older person and the sorts of activities they would be interested in. Whether it is in the home, through day centres, in residential care facilities or through community services providers, most people agreed that younger people should be placed in environments with others their own age.

One 60 year old man with dementia said that ‘respite for younger people is needed … this might be more fun and interesting than being with people who are elderly and frail’. A man whose wife was diagnosed at 54 with Alzheimer’s disease stated that, ‘being with 80 year olds is difficult due to their age and the lack of engaging activities’. A coordinator of a support group for younger people with dementia agreed that, ‘younger people need to be with other younger people… they can’t relate to older people’.

One service provider promised ‘if we got funding we would seriously look at the possibility of a cluster of young people with dementia in a day centre’. As it is expected that older people would not enjoy activities designed for younger, fitter people, it is likely that each generation’s attitudes will be similar in this respect.

Appropriate and interesting social activities

Younger people are less likely to be already involved in social groups and clubs and so, when diagnosed, may wish to start attending a day centre or similar service. For younger, fitter people with dementia, appropriate activities include going for walks, visits to museums and art galleries, or lunch out with a group. Carers of younger people in the early stages of dementia are likely to still be at work, and so there are issues to be considered, such as the opening hours of the day centre and transport, particularly for those who may have given up driving.

Transport seems to be a difficult issue to resolve for some service providers. In one instance, a 59 year old man with dementia accessing a generic day service said that he was ‘not allowed on the local Council’s community bus because [he] had dementia’. In other cases, younger people reported they were not able to access transport to services because it was provided for frailer persons, more likely to be older.
A man whose wife was diagnosed with dementia at 54 testified that ‘the Friendship Club [group for younger people with dementia] has been great for my wife as it involved people living with dementia who met once a month at first, then twice a month … now they have two groups running they are so popular … it’s good for these younger people as they are more active than older people and need something to keep them interested’.

Many of the younger people and family members consulted as part of this project were clients of Alzheimer’s Australia. While there may have been some positive bias towards the services offered by the organisation, it is still valid to highlight the good work the organisation has done for younger people.

A woman whose husband was diagnosed with fronto-temporal dementia at 52 said that ‘Alzheimer’s Australia has been excellent and dependable … they helped form a very close knit group of younger men that meet together and do all sorts of activities … something they really loved was taking photos and putting them in calendars which they later sold.’ This is an example of an engaging activity for younger people that allows them to use their existing skills and increase their self esteem.

The difficulties for staff caring for people with younger onset dementia

The range of dementias that occur more commonly among younger people can be even more challenging and confronting than for an older person. For example, a 60 year old man with early stage fronto-temporal dementia is likely to be more active and exhibit more aggressive behaviours than an 80 year old man with Alzheimer’s disease. Because of this, some service providers have indicated that caring for a younger person can be more demanding and difficult than caring for an older person where the patterns of behaviour are more predictable.

As an active, younger person has more energy and would rather get ‘out and about’ than be involved in sedentary activities, care workers reported extreme fatigue and difficulty keeping them in the grounds of their facility. A member of a dementia behavioural advisory service said ‘many people look to abscond because they are not active and engaged. A younger person is more likely to stay in an environment where they are motivated and engaged and feel they fit in’. A coordinator of a group for younger people said, ‘there is a physical difference between older and younger clients … we have one man who only wants to walk as an activity … to accommodate this is difficult … younger people tend to get bored more easily’.

A woman whose husband was diagnosed with fronto-temporal dementia at 52 said ‘we need facilities for younger people with people trained in caring for them adequately’. One service provider that offered a specific day service for younger people with dementia said it was ‘difficult to get staff to work with this group … they find it difficult to see people their own age with this disease and it can scare them away’.

There is a need for more support to be given to care workers and coordinators of day programs through improved professional training in all facilities that support younger people with dementia.

Other service providers expressed dismay at the difficulty in servicing younger clients for many of the reasons already outlined, and at the difficulty in securing funding and adequately trained staff for the work.

A social worker with an Aged Care Assessment Team (ACAT), who has had extensive experience with younger people with dementia, said that ‘I continue to be greatly concerned about the lack of appropriate care and services (both health and community support) available to people with early onset dementia’.
One service provider stated that, ‘successes have been through one on one or smaller activities – though … the opportunity to provide this support is limited due to staff restrictions’. A group of staff from another service provider expressed the view that ‘across all our services and programs younger individuals may be expected to participate in groups where everyone else is 20-40 years older and have greater co-morbidities and totally different life experiences. Many issues for carers are also vastly different … our experience of younger onset dementia (most of ours are acquired brain injuries) is that having younger people frightens the staff as it outside their scope of practice. Younger people confront them with their own mortality and they don’t feel comfortable with it’.

With adequate training and mechanisms to cope with behaviours of concern, difficulties in caring for a younger person with dementia could be reduced, enabling service providers to retain better staff for longer.

Another issue raised was in regards to people with a dual-condition, whether it was a physical or a mental health problem. In these situations, there needs to be collaboration with the professionals caring for the other condition, so the dementia does not get overlooked. Some service providers felt that this could be the case for younger people, e.g. for those with a psychiatric illness. Often they were treated for the illness while the dementia was seen as secondary. All agreed that health professionals would need to deal with life threatening diseases first if that was the case.

Service providers also raised the fact that while existing programs for younger people might work for a time, the rapidly changing progressive nature of the condition and concurrent ageing, meant that the needs of the younger people changed more over time than the needs of older people. Some service providers reported this as being the reason some of their programs were not sustainable, but most felt they were not sustainable simply because of the short term funding approach used by the Australian Government.

**Individual responses**

From the comments made by service providers, carers and younger people, it appears that an individual response is needed for respite and care services offered for younger people. Such person-centred care includes culturally and socially appropriate care. One younger man with dementia said that ‘there is no support from any agency that we have extensively checked, that is gay specific. We (my partner and I) have found this to be extremely frustrating, especially in this day and age of supposed equality’.

There may be physical limitations that carer workers have to be aware of too. One younger person with dementia described how ‘on a good day, I can cope with maybe 2-3 hours, but on a bad day my physical stamina can be as low as 20 minutes … my other problem is the size of groups that go on outings. Any more than maybe six other people around me (e.g. a bus or coach trip) can bring on severe anxiety and even vomiting’.

**Funding issues**

Many people spoke of the need for more flexible funding arrangements stating that although the collaboration between service providers was encouraged by funding bodies, it was hindered by the competitive tendering process. Some service providers felt that while there was opportunity for programs to be delivered to younger people along with similar aged people suffering from an acquired brain injury, multiple sclerosis or another neurological condition, current funding arrangements prevented it. This was mainly due to the divide between the Commonwealth funded aged care sector and the State funded disability and health sectors.
In other situations, carers spoke of area-specific services for younger people, where the service provider was given funding to deliver a program in a particular area and not outside those boundaries. Claiming that this was unfair to people who really needed that service but could not access it, these carers called for more flexibility in funding arrangements to cater for their needs. In one case, a carer felt that such funding arrangements encouraged the service provider in question to be protective of their work so no one could compete with their program in the next competitive round of funding.

**Reluctance to access respite services**

Many carers of younger people reported that they were reluctant to access respite services because they felt the younger person with dementia might feel isolated and that they did not fit in among older clients. In addition, they felt guilty about placing their loved one somewhere else, and in a place where they did not trust the service to be appropriate for an active, younger person.

A group of carers spoke of their ‘suffering from guilt when you do something for yourself that does not include your partner’. Another woman who had many younger family members with familial Alzheimer’s disease felt that the pertinent issues for her as a carer were ‘treating them normal, taking them shopping, being with them 24 hours and suffering guilt when we used respite care or placed them in a nursing home’.

A counsellor explained that in his experience ‘younger carers seem to not take up as many services overall … but tend to take up the services more readily if they are among other younger people … they feel more welcome when it is not an aged care environment’. A coordinator of the Living with Memory Loss (LWML) program felt that ‘carers of younger people don’t seem to access respite services … there seems to be a bad stigma surrounding day centres as they are seen as something for older people’.

Some service providers said that if family carers of younger people were given greater access to appropriate, affordable respite care it could allow them to care for their family member at home much further into their disease process. This would, in turn, reduce public expenditure, as less time would be spent in costly permanent care facilities.

Many carers expressed a wish to keep their loved one at home as long as possible. A man whose wife had younger onset dementia adamantly stated ‘some people are better off at home and given services when they need them’. Others also felt that ‘most people would like to care for their loved one at home, but cannot do it without help’.

It was not just carers who expressed this opinion. Many younger people with dementia felt they would prefer to stay at home as long as possible where it was more familiar and comfortable, but wanted more support for their carers.

Given the value of good quality and appropriate respite care, improvements in respite services will need to show creativity and collaboration with carers and younger people with dementia. Firstly, respite should not only be viewed as a service for the carer but also as an opportunity for younger people to be involved with each other and gain self-empowerment through targeted activities. Secondly, it is important to work with family carers in familiarising them with the services offered so they are more willing to take up the service. Some examples of innovative approaches follow.
**Mobile Respite Response Team (MRRT)**

The Alzheimer’s Australia ACT has developed a respite program that can be tailored to meet the needs of younger people with dementia and their family carers. The program is run by the Mobile Respite Response Team (MRRT), a short term in-home intervention team providing respite and education for carers of people with dementia, strategies for behaviour management and assistance in accessing appropriate services.

The MRRT coordinators identified a reluctance by carers to use residential respite for reasons including, feelings of guilt, a belief their partner may feel ‘dumped’, and a fear they would not cope with someone else doing things for them (particularly personal care). Some carers felt that life would be harder when the person with dementia came home and were concerned they would not be happy.

In response to these identified issues, the MRRT coordinators offered younger couples the opportunity to go away on weekends for a positive experience of ‘respite’ in a controlled environment. The aim was for couples to enjoy themselves and relax, hopefully diminishing their fears and reservations about respite. Carers had the chance to observe staff interactions with their partners, let go of some of their caring tasks for three days and observe how their partners coped. It also provided the couples with an entry to an informal and natural support group.

Over time there were variations to the program. Activities varied from massage therapy to yoga to prayer services, with a good mix of engaging and interesting activities suitable for all individuals present.

Program coordinators organised for the carers to be of the same sex looking after people with dementia of the opposite sex. At night time, women were accommodated in one cabin and men in the other cabin. As some couples had probably never been apart for many years, it provided them with the opportunity to slowly ease into the situation of sleeping in different venues. Some, but not all, of the weekends were for couples where the person with dementia was under 65. Weekends were staffed by an outreach worker and respite worker, and although it was hard work for these staff, the positive outcomes of the weekends were enough to motivate them for the next weekend away.

It was found that in general:
- Carers felt more comfortable with respite,
- Carers learnt from each other,
- Staff could model appropriate responses to people with dementia,
- Couples could enjoy a normal social holiday,
- Unrealistic expectations were reduced because people were with their peers,
- A firm basis was established for future integration into education and support groups,
- There was an impetus for couples to explore other respite options, and
- Many couples experienced a renewed sense of their importance as a husband and wife, not a ‘carer’ and ‘cared for person’.

(Alzheimer’s Australia ACT, 2005).

Comments such as ‘I haven’t laughed so much in years’ and ‘I can’t remember enjoying myself so much’, highlight the power of this way of introducing respite to couples as it can reduce their sense of isolation, increase understanding of dementia and the needs of their partner, and increase self-esteem of the participants.
After twelve episodes, the Program ended due to the significant responsibility for the coordinators, and difficulties running on an extremely limited budget. The coordinators felt that part of the reason it worked was the rapport they established with the clients of the MRRT, something they felt they could not pass on to others to run the Program in the future. Nevertheless, the Program provides a good example of how to creatively tailor respite services to be more suitable for younger people with dementia.

**The Sundowner Club**

There have been a number of initiatives by the Australian Government that have provided support for improved care for people with dementia, no matter what their age. One of these initiatives is the Aged Care Innovative Pool Dementia Pilot Program. In this Program, ECH Inc. in partnership with Eldercare Inc., were funded to run the Sundowner Club in Adelaide.

The Sundowner Club presented a new choice in respite care provision. It was designed to meet the special needs of clients who experience sundowning behaviour – meaning symptoms that tend to manifest in the late afternoon and early evening, such as an increased tendency to wander or become agitated. As sundowning behaviours typically occur outside usual business hours and cause distress for carers, many traditional respite care options do not cater for such behaviour.

The Sundowner Club provided an evening meal and a program of social activity for clients, as well as transport for clients from their home address by bus. At the venue, clients helped to prepare a home cooked meal and dined with other members of the Club in a small group supported setting (maximum eight clients). The activity program was available between 3 and 8pm Monday to Friday at two locations in Adelaide. Activities were designed with the flexibility to meet the needs of different groups such as men and younger people with dementia (AIHW, 2006:xii, 82-83).

It is expected that such a program would be beneficial to family carers still working where current respite services are not provided for late enough.

**Residential care**

The decision to place a loved one into residential care is difficult for a family no matter how old the individual and how good the standard of care in the chosen facility. Many carers experience a sense of guilt in making the decision as exemplified by a woman whose husband was diagnosed with dementia at 55: ‘nobody understood me putting him in a home, they felt as though I was putting him away’.

As many people expressed throughout the consultations, most people would prefer to stay in their own home for as long as possible. If the individual and their carer have been long time companions, the move out of home and into a residential care facility may be even more stressful for both. Knowing about services, government policies and costs of residential care beforehand can help them make the best decision, even if the decision has to be made quickly.

For a younger person with dementia, it appears that the decision may be even more traumatic due to the lack of appropriate facilities and consequent available places for the younger person. A dementia behaviour advisor stated that ‘there is stress on families to relinquish care for a person to a place they don’t feel is appropriate, but they have no other option and experience extreme anguish and upset … makes it even more difficult when the facility is so far away’. She also felt that ‘many families find it hard to visit their loved one … if they were surrounded by younger clients it would be much easier’.
Design of premises

Security of the premises was raised as an important issue, as a person with dementia might wander. A secure environment is essential in these circumstances, but there are also legal and ethical questions to consider when determining the type of security to use.

One health professional working in a locked psychiatric unit that housed some younger people with dementia said that this was a ‘difficult, ambiguous situation … some patients have guardians but others don’t … it is hard to know the best thing to do for these people.’

One staff member of a service provider explained how décor suited to older patients sometimes failed in keeping younger patients inside, ‘It is of assistance to ensure their room is age/experience appropriate, but given that the residents in my experience like to wander around, the time spent in the room is limited. This means that the more common areas that are generally styled and decorated to suit the older population don’t always assist them with cues, activities or a sense of the familiar’. The need to develop design and décor recommendations for facilities housing younger people was raised by other service providers.

Another issue is the greater levels of agility and fitness that younger people with dementia display compared to older people, as well as the previously discussed behavioural changes associated with fronto-temporal dementia. A group of carers of younger people with dementia raised these and other issues when discussing the inappropriateness of the aged care facilities some of their loved ones had been placed in: ‘they are in a place with frail, older people who are about 30 years older than them. Younger people with dementia are still active and quick in movements and can easily knock the older people over … they were aware of where they were and displayed difficult behaviours because they were not happy with the place they were in … the set up in a nursing home is for older people. Younger people with dementia can easily climb over the gates and get away … nursing staff find it difficult to deal with younger people with dementia … when difficult behaviour is displayed their procedure is to send the resident to a public hospital where they are restrained, given drugs etc’.

The Ritz Nursing Home, Blue Mountains NSW

During the nationwide consultations, it was found that there were no facilities that catered specifically for younger people with dementia although some facilities were known to be more amenable to admitting them than the average facility. One of these facilities was The Ritz Nursing Home in the Blue Mountains, NSW.

The Ritz is an old hotel that was converted to a nursing home in the 1970s. It is surrounded by a 6 foot fence as it was situated in the middle of the town and added security was needed. Because of this secure fence, it became apparent that The Ritz was more able than most other aged care facilities to look after those with challenging behaviours and wandering tendencies. A significant proportion, but not all, of the residents at The Ritz are younger. Some of the residents are from overseas and forty five of the 140 residents have no next-of-kin or are under the Public Guardian.

With the closing of psychiatric units around Australia in the past fifty years, ‘niche’ groups have emerged who were not catered for in any way, such as those in the age group of 18-65 needing full time and possibly permanent care.

Directors of The Ritz during the 1990s identified the need to support vulnerable people. Feeling they could handle some of the challenging behaviours, they gradually accepted younger residents with types of dementia other than Alzheimer’s disease (for example, fronto-temporal dementia, alcohol-related dementias, some with a dual condition of dementia and a psychiatric illness). These residents were considered by other facilities as too difficult to manage, with wandering being a problem if they did not have adequate grounds or security.
The management of The Ritz Nursing Home felt that its staff were adequately trained to cope with the difficult behaviours that younger people with dementia might exhibit. Sometimes younger people with dementia were admitted temporarily to The Ritz so their behaviour could be stabilised under supervision, and they could return to a previous or altered living situation.

Staff at The Ritz agree that physical aggression among younger people with dementia might be difficult for those working in most residential care facilities.

Facilities offered at The Ritz included:
- Five local doctors who visited weekly and as required;
- A psychiatrist who visited every two weeks;
- Five recreational activities officers employed to help residents attend to more holistic needs; and
- Activities for some younger residents including jobs in the garden, walks, picnics and other social events.

While the management of The Ritz admitted that its service was not perfect for younger people with dementia, it was the best they could offer in current funding limitations. They saw many younger people enter their facility without an accurate and early diagnosis of dementia and with no prior information given to them about the nature of the disease. Therefore, when a younger person with dementia entered, The Ritz would provide them with as much information as possible and offer counselling to them and their relatives. Training for staff was conducted in-house as well as externally.

Although The Ritz has been used as an example to highlight how one facility supports younger people with dementia, there appears to be very few residential care facilities in Australia that are as willing to provide permanent care to younger people with dementia in the same way.

The aged care system

The current provision of residential care for those of any age who have dementia is through the aged care sector. The aged care system is a complex set of arrangements, involving all levels of government, and a range of public, charitable, private and community providers. The care provided varies significantly, depending on the needs of the individual and what support is already available to them from their family and friends (Hogan, 2004:12).

For Commonwealth funded accommodation, an Aged Care Assessment Team (ACAT) assesses the person's needs, and they receive a Resident Classification Scale (RCS) level. While the Australian Government is responsible for funding aged care, the State and Territory Governments fund health and disability services through various health care and disability agreements with the Commonwealth.

This division between Australian Government and jurisdictional responsibilities may make it difficult for younger people with dementia to fit into services appropriately, because while their disease is catered for by the Commonwealth funded aged care system, their age means they might be an issue for the State/Territory funded disability sector.

Many younger people with dementia, their family carers, service providers and others relevant to this field have cited this State and Commonwealth divide as an extremely difficult area to work around in terms of funding arrangements and entitlements. Many stated ‘we need far more flexible funding arrangements' and ‘the rigidity of the disability, health and aged care divides means that no one wants to take responsibility for younger people with dementia … instead they fall through the gaps of the services’.
A psychiatrist who works with many younger people with dementia detailed his difficulty in getting a geriatrician to sign paperwork, as there was an uncertain diagnosis of the type of dementia, and the geriatrician would be accepting the individual with dementia into the aged care funding circle by signing the papers.

Another woman whose husband was diagnosed at 52 with frontotemporal dementia said ‘there is a lot of public sentiment about younger people with complex needs and in residential care facilities … they don’t fit in with aged care requirements but they still need complex medical attention … so where should they go?’ Such questions and examples highlight the difficult consequences of the State and Commonwealth responsibility and funding divide that needs to be addressed through improved cooperation and better understanding of ways to address service gaps.

Involvement of the Aged Care Assessment Team

A man whose wife was diagnosed with Alzheimer’s disease at 54, raised the issue of how the current Aged Care Assessment Team (ACAT) system categorises people as either low or high dependence, with high dependence requiring a person with dementia to be ‘virtually immobile and in a near vegetative state’. He felt that the way need is categorised does not adequately address the needs of younger people.

A former ACAT worker with extensive experience in working with younger people with dementia felt that among younger people, there is usually a more rapid deterioration, and this was highlighted by a number of other people consulted. Although reported extensively in literature (for example, Woods, 1999:246), it is not known whether this is due to delays in diagnosis, the types of dementia common among younger people, or another unknown reason. A more rapid deterioration causes huge problems with waiting lists for residential care facilities, because by the time a bed is available in a low care/dementia specific unit, they may have deteriorated noticeably and need high care, for which beds may not be available.

One approach might be to establish an alternative process of assessing the needs of younger people with dementia. While it may seem practical to continue using an ACAT team, it would be beneficial for ACAT teams to be specially trained to consider the unique circumstances of a younger person and their family. It would also be beneficial for an alternative process of assessing younger people to be given a distinct name, as the term ‘Aged Care Assessment Team’ indicates the assessment process is only for the aged, and can contribute to the stigma of dementia among younger people.

Young People in Nursing Homes Campaign

A significant campaign that may have influenced policy directions with regard to people under 65 in residential care facilities is the Young People in Nursing Homes Campaign. This campaign has been advocated by the Young People in Nursing Homes National Alliance (YPINHNA), a nationwide association of young people living in aged care facilities, their family members, friends and other concerned individuals and organisations. The Alliance was established in 2002.

The YPINHNA aims to ‘work together to make life in the community a reality for young people living in residential aged care’. YPINHNA strongly advocates improved community based accommodation and support for younger people, so they do not have to live in nursing homes populated by older people. YPINHNA feels that younger people in residential care facilities are inappropriately placed as the setting does not adequately support their social, emotional and intellectual needs. In addition, being surrounded by others far older than them can have especially negative effects.
The YPINHNA calls for improved rehabilitation, community access and disability services currently unavailable to younger people when they live in residential aged care. However, while the YPINHNA has been very vocal about the needs of younger people living in residential aged care facilities, it appears that most of these younger people are afflicted by diseases such as acquired brain injury or multiple sclerosis, rather than dementia. This could be due to there being little information available regarding the number and whereabouts of those younger people with dementia living in residential care, or that most are not as young as those with other disabilities.

**Senate Community Affairs References Committee Review:**

**Quality and equity in aged care**

In 2005, the Senate referred the issue of *Quality and equity in aged care* to the Community Affairs References Committee for their review. The purpose of the Committee’s review was to examine:

- Aged care workforce shortages and training;
- The performance and effectiveness of the Aged Care Standards and Accreditation Agency;
- The appropriateness of young people in residential aged care facilities;
- The adequacy of HACC Programs in meeting the needs of the elderly; and
- The transition of the elderly between acute hospital and aged care settings.

In this review, the Committee found over 6,000 people under 65 in aged care facilities in Australia, and many more at risk of being placed in aged care facilities. The Committee determined that ‘an aged care facility is an unacceptable accommodation option in most instances for a young person: they do not support the social and emotional needs of young people; there is a lack of privacy and the lifestyle is highly regimented; in some, staff are not adequately trained to provide the complex care needs of young people; and there is a lack of services including rehabilitation’ (Senate Community Affairs References Committee, 2005:xii).

The Committee also stated, ‘the current system is not providing adequate levels of service; services are fragmented; and there is a complex mix of services that are often difficult to access’ (Senate Community Affairs References Committee, 2005:xii). In response, they made recommendations for:

- A coordinated approach between the different levels of government;
- An increase in funding for community care programs;
- Increased provision of services for special needs groups; and
- Improved recognition of the role of carers in the informal care system (that is, family members who are labelled ‘carer’).

The Committee highlighted that younger people enter aged care facilities for many different disabilities including multiple sclerosis, acquired brain injuries or other disabilities. Very little information is given in the document about younger people in aged care facilities due to dementia, and there is no evidence of input and consultation between the Committee and any group representing the interests of those with dementia.

While the emphasis of the chapter on *Younger people in residential aged care facilities*, is on those who are very young, i.e. in their twenties and thirties – an age when dementia is extremely rare, some of the findings are relevant to younger people with dementia living in residential aged care facilities. For example, that ‘young people are placed in aged care facilities as there is no other option to meeting their particular needs’ (Senate Community Affairs References Committee, 2005:88), and that ‘even when accommodation is being sought in an aged care facility, it can be difficult to get an assessment for a place or to find a place.’ (Senate Community Affairs References Committee, 2005:89).
Under the *Aged Care Act 1997*, younger people with disabilities will be accepted into residential aged care only ‘where there is no alternative’. Guidelines for Aged Care Assessment Teams (ACAT) indicated that younger people might be assessed as suitable for residential aged care only if the facilities could provide exactly the type of care needed and if there was no other more appropriate service available.

The Committee heard evidence that in some cases, ACATs refused to assess anyone under 65 or insisted that they trialled other services first. Even if an individual was assessed suitable for aged care accommodation, there were long waiting lists (Senate Community Affairs References Committee, 2005:90).

These are all issues raised within the consultations with regards to residential accommodation by younger people and their carers, many of whom had been placed in aged care facilities simply because there was no alternative.

The Committee explored the concept of cluster or congregate housing and cited the mixed reactions of those involved in the Committee’s consultations, including their concerns about institutionalisation, lack of privacy and choice and poor past experience.

In other circumstances, nursing homes were found to be the best option in meeting the needs of a person, with benefits to family and networks. Some suggested that groups of people could be accommodated in a cluster or specially set aside area or wing in an aged care facility. Despite the differences in opinions offered, there was general support for an individualised approach where the needs and wants of the individual were paramount and a range of options was available.

Among its many recommendations, the Committee recommended that jurisdictions work cooperatively to improve the situation of young people in aged care facilities finding it ‘unacceptable in most instances’. (Community Affairs References Committee, 2005:127).

**Council of Australian Governments**

Since the release of the Senate Committee’s report, the Council of Australian Governments (COAG) met in February 2006 and released its Better Health for All Australians initiative. In this initiative, COAG committed to start to reduce the number of younger people with disabilities living in residential aged care services. A new five-year program was to begin in July 2006, with funding of up to $122 million from the Commonwealth, and up to $122 million from States and Territories, implemented in close consultation with younger people, their families and carers.

The program will initially target people in residential aged care services aged under 50, meaning that many younger people with dementia will not be affected (as they more commonly fall in the 50 to 65 age bracket). The program also aims to:
- Provide cost-effective alternative residential care services for younger people with disabilities;
- Improve support services for those who continue to stay in residential aged care; and
- Assist younger people who are at risk of entering nursing homes.

(COAG, 2006)

While this is good news for people under 50 who are inappropriately placed in aged care facilities, it does not provide the majority of younger people with dementia (aged between 50 and 65) with an age-appropriate alternative to current permanent care options.
**Conclusion**

Consumers have called for an individual person-centred response to meet the needs of younger people with dementia. As one man whose wife had younger onset dementia stated, ‘we need more things for younger people...this needs to be more individualistic because younger people are a minority with specific needs’. He also felt that ‘people need more information about how to enter the system ... we need a more active campaign’, because many newly diagnosed people were unsure of what was offered to them and became frustrated at the number of doors closed to them because of their age.

A diversional therapist who had worked with many younger people with dementia urged ‘we need a holistic approach that caters for all the needs of the person ... this sort of assistance helps people behave much better’. This in turn helps the person with dementia, their families and the staff working with them, whether in a day centre or a longer term facility.

Service providers were not seen as well placed to meet these needs. Younger people needed different approaches; staff needed better training to help them to manage better; and services needed the resources to meet the needs of this minority but resource-intensive group.

It appears from the consultation that choice was limited and services for younger people with dementia were seen as problematic in many regions. However, it is difficult to invest resources into specific styles of services without better information about the number, underlying condition and distribution of younger people with dementia. Otherwise, it is difficult to determine the appropriate level of funding and where services for this group are most needed. Collecting better data about those under 65 with dementia, together with targeted funding will encourage service providers to cater for this group.

In its policy documents, the UK Alzheimer’s Society recommends making small and incremental steps towards an individual approach. This may be an effective response to undertake in Australia. Such small steps will lead to longer term and sustainable improvements that are more cost effective, rather than attempting to improve the whole situation at once.
Chapter 4 – Emotional Impact

I now find myself with a lack of direction, severe depression and anxiety – younger man with dementia

I suppose the first thing that I have come to realise is that I don’t know it all and I am just as vulnerable as the next person to all that is unknown with caring for a person with dementia – a registered nurse who cares for a friend diagnosed with dementia at 54

To me, it’s painless at the moment but it wasn’t a few years ago … it seems to have slowed down a bit as I’m still quite sharp … I’m definitely not stupid as some may think – man diagnosed with dementia at 60

The diagnosis of dementia and the changes to memory and behaviour of the person affected can bear a huge emotional impact on the individual and the family around them. Feelings of shock, sadness, frustration, embarrassment, anger and loss are common.

When the person diagnosed with dementia is younger, there can be an even greater emotional impact due to many factors, including the shock of being so young, the greater impact on future life plans and the increased likelihood that children, financial responsibilities and employment may complicate the situation. A woman who works with younger people with dementia in residential care facilities felt that ‘the big things we need to tackle are grief, loss, and guilt … we see so many carers and clients presenting with depression…’

Every person’s situation and the way they react are different, so it is expected that people will experience a range of feelings. From consultations with consumers, there appears to be a number of key areas where the emotional impact is felt. This chapter has been divided to reflect these key areas.

Reactions to diagnosis

As outlined in Chapters 2 and 3, the process of getting a diagnosis can be a particular ordeal for younger people. While reactions to diagnosis are varied, difficulty in getting a diagnosis of dementia often exacerbates the emotional impact of the diagnosis itself. One LWML coordinator described dementia as the ‘invisible disability’. She felt that because of its insidious nature, someone in the early stages of dementia may look fine on the outside making it more difficult to access the support they need, compared to someone with a physically obvious disease.

Another coordinator of a support group for younger people with dementia said, ‘it’s a shock to be at that age and to be diagnosed with dementia’. One 60 year old man felt it was ‘difficult to accept the diagnosis … when you see it in writing it really hits you … I look differently at life now. I came out from the hospital and everything had changed’. Another younger man with dementia said that on diagnosis ‘I was bitter, angry … full of hate … people just don’t believe it’.

For some there was not an immediate negative reaction to diagnosis. A man diagnosed with fronto-temporal dementia at 52 stated that diagnosis ‘was a relief, then a huge hammer blow … one hell of a shock … I felt very isolated and insular to everyone around me … I was living in a whole new world … I was extremely suicidal for a long time, but then I turned it around and treated it as a joke. Now I’ve settled at doing the best I can. ‘The sad thing is that no one knows much about it … the biggest drawback is that people put their head in the sand and choose not to address it.’
This man’s comments highlight the wide-ranging reactions that an individual can progress through in response to a diagnosis of dementia and the difficulties associated with other people’s reactions to their diagnosis.

Coordinators of LWML Programs throughout Australia are well placed to make comparisons between the ways in which younger people dealt with the emotional impact of a diagnosis compared to older people. The main differences in acceptance were noted as being due to the differences in stage of life. It was felt that a younger person who is both working full time and looking after young children will find the diagnosis far more unexpected.

It was also observed that some families deny the diagnosis, as they are not sure how to deal with it and possibly do not want to take on the extra workload that accompanies dementia. However, because of its entry criteria, the LWML Program usually does not include those who are in complete denial.

One LWML coordinator observed there was an initial shock in being diagnosed with dementia, but once this was overcome, a strong transformation was evident among many of the younger people. This could be due to the depth of the emotional impact, which means there is more potential for a greater transformation once it occurs. Another LWML coordinator felt there were similar positive transformations between younger and older people from the beginning to the end of the program, while highlighting that every individual’s situation is different.

Some younger people expressed anger about the process of their diagnosis as they did not feel that health professionals treated them appropriately. Others felt the emotional burden of being isolated and not being offered much support on diagnosis. Many people stated that they had never met anyone with dementia before their diagnosis. One man described how on his first LWML day, a group of younger people with dementia started questioning their diagnosis in their peer group, as it was something they were so shocked and upset about.

It may be the sense of isolation younger people feel that accounts for one LWML coordinator’s observation that ‘there is a massive joining of the group as they all realise what they have in common … The Living with Memory Loss Program represents a powerful bonding experience as younger people tend to bond with each other more readily than older people. There is much value in having the younger LWML group as there is a social network/connection formed and people feel they ‘click’ in the group. There are also areas of common ground which helps normalise the situation for the individuals’.

Even so, after the positive transformation that such programs can invoke in people, one man whose wife was diagnosed with dementia admitted that beyond that, it is still ‘a big thing to tell people you have dementia’.

**Family impact**

Every family is different and every family’s reaction to diagnosis will be different. In the case of a younger person, they are more likely to be actively raising a family at the time of onset of dementia. Also more likely is that the family circle is larger, there are more dependents still at home and there is a husband or wife still working. This situation means the younger person’s more active and busy household is severely disrupted and the emotional, financial and social impact on the family may be far greater than for that of an older person. Robertson (1996) recommends a family system approach and provides extensive evidence about the impact of a parent’s dementia upon children.
In providing services for these clients a holistic approach is needed to take in the needs, demands and pressure of the wider circle. Firstly, the impact on any children should be considered – they may find the dementia confusing, as it is not something they would expect to see in their parents’ age group. Also, because diagnosis is usually provided using a medical model, children are unlikely to be included in the process and may need assistance in understanding what is happening to their parent. They may also have to later deal with shifts in roles in the household, eventually looking after their parent themselves. This would be in stark contrast to their peers who may be at the stage of life where they are busy with their own social lives, trying to deal with changes in their own lives (such as puberty) and likely to be looking ahead to a future of opportunities. For such families, there are also issues the person with dementia will have to face, including difficulty maintaining credibility as a parent with their child.

Some carers spoke of how their children were at critical points in their process of growing up, like sitting their final school exams, and it was difficult for them to see their parent developing dementia. Some felt that it was difficult to give their children as much attention as they normally would, because they were busy caring for the person with dementia. This had the potential to cause many problems within the family structure.

One counsellor voiced opinion held by many by saying, ‘we need family counselling – the earlier the better’. Although many people said that their children had been offered counselling and did not take up the offer, there needed to be a more consistent approach in which counselling was offered to all children of people with younger onset dementia in light of the potentially severe emotional impact.

A woman whose husband was diagnosed with dementia at 49 exclaimed ‘it’s frustrating for the children … the 12 year old has seen this presenting for the past 10 years … I know my children can’t handle seeing their mother hurting’. A man diagnosed with dementia at 60 said, ‘it hurts the children to see their parents like this’. Another group of carers of younger people with dementia identified the effects on children who were still living at home, stating, ‘they still need care and attention. Their lives change at a young age. Other family responsibilities (raising the children, working) can also increase the stress for a carer’.

A woman who has had many younger people with familial Alzheimer’s in her family expressed: ‘family is the key success factor in our case, but this has disrupted our own lives immensely … we are close and do everything to assist our family members with the disease. This sometimes causes stress on our parents [with dementia] who do not always understand the commitment and inability to leave the sick family member at home.’

Most people felt it valuable to offer counselling to the whole family including the children. In particular where the household was busy and active, families needed an opportunity to ‘put their cards on the table’ and plan for the future as early as possible. It would be important to provide counselling as soon as possible after diagnosis, as that was the time when life was most chaotic and changes in the family would be noticed more acutely.

Service providers also raised concerns about families where an older person was looking after their spouse with dementia and then a child developed younger onset dementia. This occurred in familial onset dementia, but could also occur in other families. Such a situation would be extremely difficult for the carer who must find the energy and time to look after two people, and for those with dementia, it meant that they received less attention from the carer. Such families needed social and in-home support to provide some assistance to the carer. These service providers believed that these families particularly suffered from the lack of support services available to them.
While some people were fortunate to have very supportive families, e.g. one man whose wife was diagnosed with dementia at 54 said, ‘it has brought our family closer together’, many other people did not receive that kind of support.

There were many younger people who felt their families could not comprehend that dementia could affect someone so young and so denied its existence and the extent of the impact it had on the younger person. One man diagnosed with dementia at 60 said ‘some family members don’t understand so I have steered clear of them’. Another woman whose husband was diagnosed with fronto-temporal dementia at 52 stated, ‘our children are not very supportive at all’.

With a lack of support from immediate and extended family, the emotional impact on the person with dementia and their carer was especially striking. For those younger people with dementia who did not have a spouse or other full time carer, any help they received from their family was helpful. It is hard to say when someone in the early stages of dementia will need assistance and so not having any family to support them is extremely taxing on their own emotional wellbeing. Therefore, it is even more important for effective support services to be offered to younger people with dementia and their families, but particularly when there is little or no family support already in place for the individual.

**Impact on relationships**

If a person is in a relationship when they are diagnosed with dementia, there is a huge difference to the way the relationship then evolves. Although it can depend a lot on the nature of the relationship, it appears these changes are more marked when the person with dementia is younger. This may be because older couples are more likely to have a longer and more established relationship together, and have had the opportunity to do many of the things they wanted together. There is also less shock in response to the onset of dementia in older people, causing less strain on the relationship.

In all relationships, where someone develops dementia there will eventually be an increased dependency of the person with dementia on the carer accompanied by a change in the dynamics of the relationship. Communication can also become complex and difficult as the dementia progresses, adding to the stress on the relationship.

The spouse or partner of a younger person with dementia may feel that they have been ‘robbed’ of the future because retirement is premature, and future plans cannot be fulfilled. This may lead to feelings of guilt in the person with dementia as they, if they still have insight, may feel badly that their partner is also limited in fulfilling future dreams.

Carers also spoke of their guilt for feeling that their future was robbed, as this was seen as a selfish way to think. For carers who worked, particularly those who were not able to access a disability pension and being under 65, could not access the aged pension, they might experience anxiety working, as they might feel they were leaving behind their loved one who would only get worse and need them more.

With the loss of their job and the role in the family, many younger people experienced poor self esteem. Some reported feeling belittled as though their contribution to society had lessened. Such emotional strain on the person with dementia could stress the relationship as the carer might feel the responsibility to improve their partner’s self esteem. One group of carers said that changes in couples’ relationships were hard to cope with and one spouse said she had to make an active decision to stay married to her husband with dementia and look after him. Other counsellors reported marriage break-ups, people who left their partners with dementia for another partner, and, as observed by one service provider, a man now living in the same house as his wife who had dementia, and his new partner.
The issue of role reversal was strongly apparent in many of the relationships of those consulted. For example, in a household where the wife had always cooked dinner, cleaned the house and raised the children, with the onset of dementia she was no longer able to conduct these domestic duties and so the husband had to take over. In other cases, if the main breadwinner of the household developed dementia, the other individual was often forced to work to support the household single-handedly. Pressure then remained on the working person who had to juggle a whole different set of commitments in their lives.

A counsellor for younger people with dementia and their carers identified the following issues among his clients:

- Intimate sexual issues;
- Lack of emotional intimacy;
- Role changes;
- Change of feelings towards the person with dementia; and
- Feelings of guilt for questioning what the rest of their life will bring about.

As there is usually behavioural change associated with types of dementia common among younger people, for example, fronto-temporal dementia (see Chapter 6 page 52), this can also cause complications in relationships. Some people spoke of the difficulties in caring for someone who had aggressive, angry and emotional outbursts (as a result of the pathological changes to the frontal lobe which regulates social behaviour). These problems were particularly pertinent for women whose husbands might still be physically fit and active, and might be very strong, demanding and potentially dangerous.

A woman who previously worked for ACAT explained some of the issues she saw when she facilitated support groups for partners of individuals with younger onset dementia: ‘younger people remain sexually active and are seeking affection from each other again … they may confront the staff with this … they may have lost their sexual inhibitions if it is a frontal lobe dementia, which then involves confronting behaviours. There are other issues if the person is sexually active, such as the risk of unwanted and unplanned pregnancy … also how do you tell families that the person is sexually active as there are repercussions in that … Staff really need education on these issues as this is a growing population … in the past six months we have seen four younger people with a potential fifth on respite with us now’.

Another woman whose husband was 62 with fronto-temporal dementia spoke of how she struggled with her husband’s inappropriate behaviour including masturbating in their garden and speaking with sexual overtones to other women. While she loved her husband dearly, she felt that she was ‘constantly putting out fires … you need to be as calm as possible.’ In her opinion, her husband had ‘lost all sense of reason’. She also spoke of how her husband felt invincible at times, being caught on camera shoplifting and although he was generally a very nice person, he could no longer understand why what he had done was wrong. As a consequence, his wife said, ‘our relationship is very separated … I have gone past feeling sorry for myself, I now feel sorry for him’.

Other younger people spoke of issues with intimacy and sexuality, such as the loss of passion in the relationship. Some carers described the sadness they felt when they realised their relationship would no longer be the same. They felt they had become more like a parent to their spouse and this disappointed them. One woman whose husband was diagnosed with dementia at 60 described how she felt her husband did not see her as his wife anymore, insisting that they sleep in single beds.
Other people spoke of the loss of social spontaneity in their relationship because they knew that the person with dementia would not be able to cope with change as easily as they could in the past. This disappointed some people as they felt that there was some fun now lacking in their relationship and their life.

An interesting observation was the reaction of male carers to the onset of dementia in their wives. Many men admitted that they did not take up the offer of counselling and other social services, feeling that they did not need it. A man who cared for his younger wife until she died said ‘some men feel they can look after the wife themselves … they don’t want to lose their dignity by admitting they need help’. Another man whose wife was diagnosed with dementia at 58 felt that ‘it can be a feminine thing to admit you need counselling and emotional support … many men are probably embarrassed about it so don’t take up the offer’.

It therefore appears that social support services need to appropriately target male carers to encourage them to take up the offer. This may be through the establishment of more creative and innovative programs that are gender appropriate.

**Grief and loss**

There is often a strong sense of grief and loss experienced by younger people with dementia and their families. Many people said that younger people appeared to have more insight than older people (perhaps as their type of dementia did not affect their memory first), and were therefore more emotional as they realised the extent of the consequences. A psychiatrist who sees many younger people with dementia stated: ‘there are very few effective advocates for younger people with dementia … it is a very emotive area … involves a complex grieving process for carers and patients’.

For younger people, grief seems to be more profound than for older people, as their sense of loss can be greater. This comes from having to engage in huge changes in their lives and the likelihood they will not be able to carry out their plans for the future.

Some people were upset about being forced to retire early, knowing that due to the progressive effects of dementia, they would not physically be able to do things they had always hoped to do when they retire, such as travelling. Some younger people were concerned that in the future they might not have the insight or the memory to recognise familiar faces, rendering it impossible for them to fully appreciate new grandchildren or occasions, like their children’s weddings.

They also felt guilty that they were unable to fully assist in the raising of their children, and this led to feelings of inadequacy. In addition, most acknowledged that their financial capacity was limited because of premature retirement, and needing to spend their money on things they had not previously planned for, such as respite services, medications and other services. In addition, some younger people feel upset they could not fulfil their obligation to society, wondering what they did to bring this onto themselves. A man whose wife was diagnosed with Alzheimer’s at 54 said ‘the grief is of a different sort … it creeps up slowly and hits you at various times’. Whatever the sense of loss was due to, the effects were deeply felt by most people consulted.

Like the person with dementia, the carer’s life also undergoes huge changes, and this can lead to a whole range of feelings. A group of carers of younger people identified the following feelings:

- Inadequacy in their caring role;
- Guilt when they did something for themselves that did not include their partner;
- A lack of space, time and hobbies of their own;
- Disappointment at giving up their job to become a full time carer and career aspirations becoming unattainable;
• Exhaustion from taking care of the person with dementia;
• Stress from being responsible for maintaining a house; and
• Difficulties coping when the person with dementia becomes upset, depressed or aggressive (either at their losses or because of pathological changes to the brain).

Such carers said that ‘we need support from beginning to end, even after the death of the person with dementia’.

A woman who previously worked for ACAT and facilitated support groups for partners explained, ‘those partners could hardly wait for the first meetings, to be able to talk to others with exactly the same issues …’. Many found that older carers had completely different issues so they had not returned to those groups.

While there appears to be strong benefits of support groups for both carers and the person with dementia, some people felt support groups were not accessible to those living in regional and remote areas. A woman whose husband was diagnosed with Alzheimer’s disease at 55 said that for her, ‘regular contact with a support group is out of the question, as there isn’t one in our town. We do have an early onset support group, which is a long drive of two hours there and two hours home. My husband has gained a great deal of pleasure from the small group of people in our age group who form our support group. However, we only see them once every four or five months, because of the distances we all have to travel. This is most disappointing, as we both feel stronger and more positive when we meet up with the members of the group.’

**Giving up driving**

The decision to give up driving is difficult for people of any age with dementia, as having their license taken away is a huge loss. A 60 year old man with dementia claimed ‘I’m not supposed to drive. I have the license, but I won’t give it up as it represents my identity’. It seems that in a country like Australia with such large distances between urban centres, and an infrastructure that is supportive of motor vehicles, being able to drive has an element of freedom, independence and enjoyment for many Australians. It is understandable that giving up one’s license would bear a huge emotional impact.

When the person with dementia is still allowed to drive, on the other hand, it can be extremely stressful for the carer. One woman whose husband had dementia said that she had to supervise when her husband drove as he would be very uncooperative when she took over the driving. This was a difficult situation for the couple as the husband had always been the main driver and the wife was always the passenger. The husband was not ready to accept the reversal of this role because of his dementia.

Many younger people spoke of the difficulty in giving up driving when the onset of dementia was so unexpected in their busy lives. For those with children, they could no longer drive their children to places, making it difficult to watch them in sporting matches for example. Some younger people expressed feelings of guilt as though they were letting their children down. Others felt the decision to give up driving was normally associated with old age and so for them to give up driving under the age of 65 had even more marked effects.

Frustration was also expressed at the limitations of alternative transport options, and the difficulty in getting to and from day activities. With improved transport options for people with dementia, the decision to give up driving may not be as difficult.
The stigma of dementia

Many younger people spoke of the stigma of dementia, and how this led to feelings of loss of respect and social identity as the general public did not understand the nature of their dementia. Some people reported this to have led to a loss of friends and the capacity to make new friends.

One man diagnosed with dementia at 54 stated that, ‘rejection from the general public and their lack of understanding prevents me from making a step in trying to make friends’. Another man whose mother had dementia in her mid 50s felt that ‘people are helpful on the surface but there are pockets of incompetence around the place’. A woman whose husband diagnosed with dementia at 52 said that ‘prior to diagnosis we had many friends, but now our circle of friends has dropped off dramatically’, echoing the very common sentiments of others that ‘you find out who your true friends are’.

A 60 year old man with dementia claimed ‘I can’t talk about it as people don’t understand … seems to be a stigma attached to it … I went from somebody to nobody … there is a loss of confidence … we went from lots of friends to not many at all.’

This loss of friendship, support and understanding by those around the person with dementia and their immediate family bears a huge emotional impact. With increased public understanding of what dementia is in general, improved awareness that it can occur among younger people and information about how people can best support a friend living with dementia, this emotional burden can be lessened. In addition, better social supports for younger people with dementia and their carers can make an enormous difference.

Dementia in the workplace

Chapter 5 will discuss further how younger people are likely to be in employment at the onset of dementia, and that this is often the setting where initial signs of dementia are exhibited. This can cause a whole range of reactions, including embarrassment and frustration, for the individual as well as their employers and work colleagues.

In most cases, employers noticed that the individual was not performing to their usual standard and not to the standard expected by the employer. It was reported that many employers recommended the younger person to be assessed by a medical practitioner for signs of depression, or for other reasons for their underperformance or seemingly odd behaviour at work.

At this stage, some people reported diagnoses of depression or mental health conditions by the medical practitioner; while others were referred onto specialists for further tests. Most did not expect that their condition could be dementia. From there some people were retrenched from work while others were slowly given less hours or ‘eased out of the system’.

A woman whose husband had younger onset dementia, spoke of how difficult it was for him to retire on medical grounds because his employers could not understand how dementia could affect him so young. Many younger people reported discrimination in the workplace and felt forced to retire because even after the diagnosis explained their change in performance, their employer could not find them work suitable to their cognitive ability. While there were positive stories of younger people receiving support from their employer, these were not very common.

A lack of awareness about younger onset dementia in the general public may account for the way in which employers react to the changes they see in the individual, and so improved public awareness would help improve the situation in the workplace for younger people. In addition, targeted training about dementia and related disability would help employers offer more adequate understanding, support and assistance for their employees, even as the employee is going through the difficult process of giving up work and embarking on medical retirement.
**Maintaining a positive outlook**

Many younger people with dementia and their family members spoke of the importance of trying to maintain a positive outlook on life despite the extreme emotional stress.

A man diagnosed at 52 with fronto-temporal dementia explained, ‘as one thing drops off the way side, you can find other things you can do … it’s all about a positive attitude … you can’t let it get the better of you … I’m very good at covering it up socially … the problem is that you can’t see dementia and so people don’t understand. The younger person shocks them, they just don’t understand. Alzheimer’s has always been labelled ‘Old Timers’, who’d expect it in a bloke as young as me? … However, the support we received from organisations like Alzheimer’s has been colossal – it means a lot to me and my wife’.

A woman who cared for her mother diagnosed with Alzheimer’s disease at 58, reiterated the importance of positive support and the benefits this would reap: ‘if my mother met other younger people I feel it would be great for my mother’s self esteem and knowledge. She is positive so I feel other dementia people would benefit from meeting her. She has already had a positive effect on the home assessment people and other dementia people she has met, and I am just realising how unusual her positive attitude is …’ She felt that it was important for her mother ‘to be treated as an intelligent person with a memory loss who still wishes to be involved in everyday life’.

Another woman whose husband was diagnosed with Alzheimer’s disease at 55 emphasised the value of ensuring they are kept in familiar and hopeful surroundings: ‘he feels more comfortable in familiar surroundings and lives in the hope that a cure will come along and he will once again operate the farm. It would be too demoralising for him if we sold it and moved away … I could be criticised for allowing him to live in false hope, but in practice, I do whatever I can to keep him happy, positive and motivated’.

Coordinators of a LWML program for younger people stated that there was a more intense focus on the loss of identity among the younger group. The sense of suddenness of the dementia could mean younger people experienced an unexpected change from feeling like someone to no one. Also, some simple things could no longer be done, and this frustrated the person and their carer. The coordinators of the program felt that these factors can lead to depression, but attempting to deal with loss and grief early on, and providing a positive outlook to life despite such losses could help improve the situation for everyone involved.

**Dementia Advocacy Support Network International (DASNI)**

Some younger people consulted were members of the Dementia Advocacy Support Network International (DASNI). This not-for-profit corporation was established in 2000 to:

- Promote respect and dignity for persons with dementia;
- Provide a forum for the exchange of information;
- Encourage support mechanisms such as local groups, counselling groups and internet linkages;
- Appeal for services for people with dementia; and
- Assist people to connect with their local Alzheimer’s organisation.

DASNI has evolved as an international group of people with dementia – approximately one-third of the members have dementia, and the remainder includes care partners and care professionals. DASNI activities include an internet-based support group for people with dementias, enabling people to chat online about their experiences.
As part of the consultative process, the Project Officer chatted online with two groups from around the world, of which almost all were under 65 years old. These internet chats were held twice a day and were aimed at helping ease the isolation of dementia and educates participants about living with their diseases. A woman diagnosed with Alzheimer’s disease at 59 could not speak more highly of DASNI claiming it ‘provides us the opportunity to share the same difficulties, with opportunities to meet, socialise, learn and support each other’.

DASNI’s website offers the following statement:

The stigma of dementia is very real, very cruel and widespread. There is also a lack of knowledge about dementias, the impact of new medications, and the support available. By sharing their hopes and concerns, and participating in dementia-related activities, DASNI empowers people with dementia to actively participate in their own care and treatment. We support a more accepting, more hopeful view of living with dementia. We encourage people to improve the quality of their own life by advocating for others.

(DASNI, 2006)

There are many people who attest to the positive influence DASNI has had in their lives as they feel empowered and understood. Whether it is DASNI or another organisation that works with people with dementia, or even the general public, viewing people with dementia as valued members of our society will help them deal more effectively with the emotional impact of their dementia.

A man diagnosed with dementia at 54 stated ‘I’m not depressed at all because of the love and support and care I received since I was diagnosed … I have a very positive attitude so I’m not worried about the future … I have tried to reduce stress in my life by reducing responsibility in my life … my wife and I look after each other, it’s very enriching’. Such comments show that looking after the emotional wellbeing of younger people with dementia and their family members is paramount to any steps towards improvement in this area.

**Generational Attitudes**

Throughout the consultations, a number of comments and observations were made about how the difference in attitudes in the older and younger generations, generated different emotional reactions in the two groups.

A counsellor working at Alzheimer’s Australia stated, ‘older groups are brought up in an era where they have the attitude of ‘this is our lot in life’’. Advocates from the Younger People in Nursing Homes Campaign group reinforced this with the comment that, ‘the older generation seem to be more stoic. They battle on … whereas younger people expect more from the government and health services due to surviving more horrific traumas over the years … but people are living longer under much more high care needs so they have greater expectations’.

Some service providers observed a more accepting attitude among older, retired people and attributed it to a combination of generational attitudes and a satisfaction that they have had longer to do the things they wanted in life and throughout their retirement.

In contrast, they believed ‘younger people are complicated … they have different expectations’, and they seem to look for more active solutions than older people. Some LWML coordinators felt that many younger people wanted to hold onto their lives and made more of a commitment to do all they could to maximise the quality of the rest of their lives. Usually the younger person had family living at home with them so they decided to make the most of their time together by living their lives now as though they were in retirement, doing all the things they had planned to do when they reached retirement, similar to a person who had been diagnosed with a terminal illness.
On the other hand, some observed that younger people were not expecting to die and were still depressed, but focusing their attention on the condition rather than death. As younger people were generally more engaged in a range of things in their life, they were not as accepting of the changes enforced on their lives.

These people tended to be more outspoken and stronger advocates for the rights of younger people with dementia, coming from a generation where individuals were more likely to fight for their rights and question government decisions (for example, rallying against the Vietnam War in the 1960s). As a coordinator of a program for younger people with dementia stated: ‘younger people are more willing to speak up’.

A support group leader for carers said that in her experience ‘there are also generational issues … this age group has a different attitude to their health care. They are not as accepting as those over 80 … they are more questioning, expect more, including their rights to health care. People seem to be more educated post-war. They are from an era where people who are carers understand the field much better as we have more education.’

The generation of ‘Baby Boomers’ are more likely to actively seek solutions, take initiative, ask questions, seek information and speak up for their rights. Using this willingness to raise awareness about dementia should be extremely beneficial for others in their situation.
Chapter 5 – Financial and Legal Issues

Getting dementia has been a double-edged knife for us because it not only affects you emotionally but financially as well ... we have experienced a huge loss of income with giving up work – woman whose husband was diagnosed with dementia at 56

There seems to be no allowance in the system for financial support for people under 65 with dementia – woman whose husband was diagnosed at 44 with dementia

There seems to be greater financial issues to deal with when the person with dementia is younger – we see people who haven't paid off their mortgage, are still raising kids, don't know what to do about power of attorney ... – counsellors working with younger people with dementia and carers

Discussion about the needs of younger people with dementia should not focus solely on health and social support services, but on financial, welfare and employment needs as well. A psychiatrist who works with younger people with dementia, explained that ‘clearly there are more service systems complications with the response to those with younger onset dementia – we need to involve employment, housing, insurance, welfare, [and] family support…’

Employment

As previously discussed, for many younger people, the initial signs of dementia are often first seen in the workplace, and the subsequent decision to leave work is usually precipitated by their employer.

Many younger people spoke of how their employer organised for them to be medically assessed to determine the cause of their poor performance.

Some were then advised to take extended sick leave because it appeared that they had depression or some other mental illness. Others were diagnosed with depression rather than dementia. Although some may have had a dual condition, there were many others who were incorrectly diagnosed, which then exacerbates the overall effects.

A man diagnosed with fronto-temporal dementia at 52 expressed his dismay that even though he worked in a government health department there was no understanding of his situation from his employer. He claimed that once he had left his workplace, no one followed him up to see how he was in the way he felt they would had he been diagnosed with cancer or heart disease. He felt that his colleagues did not understand dementia, and so they chose not to keep in contact. Also on leaving his workplace ‘finance was out of the question’, as he and his partner’s income had been halved.

Some counsellors felt that ‘employment is a huge issue for younger people with dementia. The disease affects their performance initially … then there are issues with redundancy and whether they are eligible for benefits’. They discussed how younger people with dementia often stopped working without knowing they might be eligible for disability insurance under their workers’ insurance or superannuation schemes. In such cases, medical specialists needed to verify the existence of the disease while the person was still working.

While disability policies are variable, there needs to be more understanding about their significance in the community, so individuals are not forced to retire or have their hours reduced to the point that they leave without any financial payment.

The financial situation of a younger person who gives up work may be affected more significantly than that of an older person who has already voluntarily retired. With the progression of the younger person’s dementia, their spouse often has to reduce their work hours, or give up work altogether to spend time caring for the person directly.
When there is no spouse, children or friends must take on the role of primary carer. These people are also forced to reduce their employment, resulting in pressure on their own lives and immediate dependents. Sometimes the person with dementia has to employ a professional carer, which is expensive without any financial assistance. For these reasons, many people identified that financial issues were a real concern for them that needed to be addressed. One man who was diagnosed with dementia at 60 stated, ‘we worry about our finances in the future … but we must live in our means.’

Some carers commented that ‘financial burdens are now on your shoulders’ and ‘we worry about having to take care of bills and expenses when our partner was always the main breadwinner and finances are just cut off’.

One spoke of the cost of additional expenses, as she had bills of up to $10,000 for car accidents in which the person with dementia was involved. Others spoke of the ongoing worry of their future financial situation.

Families of younger people are likely to be in more complicated financial situations than previous generations, with their money located in a number of different trusts, investment properties, businesses, and mortgages that can extend for up to thirty or forty years. With the cost of housing increasing, current mortgage holders are committed to costly, long-term repayments of debts.

Superannuation is another area severely impacted. By law, superannuation can only be accessed when someone reaches the minimum age set by law, known as the ‘preservation age’. Once an individual reaches that age, they are able to access superannuation benefits without having to retire completely from the workforce. Preservation age is between 55 and 60 depending on the individual’s date of birth. Individuals can access their super earlier than the preservation age on the grounds of:

- Permanent incapacity for work;
- Severe financial hardship; or
- Compassionate grounds.

Many younger people with dementia spoke of the difficulty accessing their superannuation due to not having received a formal diagnosis. Some mentioned this was because their clinicians were hesitant to diagnose dementia when they could not determine the exact type. This further highlights the implications of delayed diagnosis for a younger person with dementia and their family.

Another woman whose husband developed Alzheimer’s disease at a young age felt that finances were at risk due to mismanagement by the person with dementia – e.g. selling shares at inappropriate times or investing poorly. This can cause huge problems for families where the person with dementia has primary responsibility for finances and their problematic financial management is not noticed early enough.

In addition, a number of carers were concerned about the legal implications of dementia, and felt that obtaining an early diagnosis was important in planning ahead. Younger people are less likely to have appointed an enduring power of attorney, or written a will. This means that with the onset of dementia, there is only a small opportunity for the person to look after these matters while they are still considered of sound cognitive ability.

Carers also called for a national unification of powers of attorney, for those people who moved interstate and had to prepare another power of attorney document. The process can be complicated and difficult; particularly as by the time of preparing the second one, the person with dementia may not have the cognitive capacity to re-appoint power of attorney.
Welfare services

Many people spoke of the frustration experienced in accessing Centrelink services, and the desire to receive consistent advice from Centrelink staff regardless of the location. One carer expressed that ‘going to Centrelink was extremely stressful for the first 12 months after diagnosis’.

While some that felt Centrelink staff were extremely helpful, others felt they were not. This could be due to disappointment at Centrelink staff not being able to provide the government subsidies that some people sought. Speaking to a social worker at Centrelink who has dealt with a number of younger people with dementia, there appeared to be inconsistencies between people’s expectations, based on their standard of living before the onset of dementia, and the assistance that Centrelink could provide after the diagnosis of dementia.

She discussed how she saw many younger people with good jobs and an extremely good standard of living, but also paying off large mortgages. Some expected Centrelink to cover the cost of maintaining this standard of living despite the limitations of a reduction in household income. This puts pressure on Centrelink, which is governed by tight regulations as to how public money should be spent on welfare services.

However, the social worker also conceded there were many flaws as certain services might be more accessible for those on pensions. For example, financial assistance for items like continence pads and medication is provided to those on a government pension, while someone with dementia whose assets prevent them from receiving a pension may be in need of financial assistance for essential items, but not able to receive it. She also said that ‘without any national statistics about the prevalence of younger people with dementia, the current legislation appears to be prohibitive to accessing payments for this group of people … we don’t know how many people we are talking about’. Therefore, the increased awareness of younger onset dementia and an understanding of the actual numbers will reap benefits in more appropriately funding welfare services.

Many carers spoke of the incredibly complex Centrelink paper system, and the social worker also admitted this to be the case. One woman whose husband was diagnosed with dementia at 57 felt that because public spending on welfare services appeared to be so tightly controlled, layers of paperwork and regulatory steps were added without considering the additional confusion and adverse effects on those trying to navigate by themselves through the welfare system.

Others spoke of the financial assistance they were entitled to if they agreed they were living under the same roof but no longer in a marriage-like relationship. This does not mean that the couple needs to be divorced; rather, if the dementia has progressed so much that the relationship is no longer what it used to be. While most carers felt there was nothing wrong in making that known to Centrelink for the purposes of seeking financial assistance, one counsellor felt this had an emotional impact on some of the carers he saw, as ‘it magnifies the isolation they feel and the non-caring attitude they experience as carer … feel it is like being separated or divorced to get a pension’.

Overall many people felt a need for clearer explanations for navigating the welfare system. They also expressed the need for more direct assistance to enable carers to understand what they were entitled to while caring for a person with dementia.
It appears that there is a greater financial impact of the onset of dementia among younger people and that more adequate services are needed for families to plan as best they can for the future. While the Living with Memory Loss Program provides couples with an opportunity to work through problems and plan ahead, there are many people who need more assistance or who unable to participate in the LWML Program for various reasons.

Further assistance is needed for families of those with younger onset dementia so they can more effectively plan for their financial future, learn what they are entitled to from Centrelink, and deal with the financial losses incurred due to loss of income.
Chapter 6 – Various Types of Dementias

There is a wider variety of types of dementia that affect people under 65. This means that the conventional understanding of dementia in older people is not always useful for younger people, particularly in regards to behavioural change and genetic risk. Access to genetic counselling and testing (if requested by family members) is important although concerns were expressed about the possibility of employment- or insurance-related discrimination on the basis of genetic predisposition.

As there is a higher incidence of rarer causes of dementia in younger people, a clearer understanding of the implications is needed in all areas of the community. For dementias caused by other primary conditions such as Parkinson’s, collaboration between service providers and/or special interest groups will provide improvements in information and service provision.

**Fronto-temporal dementia**

Fronto-temporal dementia is the name given to any dementia caused by damage to the frontal lobe of the brain. The frontal lobe governs mood, behaviour, decision-making, judgement and self-control, and so damage to this area can lead to alterations in personality and behaviour, the way a person feels and expresses emotion, and loss of judgement. Over time, a person with fronto-temporal dementia may become disinhibited, apathetic and show a change of character. For example, they may have been very considerate of others in the past but now show insensitivity. Some people with fronto-temporal dementia can also become obsessive, and repeat the same action over and over again (Alzheimer’s Australia, 2005d).

It is estimated that about 50% of people with fronto-temporal dementia have a family history of the disease, due to a mutation in the tau protein gene on chromosome 17, which causes abnormal tau protein to be produced. Other risk factors are less well known (Alzheimer’s Australia, 2005d). Further research is underway to identify other genetic causes and potential treatment targets.

A greater understanding of fronto-temporal dementia is needed among health professionals and respite workers who deal with those people affected. Greater understanding and support will also support carers who have to cope with the potentially aggressive or socially inappropriate behaviour of the person with Fronto-temporal dementia.

**Alcohol related dementia**

Alcohol related dementia is a form of dementia caused by excessive drinking of alcohol, affecting memory, learning and other mental functions. Korsakoff’s syndrome and Wernicke/Korsakoff syndrome are particular forms of alcohol related brain injury linked to alcohol related dementia. It is currently unclear if alcohol has a direct toxic effect on brain cells, or if damage is due to a thiamine deficiency caused by the nutritional problems that usually accompany heavy use of alcohol.

Symptoms can vary from person to person, but symptoms include:
- Impaired ability to learn new things;
- Personality changes;
- Problems with memory;
- Difficulty with clear and logical thinking on tasks that require planning, organising, common sense, judgement and social skills;
- Problems with balance; and
- Decreased initiative and spontaneity.

(Alzheimer’s Australia, 2005e).
At the early stage of the disease, problems may be reduced or reversed if the person stops drinking alcohol, improves their diet and replaces vitamins (especially thiamine and vitamin B1). Many people who develop alcohol related dementia are young. It means that programs are required to target heavy drinkers early on, to attempt to reduce the damage to their brain, and limit the effects of dementia on themselves and their families. It would be pertinent for campaigns aimed at preventing alcohol misuse, to include warnings about the possibility of developing dementia.

Indigenous communities were identified as a particular group where alcohol related dementia may be a problem for people under 65. With a lower life expectancy among the Aboriginal and Torres Strait Islander people than the rest of the Australian population, they may also experience a premature onset of other types of dementia.

A woman working in the dementia field among Aboriginal and Torres Strait Islander communities outlined the main issues in Indigenous communities in her experience as being:

- A lack of understanding of dementia;
- A lack of resource material that Aboriginal and Torres Strait Islander people can understand simply;
- Resources that are inappropriate for Indigenous people;
- A need for early intervention and prevention as dementia is usually diagnosed extremely late;
- A reluctance among Indigenous people to visit the doctor;
- Many combinations of forms of dementia; and
- A need for a holistic and community development approach in tackling dementia among Aboriginal and Torres Strait Islander communities.

She also mentioned a need for a prevalence study of the numbers of Aboriginal and Torres Strait Islander people with dementia, as this helped workers on the ground to plan programs, and policy makers to allocate adequate funding.

**HIV/AIDS related dementia**

When someone has the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS), they may develop a complication to the disease known as HIV/AIDS related dementia. While it is uncommon in people in the early stages of the disease, it appears to increase as the disease advances to around 7% in people not taking drugs to curb the HIV. Not everyone with HIV/AIDS will develop dementia, but some will. HIV infects nerve cells in an indirect way as immune cells already present in the brain are used by the HIV reservoirs to damage the nerve cells.

It is difficult to know whether symptoms are attributable to dementia, the HIV/AIDS, or another condition, as people with HIV infections often develop other brain disorders or illnesses, and have multiple diagnoses. Possible symptoms of dementia are:

- Difficulty concentrating;
- Difficulty remembering phone numbers or appointments;
- Slowed thinking;
- Taking longer to complete complicated tasks;
- Difficulty keeping track of daily activities;
- Irritability;

---

1 Initiatives like the Alzheimer’s Australia National Indigenous Forum on Dementia in November 2006 and the developments in cognitive assessment screening will contribute to better diagnosis and other services for this population.
- Unsteady gait or difficulty keeping balance;
- Poor coordination;
- A change in handwriting; and
- Depression.

The results of mental status tests and other mental capabilities may be normal in the early stages, as language and recognition are rarely affected in the early stages (Alzheimer’s Australia, 2005f).

In Australia, there have been no studies into the prevalence of HIV/AIDS related dementia, making it difficult to determine the appropriateness of specific services for this population group. In NSW, the AIDS Dementia and HIV Psychiatry Service (ADAHPS) provides a state wide tertiary service for people with AIDS dementia and HIV-related psychiatric conditions. ADAHPS is comprised of five integrated component services that have been developed and implemented by Central and South Eastern Sydney Area Health Services.

One of these components, that has been operating since 1997, is ADAHPT (formerly the AIDS Dementia & HIV Psychiatry Team). It is a multidisciplinary outreach service comprising specialties such as nursing, social work and psychology, to address the needs of people who are HIV positive and have complex needs (such as, those who have or are at risk of developing some form of brain impairment or dementia). The team is committed to issues of confidentiality and overcoming stigma often associated with HIV/AIDS, and for this reason has altered its name to simply an acronym to reflect this philosophy (NSW Health, 2006).

While ADAHPT was the first component of the service to accept referrals, other components of the service are:
- A residential facility (‘The Bridge’, Glebe - Royal Prince Alfred Hospital);
- Respite/step down facility (Sacred Heart Hospice - St Vincent’s Hospital);
- Psychiatric support services (St Vincent’s Mental Health Services and Royal Prince Alfred Hospital); and
- An acute stabilisation unit (St Vincent’s Hospital).

The ADAHPT website reports that these services were developed in response to a widely perceived need across NSW, for improved ways of dealing with the complex issues related to AIDS dementia and HIV psychiatric conditions. The service provides medical, psychiatric, palliative, psychosocial and community care assistance (NSW Health, 2006).

‘The Bridge’ is a residential facility run in Glebe, Sydney, as part of the Royal Prince Alfred Hospital. (A Nursing Unit Manager was consulted as part of this project.) The Bridge has provided residential care to many people with HIV/AIDS dementia, all of which are under 65 (the youngest resident ever cared for was 23). They cater for many people with mental health conditions as well as dementia and HIV/AIDS, with extremely complex health and social needs. The Bridge currently houses 11 residents – 10 permanently and one short term/respite. Although it is not intended to be a permanent residence, these people are often so isolated and vulnerable that they have no other place to go and end up staying for a few years.
While The Bridge sounds like a suitable facility, it is a two storey, old house (over 100 years), with steep staircases that are not suitable for someone with an unsteady gait, as many with HIV/AIDS related dementia develop. The Central and South Eastern Sydney Area Health Services, following recommendations made during a Departmental review, are now looking for a different facility to house the service, acknowledging this as a major growth area in HIV/AIDS care. Many of the residents also have a mental illness and their behaviour can be extremely confronting for staff. Therefore, it is difficult to find good, permanent staff. To attend to the needs of people with health problems due to HIV infection, mental illness and then dementia, staff need to be well trained in a number of areas and able to handle the complexities of the residents’ needs.

Staff at The Bridge were keen to improve communication between their organisation and Alzheimer’s Australia in order to break down barriers to better care for those affected by HIV/AIDS and dementia. It would be beneficial to take this to a wider scale with improved collaboration and communication between the HIV/AIDS field and the dementia field, so service gaps can be identified and steps taken to resolve them.

**Dementia and Down syndrome**

Down syndrome occurs in about one in every 860 babies and is caused by an extra copy of chromosome 21 in each of the body’s cells (Down Syndrome NSW, 2006). The extra chromosome causes mental retardation and atypical facial and bodily characteristics.

Chromosome 21 also houses the amyloid precursor protein gene. Malfunction of this gene can lead to the accumulation of beta amyloid in the brain, which become amyloid plaques that are characteristic of Alzheimer’s disease. Therefore, individuals with Down Syndrome have an extra copy of this gene, and double the chance of an excessive development of plaques (Alzheimer’s Association US, 2006). This is often confirmed later at autopsy.

It has been found that the prevalence of dementia is significantly higher for adults with Down syndrome compared to other adults (Holland, Hon, Huppert & Stevens, 2000), although not all people with Down syndrome develop dementia (Zigman, Silverman & Wisniewski, 1996).

With improvements in nutrition, effective prevention of infectious diseases and improved medical treatment of congenital heart disease, life expectancy for someone with Down syndrome has increased dramatically in recent years to an average of around fifty years. The incidence of dementia in people with Down’s syndrome follows a similar pattern to the general population except that it occurs some thirty or forty years sooner. That is to say, approximately 40% of people with Down’s syndrome in their 50s will show some evidence of dementia. People with Down’s syndrome and dementia benefit from an early diagnosis of dementia so that they can be given optimal medical and social care. (Down’s Syndrome Association, UK, 2005:4). This population must be considered when looking at the needs of younger people with dementia.

As the cognitive ability of someone with Down syndrome is different to the rest of the population, diagnosing dementia must take a different approach to determine a decline, compared to their normal cognitive abilities. It is also important that carers and professionals do not mistake a potentially reversible condition for dementia. Careful, expert diagnosis is essential. There is also a need for those working with people with Down syndrome to have a better understanding of the effects of dementia and how to manage changed behaviours as they arise.

At the centre of any policy relating to dementia among those with Down syndrome, must be the individual and their family support network. This is vitally important, as it is likely that the family of someone with Down syndrome has been caring for that person for a long period of time (longer than the family of another younger person with dementia). Both families’ needs are important, yet likely to be different.
**Dementia among those with other intellectual disabilities**

While it has been found that the prevalence of dementia among adults with an intellectual disability, excluding those with Down Syndrome, appears to be similar to that of the general population (Janicki & Dalton, 2000; Zigman et al., 2004), the premature ageing of this population group means that those who do develop dementia, tend to be younger.

It is important to consider their particular needs, as people with intellectual disabilities are less likely to be married or have children, and have limited employment opportunities, thus restricting their financial resources (Bigby, 2002). Therefore, a younger person with an intellectual disability who develops dementia has complex needs, encompassing health, social and financial needs for themselves and their family.

As a result, person-centred care is even more necessary. While this is a familiar notion in the field of intellectual disability, it must extend further to care for those who develop dementia. Although good work is being done by the Centre of Intellectual Disability Studies in NSW to improve screening for dementia among the intellectually disabled, as with Down Syndrome dementia, further work needs to be done to bridge the divide that exists between disability and dementia, and prevents advances for these individuals and their families.

**MS related dementia**

As with the other previously mentioned primary conditions, multiple sclerosis (MS) can affect many aspects of an individual’s life, and so the additional development of dementia creates very complex needs.

MS is a disease that affects the central nervous system and can, to varying degrees, interfere with the transmission of nerve impulses throughout the brain, spinal cord and optic nerves. Over time, MS can result in the impairment of motor, sensory and cognitive functions to a greater or lesser extent. MS affects three times more women than men, with up to 1,000 new diagnoses each year in Australia, most often diagnosed in their early thirties (McLeod, Hammond and Hallpike, 1994). Therefore, those who develop dementia additionally to the MS are likely to be under 65.

Cognitive impairment among people with MS is relatively rare, affecting up to approximately 10% of people with MS. However, it has only been in recent years that cognitive impairment amongst those with MS has been acknowledged. This is mainly because the relatively preserved attention, language and social skills in the presence of otherwise severe cognitive impairment in MS make it hard to detect on clinical interview alone. Also, anecdotal evidence suggests that in the past, clinicians have not been encouraged to look for cognitive impairment in MS because it has traditionally been considered to be a purely musculo-skeletal neurological condition. One might also make the assumption that there is additional stigma associated with developing dementia when one is already impaired with a neurological illness such as MS. Hence, a diagnosis of dementia may not be made.

There is very little Australian literature on how dementia affects those with MS and little to guide health professionals working in this area. This is an area where organisations such as the MS Society and Alzheimer’s Australia, could collaborate to produce guidance to those working in this field, as well as support, information and advice specific to this population group.
**Huntington’s dementia**

Huntington disease is a genetic, neurodegenerative disorder that causes progressive deterioration of physical, cognitive and emotional abilities. This can eventually lead to severe incapacitation and eventually death, generally 15-25 years after onset. Huntington’s disease often affects people between the ages of thirty and fifty at the rate of approximately 7 people per 100,000 Australians (Australian Huntington's Disease Association, 2006).

Dementia occurs in the majority of cases of those with Huntington’s disease, and because they are usually under 65, they are considered to have younger onset dementia. Freeth et al predicted in 1995 that there were about 750 people under 65 years of age with a diagnosis of Huntington’s disease in Australia (Freeth et al, 1995: 63), and so most of these may have or will develop dementia.

Through its website, the Australian Huntington’s Disease Association explains that in Huntington’s disease, cognitive ability does not correspond with the severity of the movement disorder. Although Huntington’s disease is an autosomal dominant, genetic disorder that runs in families, the Australian Huntington’s Disease Association of WA suggests that cognitive deficits are not genetically related – that is, a child of an affected person will not necessarily follow their parent’s cognitive changes. (Australian Huntington’s Disease Association WA, 2006).

As Huntington’s disease is genetic, a child that inherits the gene for Huntington’s disease will eventually develop the disease in their lifetime. Therefore, genetic counselling has a valuable role in the services to be provided to those with Huntington’s disease.

Freeth et al (1995) also found there are many barriers to the use of mainstream services by people dealing with Huntington’s disease. Being so young, and often with psychiatric and physical features because of their disease, many were reluctant to use Home and Community Care (HACC) services, day centres and residential services. This reiterates the point made by many of the younger people consulted – that they find it difficult to access services predominantly designed for older people, rather than younger people, hence the call for age-specific services to meet the needs of this population group.

**Conclusion**

Taking into account the various types of dementia common among younger people, it is important to get better estimates of the number and characteristics of the people affected.

There is a real need to raise awareness about the different causes of dementia, the wide-ranging effects it can have on a younger person and their family, and the ways in which a range of complex needs can be met.

With improved public awareness of what dementia is and how it can affect people under 65, stigma associated with younger onset dementia will be broken down and replaced with more understanding and willingness to provide services that meet the needs of the individual.
Exploring the needs of those with younger onset dementia

Although most dementias affect people who are older, occasionally younger people are diagnosed with dementia. The term younger onset dementia is usually used to describe any form of dementia in a person under the age of 65 years. While each person’s experience with dementia is different, there are some particular issues unique to younger people with dementia that Alzheimer’s Australia would like to explore.

Alzheimer’s Australia has received funding from the Australian Government to conduct a national project to identify and map the needs of younger people with dementia and to develop recommendations for future initiatives in this area. A policy officer has been employed at the NSW office to work on this project. The policy officer will be consulting with a number of state and territory offices of Alzheimer’s Australia and their relevant working parties, in addition to independent service providers and other special interest groups whose clientele experience some similar issues to those with younger onset dementia. We seek your valuable feedback on the following key points:

- The range of experiences people have had with younger onset dementia
- The pertinent issues for people with younger onset dementia and for their carers
- How you have been involved in addressing these issues or have seen them being addressed
- The key success factors and areas of weakness in the way issues for younger people with dementia and their carers have been addressed
- Any improvements or further action you can identify that could help better address the needs of people with younger onset dementia
- Any other comments that you think will add value to this project.

We encourage you to provide your feedback to the NSW Policy Officer, Marguerite Tyson on (02) 8875 4634 or mtyson@alznsw.asn.au

If you are happy to talk to Marguerite over the phone, you may contact her and she will organise a time to call you back.
Attachment B

Questions pursued at interviews with younger people with dementia and family members

1. What is your experience with younger onset dementia?

2. What do you see as the pertinent issues for people with younger onset dementia?

3. How have you been involved in addressing these issues? Or what have you seen to be done in addressing these issues?

4. What are the key success factors and the areas of weakness in the way issues for younger people with dementia have been addressed?

5. Can you identify any improvements or further action that could be taken to better address the needs of people with younger onset dementia?

6. Do you have any other comments that you think will add value to this project?
Exploring the needs of those with younger onset dementia –
Project information sheet

Purpose of project

Although most dementias affect people who are older, occasionally younger people are diagnosed with dementia. The term younger onset dementia is usually used to describe any form of dementia in a person under the age of 65 years. While each person’s experience with dementia is different, there are some particular issues unique to younger people with dementia that Alzheimer’s Australia would like to explore.

Alzheimer’s Australia has received funding from the Australian Government to conduct a national project to identify and map the needs of younger people with dementia and to develop recommendations for future initiatives in this area. A policy officer has been employed at the NSW office to work on this project. The policy officer will be consulting with a number of state and territory offices of Alzheimer’s Australia and their relevant working parties, in addition to independent service providers and other special interest groups whose clientele experience some similar issues to those with younger onset dementia.

We invite you to provide your views on the following key points:

- The range of experiences people have had with younger onset dementia;
- The pertinent issues for people with younger onset dementia;
- What is being done to address these issues and the key success factors and areas of weakness;
- Any improvements or further action that could help better address the needs of people with younger onset dementia; and
- Any other comments that will add value to this project.

Interview process and data collection

You will be asked to take part in a semi-formal interview that may take place over the phone or in person, depending on the circumstances. The interview will take about 30 minutes to one hour of your time, depending on how much you’d like to contribute. You can choose to involve your partner or a family member or participate by yourself. For face-to-face interviews we can arrange to meet at a mutually convenient location although we would prefer to use a private room here at the nearest Alzheimer’s Australia office if possible.
You may decline to answer any or all of the questions and may withdraw from being involved at any time.

If you agree, we may tape record the interview as that helps to understand the information more accurately. Otherwise we will just take notes.

You will be asked to sign a consent form to give your permission. However you are free to stop the interview or withdraw at any time and there will be NO repercussions for you and the support you receive from Alzheimer’s Australia will still continue.

In accordance with the Principles of the AANSW Privacy Policy Procedures you are ensured:

- The right to privacy.
- Personal details will be managed with diligence and confidentiality.
- AANSW will be open and accountable about these procedures.
- All staff involved in data collection will sign a confidentiality agreement.
- An appointed Privacy Officer shall ensure proper implementation of procedures.

Alzheimer’s Australia has approved this work and it has the backing of the Australian Government Department of Health and Ageing.

Any questions regarding the study or your part in it can be answered by calling Marguerite Tyson on (02) 8875 4634 or emailing: mtyson@alznsw.asn.au

We would be very pleased if you agree to assist us in obtaining more information about this very important topic.
Project Title: Exploring the needs of younger people with dementia

Investigator: Marguerite Tyson

1. I have read the information sheet and the purpose of the research project has been explained to me. I understand and agree to take part.

2. I understand that I may not directly benefit from taking part in this project.

3. I understand that information gained during the project may be published but I will not be identified and my personal details will remain confidential.

4. I understand that the interview may be tape-recorded and notes will be taken to assist the researcher. The tapes and notes from the interview will be stored in a locked environment for 5 years.

5. I understand that I can withdraw from the project any stage and that this will not affect the support I receive from Alzheimer’s Australia.

6. I confirm that I am over 18 years of age.

Name of Participant.................................................................................................................................

Signed...................................................................................................................................................

Dated....................................................................................................................................................

I certify that I have explained the study to the participant and consider that he/she understands what is involved.

Signed...................................................................................................................................................

Witness..................................................................................................................................................
Attachment E
List of those consulted

29 younger people with dementia
31 family carers of younger people with dementia
Dementia Advocacy Support Network International (DASNI) – two chat rooms predominantly comprised of younger people with dementia
NSW Carer Support Group Leaders forum
Carers Australia

All State and Territory offices of Alzheimer’s Australia
Alzheimer’s Society UK
Alzheimer’s Society Scotland

Neuropsychiatry Team, Royal Melbourne Hospital
Central Coast Primary Dementia Care Network, NSW
Central Coast Primary Dementia Care Network, NSW – Younger onset working party
Austin Hospital, Brain Disorders Unit, Victoria

NSW Council for Intellectual Disabilities
NSW Centre for Developmental Disability Studies
MS Society NSW
Down Syndrome Association NSW
Huntington’s Society, NSW
Brain Foundation Victoria
Younger people in nursing homes campaign group

SA Northern Collaborative Project Dementia Action Working Group - Younger onset interest group
The Bridge, Glebe, NSW - respite home for people with HIV/AIDS related dementia
The Ritz Nursing Home, Blue Mountains NSW – residential care facility that caters for some younger people
Community Options, ACT
Anglicare, Nepean Commonwealth Carer Respite, NSW
Mercy Community Care, NSW
Baptist Community Services, NSW

Social worker at Centrelink
Appendix: Literature Review and Lessons from Overseas

As the populations of developed countries age, it has become evident that the prevalence of dementia is also increasing. Recognising the potential dementia has to become an enormous public health problem for Australia, more effort and funding has been invested into research into dementia in recent years.

There are dilemmas in the area of dementia research and one of them is striking the appropriate balance between biological, psycho-social and clinical practice research (Alzheimer’s Australia Virtual Group, 2004). There is a growing body of literature about the medical features of some of the dementias that are common among younger people. Such research includes reviews of approaches to diagnosis, investigation and management of patients with younger onset dementia (for example Sampson et al, 2003) and examinations of the biological differences between dementias common among younger people compared to those among older people.

This literature review does not address specific clinical management of individuals with younger onset dementia, but rather considers overall management including diagnosis and care. It also provides a general overview of the literature about the prevalence and general social effects of younger onset dementia in both Australia and overseas.

United Kingdom

Most of the literature about younger onset dementia has been produced in the United Kingdom (UK). It covers:

- Studies of prevalence;
- Effects on carers;
- Stories from people with younger onset dementia;
- Overviews of service use; and
- Strategies for improvement in some aspects of this field.

A comprehensive, international, English language literature review was conducted by Beattie et al (2002), examining all of the available studies related to younger people with dementia. It found that 69 of the 74 relevant articles identified were from the UK. The need for specialist, flexible, age-appropriate and dedicated services was a central theme found, with a person-centred approach advocated in an individual or ‘tailor made’ model of care. This recommendation was based largely on the practical experience of professionals and paid carers, rather than scientific evidence.

Other research by Harvey (1998), indicates that there are over 18,000 younger people with dementia in the UK, which the UK Alzheimer’s Society suggests is likely to be an underestimation of the true numbers (Alzheimer’s Society, 2005a). This 18,000 represents about 3% of the 600,000 people in the UK with dementia. Harvey reported epidemiological data and bottom-up costings for younger onset dementia (termed pre-senile dementia in the report) conducted by the Dementia Research Group in the UK. Specific findings, supported in other research, were that:

- Compared to the older population, there is limited information available about the epidemiology of younger people with dementia;
- Fronto-temporal dementia is a common form of younger onset dementia. Alzheimer’s disease is not as common as it is among older people, and dementia with Lewy bodies is rare among younger people;
- As with all dementias, diagnosis can be devastating, but for someone under retirement age and with financial and family responsibilities, it can be even more distressing;
• Following the publication of the UK Alzheimer’s Society’s strategy document on younger onset dementia, it has been claimed that many Health Authorities and Trusts began to consider the needs of this group in their area;
• Between six and sixty percent of patients, depending on their diagnosis, did not undergo neuroimaging as part of their diagnostic process;
• After diagnosis, long term support and aftercare was needed for individuals as high levels of non-cognitive symptoms were identified amongst the group with younger onset dementia. Among their carers, there were reports of extreme distress and burden, and so effective community care was needed to support both groups;
• Younger people were relatively low users of community care resources, leading to lower than expected overall costs for the group. However, there was higher usage of residential care which was estimated to have twenty times the cost of community care;
• The mental health needs of carers were found to be substantial, with more than half reporting a degree of stress that could be considered a formal psychiatric illness – only a small number of these people reported that their needs were recognised;
• In terms of cost, dementia among younger people appeared to be relatively more costly than dementia among older people. While the study did not consider indirect costs, a younger person and their primary carer were more likely to sacrifice more years of work, bearing a higher economic impact;
• The average cost of alcohol-related dementia was the highest per person, with vascular dementia and fronto-temporal dementia also costly. Alzheimer’s disease was the second lowest in average costs; and
• Individual packages of care were recommended for younger people.

Harvey also noted the changes in the mental health field during the 1980s that had contributed to recognising younger people with dementia as a distinct patient group. Prior to the eighties, people with dementia under 65 years, would have been cared for by a psychiatrist in an institution who, in that era, would have been responsible for all ages with dementia.

From the early 1980s, there were changes worldwide to dementia care, similar to the way in which care for people with other chronic conditions was also changing. The strong shifts from institution-based service to community care meant that people with dementia were more likely to be cared for in their homes than long-stay institutions. Instead of conventional medicalised and institutional care, the new social model of dementia care was to be responsive to patients’ psychological, social and emotional needs (Fleming et al, 2003:88).

Along with deinstitutionalisation, the development of geriatric services resulted in dementia care being predominantly catered for by geriatricians and psycho-geriatricians. For a younger person with dementia this meant a rigid exclusion from a variety of specialist services. Neurologists were usually responsible for diagnostic assessment but not follow up. Specific dementia services were provided by geriatricians designed to cater for older people. Even when able to access geriatric services, this had distressing implications, as the younger person and their family were among clients 20-40 years older than themselves (Quinn, 1996). Consequently, the majority of younger people with dementia were cared for by their families in the community (Delaney and Rosvinge, 1995), and accessed very minimal services (Baldwin, 1994; Newens et al, 1995). Baldwin (1994b) and Sperlinger and Furst (1994) found that these family carers were generally stressed, but accepting of their role.
UK Policy documents

The Alzheimer’s Society in the UK has produced a number of documents about the status of younger people with dementia, and its mission to improve services available for this group. The Society’s policy document: *Younger people with dementia: an approach for the future* (Alzheimer’s Society, 2005b), presents a review of the Society’s position on younger people with dementia based on an evaluation of its programs, widespread consultations and surveys, and the establishment of a working group to produce a strategic plan to support younger people, their carers and families in England, Wales and Northern Ireland. It discusses two key themes:

- The need for specialised services for younger people with dementia; and
- The role of the Alzheimer’s Society in helping to improve the support offered to younger people, including priorities for short and longer term.

The document provides information about the issues younger people with dementia face, including problems with delayed diagnosis partly due to lack of awareness among medical professionals, who often dismiss younger people as being stressed or misdiagnose them with depression (Quinn, 1996).

The Society notes that younger people may be at work when diagnosed, have a young family, be more physically active than older people, have greater financial commitments, such as a mortgage, and are more likely to have a rarer form of dementia.

The document refers to a number of studies that outline the difficulty that younger people find in accessing services, such as being made to ‘fit’ a service, rather than the service fitting their needs (Furst and Sperlinger, 1993; Keady and Nolan, 1997), experiencing varying levels of care and support (Allen and Baldwin, 1995; Barber, 1997), and a general feeling among many younger people with dementia that they are ‘lost’ in the gaps between services.

The Alzheimer’s Society has presented a number of recommendations to resolve some of the issues for younger people with dementia, particularly with regard to the services available to them. These include removing some of the age related barriers by:

- Raising awareness of younger onset dementia among health professionals;
- Removing discriminatory age barriers to dementia services;
- Appointing individuals who are responsible for younger people (similar to case managers); and
- Developing clear pathways through care services.

The Society also recommends that the needs of younger people with dementia require an individualised response, which addresses them exclusively as a separate group with distinct needs, but also inclusively as part of the larger group of people with dementia. This may necessitate the provision of services that cater for younger, more active people rather than traditional dementia services set up for people of an older, less physically active generation.

It is difficult to assess the influence the Alzheimer’s Society has over public policy and external service provision for younger people. The Society suggests that many of its recommendations from its 1996 strategy for younger people with dementia have, in some way, been incorporated into the recommendations of other agencies, for example, policies like the National Service Framework for Older People (UK Department of Health, 2001) and the UK Royal College of Psychiatrists (2005). The Society’s Charter for Younger People with Dementia (at Attachment 1) has been used in policy documents and referenced in many guides for services for younger people with dementia. The development of this charter is a key step in acknowledging and respecting the needs of younger people as it sets a standard that appropriately values this sector of the population.
National Service Framework for Older People

Another milestone in recognising younger onset dementia as an area of need is the National Service Framework for Older People (2001), produced by the UK Department of Health, which sets the standard of patient care provided by the UK National Health Service (NHS). In this Framework, dementia is regarded within the mental health field under the NHS. Therefore, services for younger people with dementia are generally provided by the health sector rather than the disability or aged care sector – a marked difference to the nature of service provision in Australia.

The document outlines that working arrangements and protocols should be developed for making and accepting referrals from hospital and mental health specialists, primary and social care services and the adult mental health service, where many of the younger people with dementia will be found. The Framework sets a standard for continuity of care when patients transfer from these mental health settings to specialist services for older people (Department of Health, 2001:106). It also outlines that specialist mental health teams should make links to voluntary organisations and support groups such as the Alzheimer’s Society (emphasising in some degree the Society’s influence).

In a pledge for action, the Framework calls for the NHS and councils, to: ‘review current arrangements, in primary care and elsewhere, for the management of dementia in younger people, and agree and implement a local protocol across primary care and specialist services, including social care’ (UK Department of Health, 2001:106).

This mandate is a strong step towards recognising the unique needs of younger people with dementia, and, although it did not offer further practical solutions to resolve the issues, the manner in which the UK Department of Health has accepted responsibility for this area has provided good leverage for improvements in the area.

Services for Younger People with Alzheimer’s Disease and Other Dementias

The UK Royal College of Psychiatrists (the College) responded to the influx of younger people with dementia to old age (also known as geriatric) psychiatry services during the 1990s, by joining the Alzheimer’s Society in releasing a policy paper in 2000 outlining services for younger people with dementia.

While the document is said to have been well received and some recommendations put into practice, a College review found that no health area had fully implemented all the recommendations. The Royal College of Psychiatrists recently released a revised version of the document, Services for Younger People with Alzheimer’s Disease and Other Dementias, once again co-published with the UK Alzheimer’s Society. The document builds on the two key recommendations of the original document:

- That an incremental approach be taken with two key players appointed from the point of presentation: a named person responsible for planning and a consultant clinician (for example, the old age psychiatrist) to act as a focus for referrals; and
- The creation of a local service involving networking with people already involved in servicing younger people in that area.

In the document, the College calls for more attention to services for people with alcohol related dementia, familial forms of dementia, and with learning disabilities and dementia.

The College notes that as alcohol related dementia is a preventable and, in some cases, treatable form of dementia, representing about 10% of younger onset cases according to Harvey et al (2003), it is important that effective measures be taken to develop the provision of support and care for people with alcohol-related brain impairment.
It suggests that about 40% of people with Down Syndrome in their early fifties have been found to have dementia (Royal College of Psychiatrists and Alzheimer’s Society, 2005:14), and that there is a higher prevalence of dementia among those with learning disabilities than the general population.

It called for more support for psychiatrists and other professionals working in specialist learning disability services, to better service those who develop dementia. Some reference is made to the incidence of HIV-related brain impairment, dementias caused by prion diseases and familial forms of dementia and the need to increase awareness among old age psychiatrists. The document recommends that contact between old age psychiatry and genetic counselling services, where available, should be encouraged (Royal College of Psychiatrists and Alzheimer’s Society, 2005: 14-15).

The College emphasises the importance of improved coordination and liaison between specialist areas, especially in the early phase of the illness when a range of specialists is usually involved in the diagnosis. In particular, collaboration between old age psychiatry and neurology is stated as a crucial factor. The Association of British Neurologists has expressed interest in becoming more involved in this area and so, a joint working group with the Alzheimer’s Society, the College of Neurologists and the College of Psychiatrists has been recommended to work on the next edition of the policy document.

The document provides evidence of the value of communication across disciplines and professionals, as well as improved general awareness of younger people with dementia regionally and nationally. In some areas of the UK, the emergence of regional forums for younger people with dementia has helped this markedly. Regional forums meet regularly, usually every quarter or 6 months, and give service providers an opportunity to meet with others, share experiences and good practice, and learn about new developments in their local area (Royal College of Psychiatry and Alzheimer’s Society, 2005: 24).

**Literature about the need for appropriate services**

While the UK awaits the outcomes of the implementation of the aforementioned policies, there is an abundance of literature that highlights the specific needs of younger people and the difficulties in finding appropriate services.

Ferran et al (1996) provided the clinical characteristics and level of service use among 200 younger people. The study confirmed the findings of previous studies (Marsden and Harrison 1972; Ron et al, 1979) that there are significant difficulties with the clinical diagnosis of dementia among younger people. For example, after comprehensive assessment of all patients, one third were given an unknown diagnosis or an unspecified dementia diagnosis. Poor emotional wellbeing was also found among the patients. The study concluded there is a need for specialised, multidisciplinary services for younger people, both diagnostic and supportive. This could mean coordinating, supplementing or modifying existing services, if deemed a more appropriate approach than creating them (Ferran et al, 1996).

Freyne et al (1999) also conducted a comparative study of the clinical characteristics of those with younger onset dementia and later onset dementia, measuring the level of carer burden in both groups. It was found that carer burden was significantly higher among carers of younger people, although there were no significant differences between the groups in the severity of dementia or behavioural disturbances. An inverse relationship was found between the carer burden and the patient’s age, with the authors suggesting that community care for those with dementia needed to be further encouraged.
Another UK study assessed the health needs of younger people with dementia living in Leeds and evaluated the current provision of services for them (Williams, Cameron and Dearden, 2001). The study explored the route to specialist services for these people, and found that it was often uncoordinated with multiple referrals, making patients feel like they were moving from ‘pillar to post’. Thirty eight different pathways of care were identified, with many referrals between psychiatry and neurology. Younger patients reported extreme emotional distress, particularly due to their decreased ability to take part in everyday life. Most carers reported that they had not received sufficient information, practical help, support or counselling along the confusing path of service provision.

Recommendations included the establishment of a multi-disciplinary diagnostic service that would reduce the time between first referral to diagnosis and follow-up. Reiterating the outcomes of many other studies, the authors also recommended the establishment of a single gateway to information, advice, expertise and appropriate care (Williams, Cameron and Dearden, 2001).

Younger people with dementia – a guide to service development and provision
The Alzheimer’s Society’s publication Younger people with dementia – a guide to service development and provision (Alzheimer’s Society, 2005c) looks in detail at the development of services for younger people with dementia, and the factors that contribute towards providing a quality service.

Specific guidance is provided, drawn from the good practice and experiences found in existing services. The Society suggests that the estimate of 18,000 younger people with dementia is likely to be an underestimation and that epidemiological studies suggest that the numbers in this group are significant enough to justify separate recognition including specialist services.

The publication notes that in the UK, clear patterns have emerged from locally based research studies documenting the needs of younger people. These include:

- The need for an accurate and comprehensive diagnostic service, in the context of improved awareness of younger onset dementia in primary care;
- That younger people with dementia have greater physical strength and abilities to be taken into account;
- They may also have complicated and stressful emotional and family issues, particularly where there is heavy financial commitments (such as a mortgage);
- Consideration of the needs of the primary carer and the surrounding family is warranted, particularly where children are being raised; and
- The higher prevalence of the more uncommon causes of dementia among younger people justifies service provision that reflects this diversity.

The Society provides three examples of services specific to younger people that have been set up in the UK, and looks at some of the considerations that policy makers and health professionals should take into account when planning a service for younger people, based on research, observation of services and experience. These considerations cover:

- Referrals to the service;
- Assessment of the user’s needs and risks;
- The care plan of the person with dementia;
- Monitoring and review of the services offered;
- Possible suspension and withdrawal of service;
- The physical setting and size of the service;
- Transport issues;
- Meals and refreshments;
- Activities and stimulation;
- Personal care of the clients;
• Health and safety;
• Staff recruitment;
• Training and development; and
• Marketing of the service.

Examples of services for younger people
In the UK there are a variety of services offered to younger people with dementia, including those that are home-based, day centres or residential care facilities. The Clive Project is the only service specifically for younger people with dementia in Oxfordshire in the UK. It has developed a comprehensive information resource on a wide range of issues relevant to younger onset dementia.

The resource estimates there are about 190 younger people with dementia as the primary diagnosis in Oxfordshire and the majority of these people are between 50 and 65 (The Clive Project, 2003:8). The resource provides information about dementia in general, how to get a diagnosis (including advice in dealing with the general practitioner), what to do after diagnosis, some local counselling services, research and treatment, where to get help, how to take a break, assistance with dealing with financial and practical matters, how to get out and about, and ways people can be involved in campaigning, challenging and commenting on the issues of younger onset dementia. The resource provides a comprehensive guide to local services for younger people and takes the holistic point-of-view that ‘dementia affects many aspects of life’ (The Clive Project, 2003:2).

Since 1998, the Clive Project has run a home-based service for younger people with dementia. Named after Clive Beaumont, a younger man with dementia, the Clive Project aims to support younger people with dementia in Oxfordshire in pursuing activities of their choice. Trained support workers partner people with mild to moderate symptoms of dementia and provide between 2-4 hour sessions per week of highly flexible, individually tailored content. Emotional, practical and health promoting support is not only provided to the younger person, but also to their family and friends. Information and referral to services are provided, and an opportunity for regular breaks from caring is also available for the family when needed (The Clive Project, 2003:28).

The Templeton Day Centre in the Harrow and Hillingdon areas of the UK, is an example of a day centre specifically for younger people with dementia. As the literature on this area highlights, younger people feel that they do not fit into day centres where the clientele are at least twenty years their senior, and there is a need for stimulating activities specifically catered for younger people.

The Templeton Day Centre provides the solution to both of these problems. Run by the Harrow and Hillingdon branch of the UK Alzheimer’s Society, the centre has two lounges, a dining area, activity room, counselling/meeting room, six toilets, a bathroom with laundry facilities, and a paved terrace and garden with countryside views. Up to 15 people per day can be supported by the centre, for three days a week, with priority given to younger people with dementia (although there is no age limit). A variety of activities are offered, including discussions, outings, aromatherapy, art, gardening, music and quiz nights (Alzheimer’s Society, 2005c:24). Information is also available in Punjabi.

A UK example of a residential care facility specific for younger people with dementia, is that at Lock Cottage – Merevale Residential Home in Warwickshire. In the privately owned residential home, Lock Cottage is a converted, lock keeper’s cottage that provides a home for four younger people with dementia. Designed like a normal home, the residents each have their own room with ensuite, and can decorate the facility as they please. They are supported in their use of the small but fully equipped kitchen, and are encouraged to get involved in everyday activities, including tasks around the house and garden, and care for a motor car. Aromatherapy and reflexology are also provided, and are claimed to have led to a reduction in medication. The age range of the residents is 39 to 59 years.
Four other beds are used in the main Merevale Home for younger people in the later stages of dementia (Alzheimer’s Society, 2005c:26).

**Website about Younger People with Dementia**

The *Younger People with Dementia* website, established by the UK Alzheimer’s Society, provides a user-friendly gateway to information, support and other services. The website’s home page has a number of links to news and events, information, publications, services in the UK and national conferences. Members of the public can also sign up to YPWD news, an email newsletter about the Society’s work.

Information is provided on the website about the Alzheimer’s Society’s training program *Supporting younger people with dementia and their families,* that is run twice a year. There are also many links to international websites about younger people with dementia and further resources. The Society sees this website as being very useful in locating as much information as possible in a single area, and being linked from the Society’s home page is also helpful. It is estimated that the Younger People with Dementia section generated between 1,000 and 2,000 visits per month. More importantly, it gives younger people a separate identity and emphasises the distinct needs of the group (Cosgrove, 2006). This is a particularly powerful tool given the increasing use of the internet in today’s society.

The Younger People with Dementia website contains a link to an online database of over 100 services around the UK specifically for younger people with dementia and their families, including day centres and clubs, nursing care, respite and residential care. By simply clicking on a location in the UK, one of ten options of service type in the area is brought up. A brief overview of the service is provided, including names, contact email addresses and phone numbers, the area covered by the service, what provisions are provided, and a link to further online information about the service. The Alzheimer’s Society believes the database is a useful tool as it can help signpost people towards services, as well as acting as a mapping tool for the development of appropriate support.

**Conference on Younger Onset Dementia**

Since 2001, the UK Alzheimer’s Society has run annual conferences about issues related to younger onset dementia. The conferences have covered themes such as younger people and social exclusion, quality services for younger people with dementia, rarer causes of dementia, and collaboration between neurology and old age psychiatry in the diagnosis and management of younger onset dementia.

The multiple opportunities presented with such a conference include:

- Providing a forum for younger people and their family members to share ideas and experiences with service providers;
- Highlighting issues affecting younger people and their families in accessing timely and accurate diagnosis, appropriate community support services and residential care;
- Raising awareness of the specific needs of younger people and their families and gaps in existing services;
- Showcasing models of practice from Australia in meeting the needs of this target group;
- Exploring systems challenges presented by this target group (for example, the divide between the aged care, disability and health care systems);
- Sharing resources to inform practice with this target group; and
- The possibility of creating a national network of service providers and consumers which can continue to share information and ideas and advocate for the needs of this target group.
Other literature

The Journal of Dementia Care, launched in 1993, is a multidisciplinary, bi-monthly journal aimed at professionals working with people with dementia. Since its inception, the Journal has published a number of articles highlighting the unique needs of younger people, as well as providing information on the launch of new services in this area.

Some articles provide individual experiences of younger people. For example, the article by Isaacs (1998) describes how Alzheimer’s disease affected two individuals under 65 years. Isaacs stresses that awareness and understanding of the feelings that they experience is crucial to successful support. Some guidance is provided about the process of informing the individual of the diagnosis, with suggestions that diagnosis be given with discretion and sensitivity, with immediate follow up counselling for the individual and their family members.

Duncan (1998) discusses the genetic and family issues for a young person with familial Alzheimer’s disease (FAD), noting that it does not differ pathologically or clinically from sporadic Alzheimer’s disease, but usually has a younger age of onset (with signs appearing in the thirties upwards). Issues such as deciding whether to get married, have children or plan a career, strain in relationships. Not knowing who will develop the disease in the family and whether to seek genetic testing are all further complications in the situation. Even genetic testing for Alzheimer’s is not straight forward due to the number of chromosomes involved. Duncan asserts that the ‘effects of familial dementia on the affected individual and their families should not be underestimated’.

An article by Pollen (2004), presents a personal account of the difficulties he and his wife, who was diagnosed with Alzheimer’s disease at 47, faced in regards to employment and health services.

Chaston, Pollard & Jubb (2004) discuss the unusual proactive approach to improving awareness of younger onset dementia and empowering younger clients to have a say about the care they receive. They say that dementia being unusual in those under 65, contributes to a delay in diagnosis (Ferran et al, 1996), while other literature highlights that few people are informed of their diagnosis by practitioners (Rice and Warner, 1995), and are rarely directly asked about what they want from their services (Reed et al, 2002). The authors conclude that younger people with dementia are a marginalised group who are often ‘fitted in’ to existing services that do not necessarily cater for their needs.

Other articles in the Journal of Dementia Care cover areas such as groups providing social activities (Casey, 2004), the importance of integrated care pathways (Saad, 2004), an overview of two forums to address services and seek solutions (Gutteridge & Heiser, 2004), a user and carer’s view of the Manchester Younger Persons’ Dementia Service (Shlosberg et al, 2004), and attempts to provide person centred care for younger people in the Birmingham Working Age Dementia Service (La Fontaine, 2004). Nurock (2000) describes her story as the wife of a general practitioner who developed Alzheimer’s disease in his fifties. She emphasises how improved primary care might have reduced the devastation her family experienced (Nurock, 2000).

Ireland

In August 2005, the Alzheimer’s Society of Ireland released the policy document Early-onset Dementia: the needs of younger people with dementia in Ireland. The document was based on the outcomes of a study of 61 cases of younger-onset dementia in Ireland. The study explored the most pertinent issues emerging, namely:

- The need for a timely diagnosis;
- Informing the person with dementia about their condition;
- Supporting flexible care arrangements;
• Improving home help, day care, respite care, residential care, and medical care;
• Providing counselling; and
• Improving financial supports.

The document covers the difficulties of predicting numbers of younger people with dementia in Ireland as there are not precise estimates of the numbers of people of any age with dementia in Ireland. Applying prevalence rates of dementia from European studies to the 2002 population in Ireland suggests that there are currently 33,000 people with dementia, of which 3,500 are under the age of 65 (Alzheimer’s Society of Ireland, 2005: 2).

From the study of 61 people, the document provides further information about the symptoms of younger onset dementia and aspects of the experience of dementia, including relationships with partners and children. Recommendations provided for services relating to younger people with dementia include:
• An awareness campaign among general practitioners;
• A public awareness campaign by the Alzheimer’s Society;
• A sustainable set of care arrangements that respects the wishes of the person with dementia and their family;
• An increase in the overall level of home help;
• Specific support groups to be set up;
• An improvement in respite facilities, including specific services for younger people;
• Improved residential care facilities through increased number of residential care places for younger people and a review of the access criteria;
• More counselling services;
• A review of financial supports; and
• Reduced fragmentation of services for the elderly, disability services and mental health services.

United States

In the United States there have been several studies highlighting the unique needs of younger people with dementia, and a number of reports of the biomedical aspects of some of the more common types of dementias affecting younger people.

A notable policy report recently released by the Alzheimer’s Association, Early Onset Dementia: a national challenge, a future crisis, provides a preliminary view of the unmet needs of Americans with early onset dementia and their families. The report uses information from a national study known as the Health and Retirement Study (HRS) and a 2004 Alzheimer’s Association study, among others to draw the conclusion that younger people with dementia are a vulnerable group with unique circumstances and specific needs that are often not met.

The report gathers evidence of the numbers of those with younger onset dementia in the United States from the HRS – a large-scale, longitudinal survey of a nationally representative sample of people aged 50 and older in the US, including those living in residential care facilities. The HRS found that 480,000 Americans aged 55-64 had cognitive impairment at a level severe enough to be considered disabling (University of Michigan, 2000). It quotes that some commentators estimate that 6-10% of all people with Alzheimer’s disease may have onset of symptoms before age 65 (Alzheimer’s Association, 2003; the Mayo Clinic, 2005).
From the HRS study, responses to the Alzheimer’s survey (94 responses were completed by younger people with dementia and/or some family members or care partners) and a study of those with younger onset dementia (Harris & Keady, 2004), six main areas of concern were identified for younger people with dementia. These areas are:

- Difficulty getting an accurate diagnosis;
- Loss of employment and job-related income;
- Difficulty obtaining Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) and other disability payments;
- Lack of health insurance and high out-of-pocket expenditure for medical care;
- High out-of-pocket expenditures for long-term care; and
- Lack of appropriate medical care, residential care and community services.

Most of these issues were brought up in literature in the UK. However, due to the health and community care system of the United States being largely a private, user-pay system, financial issues are compounded for those living in the United States.

The report provides a number of steps to help reduce the problems raised:

- Promotion of greater general awareness of younger onset dementia;
- Research to develop more precise information about the prevalence of those with younger onset dementia, and the diseases and conditions that cause their dementia. The report indicates this is necessary to support greater general awareness, training for medical, residential care and community service providers, and planning for services;
- Research on approaches to preventing and delaying the onset and progression of diseases and conditions that cause dementia among younger people; and
- Engaging younger people with dementia, as individuals or in groups, (e.g. the Alzheimer’s Association consumer groups, and DASNI – Dementia Advocacy Support Network International), plus families, researchers, health care and community service providers, employers, human services personnel, government agencies and private organisations, to identify the needs of this population group and plan appropriate services for them.

An interesting set of suggestions made by younger clients of the Alzheimer’s Association recapitulates that it is imperative to include the person with dementia in decisions. The younger members’ suggestions were to:

- Provide services that reflect the needs of younger people with dementia based on their perceptions of their needs;
- Never assume that the person with dementia is doomed or incapable;
- Increase knowledge about younger onset dementia and sensitivity to the feelings of people with the condition, among doctors and other health care professionals;
- Provide support groups specifically for younger people with dementia;
- Provide opportunities for social interaction;
- Provide opportunities to work on a volunteer or part-time basis;
- Provide adult day programs for younger people with dementia; and
- Provide help for the person’s family, especially young children and teenagers.

Family members and other care partners provided similar suggestions:

- Provide information about younger onset dementia and available services;
- Increase knowledge about younger onset dementia among health professionals;
- Provide support groups specifically intended and convenient for families of people with younger onset dementia;
- Provide adult day care that meets the needs of younger people;
• Provide in-home respite care and supervision;
• Provide transportation; and
• Provide work and volunteer opportunities.

The report acknowledges that while solutions offered may seem unrealistic, as they are interrelated, progress in one area is likely to lead to progress in another. This is an important consideration in implementing changes in Australia particularly where there are limited or no services for younger people with dementia. Throughout the report, incremental changes have been recommended that take into account the constraints of the system in which services may be provided.

Attachment 2 outlines the steps recommended by the US Alzheimer’s Association to reduce the problems affecting younger people with dementia and their families, including the areas of diagnosis, loss of employment and inadequate services in the health, community and residential care setting. Many of these solutions focus on better training for health professionals and linking in with employers to provide understanding and practical options for the person with dementia who is often still working at the onset of the dementia.

A study by Harris (2002) provides more information on the experiences of younger people, using a social model to highlight their needs and provide recommendations for social workers in the field. Through focus groups, face-to-face interviews and online interviews with 23 younger people with dementia, Harris found that the main issues facing this group were:

• Trouble obtaining a proper diagnosis;
• Issues of selfhood and self esteem;
• Changing roles and relationships in the family structure;
• Awareness of change in self;
• Workforce/retirement/financial issues;
• Extreme social isolation;
• Off-time dependency (that is, dependency on others earlier than expected due to dementia); and
• Boredom and lack of meaningful occupation.

Harris concluded, ‘being diagnosed with a dementing illness at a young age is a unique experience with different struggles and challenges’ (Harris, 2002:16). He provided suggestions for social workers in the field, including:

• Improved diagnostic services for younger people;
• The treatment of younger people as equal partners in their medical care (a crucial generational difference compared to older people);
• More opportunities for younger people to take a proactive role in dealing with their disease;
• Improved genetic counselling;
• The eradication of stereotypes of those with Alzheimer’s disease;
• Peer support groups for younger people with dementia;
• More awareness in general about younger onset dementia;
• Financial counselling; and
• An awareness of the impact dementia has on the whole family, including children.

(Harris, 2002:17-18)
Another important initiative from the United States is the production and distribution of Perspectives, an 8-page quarterly newsletter for people with dementia. Originally only available in print, the newsletter is now available by email. It covers personal experiences of people with dementia, updates on research, tips on living with dementia, in-depth information on particular topics such as driving or support groups, and a question and answer column.

**New Zealand**
In New Zealand, the Alzheimer’s Association offers an information sheet on its website: *Younger People with memory loss* directed at those who may be worried about changes in their own abilities or someone they know. The information sheet provides details about the process of diagnosis, with reasons for the extensive testing process, and the difficulties of diagnosing a younger person with dementia, warning the younger person that the process may be lengthy.

Information is given about employment and financial matters, advice for carers, partnership, children and the link between Down’s Syndrome and Alzheimer’s disease. No information is provided about services specific to younger people with dementia.

**Australia**
In Australia, there is a growing interest in the needs of younger people with dementia. While numbers appear to be small and geographically spread across the country, there does appear to be sufficient younger people in the various regions who would benefit from a suite of specific services.

**The National Framework for Action on Dementia**
The main Australian policy document that provides the blueprint for services for people of all ages with dementia, is the *National Framework for Action on Dementia* prepared under the auspices of the Australian Health Ministers’ Conference (AHMC). It estimates that the number of people with dementia under the age of 65 will rise from about 9,990 in 2005 to 14,220 in 2020 (AHMC, 2006:2). The Framework provides significant progress towards acknowledging the unmet needs of younger people with dementia, as it identifies them as a distinct group with unique needs that are not met through current service arrangements.

The aim of the Framework is to provide an ‘opportunity to create a strategic, collaborative and cost-effective response to dementia across Australia … guided by a shared vision that seeks a better quality of life for people with dementia, their carers and families, and identifies achievable goals for all Australian governments that will make a positive difference’ (AHMC, 2006:1).

Five key priority areas have been identified in the Framework:
- Care and support;
- Access and equity;
- Information and education;
- Research; and
- Workforce and training.

The Framework looks beyond aged care to consider the health care and support dimensions of dementia, while acknowledging housing and income support are outside the Framework’s scope. The document includes initial information about the impact of dementia, then addresses each key priority area, and finally provides a brief overview of how the Framework will be implemented and evaluated. In each key priority area, a number of actions have been assigned to the responsibility of a lead agency (either a State/Territory or the Australian Government).
The Framework acknowledges that the Australian service system providing care and support for people with dementia and their carers is complex, and due to its haphazard nature at times, has areas of service duplication and gaps that go unnoticed. This is an important acknowledgement with regards to younger people with dementia.

Younger people are identified as a target group for improving access to care and support (AHMC, 2006:12), and as a group for which research is needed into what support, care and education works best (AHMC, 2006:14).

The Framework also considers the prevalence of dementia in Aboriginal and Torres Strait Islander communities. While mortality is higher in these communities, suggesting that fewer Aboriginal and Torres Strait Islander people reach old age (when dementia is more common), higher morbidity rates suggest that dementia could be a problem because of earlier aging among this group. This means that many of those with dementia who are Aboriginal or Torres Strait Islander people are likely to be under 65. However, little is known about the prevalence and impact of dementia in these communities, so the Framework calls for more research to plan and develop effective support for these communities. The Framework has set improvement in research and access to care and support for Aboriginal and Torres Strait Islander people as priorities for action.

The Framework also notes the prevalence of dementia among people with Down syndrome – found to have a dementia prevalence of between 20 and 55 percent in those aged 50 to 59 compared with 1 per cent for the rest of the population (Zigman et al, 1997). The Framework highlights that ‘comprehensive linkages between dementia services and other parts of the health care and disability support systems are required to meet the need of people with a dual diagnosis’ (AHMC, 2006:4). Reducing barriers to care and support for people with dementia and another cognitive impairment/dual diagnosis (including those with Down syndrome) is identified as a priority for action, along with improving research in this area.

**Alzheimer’s Australia**

As the peak body for those with dementia and their family carers, Alzheimer’s Australia provides information, services and community advocacy for this client base, including younger people. As the majority of those with dementia are over 65 years, most of the organisation’s clientele are older. However, there are good models of social support and care in place for younger people with dementia and their families and carers (e.g. Living with Memory Loss Programs, respite services for younger people, friendship clubs and forums).

Alzheimer’s Australia offers the public a number of fact sheets about younger onset dementia, and guides about planning ahead and employment issues. In addition, libraries in each State and Territory organisation offer a number of articles about the issues faced by younger people with dementia.

**Signposts** is a document published in 2002 by the former Alzheimer’s Association of NSW with funding from the NSW Department of Health as part of its Care for Carers initiative. It provides information identifying resources to assist families impacted by dementia prior to 65 years of age. The resource is aimed at families of younger people and health professionals working in the field, providing basic information about the main issues, telephone numbers, and sources of further information that can be accessed when needed.
The document notes the specific characteristics of those diagnosed with younger onset dementia, including the greater likelihood that they are raising a family, may still be working, have significant financial commitments, and responsibilities in their extended family and the community (Alzheimer’s Association NSW, 2002: 3). It provides detailed guidance about:

• How to manage the difficult period after diagnosis;
• How to notice symptoms of depression and anxiety in the younger person recently diagnosed with dementia;
• How to plan for the future (whereby involvement of the individual in the decision making is imperative); and
• Some detail about living arrangements, social activities and residential care options for the person with dementia.

The document also stresses the importance of the carer accessing respite care, to give carers the opportunity to recharge and avoid ‘carer burnout’.

Information is given about programs run by the Alzheimer’s Association for younger people with dementia and their carers, including Living with Memory Loss Programs, carer support groups, counselling, the Dementia Helpline and the National Dementia Behaviour Advisory Service.

Contact details of other relevant programs or agencies are also given, including Aged Care Assessment Teams (ACAT), Carers Australia, Carer Respite Centres, Commonwealth Care Link Centres, financial planning information and assistance, the Guardianship Tribunal, the Office of the Public Advocate and guidance on complaints resolution. Websites that provide further information have also been listed.

Signposts provides valuable initial information for a younger person recently diagnosed with dementia and for their family members and other health professionals. Accompanied by the Alzheimer’s Australia fact sheets on Younger Onset Dementia, it is an excellent overview of the many social, financial, emotional and future considerations a younger person with dementia faces. While the document at present is out-of-date, it would be beneficial if updated and re-released in memory clinics, general practitioners’ surgeries and Alzheimer’s Australia offices across Australia.

The Young Mind – Issues in relation to young people and dementia
Another policy document that provides a good overview of the needs of younger people with dementia in Australia is by Freeth, commissioned by the Alzheimer’s Association (1995). While it is difficult to obtain a copy of this document, The Young Mind – Issues in relation to young people with dementia, it describes in detail a research project about issues in relation to young people and dementia.

Freeth used a wide range of sources, including personal consultations with carers of people with younger onset dementia in all states/territories, and with health and human service professionals in Australia and overseas; a literature review; and a national survey of carers, which the document claims was the one of the most extensive to date (Freeth, 1995:4). It appears that this is still the case, as there have been no national surveys of carers of younger people with dementia conducted in Australia since Freeth’s work.
Freeth concludes that as dementia under 65 is uncommon and may develop in a seemingly fit and physically strong person, formal recognition that something is wrong can be a long and frustrating process. Due to difficulties in getting a diagnosis, Freeth found it is often difficult to track down and identify these younger people with dementia and their carers. Freeth’s recommendations cover government reviews of national and jurisdictional action plans for dementia, so that the needs of younger people with dementia are identified. The National Framework for Dementia shows some progress in this area although there is potential for further work in implementing particular programs.

Other recommendations by Freeth include:
- The development and promotion of strategies to increase the rate of post mortem investigations for people with younger onset dementia;
- A review of the effectiveness of memory clinics for assessing dementia in general; and
- A review of the role of the Aged Care Assessment Teams to promote standard approaches to younger people with dementia.

Freeth calls for the implementation of programs to educate and assist GPs and other medical specialists in managing younger people with dementia, with further counselling for individuals and families, and two new programs among Alzheimer’s Association offices for support groups/structures for the individual and their children.

While Freeth did not believe the establishment of a specialised day centre service to be feasible at the time, he suggested alternative strategies to provide day care services, including clustering in existing day services with specific programs for younger people (e.g. a mobile service or longer opening hours to cater for carers working full time hours). He also recommended a review of accommodation policies that addressed the physical design of residential care facilities that house younger people with dementia, the exploration of cohabitation of different groups of younger people with similar needs and the need for better education and training programs for staff caring for younger people.

A list of Freeth’s recommendations can be found at Attachment 3. While the report covers some important research in this field, it must be remembered that the project was conducted in 1995 and some ground work has been done since. However, there is still much work that could be done in areas highlighted by Freeth and his colleagues back in 1995.

The Long and Lonely Road
Another document prepared by Alzheimer’s Australia in 2003 is called The Long and Lonely Road. It provides a qualitative description of the experiences of carers, highlighting issues such as the importance of an early and accurate diagnosis, concerns about residential care, the inappropriateness of day programs, the emotional impact of the diagnosis and the need for carers to look after themselves as well as the person with dementia (Alzheimer’s Australia, 2003).

Alzheimer’s Australia National Consumer Summit
The Alzheimer’s Australia National Consumer Summit on Dementia of October 2005 included many younger people with dementia and family carers. It was a milestone in the history of the organisation as it was the first time that people with dementia and family carers were gathered together to set out their priorities for the development of dementia care services and dementia research in Australia.
Around fifty consumers from all States and Territories were involved, including both people with early stage dementia and family carers. The Summit was important in assisting these people to self advocate with greater confidence through being involved more directly with the political process. The underpinning principles of the National Consumer Summit were that people with dementia and carers need:

- Support to help them maintain their quality of life;
- To be supported in their homes;
- To be recognised as partners in decision making about care options;
- Access to contemporary quality care provided by trained, accredited and appropriately remunerated workers; and
- To see a national symbol for cognitive impairment.

(Alzheimer’s Australia, 2005: 67).

Consumers agreed on a seven point action plan for change (Attachment 4).

Of particular note to younger people with dementia is Action Point 1 – ‘Improve the assessment and diagnosis of dementia’. The Summit called for ‘upskilling’ of general practitioners in their knowledge and understanding of dementia, through a National GP Dementia Practice Project to identify and respond to the needs of GPs in the effective diagnosis and management of dementia (Alzheimer’s Australia, 2005:69).

Action Point 3 – ‘Ensure easy access to quality community care services’, acknowledges the complexity of the community care system and the difficulties people find in navigating it. One recommendation calls for care packages to be portable and more flexible, so they respond to the changing needs and circumstances of the person with dementia and their family members – this is particularly important for younger people whose needs are often unique and require an individual response.

In Action Point 4 – ‘Provide more flexible responses to supported accommodation in the home and in residential care facilities’, it was recommended that new models of support be developed including specific care and services to address the needs of those with younger onset dementia and those living alone.

All other Action Points have implications for younger people with dementia and their family members, as they affect social, financial, legal and health needs.

**Conclusion**

The literature that relates to younger people with dementia highlights a number of important issues covering diagnosis, employment, financial issues, emotional impact, access to services, the differing nature of the various types of dementia more common among younger people, and the huge deficit in information, research and prevalence data about this group of people.

That younger people with dementia have distinct needs is not a new concept in Australia, as the issues have been raised consistently over the last fifteen years. The challenge is now to identify the best mechanisms to use to address unmet needs for this group.
Attachment 1
UK Alzheimer’s Society
Charter for younger people with dementia and their carers

All younger people with dementia, their families and carers should have access to comprehensive, specialist services from diagnosis to long term care.

Early diagnosis, assessment and referral
GPs should have the relevant skills, training and support to recognise the symptoms of dementia in all age groups and refer people to a specialist consultant who can make a diagnosis and provide ongoing medical supervision.

Access to specialist services
Younger people with dementia should have access to a full range of specialist support services, including home, day, respite and continuing care, which recognise the different life circumstances and environment of younger people and their carers. Specialist counselling should also be made available.

Adequate financial support
There should be adequate financial support for younger people with dementia and their carers to enable them to meet the extra costs of caring for dementia.

Good employment practice
Employers and the social security system should adopt good employment practices that recognise dementia as grounds for early retirement and that protect a person’s entitlement to pension rights and other benefits.

Education, training and information
There should be appropriate education, training and information for all health and social services professionals to ensure an effective and sensitive response to the needs of people with dementia and their carers.

Attachment 2
Alzheimer’s Association United States:
Steps That Could Be Taken To Reduce the Problems Confronted by People With
Early Dementia and Their Families

1. Difficulty getting an accurate diagnosis
   • Raise awareness among doctors about early onset dementia and the importance of accurate
diagnosis.
   • Provide training for doctors about how to diagnose early onset dementia.

2. Loss of employment and job-related income
   • Raise awareness among employers and human resources personnel about early onset
dementia.
   • Develop and disseminate information about work accommodations for people with early onset
dementia and how the legal requirements for work accommodation apply to this condition.

3. Difficulty obtaining SSDI, SSI, and other disability payments
   • Develop and disseminate accurate, easily accessible information about SSDI, SSI, and other
disability programs; encourage timely applications; and provide help with applications.
   • Analyze the reasons for SSDI and SSI denials, including denials based on a person’s alleged
ability to work; advocate for any needed changes in the procedures used to determine
disability.

4. Lack of health insurance and high out-of-pocket expenditures for medical care
   • Eliminate the 2-year waiting period for Medicare for people who qualify for SSDI.
   • Extend Medicaid to people who qualify for SSI but have income above current income limits.
   • Exempt people with dementia from the new requirement for proof of U.S. citizenship for
Medicaid if they cannot, because of their dementia, provide the required documents.
   • Consider people with early onset dementia in all initiatives to expand affordable health
insurance.

5. High out-of-pocket expenditures for long-term care
   • Provide accurate, easily accessible information about all sources of funding for long-term care.
   • Reduce restrictions on Medicaid-funded nursing home care and increase access to Medicaid-
funded home and community-based care for people with early onset dementia.
   • Extend eligibility for AoA-funded home and community-based services and family support to
people under age 60 with early onset dementia.

6. Lack of appropriate medical care, residential care, and community services
   • Conduct research on the characteristics and service needs of people with early onset
dementia.
   • Develop and deliver training for health care professionals and residential care and community
service providers about treatment, services, and communication with people with early onset
dementia.
   • Evaluate the effectiveness of various services for people with early onset dementia and their
families.
   • Develop new services to meet the needs of people with early onset dementia and their
families.

Attachment 3
The Young Mind – Issues in relation to young people and dementia
List of recommendations

1.1 The Commonwealth Government should review the National Action Plan for Dementia so that the needs of people with early onset dementia and their carers are identified and program responses and outcomes delineated.

1.2 Dementia strategies should be developed at the State/Territory and regional level to ensure that local, regional and State/Territory variations are appreciated, documented and acted on. Once again these dementia strategies need to target those groups for whom early onset dementia is an issue, document the need and develop action plans that will ensure that services are sensitive to the issue.

1.3 There is a need to develop and promote strategies that will increase the rate of post mortem investigations for people with early onset dementia. These strategies may best be undertaken in cooperation with broad community education programs targeted to increase general post mortem rates and/or organ donation.

2.1.1 There is a need to review current policy and program initiatives in the area of dementia diagnosis and assessment by government and non-government agencies to incorporate strategies that take heed of the needs of people with early onset dementia and their carers.

2.1.2 The Commonwealth and State/Territory governments should undertake project funding to determine the effectiveness of memory clinics for the assessment of dementia in general, and early onset dementia in particular, and should establish a planned approach to their development.

2.1.3 The Commonwealth Government should review the role of ACATs in relation to early onset dementia to ensure sufficient sensitivity to the needs of this group, standard approaches, adequate resources and improved research and information functions.

2.1.4 The Alzheimer’s Association has proposed the implementation of a number of dementia initiatives for GPs, namely:

- The development of an assessment protocol and screening instrument for the diagnosis of dementia.
- Provision of this information on a laminated plastic card available to all GPs.
- Provision of a diverse educational program to supplement this information.
- Encouragement of better coordination and shared-care models in cooperation with ACATs, Aged Care Community Services, community nurses and other aged care providers.
• Targeting of GP undergraduate training and continuing education programs. Information on the diagnosis and management of young people with dementia should be included in those initiatives.

2.1.5 Other health professionals, such as neurologists, should also be included in the above education initiatives.

2.1.6 The Commonwealth Government should fund research/evaluation projects that look at the management regimes of young people with dementia.

2.2.1 The Home and Community Care (HACC) Program should target people with early onset dementia and their carers.

2.2.2 The establishment of specialised day centre services is rarely feasible, but other strategies are possible, namely:

• Regional dementia plans may indicate zones where adequate numbers exist for the establishment of day services for young people (under 65), particularly where the needs of a number of different groups can be met, such as people with head trauma and people in the mild to moderate stages of dementia.

• Clustering in existing day services and enhanced funding to provide some add-on staff for young people with dementia in those services.

• Provision of a mobile service targeted at small groups of younger people with similar needs, such as head trauma and mild to moderate dementia.

• Better mapping and coordination of services regionally and locally so that already existing services/groups may be able to incorporate younger individuals with dementia.

• Improving consultation and research processes at State and regional levels so that common needs of younger people can be documented and met, and creative solutions found and shared.

• Reviewing current day services in regions to ensure that the needs of young people and their carers can be addressed. This may include more flexible operating hours so that carers working full time are catered for and provision of more emergency and weekend day care.

2.2.3 The provision of more flexible respite services, such as mobile and in-home respite, needs to be expanded in the HACC Program.

2.2.4 The Commonwealth Government, in conjunction with State/Territory governments, should seek to expand the availability of case management service models in the community and to ensure that they are accessible to young people with dementia. This may mean the need for an outreach capacity.
2.3 Family counselling services, including those provided through the Alzheimer’s Associations, need to meet the counselling needs of younger people with dementia and their families.

2.4.1 The Commonwealth and State governments should review the provision of accommodation services, and in particular nursing homes and hostels, to young people with early onset dementia and related disorders to ensure that the needs, values and expectations of a younger generation are identified and met.

2.4.2 The Commonwealth and State governments should cooperate to establish project and evaluation funding for alternative models of residential care to young people both as new, stand-alone projects (where population allows) and as part of existing facilities. Projects that explore cohabitation of different groups of young people with similar needs should also be incorporated.

2.4.3 Any review of accommodation policies needs to address the physical design of residential services. Physical design was given a high priority by people in this study and it is clear that the expectations of a younger generation of what is adequate and appropriate in residential care are different. Large, institutional settings with little privacy and a medical model orientation do not meet contemporary values.

2.4.4 Strategies should encourage clustering and provide enhanced funding for staff who can provide a younger focus in existing residential services. Again better regional mapping and coordination of services can help to identify services where such innovations are more possible, where the need for such innovations is greater and can indicate how different services can cooperate and/or use specialist, mobile personnel to improve their service to younger people.

2.4.5 The high priority given to staff attitude, competence/knowledge, and atmosphere suggest that the quality of care can be enhanced by better education and training programs, not only about dementia in general, but also about the needs and expectations of younger people and their carers. Training strategies for residential care workers should incorporate these issues.

2.5 A conference on early onset dementia may be one option to improve communication across the agencies and interests in early onset dementia.

2.6.1 The Alzheimer’s Associations should develop a common policy in relation to early onset dementia and seek greater uniformity in their role across Australia in relation to this group, for example, in the provision of regional counsellors, and the development of literature and program initiatives.
2.6.2 The ability of the Alzheimer’s Associations to analyse their current role in early onset dementia, which may already be considerable and growing, is constrained by inadequate information systems. While this is currently being improved and standardised it is an area that needs to remain a high priority and should be adequately funded.

2.6.3 The Alzheimer’s Associations should consider nominating one existing staff position that has, as part of the job description, a coordinating role in early onset dementia, both in and outside the agency. This already occurs on a defacto basis in some States, but should be more formalised. For States/Territories with none or only one full time staff, such as the Northern Territory and the ACT, liaison and resourcing through an adjoining State Association is indicated.

2.6.4 The Alzheimer’s Associations should promote greater interaction, liaison and cooperation between the many agencies and individuals dealing with early onset dementia. While this already occurs it has not been tackled in any systematic way and there is considerable scope for cooperative action in areas like research, advocacy, public education and innovative service development, such as in the development of day care/diversional programs.

2.6.5 The Alzheimer’s Associations should ensure the importance of early onset dementia in their own policy and resource allocation processes and that its appropriate place is promoted in public forums, such as Alzheimer’s Week or the National Alzheimer’s Conference, and in training, public relations and advocacy activities.

2.6.6 The Alzheimer’s Associations should seek to improve the level of funding for research in early onset dementia, not only in terms of bio-medical and epidemiological research, but as part of more comprehensive social research.

2.6.7 The role of the Alzheimer’s Associations in the counselling of individuals and their families with early onset dementia should be reviewed. Given the complexities of the psycho-social issues faced by these individuals and their families it is important that referral to centres of excellence, or to services with specialist skills such as family counselling, is promoted in the general counselling framework now in place.
2.6.8 Two program initiatives would appear to be called for in the area of early onset dementia, namely the development of support groups/structures for the person with dementia and for the children of people with dementia. The Alzheimer’s Associations are ideally placed to undertake a greater role in this area, in conjunction with other agencies with interests in this area. This has already begun to occur in some States, most notably in South Australia. Project funding from the Commonwealth and State levels should be sought to establish, manage and evaluate the benefits of such service initiatives. Funding for add-on personnel and activities will be required if meaningful support opportunities are to be developed, e.g. support groups, weekend camps, outings, telephone support links, etc.

2.6.9 The Alzheimer’s Associations should seek project funding to explore the need for improved financial counselling services to people with early onset dementia.
Attachment 4
National Consumer Summit on Dementia, Parliament House 5-6 October 2005
Alzheimer’s Australia and Parliamentary Friends of Dementia

Fundamental Principles

People with dementia and carers need support that will help them to maintain their quality of life.

People with dementia need to be supported in their homes.

People with dementia and carers need to be recognised as partners in decision making about care options.

People with dementia and carers need access to contemporary quality care provided by trained, accredited and appropriately remunerated workers.

People with dementia and carers need to see a national symbol for cognitive impairment so that people with dementia are treated appropriately in the delivery of service.

Seven Action Plan for Change

Action Point 1 Improve the assessment and diagnosis of dementia
Action Point 2 Improve the responsiveness of acute care so it better meets the needs of people with dementia
Action Point 3 Ensure easy access to quality community care services
Action Point 4 Provide more flexible responses to supported accommodation in the home and in residential care facilities
Action Point 5 Increase the recognition and understanding of the financial cost and legal implications of dementia
Action Point 6 Promote and ensure greater public awareness and understanding about dementia and risk reduction
Action Point 7 Increase investment in dementia research

Key Priorities discussed in pre-summit consumer consultations

1. Financial support
2. Community care services
3. Residential care
4. Medical practitioners
5. Consumer empowerment
6. Acute care
References
(as at 21 March 2007)


http://www.alz.co.uk/havedementia/earlyonset.html


http://www.alzheimers.org.uk/How_is_dementia_diagnosed/PDF/i_diagnosing.pdf

http://www.alzheimers.org.uk/Facts_about_dementia/PDF/402_LewyBodies.pdf


http://www.alzheimers.org.uk/Younger_People_with_Dementia/index.htm

http://www.alzheimers.org.uk/News_and_campaigns/Policy_Watch/ypwd.htm


http://www.ahda.asn.au/

http://www.aihw.gov.au


