Report for the Department of Health and Ageing

in relation to services for

Consumer Engagement in the Aged Care Reform Process

from

Alzheimer’s Australia

December 2011
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<tr>
<td>ACAR</td>
<td>Aged Care Approval Round</td>
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<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
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<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<td>CoTA</td>
<td>Council on the Ageing</td>
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<td>CDC</td>
<td>Consumer Directed Care</td>
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<td>DoHA</td>
<td>Department of Health and Ageing</td>
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<td>EACH</td>
<td>Extended Aged Care at Home</td>
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<td>EACH-D</td>
<td>Extended Aged Care at Home - Dementia</td>
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<td>GLBTI</td>
<td>Gay, Lesbian, Bisexual, Transgender and Intersex</td>
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<td>GRAI</td>
<td>Gay, Lesbian, Bisexual, Transgender and Intersex Retirement Association Incorporated</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>HACC</td>
<td>Home and Community Care</td>
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<td>PC</td>
<td>Productivity Commission</td>
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<td>YOD</td>
<td>Younger Onset Dementia</td>
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EXECUTIVE SUMMARY

The Department of Health and Ageing (DoHA) commissioned Alzheimer’s Australia to conduct a series of consumer consultations in response to the Productivity Commission’s report *Caring for older Australians*. Sixteen consultations were held nationwide, as well as an online survey for those unable to attend. Approximately 1000 people attended the consultation and 200 responses were received. Across all consultations as well as responses to the online survey, the overwhelming view of consumers was that the aged care system is not working well for people with dementia, even less so for diverse communities. For those with younger onset dementia (YOD) there are no age appropriate services. Consumers are frustrated that they are unable to get the services they need and that the services that are available are often inflexible and of poor quality.

The consultations suggest that the Productivity Commission (PC) has underestimated the issues that continue to beset aged care in the provision of care for people with dementia both in the community (and particularly respite care), in residential care, and in the broader health system. The challenges to accessing appropriate services are even greater for individuals with severe behavioural and psychological symptoms of dementia (BPSD) and those with YOD.

If one of the objectives of aged care reform is to assist those who are able, to stay longer in the community a priority is for more community services delivered flexibly that respond to the needs of individuals and their family carers. Consumer directed care (CDC) models are central to that goal.

For many people with dementia, placement in residential aged care will be inevitable and the consultations suggest that there are serious concerns about the quality of care and the difficulty the family carer has when making choices between facilities that all claim to provide quality dementia care. Consumers feel that to improve quality of care there is a need to address workforce issues including equitable pay, training and staffing levels.

The priority for people with dementia and their families is a focus on the basics of improving care services, hence it is important in undertaking reform that the possible establishment of new organisational and program structures does not distract from the extent to which the current arrangements are failing older people every day.

The consultations were a reminder that the quality of life of people with dementia is impacted by issues in the health system. Again in these consultations a key concern was delays in diagnosis and failure to refer to support services. A number of consumers also had poor experiences with the acute care sector. Consumers were also concerned about the future and the need for investment in research.

For the person with dementia the journey needs to start with a timely diagnosis, referral to support services, properly resourced assessment services and a link worker (not a call centre) to provide guidance when needed. For the family carer access to dementia education, support in managing BPSD and flexible respite is key. If the basics are covered in the reform process, there may be some chance of the stories told by people living with dementia being more positive in the future.
INTRODUCTION

Alzheimer’s Australia was commissioned by the Department of Health and Ageing (DoHA) to undertake consumer consultations based on the Productivity Commission (PC)’s report *Caring for older Australians*. These consultations aimed to:

- provide the community with information about the report and aged care reform;
- gather feedback and information from consumers;
- highlight any emerging concerns from consumers; and
- enable Alzheimer’s Australia to provide this feedback to DoHA.

Sixteen consultations were held across Australia in capital cities, regional centres as well as consultations for people from culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander and gay, lesbian, bisexual, transgender and intersex (GLBTI) communities. Attendance ranged from 30-200 people. It is estimated that over 1000 people attended the consultations in total. An online survey was also developed to enable those unable to attend the consultations to provide comments, and there were approximately 200 responses to that survey.

The approach taken to the consultations was to encourage participants to tell their story rather than focus on the PC’s report.

Location and dates of consultations are below:

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Type of consultation</th>
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<tbody>
<tr>
<td>13 October 2011</td>
<td>Canberra Parliament House, ACT</td>
<td>National</td>
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<tr>
<td>17 October 2011</td>
<td>Merimbula, NSW</td>
<td>Regional</td>
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<tr>
<td>18 October 2011</td>
<td>Canberra, ACT</td>
<td>General</td>
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<td>19 October 2011</td>
<td>Sydney, NSW</td>
<td>General</td>
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<td>20 October 2011</td>
<td>Brisbane, QLD (Minister attended)</td>
<td>General</td>
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<td>21 October 2011</td>
<td>Sydney, NSW</td>
<td>CALD</td>
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<td>25 October 2011</td>
<td>Adelaide, SA (Minister attended)</td>
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<td>26 October 2011</td>
<td>Geelong, Vic</td>
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<td>27 October 2011</td>
<td>Melbourne, Vic (Minister attended)</td>
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<td>27 October 2011</td>
<td>Melbourne, Vic (Minister attended)</td>
<td>CALD</td>
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<td>28 October 2011</td>
<td>Hobart, Tas</td>
<td>General</td>
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<td>31 October 2011</td>
<td>Darwin consult, NT</td>
<td>General</td>
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<td>1 November 2011</td>
<td>Alice Springs, NT</td>
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<td>Alice Springs, NT</td>
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<td>3 November 2011</td>
<td>Perth, WA</td>
<td>General and GLBTI</td>
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<td>4 November 2011</td>
<td>Mandurah, WA</td>
<td>Regional</td>
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This report provides an overview of the main themes that were highlighted in the general, CALD, GLBTI, Aboriginal and Torres Strait Islander and regional consultations. Each consultation was recorded, and input was also sought from consumers that did not speak at the event through written comment forms. These comments and responses to the survey have been compiled and included in the key findings and are summarised in this report. Detailed notes from each consultation are provided in the appendices.
GENERAL

Below is an outline of the themes that emerged from the national general and regional consultations, feedback forms and the online consumer survey. Appendix A – General consultations contains more detailed notes from these consultations.

Information and access

Participants reported difficulty navigating the aged care system and found the multitude of forms, pamphlets and information overwhelming. In several cases consumers reported hiring a broker at the cost of $500-800 to assist them in finding a suitable residential aged care facility. There was an interest in a single point of access and information as suggested by the PC but concern about how it would work at the local level. A number of people suggested that a ‘key worker’ similar to the model of a ‘breast care nurse’ or ‘diabetes educator’ could assist consumers through the dementia journey. Individuals wanted access not only to information but to personalised advice and recommendations.

Concerns were also raised about the Aged Care Assessment Team (ACAT) assessment process. Many consumers reported long waiting periods before getting an assessment and then again having to wait to get access to appropriate services. Consumers had concerns about the accuracy of the ACAT assessments and noted that individuals had different levels of functioning on different days and that this variability was not captured in a single assessment.

Individuals also reported concerns about the level of services they had access to. They indicated that there was significant inconsistency across what types of services could be included in community care packages (bathroom cleaning but not dusting) and that barriers between packages meant that they had to switch providers when the person’s level of care need increased. Carers also said there is a need for more flexible hours (after 5pm and weekends) and a need for access to services that met their needs rather than the needs of the service providers.

Access to appropriate services was noted as being particularly problematic for individuals with YOD, those with severe BPSD and individuals with an intellectual disability. Individuals with YOD and their families found that services and activities for people with dementia were mostly designed with the preferences of older individuals in mind. Families of individuals with severe BPSD indicated that services often turned them away and were unwilling to provide care for individuals with severe BPSD.

The PC’s recommendation for a single point of information and assessment may address some of the consumers concerns about the current level of confusion and difficulty with the aged care system. The challenge is in the implementation of the Gateway in a way that connects consumers to local information, networks, and services and avoids overwhelming consumers with too much information. Similarly, assessment services within the Gateway need to be adequately resourced to avoid the same problems that are currently experienced with the ACAT assessment process. At the consultations it was clear that consumers value developing relationships with a key contact person and in regional areas there is much scepticism about having to call a national telephone number to get access to local services.
“My pathway into the services was fragmented and chaotic, serendipitous. I learnt everything by accident. Going to the social worker saved my life, she sent me off on the right path.”

“I would like [the government] to consider a case manager that works with the family. So you have one holistic management process. I could then go to the person who knows me, and when I get depressed I would know what to do.”

“I have a HACC cleaner, and I can only get a basic service. They clean the bathroom and can’t wipe the window sill because that’s dusting.”

“Many ACAT teams are reluctant to give out EACH-D packages. We went through three providers before we got what we needed.”

Community Care

Consumers emphasised that they wanted to keep people living at home for as long as possible and that community care was an important factor to support this.

There was concern about the lack of continuity across packages of care. Some individuals noted that when the person with dementia required a higher level of care this meant that they had to change their package and as a result change their service provider. Some found this distressing as they had built up a relationship with a carer. Consumers also questioned whether the level of care even in the highest community package (EACH-D) was sufficient for people with dementia. One response to the survey indicated that they believe that people should have access to 24 hour community care if that is what is required to keep people at home.

Consumers were also concerned about how much of the care package was directed towards hours of care and how much was spent on administration of the funds. In some cases administration costs were as high as 50%, which meant relatively few hours of care were being provided. Some participants had been involved in the trial of Consumer Directed Care (CDC) packages and were very positive about the flexibility they provided and the transparency in terms of administration costs.

If implemented, the recommendations made by the PC in regard to separation of accommodation and care will mean that people will have greater options of where they receive care. This fits well with the desire of most consumers to stay in the community. There may be a need to manage expectations of access to full time community care.

Consumers are unaware that in some cases the cost of providing care for someone in the community will be prohibitive.

“Different staff came in each day. I heard screams coming from the passage, the strange women came in to rip the shirt off my father, she said ‘I have 20 mins to do the shower and I have to go’. This is not good enough. People with dementia need time.”

“My wife has younger onset dementia. She had behavioural issues and stayed a year in a facility that had appalling conditions. I then was able to get on a trial for a consumer directive care project. It has made a huge difference. It has taken off so well, one comment from a man in the group was “first there was button up boots, then we had sliced bread, and now there is CDC”
“I can’t get my head around the admin fees that take 50% of the package. It equates to about $250 a week, so he is getting half of what the package is worth. I don’t see how this is justified. We are struggling.”

Residential Aged Care

Consumers have significant concerns about the quality of care provided in residential aged care facilities. Many people gave examples where the health of care recipients suddenly declined after entering residential aged care. Often this was caused by reduced mobility and physical activity during the stay in the facility. This issue may be of particular concern to people with dementia as they are less able to self advocate or indicate a desire for assistance with physical activity. Consumers noted that the system currently rewards providers based on the level of care needs and this provides little incentive for providing rehabilitation or restorative care.

Consumers also noted the link between quality of care and workforce issues such as staffing levels, training and pay. The relationship between the care staff and person with dementia was also valued. This relationship enables staff to have a better understanding of the personal history, needs and preferences of the individual with dementia. Consumers indicated that this is difficult to maintain these relationships because of the high turnover of staff. Constantly changing care staff can be confusing and disorienting to a person with dementia.

Carers were also concerned about the use of physical and chemical restraints including antipsychotics used in residential aged care facilities. There were concerns that staff were not taking the time to address the causes of the behaviours. In some cases, consumers indicated that the behaviours of the person with dementia were made worse by inappropriate care.

The physical environment of the aged care facility was also considered to be important. Participants provided examples of facilities that were not well designed for people with dementia and did not have appropriate signage or secure outdoor areas for walking. Participants were also concerned about the rights of the person with dementia and implications of locked wards.

Other concerns were the costs involved with residential aged care and that it had not been easy to switch between providers if you were not satisfied with the quality of services. Some noted that each individual may have a different way of thinking about the quality of a facility and that it would be difficult to have a universal measure of the quality of care.

The recommendations of the PC on published quality indicators and on setting appropriate care prices based on fair and competitive wages and the appropriate staffing levels will go a long way to addressing the concerns of consumers about the quality of care. It will be important that the funding for the care of individuals with dementia accurately reflects the cost of care including the need for dementia training for staff.

“What degree of training do carers get that go into nursing homes? My wife is in a nursing home, they move her with a lift, and she sits in a chair all day, with her clothes all screwed up after they have taken the hoist away. They don’t care.”
“My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other peoples rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser.”

“Humanness, friendly smile and ‘are you ok?’ this is driven by the culture of the organisation, not accreditation. Get back to basics.”

**Respite**

Participants discussed the importance of respite to both the carer and the person receiving care. Many consumers reported difficulty in accessing respite care services they needed. They described services that were inflexible, did not provide sufficient hours of care or were unable to cater to clients with high care needs or BPSD. Carers indicated that in many cases they were either turned away or service providers would be calling during the respite period for assistance with managing behaviours. Some reported not using respite anymore because the person with dementia came back in poor health or distressed. Some people discussed the need for respite services with sufficient hours for carers who were trying to maintain employment.

Carers also described respite services that worked well. These included a Day Centre respite service in WA, a cottage respite service in the ACT and a walking group for men with fronto-temporal dementia held in Victoria.

There were also discussions about more flexible models of respite including being able to employ family members and friends. Some were concerned about cashing out in terms of responsibility and potential for exploitation. However, respite provided through activities with friends or family was also seen as positive and particularly beneficial to people living outside of the city.

The broad concern about respite suggests more needs to be done in the reforms to improve respite for people with dementia than just a small trial. Consumers want access to respite services that are flexible, available when they need it, and cater specifically for people with dementia including those with high care needs or BPSD.

“It is horrendous trying to find respite for high care.”

“I could come with my husband to respite, that to me was a perfect model for respite. If the daughter or wife or carer can be admitted it is a perfect model.”

“I think to be able to cash out would be of assistance for us as we live out of the city.”

“I have the benefit from a day centre at Alzheimer’s Australia, there is a lot of companionship and the carers are terrific. It makes the world a bit better.”

**Workforce**

Consumers expressed significant concerns about how workforce issues were impacting on the quality of services. Many consumers felt that there was not enough staff in a facility to provide quality care to the residents. Consumers expressed concern about training arrangements and noted that short courses were not sufficient to provide staff with the necessary skills to care for people with dementia and manage behaviours. Consumers were also concerned that nurses and care staff were not receiving equitable pay and that as a result many people were leaving aged care for other professions. This was a particularly big
problem in Western Australia where staff were leaving for lucrative jobs in the mining sector. There were also questions of how entitlement will work unless there is more staff to provide more services.

“Staff to patient ratio needs to be raised greatly.”

“More education is needed for staff. I asked [the staff] why one lady wears one slipper and one shoe and I was told it was because it was just her personality, one of her peculiarities. I looked and she had an infected toe, the staff didn’t even know about it. I have a great concern about residents with dementia.”

“In every facility I have been to in the last 3 years, the major comment is the pay, recognition and understanding the value of people working in aged care. At least make the pay equal and value what they do.”

End of Life Care
Consumers are concerned about the quality of care received at the end of life. Individuals gave examples of how staff did not respect the wishes of the person with dementia at the end of their life and the guilt that this has caused in the family. Others talked about the difficulty in getting access to palliative care and being told that people with dementia do not die quickly enough to be eligible for palliative care. There was agreement that there needed to be more information and awareness about the importance of putting in place advance care plans and power of attorneys. In the Northern Territory there is particular concern about the legal options around end of life choices.

Consumers want access to palliative care and to ensure that the wishes of the person with dementia are respected at end of life. The PC has made recommendations to ensure that providers have access to funding for palliative care and that staff are trained to discuss advance care directives. For people with dementia the challenge is that advance care planning should ideally occur before entering into a residential aged care facility in order to support the person with dementia being involved in decisions about their end of life care. Also, the funding suggested by the PC may not address the challenges people face currently being told that the person is not “dying fast enough” to be eligible for palliative care.

“I’ve been told that if my mother does not die fast enough in a palliative care setting she will be sent away. I am fighting for my mother to die in a palliative facility because I am told she is not worthy.”

“There is nothing in place to allow us, once diagnosed, to make the decisions that are important to us. We need the force of law, which is available to every Australian citizen except those in the NT.”

Support for Carers
A common theme in the consultation was the need for better support for carers including counselling, education and information. Carers were overwhelmingly positive about the support they received from consumer organisations such as Alzheimer’s Australia and Carers Australia. They were particularly positive about the Living with Memory Loss course which provided important information and support soon after diagnosis. Some people did not know about the services available for carers until later in the dementia journey. A number of
people wanted more information on how to handle BPSD. Others were concerned about how they could take better care of their own physical and mental health.

Consumers were also concerned about the financial implications of being a full time carer. They felt that the Carer Allowance and the Carer Payment were not sufficient. There was concern that the Carer Payment is means tested. A number of people talked about having to separate from their partner in order to be eligible for the Carer Payment which they needed to survive. Some also suggested that there should be a superannuation component to the carer’s payment particularly for younger carers to ensure they have sufficient retirement savings.

Other issues that were raised included the impact of programs that carers were relying on ending suddenly because they had received time-limited funding. Carers in Hobart raised the need for an organisation which represents and advocates for consumers of the aged care system (separate to existing organisations like Alzheimer’s Australia or CoTA). Others indicated a need for better mediation systems for disputes with aged care providers.

The evident stresses and strains on carers supports the approach of the PC to also assess and better support carers – including through flexible respite care and counselling services.

“One gap could be for carers who work full time and finding support groups that are flexible, such as evening times.”

“I look after mum; all care professionals encourage me to keep mum at home as long as possible. I asked about carers pension at Centrelink, which is means tested. I have a two income family, so I am not eligible and will have to separate from my husband in order to survive.”

Younger Onset Dementia

Participants at the consultations raised the particular challenges that individuals with YOD and their families face including difficulty accessing appropriate services, and unique financial (e.g. as a result of loss of employment) and social challenges (e.g. counselling of young children). Some questioned whether the rates of people with YOD were increasing and suggested that with access to earlier diagnosis there would be more recognised cases of YOD. They indicated that there was even greater difficulty getting a diagnosis as many doctors would not consider a diagnosis of dementia for a young person. There is also difficulty getting access to appropriate services and supports as most services for people with dementia cater to an older population.

Participants suggested that there needs to be different models of respite, residential care and support services for individuals with YOD and there was a call for separate facilities or at least specialised areas within a facility for individuals with YOD. For example the Side by Side program in South Australia enables individuals with YOD to work as volunteers at Bunnings, this was seen to be a successful model of engaging individuals with YOD with meaningful activities in the community.

Carers of people with YOD expressed bewilderment about where they fit into the system and whether aged care reform would address their needs. The PC has indicated that individuals with YOD should be able to access the services that best meet their need regardless of the funding source. There is no real comment in the PC report of how the system will ensure that individuals with YOD have access to the specialised support and services that they need.
“My wife was diagnosed at age of 57. When we needed help we were refused. We were told to keep away from the aged care homes. This is because it is only available for people over 65. The PC Report on Caring for older Australians should be changed so it is inclusive of all Australians no matter their age.”

Restorative Care
At the Hobart consultation, there was a particular focus on restorative care. Participants indicated that there needs to be a greater focus on what the person with dementia can still do and help them to retain those skills. More broadly the discussions at the consultations were supportive of models of restorative care or wellness, as concerns were expressed about services not maintaining people’s physical health and skills. Consumers highlighted the need to create a system where providers were rewarded for keeping people well and active.

“Carers have no idea about how to take a therapeutic approach to activities. I get mum to do up her buttons and feed herself and engage herself in whatever way possible and her mood is so much better when she has carers that use those approaches.”

Primary Care
The challenges faced by those living with dementia are not confined to the aged care system. Many participants at the consultations expressed concerns about the process of diagnosis and indicated that there was a gap of several years between first seeking assistance from a GP before a diagnosis was made. Getting a diagnosis was particularly problematic for individuals with YOD who are often misdiagnosed with depression. Questions were raised about cognitive screening and the link between early diagnosis and keeping people at home for longer.

Carers felt that GPs were not listening to their concerns about changes in the person who had dementia. Instead GPs were relying on responses on a single occasion to a standardised memory screening tool. Participants brought up other factors which may have contributed to the delay in diagnosis including the need for better training for GPs, difficulty speaking to the GP about their concerns in front of the person who has dementia and a lack of understanding about the benefits of early diagnosis of dementia. Consumers were troubled that without a diagnosis they had no access to services.

There was also concern about access to primary care once a diagnosis was received. Individuals spoke about feeling that once a GPs gave the diagnosis there was were no longer any interest in providing further care. There is also difficulty in accessing GPs for people who live in residential aged care facilities. One carer gave the advice that once you get a diagnosis you have to shop around for a GP who will provide care in aged care facilities to ensure continuity of care.

“My mum has been diagnosed for four years. But, there was something wrong ten years before that.”

Community Awareness
There were concerns about a lack of awareness in the community about dementia. A number of people talked about friends and families who stopped visiting and calling after the
person with dementia received a diagnosis. Individuals with YOD indicated that they face a particular difficulty in community understanding and told of people not believing it was possible that they had dementia. Others mentioned how helpful it was when community members understood dementia and were able to assist when someone was lost or confused. Participants also expressed a concern about the lack of awareness of the link between physical and brain health.

Participants had a number of suggestions to address community awareness including: pamphlets for doctor’s surgery, school programs, and public health campaigns.

“Community, education and awareness. People should be aware that there are things you can do in your lifestyle to help the prevention of dementia. Good awareness will reduce stigma, and make early diagnosis easier. This will result in less denial and more discussion about end of life etc. We won’t get it unless we get an overall good community awareness program going.”

**Research**

Some consumers raised concerns about the level of funding for dementia research. There was a broad recognition that research may not be able to assist them or the person they are caring for but that it was important to avoid future generations facing the same challenges. Others talked about their experience participating in research and expressed a desire for more feedback about the outcome of research studies. Research into the positive effects of dementia was recommended to improve the lives of those living with the condition.

Although the potential benefit of investment in dementia research was discussed in the text of the PC report it was not included in any of the recommendations.

“I am a carer for my husband with Alzheimer’s. I spent the previous 40 years as a medical researcher. I would like to emphasise that we need a massive amount of money for research. Co-operative research centres for Alzheimer’s.”

“Research into the effects of positive experiences on people with dementia and on the ways in which this can be used to the benefit of those with dementia and for their carers.”

**Acute Care**

Consumers had significant concerns about the quality of dementia care received in hospitals. Again consumers saw the quality of care being dependent on staff training and staffing levels. Carers told of experiences where they were asked to stay in the hospital to provide personal care such as bathing and showering. Others said that if they were not able to come in to the hospital the person with dementia would not have been fed. One consumer expressed concern that the hospital was not interested in treating her family member because they did not see her has having a sufficient quality of life to merit any further treatment. In Tasmania there was significant concern about the closure of the Nell Williams Unit, a specialised dementia unit at the Royal Hobart Hospital. It was recommended that specialised dementia units be provided at more hospitals. Information on local programs to address dementia in hospitals is provided in *Appendix F - Alternative models of hospital based care.*
“The Nell Williams Unit was a specifically designed aged care emergency unit in the Hobart Hospital. It won an international award. Within 12 months they closed it down, for no reason other than bed pressure.”

“Acute care policies need to be overhauled, there needs to be better education and staffing to deal with what Alzheimer’s and dementia patients need.”
SPECIAL GROUPS CONSULTATIONS

Alzheimer’s Australia conducted specific consultations that focused on listening to the perspectives of people from CALD backgrounds, GLBTI, Aboriginal and Torres Strait Islander and people in regional centres.

Culturally and Linguistically Diverse Groups

CALD consultations were held in Sydney and Melbourne. There was an excellent response from the CALD community. Close to 200 people in total representing the Afghan, Arab, Assyrian, Chinese, Croatian, Egyptian, Filipino, Finnish, Greek, Indian, Italian, Korean, Lao, Maltese, Romanian, Russian, Sri Lankan, Turkish, and Vietnamese communities attended the consultations. Local staff arranged for translators to attend both consultations.

Detailed information from the consultations, Q&A forms and the online survey are at Appendix B – CALD consultations.

Primary Care

A number of consumers shared their experiences with trying to get a diagnosis of dementia. There was concern about the time it takes to get a diagnosis and also that individuals are often misdiagnosed with depression. The need for using culturally and linguistically appropriate assessment tools, such as the Roland University Dementia Assessment Scale (RUDAS) was also highlighted. Some participants also spoke about the different cultural meaning of dementia and the stigma which kept some from seeking a diagnosis or services.

“We found it a struggle just to get my mother diagnosed. Then she was put on a wait list. I did not know how neglected or isolated the Turkish community was until I experienced it. We need trained staff that can diagnose people from all backgrounds. I had to get the diagnosis done privately because I was confronted with a dead end wall.”

“I would like to touch on the stigma associated with dementia. I belong to a small Tamil community. If a member in our family had dementia they would not divulge.”

Information and Access

Many participants indicated difficulty in understanding the aged care system. There was a strong preference for verbal information instead of piles of pamphlets. In some cases individuals indicated that they did not want the responsibility of having to choose a service and would prefer a recommendation. Others discussed difficulty in accessing information in their language.

“[to assist me as a carer I need] translated information about aged care and dementia support.”

There was overall a positive response to the idea of a central place to access information as long as it was appropriate and available in the language of the individual. One person questioned whether money should be spent in setting up a new front end and suggested that it would be preferable to provide better funding for existing services.

“When mum was diagnosed I got a pile of advice in papers, but I want someone to talk to me. I want them to tell me what we need to do. I will never read that.”
“Centrelink gave me pamphlets, told me to choose, but I can’t choose, they know better and what is best.”

Access to services
Participants at the meeting expressed concern about access to culturally appropriate services, education, activities and bilingual staff. Culturally specific service providers indicated that they were unsuccessful in their application to the Aged Care Approvals Rounds (ACARs) which meant that they were unable to provide the specialised services that they felt were needed in the community. While there may be a number of reasons why applicants were unsuccessful in the ACARs, concerns were raised that not enough funding is being provided to culturally specific services. There are also concerns around the lack of services for people with YOD, waiting times for assessment, and the artificial boundaries between what services can provide. One provider indicated that there had been a change in Government regulation regarding whether providers were required to develop cultural plans for clients and that this had a negative impact on residents from multicultural backgrounds.

“We need culturally specific facilities but the government does not favour this. I believe that every nursing home should be multicultural – we are a multicultural society.”

“If you go into a nursing home or hospital getting someone to speak your language can be very difficult. Unless you have someone to make this work the person with dementia is going to be suffering”

Community Care
Participants indicated that access to community care was very important to people from CALD backgrounds. Many families feel a responsibility to care for the person at home and go to lengths to avoid placement in residential aged care. There was concern about a lack of services and long wait times for assessment. There were also questions as to whether the hours provided in community care packages were sufficient.

“The Vietnamese community prefers community care. When we assess people for aged care packages we see that the level of care needed is quite high. Before getting assessed, the children look after a mother who has dementia. They take turns. So their mother moves from one place to another so they can cope.”

One respondent also raised particular concerns about the services that refugees may require.

“Afghan community aged people stay at home and they don’t go out at all. These people need to stay together and they have a lot of problems like depression because they lost everything in the war time. There is no place for them or any funding for a program to help these people.”

Residential Aged Care
Concerns were raised about the quality of care provided in residential aged care facilities. There was also distress caused due to the lack of culturally relevant activities and services and the lack of interpreters.
“In nursing homes the accreditation requirements are good but as soon as the accreditation team leaves it changes... It is really important to have quality for all older Australians regardless of where they are coming from”

“Social isolation caused by lack of contact with people who speak the same language. Ethnic aged care volunteer services such as ethno-specific Friendly Visiting Programs not received well in residential care facilities.”

Respite
There were a number of concerns raised about access to flexible respite that was culturally and linguistically appropriate. Individuals suggested that there was a need for longer hours of respite particularly for carers who were continuing to work. Despite the desire for more flexible services, individuals raised concerns about cashing out and how people from non-English speaking backgrounds would manage funds. Some suggested that such a system could lead to additional disadvantage if appropriate safeguards were not put in place to protect this vulnerable group. Providers indicated that many CALD individuals are already reluctant to take up formal services and that the cash-out option may make people more likely to avoid using formal services.

“I have been asked ‘Why are you crying? Why do you have so much difficulty putting your mum in respite?’ My mum doesn’t speak English. There were no services available that met her needs. She didn’t fit into your equation or policies. I am sure I am not the last.”

“There is a great need for flexible respite. Services that suit clients and carers, not just providers.”

Workforce
There were concerns about staffing levels, pay and training as well as the availability of bilingual workers.

“I want to know, who sets the benchmark for the payment of carers who work in nursing homes? The people who are working in these areas should be admired and I wonder if they are really compensated”

One service provider shared an example of how they have addressed the shortage of bilingual workers:

“There is an agreement between Holland and Finland; we can use the students in their final year of university. We have about 12 students. They bring their language skills and culture and the clients love them.”

Support for Carers
Some respondents felt that the focus of the PC had been on the physical care of people but not enough consideration had been given to how to support carers, particularly as people stay in the community longer.

“We are all used to physical care issues, but the emotional aspect around dementia has not been addressed by the PC. Where do you go for services at the point of a personal crisis?”
There was also concern that there are a number of innovative services that are well received by the community but which only receive funding for a single year. When that funding ends, the community is left with a gap in services which they had started to rely on.

“I was involved in a project this year educating carers to how to live better with a person with dementia. The project was excellent, but it raised hope in the community, then the funding finished. We need more programs like this funded for more time.”

Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI)

A GLBTI consultation was held in Alice Springs, NT and with representatives of Gay, Lesbian, Bisexual, Trans and Intersex Retirement Association Incorporated (GRAI) in Western Australia. We also had a number of responses to our online survey from individuals who identified as GLBTI. More detailed notes from the Alice Springs consultation, the survey and a letter from GRAI are included in Appendix C – GLBTI consultations.

The themes which emerged from the consultation, discussion and survey responses are outlined below, but are also captured in this quote:

“As a gay man I need services that have staff that understand me being gay and with whom I can feel safe and with whom I can have some chance of understanding their reactions to me. If we cannot express our deepest feelings openly, honestly, without shame or fear, in our old age, then we are a failed society and there is no care, just service.”

Information and access

GLBTI advocates indicated that aged care service providers should state on their website or in their brochures if their staff are trained in GLBTI sensitivity. There is also a concern about the heterosexual subtext to information and being able to access information in a culturally safe environment.

“Need to remove heterosexual subtext to information, access, entry (e.g. wife/husband unless the law changes)”

“Accessing information needs to be in a culturally safe environment where the risks of self-exposure are less than the immediate benefits. For gay people, dealing with others who are gay may not always be the answer but it is a great start.”

Discrimination/Stigma

Participants indicated that GLBTI individuals often experience discrimination in aged care facilities. An example was given of staff refusing to provide care upon learning about the person’s sexuality.

“A carer bathed a woman, and when she found out she was a lesbian she left, it was discrimination. She was suddenly left without a carer.”

Many older GLBTI individuals choose not to be open about their sexuality with care providers because they are fearful of discrimination. This can raise particular difficulties in community care where GLBTI people may not want outsiders coming in to their home. This can also complicate the partner’s role in care provision and decision making.
There was also an example given where the person with dementia shared his sexual identity which had been kept quiet for many years. This raised difficult issues for family and staff.

**Sexuality**

There is a lack of recognition of sexuality of residents in aged care regardless of sexual identity. This can mean that individuals are not given privacy and that any expression of sexuality is considered a behaviour which needs to be managed.

“There are huge challenges around gender and sexuality issues, in the home or in a residential setting.”

**Workforce**

There is concern that aged care staff need training and education to increase awareness of GLBTI issues. There needs to be more GLBTI staff too, who are able to connect GLBTI people to their communities.

“It’s all about education and saying lets have the whole spectrum of people being carers.”

“Education and training to increase sensitivity and awareness of staff and residents of facilities to the entitlements of GLBTI people (both home and residential care).”

The representatives of GRAI also discussed a recent research report they had released about GLBTI issues in aged care. They found that 86% of aged care providers surveyed were not aware of any GLBTI individuals in their facility. The survey also indicated that facilities did not provide staff training on GLBTI issues and only two facilities provide training for staff on sexuality.


**Advance Care Planning**

Concerns were raised about the Northern Territory having unique legal issues surrounding end of life planning and guardianship. One person said that it is impossible to nominate guardianship before a person is declared incompetent. As a result it can be hard for a GLBTI individual to nominate their partner to make end of life decisions for them. In some cases this means that their wishes are not carried out as families, who the person with dementia has been estranged from for many years, step in to make the decisions.

**Residential care**

There is concern about staff and residents responding negatively to people who cross dress and the need for more privacy from staff.

“Sitting at a table at a residential facility and someone is in drag, and then the wig gets knocked off, everyone screams, how demeaning.”

**Community Care**

People feel the need to hide their sexual identity from carers who come into their home due to a history of discrimination and ridicule.
“When some people receive home care they sanitise their homes, hide magazines and take pictures down so they are not found out. They are frightened.”

HIV
People who have HIV are at risk of HIV-related dementia. Stigma and discrimination around caring for someone with HIV still exist. There was suggestion that staff need to be trained in best practice for HIV.

“People on antivirals are more likely to get dementia. That will be their next wave as people with HIV are living longer.”

Aboriginal and Torres Strait Islander
An Aboriginal and Torres Strait Islander consultation was held in Alice Springs. The themes which emerged from the consultation are outlined below. Detailed information of the consultation is in Appendix D – Aboriginal and Torres Strait Islander consultation.

Education/Awareness
Many Aboriginal and Torres Strait Islander people have a different understanding of dementia than the mainstream community. Dementia is at times equated with “being mad”. There is a need for culturally appropriate dementia education and awareness raising activities.

“Living in our Aboriginal community, it is all under one thing, if you assigned a mental problem, you are just seen as ‘mad’. Now there are differences and that needs to be explained to people.”

“My sister is in the first stage of Alzheimer’s, she is in so much denial it is not funny.”

Access to Services
There is a lack of services in remote areas and a need for mobile medical services. This is particularly important for the Aboriginal and Torres Strait Islander community as they have a special connection with ‘country’. Leaving their community to access services can have a detrimental impact on their health.

It was also discussed that services in the NT are currently provided by shires, and people feel that this results in less community control.

“For indigenous people in remote communities, if they need particular levels of care, they have to come to Alice Springs.”

“When aboriginal people leave their community there is a huge void. Country heals people, it is their medicine. When they are back there their whole being, and essence of what makes them Aboriginal, is healed. People desire to get back as soon as possible.”

Younger Onset Dementia
Participants brought up the higher incidence of YOD in the Aboriginal and Torres Strait Islander community. They questioned whether the government’ should be looking at just aged care, or broader issues that encompass YOD as well.
“Person support – not aged care. It is prevalent in Indigenous people that they get younger onset dementia. If it is an aged care thing then they shouldn’t be getting support.”

Aboriginal and Torres Strait Islander Culture
A number of concerns were raised around health care fitting in with the Aboriginal and Torres Strait Islander culture. Remote area nurses are needed so that Aboriginal and Torres Strait Islander people do not have to leave their community to seek services.

“Country heals people, it is their medicine.”

Issues were also raised around Aboriginal and Torres Strait Islander people reverting back to their original language and forgetting English once they have dementia.

Workforce
Participants suggested that there needs to be increased levels of care staff, particularly Aboriginal and Torres Strait Islander workers and those that are experienced in working in the bush. More incentive needs to be given to people to join the health workforce, including a career path and increased pay.

“It’s not a career path, and that is a huge issue for Indigenous people. If you were in the police force, you would be a sergeant after 10 years.”

Respite
Cashing out for respite was discussed as a positive option that would need some protection. For example, the option of having a case manager to help with organising the respite was recommended.

“I would love to be able to pay family for the services they do.”

Residential care
Participants indicated a desire for residential aged care which was located in their community, provided high quality care and also enabled them to make choices which were consistent with their culture. Participants indicated that the quality of care “in the bush” was quite variable and in some cases very poor. Several concerns were raised about rules and regulations that result in limited choices for residents. For example, one participant indicated that a Aboriginal resident expressed a desire to eat outdoors but was not allowed to due to safety regulations. Another indicated that the regulations resulted in decreased choice in activities and food.

“We have to treat people as people. Cut out expectation and regulations that prevents us from supporting people.”

Regional
Regional consultations were held in Merimbula NSW, Geelong Vic, and Mandurah WA. Alzheimer’s Australia QLD staff also interviewed consumers in regional areas of QLD and provided a DVD of these responses which are included in the discussion below. Detailed notes of the consultations, answers to the Q&A sheet, response to the online survey and a transcript of the DVD is included in Appendix E- Regional Consultations.
Primary Care
A number of consumers suggested that the process involved in diagnosis of dementia could be improved. Consumers claimed that the waiting times to see a specialist were too long, as well as the length of time before diagnosis.

It was suggested that there is a need for more GPs to undertake training and be provided more information about the diagnosis of dementia, particularly due to a lack of specialists in rural areas. It was also discussed that GPs should be encouraged to take interest in the patients after diagnosis, by visiting the residential care where patients are residing.

“I took my mother to the GP, and he didn’t seem concerned. There was no suggestion to refer her elsewhere. A big problem in regional areas is we go to GPs for help. Unless they have had personal experience with dementia they take no notice of the carer and their concerns. There is a lack of medical professionals we have access to in regional Queensland”.

Information and Access
The aged care system was seen as complex and difficult to navigate, even for those who have a professional health background. Therefore, there was importance placed on organisations such as Alzheimer’s Australia as a first point of contact; however there is still a need for one central point of information and relevant for people in regional Australia.

“More information is needed especially for people from regional, rural and remote areas.”

Consumers expressed reluctance to call a national telephone number and preferred to talk to local people who know about regional services. They also highlighted how well local networks worked in regional areas.

“If I wasn’t in health industry it could be difficult to know where to go, but once we make contact with one service they then recommend the next services. Good networking.”

Waiting times for assessments and access to services is difficult, timely and expensive, especially in regional Queensland, where there are only two or three geriatricians in the regional areas. They felt there was a high demand for a permanent geriatrician, and that the fly in fly out arrangement was not suitable. Overall it was felt that there was inequity between rural and metropolitan access to specialist services. One recommendation was the use of Skype to discuss results with specialists, rather than travelling for two hours for a two minute consultation.

“I had to travel 620kms from Rockhampton to the Sunshine coast. It would be beneficial to us to have a geriatrician.”

“It is very difficult to get a review by a psycho-geriatrician or neurologist, especially in rural Australia.”

Community Care
There is a need for more resources in regional areas so that carers can keep loved ones at home longer. For example, in Townsville there are not enough HACC services. These resources also need to be consistent and appropriate to the individual.
Consumers were also concerned about the waiting time it takes to be assessed for care.

“Consumer directed care would suit us but where do I find that in my area?”
“Care services? Near non existent in rural areas outside of the large towns.”
“It takes too long for an assessment to happen in country areas.”

Respite
Consumers want access to flexible respite that provided quality care and did not have long wait times. Consumers also felt respite should have better environmental design, consistent staffing who are better trained, provide social interaction, and be able to deal with changed behaviours.

“I put my husband in care and had to pick him up again because they couldn’t handle him.”

Support for Carers
Consumer’s placed a lot of importance on the support of local Alzheimer’s Australia outreach services including programs like Living with Memory Loss and memory lane cafes.

“My husband had Alzheimer’s. I felt so alone. Through Alzheimer’s I get help, I am not so alone anymore.”
CONCLUSION

Across all 16 consultations, the overwhelming view of consumers was that the aged care system is not working well for people with dementia, even less so for people with dementia in diverse communities. Consumers are frustrated that they are unable to get the services they need and that the services that are available are often inflexible and of poor quality.

There are a number of themes that emerge from the consultations which have been reviewed in this report. The priority for people with dementia and their families is a focus on the basics of improving care services and being empowered to be involved in decision making about care. Three main areas emerge as a priority for consumers: diagnosis/assessment, community care services, and quality of services.

Diagnosis/Assessment

For the person with dementia and their family the journey needs to start with a timely diagnosis, referral to support services, properly resourced assessment process and a link worker to provide guidance when needed. Having these services in place early in the disease process has an impact on the whole of the dementia journey.

It was clear throughout the consultations that people thought an impersonal government bureaucracy such as a national Gateway would not be enough to address the need for better information and support. Consumers are not looking just for information but also want guidance and support to make decisions. Consumers indicated a desire for a single ‘case manager’ or ‘dementia nurse’ who could support them throughout the journey from diagnosis, assessment to decisions about residential and community care. Consumers are flooded with information but don’t know how to choose amongst different providers and services. For individuals who did have a key worker they could rely on, the personal relationship with that person was invaluable.

Adequate resourcing of a Gateway would also be key. Consumers currently spend years trying to get a diagnosis and once they finally receive a diagnosis are told they have to wait to get an assessment. Consumer confidence in the assessment process will not improve without a reduction in wait times and staff who understand the special concerns of people with dementia.

In the regional consultations there was a particular concern about whether information in a Gateway would be locally relevant and a reluctance to call numbers that might be answered by someone who is not in their local area and therefore does not know the services that are available. Consumers expressed a reluctance for a new system to replace existing networks which they found to be working well.

Community Care Services

Consumers have a strong desire to keep the person with dementia living at home for as long as possible. But it is clear that this can not be done without the appropriate supports and care services. The current system of community care packages are seen as inadequate and inflexible. Consumers face long waits before they can access services. The lack of transparency in administration costs and artificial barriers in what services can and can not provide leave consumers feeling cheated of the care they so desperately need.
For a person with dementia to remain in the community there is a need for adequate support for carers. This includes flexible respite services that are available when and where they are needed. Day centre models are important for carers who want to continue to work and keep the person they are caring for at home. Ideally, these services also provide the person with dementia with the opportunity for social engagement and participation in meaningful activities. Access to these services is even more difficult in regional or remote areas where carers may have to travel a distance to get only a few hours of respite care.

Increasing community care packages, access to consumer directed care and more flexible respite may address some of these concerns. At the same time, consumer expectations need to be managed. The notion of entitlement to the care that is needed has given some consumers the sense that they may have access to as many hours of community care as they need to keep the person at home.

Quality
Consumers have significant concerns about the quality of aged care services. They have an expectation that any reform of aged care should result in improved quality of services. There is a lack of confidence in current mechanism to address poor quality such as the Complaints Investigation Scheme or the Accreditation Agency. Consumer confidence in the aged care system could be improved by funding community visitors schemes, better access to advocacy services and meaningful consumer involvement in regulation and the complaints processes.

In the late stages of dementia it becomes very difficult to provide the level of care required in the community. Consumers become desperate to find a residential aged care facility that will provide quality care for the person with dementia. It is clear from the consultations that the current quality is often inadequate and at times extremely poor. Many facilities indicate that they provide ‘dementia specific care’ but often this only means that there are locked wards.

Providing quality care to individuals with dementia who often have behavioural and psychological symptoms is challenging. Consumers spoke of understaffed facilities and staff who lacked the training to provide appropriate support to residents. As a result, staff may resort to physical and chemical restraint to manage challenging behaviours. Residents then quickly deteriorate because a lack of physical activity and mental stimulation. Consumers want residential aged care facilities that have appropriate levels of staffing, fair wages for staff and training to ensure staffs are able to provide appropriate care. They want a model of residential aged care that focuses on maintaining skills and physical health instead of one which rewards dependency.

Concerns about quality extended to end of life care. Carers expressed concerns about the person with dementia not having access to palliative care because they were not dying quickly enough. Others indicated that people with end stage dementia were rushed to hospital or given antibiotics against their wishes.

Access to appropriate, high quality care is even more difficult for those with younger onset dementia. There is a need for specialised services which support these individuals and ensure access to appropriate activities and interaction.
APPENDIX A – GENERAL CONSULTATIONS

Minutes from consultations

Consumer summit – National Consultation
13 October, Main Committee Room, Parliament House.
Panel: Glenn Rees, Sue Pieters-Hawke, Professor Brodaty and Paul Gregerson
Chair: Ita Buttrose
Attendees: approx 200 consumers

Main themes
Primary Care
- Difficulty getting a diagnosis
- Questions about cognitive screening
Community Awareness
- Need for a holistic approach to brain health
Community Care
- Need for consistent staffing
- Preference for flexible consumer directed care
Residential Care
- Care recipients health declining suddenly after entering residential care
- Rights of the person with dementia and implications of locked wards
Respite
- Family member not being allowed to stay with the person during respite care.
Workforce
- Staff levels
- Training
Special Groups
- Lack of appropriate services and support for younger onset dementia
- Need for different models of respite and residential care
Support for Carers
• Carer pension not adequate and means tested
• Difficulty getting home modifications which could assist carer in keeping person with dementia at home.

Research
• Need for more research funding

Comments
Primary Care

My three main concerns are diagnosis, diagnosis, diagnosis...convincing GPs to diagnose and families to get it.

I wonder if government would provide funding for assessments, early screening.

My mum has been diagnosed for four years. But, there was something wrong ten years before that.

Henry mentioned medication, but I was not once offered any medication all the doctors said is – dementia is just a part of ageing, get over it and move on. All the places we went to seek help there was nothing, just one dark journey.

Community Awareness

Need to have long term thinking...now we are looking at alcohol, drugs, obesity and potential for vascular dementia. I will challenge the minister that there is a whole of government approach. We need a clean environment, clean air, and safe walking places, to minimise the damage to our brain. There is a lot of talk about hospitals, but the hospital is too late, we need a good health care system.

Community Care

The main problem with care was a different person every coming every morning. The strange faces were very confusing! He would tell them to bugger off when asked to be put in a shower and have the pad changed. Family could do it and it was only when the same person came everyday that he would settle down and let the carer do it. The same face and same voice meant that his basic instincts returned and he was cooperative. Providers of care services are given a list of tasks, and need to tick off lists; it’s not about helping the person become comfortable.

I am a case manager for Illawarra, still waiting for client and carer to direct what services they want, not dictated by guidelines. We have 5 CDC packages in Illawarra.

I cared for my mother and husband, luckily I am able to keep husband at home. Most people would like to be cared for at home and die with dignity.

Person centred care is important. We need to get people doing individual projects that suit peoples interests. Also, we need more home care that is person centred.

Residential Care

12 weeks ago mum could walk, talk and eat, then after entering a nursing home she quickly went downhill and suffered 14 falls and strokes. Now she cannot walk,
talk or eat. In eight weeks I had a functional mum to nothing. It is heart wrenching, there is a huge impact on family, and I am now terrified of getting it.

I have been working in aged care for over 20 years; my concern is the diagnosis on dementia and Alzheimer’s. When we place people in dementia specific units, we are locking them away. We can’t do this to asylum seekers or to mental health patients. There needs to be a reassessment of residents going into aged care because right now people are never reassessed again. People decline within 6 months to not walking, communicating etc. People with dementia need better respect and better dignity. Look at human rights and compare to people treated in dementia units, it falls short, we are way behind!

The facilities at residential care need to be addressed. The care in Israel only provides accommodation with double rooms. This is an excellent idea as gives comfort to the person with dementia, as nurses are busy with other people.

Respite

I care for my mother, who has YOD. Respite took her for one day, and can’t take her now; too much hard work...all she did was wander. I wanted to stay with my mother while she was at respite but was told I couldn’t. I tried to explain I didn’t want a break from my mother I wanted a break from being her carer, showering her, feeding her. I wanted time with her when I could just be a daughter. They wouldn’t let me and said I had to use this time as a break.

Workforce

Staff to patient ratio needs to be raised greatly.

Education and training for carers in high and low care is the same, they only need a certificate 4. It is disgraceful! If you are in general nursing you can post grad to midwifery, why is there no extra training for people looking after people with dementia?

We need to address how the money is spent. Need money between the people needing care and providing care, need money to educate people, they are not being trained to provide the care that people need across the board. Not receiving information they need to understand about dementia.

End of Life Care

Palliation, people die from this, people should be able to die with dignity, and community nurses shouldn’t have to fight with palliative care about dementia not being palliative because it isn’t dementia.

Younger Onset Dementia

There needs to be age appropriate care assessments. You can’t get an ACAT assessment under 65.

I am tired of hearing the word ‘age’ and that YOD is rare, dementia is not a normal part of ageing, I was 46 when I was diagnosed. It is hard to get appropriate services for YOD. [We need] education for employers, help for children, home and community care, appropriate respite care. Think about palliative care while we are waiting for a cure.
Spouse of YOD sufferer. Like more emphasis placed on YOD. Want to know how many people are here for YOD? [Approx. 1/3 of the room] I work full time and care for husband who has now moved to nursing home. Spoke to a lot of people, different types of support were offered, morning help, but the care workers did not have any training in Alzheimer’s. No help [is available] for a man in 50s with Alzheimer’s. As illness grew, the doors closed. YOD have different needs, we still have a mortgage to pay. [My] husband is the youngest in his nursing home.

Miss out on assisted care between 50 and 65. Need age appropriate services, respite care. Need more training for GPs. There needs to be more training for people on the ground, more funding for research.

My wife is 63 and had 2 years in aged care. Facilities need to look at persons needs, not the aged care. A lot of places would only offer things not appropriate for YOD.

I was diagnosed with Benson’s disease, which affects the visual part of the brain and I was diagnosed with YOD last year. I am 57 now. It hurts is when people say that people who have these types of things are over weight, drink alcohol, and don’t look after them selves. I have done none of these things. I also exercise. I was principle of school in WA...I have lived a healthy lifestyle and used my brain. What part do epidemiological studies play? How much is hereditary? Both grandmothers had dementia, and mother took own life at my age. Is that why my mum took her own life? Is it because she saw what her mother and mother and law went through with dementia?

Support for Carers

I look after mum; all care professionals encourage me to keep mum at home as long as possible. I asked about carers pension at Centrelink, which is means tested. I have a two income family, so I am not eligible and will have to separate from husband in order to survive.

We need to see changes form Centrelink to support carers. Would like to see things like environmental initiatives e.g. solar panels, we need help with houses e.g. ramps, etc, people need support people living in their homes longer.

Research

Challenge to everyone to involve school groups to raise funds for research.
Canberra Consultation
18 October, Southern Cross Club, Woden, ACT
Panel: Glenn Rees, Gayle Sweeney (Aged Care Business Manager, Anglicare)
Chair: Jane Allen (CEO Alzheimer’s ACT)
Guest: Evan Mann (Carers Australia)
Number of attendees: 45

Main Themes
Primary Care
- Difficulty getting a diagnosis particularly for those with younger onset dementia
- Importance of GP listening to family carers about changes they have noticed.
- Link between early diagnosis and keeping people at home for longer

Information and Access
- Difficulty getting access to information
- Wait times for assessment and access to packages
- Artificial barriers between state ACAT services
- Need for a case management model

Community Care
- Changing level of needs leads to consumers having to change to different packages with different service providers

Residential Care
- Quality of care is often poor
- Importance of physical environment
- Importance of communication with staff
- Problem of not being able to easily switch between providers.

Respite
- Need for flexible respite where providers are not calling carers to seek help with behaviours or medication

Workforce
- Staff levels, and training are of concern
- Need for pay parity to attract good staff
- Question of how entitlement will work unless there is more staff to provide services

End of Life Care
- Importance of dying at home with dignity
Focus on quality care at end of life
Need for greater awareness about advance care plans

Support for Carer
Need for support to assist with depression
Importance of community awareness and support

Comments
Primary Care

My concern is if we want to keep people at home, then we need to get in early with an assessment. My husband has early onset dementia. I made an appointment with the GP and listed out all the signs I had noticed. I asked that he do an assessment of him. But when it came to his mental assessment which was performed by the nurse, she said his cognitive skills were good. She said he had slightly impaired social skills. This is not at all what my husband is like. The longer it goes without diagnosis the worse it gets.

My husband was diagnosed by accident. I had noticed changes but you think it is just old age and being forgetful. It came to light when he was about to have knee surgery. He was sent for extra tests that revealed high red blood cell count affecting cognitive abilities. After 6 months, and being sent to a clinical psychologist, and then to a neurologist, it was still like walking into a brick wall. Finally we were told it is a degenerative disease, Alzheimer’s, and then we were sent home with no idea with what to do next. The whole experience was slow; we were diverted onto something that was not the main issue.

I noticed the difference with my husband’s behaviour. I rang the psychiatric ward of the hospital. They referred me to the geriatrician who came to the house, made a diagnosis and then referred me to the dementia group.

For us we went to the GP, then went straight to geriatrician, then to Alzheimer’s Australia (AA), and never looked back. AA said come along to the ‘living with memory loss’ course, and it started us on our journey.

I had trouble getting diagnosis for my husband Chris, he has younger onset dementia. I was referred to a neuropsychologist. He said he could have Alzheimer’s but that they didn’t want to diagnose young people with it so they told him he had depression. My husband said ‘I am not depressed’ but they took no notice. Chris was given the wrong medication and denied access to services. If we want to keep people out of aged care and stay at home longer we need the right diagnosis.

My late mother enjoyed good health and visited her GP infrequently, so her GP didn’t detect the signs. My GP [in our social network] observed her and suggested she get an ACAT assessment. She was diagnosed with dementia and was placed in a dementia hostel.

Information and Access
My pathway into the services was fragmented and chaotic, serendipitous. I learnt everything by accident. Going to the social worker saved my life, she sent me off on the right path. But what would have happened if I hadn’t encountered the social worker?

A lot of EACHD packages are going vacant. People don’t know what services are available and have to wait too long for an assessment to get access to services. This leaves providers with services they can’t provide.

People can’t navigate the aged care system. This comes down to many hours spent on phones explaining to people how to get the right services.

In NSW the ACAT team has no waiting list but there is no ability to use it in the ACT – this seems incredible. The barriers between services are huge.

[PWD] I have a mix of problems. For me it is vascular dementia, diabetes, and a string of other things that is common among older Australians. I get a lot of help from Alzheimer’s and diabetes association, but these two associations don’t talk to each other. There are a lot of things happening but they don’t add up to what I need.

Under the current health reform process there is a great opportunity for dementia to be put on the agenda of newly established Medicare Locals.

I would like [the government] to consider a case manager that works with the family. So you have one holistic management process. I could then go to the person who knows me, and when I get depressed I would know what to do. I need someone to develop a relationship who knows me, the family and circumstances.

Community care

I have a client who is unhappy as she has lost a service provider who did things for her. Because her needs increased and she had to go on a different type of package she lost someone.

Residential care

When the time came for mother to be put in aged care hostel, my sister who is a doctor relied on medical nurses [for advice]. My sister would also drop in at random times to double check. We don’t trust the system. We need to do something about not improving the situation.

I researched so many facilities to the point I went to volunteer 2 days to get a feel of how the staff were treating the patients. I chose one, and after only 3 days I found mum in a soiled bed, and dinner left on the side table. She needs to be fed; she has dementia and can’t do it herself. On day 12 the night staff forgot to pull the high rail up and she fell out of bed, they didn’t even call the ambulance to see a doctor.

We thought of community care and people coming in. But I don’t understand the packages. So my sister and I became the package. People would say do you have meals on wheels; no it’s my sister Mary. But something had to give, so my mother went into respite, and she hated it. She is CALD, she is Asian. She expects her daughters to care for her. She didn’t want strange people coming into her house.
So we continued until it couldn’t happen anymore. Then she went into residential care. We chose the right place through going to different places for respite.

My husband is in residential care now. There is great communication with staff. I like the layout of the place. In so many places there were locked doors and blank walls. I also like all the activities and outings.

My husband had Younger Onset Dementia, and I knew he would have to go to care. I visited a number of facilities and wasn’t happy with any of them.

My mother was in a couple of facilities before I eventually found the right home I was looking for: skilled professional staff 24 hours a day. I wanted to know that people knew what they were doing. I wanted them to look at my mother in a holistic way and I wanted to see the residents happy and content. Those that could were busy, and peaceful, and there were sunny places to sit. I think you have to judge a place by the smell test.

My grandmother was lucky she had me who worked in aged care. A lot of people ask around, in the end we had to take the choice that was available to us.

The problem is the lack of choice, once you make the decision you are stuck with it. If you pick it and it is the wrong place it should be easy to say sorry we want to go somewhere else. People feel they have to get decision right because they have to stay.

Respite

Respite is hugely important. I am younger and had a career which I had to suspend. No other family members were willing to do anything. I would not have survived without places like the cottage. It must be cheaper to keep people at home so I would imagine more places like the cottage where you can have short term respite – beyond the 63 day system, it is absolutely crucial because otherwise you burn out. If the carer collapses it is a disastrous situation.

Husband has Parkinson’s, dementia, blind, and arthritis. I have to go home now to give him his tablet. I agree that respite is important, but it has to be flexible, sometimes the carer that comes can’t give medication.

Workforce

Without pay parity we will not be able to keep experienced people in the aged care workplace. We want people to have good care and feel that their families are being looked after. DoHA set a whole lot of standards but we are battling getting adequate staff.

More education is needed for staff. I asked [the staff] why one lady wears one slipper and one shoe and I was told it was because it was just her personality, one of her peculiarities. I looked and she had an infected toe, the staff didn’t even know about it. I have a great concern about residents with dementia; they must be treated as individuals, and treated with care and dignity.

The NDIS report came out the same time as the PC report. Just the NDIS is going to require double the workforce we have already got, it is a huge issue. If nothing happens [to increase the workforce], for all the good intentions there will be no one
to provide the services we want. The government will need to provide the funding and training for staff.

It shouldn’t be that everyone who wants to work should have to have all these qualifications. You should be able to go to Jo who has an interest and wants to provide care and pay him to support me.

Entitlement is a wonderful idea. But, we can’t afford more staff and we can’t find them. Anyone paying off a mortgage is going to get the best pay they can find. We won’t have [entitlement to care] unless we have better pay, and improve the skills of the carers. I am concerned about the RNs retiring soon as there will be no one there.

Employ people from our own communities, especially in CALD, remote and indigenous communities, especially for young people who don’t want to attend respite with older people. It would be great if we could get cash and employ people from our own communities.

End of Life Care

We need more resources in palliative care, more skilled workforce, knowledge and awareness of palliative care and dying in general. 40% of people would like to die at home; only 16% do, so it is a matter of choice.

My daughter came to us saying, ‘what is your end of life plan’? Her and her husband had already done it!

When mum was dying we went to see her, she was on her back, her mouth wide open, looking distressed. She was on her back because of bed sores, but we were not worried about bed sores at that point.

I have just organised my own funeral but I haven’t thought about the rest. I really should think about an advance care plan.

Support for the carer

My plea is for more support for the carer. The depression that I suffer as a carer can be very bad. You can’t deal with the person with dementia, and you are also liable to do something that you usually wouldn’t.

We need community awareness and start to share responsibility around. When you are in a situation of needing help, often there are lots people around but they need to be asked. This works much better than paid support.
**Sydney Consultation**
19 October, Alzheimer’s Australia NSW, North Ryde
Panel: Glenn Rees, John Watkins
Chair: John Watkins
Number of attendees: 22

**Main Themes**

**Primary care**
- Length of time between symptoms and diagnosis
- Role of family in getting the diagnosis and concerns about responsibility.

**Information and Access**
- ACAT team not listening to family
- Assessment not being accurate
- Cognitive impairment considered not sufficient to get access to care
- Wait list for services
- Stigma resulting in people not seeking services
- Barriers between services
- Information referral pathways.

**Community care**
- Inequities across locations
- Staffing
- Flexibility

**Respite**
- Need for more flexible respite with longer hours
- Staffing consistency

**End of Life Care**
- Staff not respecting wishes of individuals and their families
- Difficulties with family disputes and guardianship tribunals
- Power of attorney

**Support for carers**
- Health impacts of caring role
- Need for counselling and support

**Special Groups**
- Needs of individuals with intellectual disabilities
Lack of appropriate services especially for those with BPSD

Comments

Primary Care

My mother has frontal temporal lobo dementia. As it is not Alzheimer’s and not as common it was difficult to receive diagnosis. She was 67 and young and living alone. From a distance, we tried to help her to get a diagnosis when we were observing some odd things happening, and she was unaware, it was difficult to get access to medical help. She had a good GP but she couldn’t express these things. I tried to tell the GP. He said something was wrong. She was sent to a neurologist who said there wasn’t much of a problem. People say she is ok, getting older, a bit of memory loss, tired and depressed. Annually for three years mum was sent to neurologist. He said she didn’t try hard enough on the tests. She was doing her best but wasn’t able to advocate for herself. I wasn’t her guardian so we were trapped. The following year the neurologist said something was wrong and left us at that. Finally we got to the point when I had to be so forceful to say this is not ok. Finally we were put in touch with a geriatrician and we got a diagnosis. Positive – the geriatrician was very helpful, he specialised in difficult cases.

Part of the answer is early diagnosis, when the person has capacity to make directives for the family. They can make decisions for their own life.

My mother called and said something is wrong I need help. I called the GP. She talked about the problems with her memory. The GP referred us to get a brain scan. I was asked to fill out a form saying how did mum change. And I felt I can’t be responsible for her because classified as dementia if I filed in form. I called my sister so that we could do it together. The doctor was fantastic. The doctor said you know you have Alzheimer’s and you know it is fatal. Mum was ok with that.

Information and Access

To have an ACAT assessment – the approach is they ring my mother’s home to make an appointment. But she was saying no thank you; she didn’t know who they were. She thought they were people trying to sell her things. [As a result] ACAT were closing her file, not responding to the GP or geriatrician. Then I would contact them, put her on the list and it all happened again. Because of privacy they couldn’t deal with me, they could only deal with the patient.

When mum moved into care, the assessment they did for her, they asked her who Charlie Chapman etc is, she knew all that. But she passed the test and they told us she wasn’t sick enough to come. I had to go back to the geriatrician and the GP who wrote a letter to provide proof. They accepted her. Dementia was not a good enough reason. She had to have at least $50 worth of medical expenses to be eligible for care. She had to be physically unwell.

People don’t come onto the programs because of social stigma. There needs to be community awareness of YOD. We need buddies to walk the person with dementia through the life process.
The main problems were trying to get the package. The lady rang to say she was coming, and didn’t explain who she was. So I cancelled her, this meant they took her off the ACAT assessment waiting list.

I have no idea or experiences what services are available. We were told by ACAT to get a HACC package and that was fantastic. But by that time she was so far along she was beyond these things. I tried to get access to information about services by the web and DoHA, which was like wading through mud. Another difficulty was dealing with Centrelink. Things were so compartmentalised. Then they would tell me I would have to go back to DoHA, but I couldn’t access them physically, couldn’t find what I needed on their website. At this point you are so over tired, over burdened, over stretched and over worried that everything is so much harder.

Gateway – there is not an obvious central point to find out things at the point of diagnosis. I needed a phone number – AA is a central point of call, helpful because it is non government. It is helpful to have a central place to get information.

I stumbled upon a publication that had a list of all the places in one place. Lists by geographical area that was very helpful but took me a long time to get hold of it. If I had known more about AA it would have helped. I appreciate AA advertising, once I found out about central phone number [dementia helpline] to call that was a significant move forward. Finding a low care dementia specific place was very difficult. My mum has since come into one and it was terrific.

Mum needed more help, we got a reassessment of the ACAT, [and they found that] she needed more help, but she couldn’t get it if she lived at home by herself because she had to be assessed as needing to go into a nursing home. So the only thing we could do was get community help from lifeline. They took her once a week. But I couldn’t access any more care even though they clearly acknowledged she needed more care in the home.

Community Care

You need people to come and do community care, where do you find them, how do you pay for them?

Need more flexibility in community care.

There is inequity of service delivery across different locations.

Respite

I know there is problems with funding but money could be better spent. My husband goes to a dementia unit one day a week, it half hour from home, 10-3.30. So it doesn’t allow me to work those days so it’s not such a great help. I feel that I could be more use to the community if they could make the hours longer and provide transport. I joined one of your support groups, it is helpful but it makes me gag if people think it is the be all and end all. I would rather emphasis put on the community so they can help. On a recent holiday my husband was delusional. I have the opportunity to go away with my daughter and I can’t go as I can’t get my husband into respite. Emphasis on community care would enable me to work longer and keep my husband at home longer.
There is lots of waste. I have a friend in charge of a day centre for dementia. These people are supposed to have a carer there, but a lot of the time the carers are not around, sitting in the care, not doing what they are paid to do. There is a hell of a lot of waste in the administration of a nursing home. Admin staff would have a company car and go off for lunch and the nurses had a huge amount of accountability, but I had very undertrained staff coming in from 476 visas from china, they were terrified, couldn’t speak English. All this money and payment of people – there is a lot of inequity and waste.

There is not a lot of consistency in services. No point getting different workers to come in and shower a person. The time the carer should be spent having respite is spent instructing the new worker. It is hard for the carers to have faith in the services they are entitled to.

End of Life Care

My mother passed away last year. We looked after her at home. After entering the home it was extremely undignifying. She couldn’t swallow, lost weight, under 40kg, lost her sight. I am still feeling that I left my mother down. She used to say you will know what to do…presumably sleeping tablets. The cause of her death is dementia and genetic. I have requested palliative care. I don’t want my grandchildren to see me curled up with contractions. I wake up at night thinking about it. My mother’s wishes were not taken note of. I had to plea that mum would not be taken to hospital in ambulance. They were giving her antibiotics to keep this poor lady alive.

My mother is in a nursing home, I suffer confusion and grief about our experience. My mum passionately wanted to stay at home. She had short term memory loss. The GP put us in touch with an assessment team and geriatrician. She was diagnosed with Alzheimer’s. I am also a RN, so I knew how to put things in place around the home, putting notes around the place and respected her. I tried to convey this to my sister and brother who didn’t understand her needs. I thought I was managing things for the family but it got to the point my brother and sister said the only place mum should be is in care. It was a huge shock. They changed the power of attorney and lots of awful stuff. So I had a lot of grief. She then had a fall and was not able to go back home. This caused more arguments with family. The guardian now is in charge of her and I find that very distressing as the guardian isn’t that interested in her. I have accessed AA for some counselling. But I wish I had more access and understanding, so that our family could be brought together to talk about mum’s needs. The care is institutionalised; it is so distressing for her. She has put on 22kgs of weight because of the antipsychotics. It is a slow terrible grief declining to nothing.

I wish there was more credit given to the person who has been the main carer. There should be different ways [to handle disputes] rather than going through the guardian tribunal. My family was trying to discredit me and all my history of nursing.

Wife’s mother has Alzheimer’s, for me it is déjà vu, over 2 years ago my first wife died of cancer. At the time we were looking after her mother who had dementia. We got a lot of flack from family as we had to start to think of mum going to
another place, there were considerable problems at home. She could have easily crossed the main road and killed herself. Her doctor wasn’t completely convinced as she always presented well until she was put into respite care. The doctor who was called out every night decided she needed to go into care. At this stage my wife who was power of attorney, but had cancer. Her disease was terminal. As a result when my wife dies, before her mother, I was getting bills from hospital, I took them to the bank but had no authority. No one told me any different until I made further inquiries. I had to pay bills out of my own money which was running out. Someone said to go to social security, and I got her pension transferred and became her guardian. It was not well known you could do this. Once a person is deceased, immediately some government body should be in contact with family to advise what they should do.

Support for Carers

The attitude is that the carers should look after people, but this leads to an early grave. My sister has been so caring that she had made her unable to walk without assistance because she was in bed all the time. There is only one little bit of brain knocked out and we should work around it. There is space for a different sort of carer – not just palliative care – but someone who actively activates a person with Alzheimer’s. If I had made her do more things with supervision she could have maintained her abilities. It would have been an opportunity to try and keep her out of a nursing home. One category of carers does not cover everything.

I am a YOD coordinator from central coast. I provide a social support service for YOD. A lot of people when told initially deal a lot with grief and denial. This prevents them coming onto the program. The carers say I am young and strong enough which leads to problems later on. I would like to see the buddy seeing the people through by working with their abilities.

Then you come to the carer, the older generation are proud and they want to keep their dignity and don’t want to receive help. The younger generation know what their entitlements are and ask.

More credit needs to be given to the long term carer. They know more about the person than anybody else.

My mother had dementia before she passed away. I was stressed and depressed and went to grief counselling. 3 years later I was depressed and upset and it cost me my marriage.

I have been a carer for 14 years. My husband died and six months later my daughter was diagnosed with an illness. The most important thing for a person is medication. Taking it when they should have it and also love, faith, hope and care and a lot of support and patience. Because they do flare up. Because what is the sense of trying to pacify them, as you can make them worse. Listening to the speakers here today has been a great eye opener to me.

Special Groups

Intellectual Disabilities
Initially you talked about aged people, YOD and psychiatric, there is also a growing group of people with dementia – those with downs syndrome. I have a sister with Down syndrome and dementia. The problems with getting ACAT are enormous – they refused her, and so did the nursing homes, they don’t take disabled people. These people fall between the gaps.

Couldn’t get assessment for my sister with Down syndrome until she had an accident and I stood up in hospital and said I can’t take her home. We were told [by the hospital] to get her out of here we need the bed. I was given a few names. The first thing the induction person said ‘well of course she can’t afford to come her’ then she said ‘she is younger she will be dangerous’. The hospital and the specialist at the hospital were rude and told us we were over protective. We finally found a place where she was accepted. She was on a list for a group home; the emergency list for a group home is 18 months – 2 years. By the time she got there she was not accepted.

Younger Onset Dementia

I am primary carer as my father who has YOD. We didn’t get a diagnosis until we hit a crisis. He had symptoms for a long time before we got a diagnosis. By the time he was willing to accept help his friend took advantage of him financially. I had to go through the guardianship tribunal as dad didn’t have power of attorney in place. The process is very difficult. I cared for him for 6 months, and then we moved him into care. Initially low care, not dementia specific. I could not put him in one at that point. The dementia got worse; the care staff did not have adequate understanding of people with dementia. We had to move him into dementia specific unit. The case manager went on leave, and dad went on a very long walk. My father always liked to go for walks and now with dementia he would lose track of time. They told me he was wandering and the police were called. The staff on charge had no idea what they were doing. They called and said he couldn’t stay and I had to move him. They gave me numbers for high care dementia specific facilities. Those places said there is no way you need high care. I went in to take my father to look at another place and the nurses said to pack your bags, he has to go. The care manager of the facility we visited said we will take him on a trial run but if he is aggressive we can’t keep him. The care manager made it clear she didn’t want him because he was much fitter and younger than other residents. She called after 2 days and said he can’t stay. I was given no advice on where to go. The dementia specific place he moved to, the staff had no idea about dementia, I mentioned a medication and they didn’t know what it was. I got advice to get an assessment from a psycho geriatrician, but they said he is not aggressive. By word of mouth I found another place which was amazing. He has been there since Feb and we have not had a single incidence of aggression. He calls it home, he hugs the staff. If he did that previously he was accused of sexual harassment. We need staff that know about dementia, and know how to treat the residents.
Brisbane Consultation
20 October, Chermside Kedron Community Church, Chermside
Panel: The Hon Mark Butler, Glenn Rees, Athena Ermides (General Manager, Berlasco Court Caring Centre)
Chair: Victoria Beedle (CEO Alzheimer’s Australia QLD)
Attendees: 71

Main themes
Primary Care
- Length of time till diagnosis
- Inaccurate diagnosis
- Need for more awareness
- Not listening to carer

Information and Access
- The need for more geriatricians in regional areas
- Lack of services available for those with severe BPSD
- Lack of appropriate services for YOD
- Inconsistency across what types of services can be included in a community care package (bathroom cleaning but not dusting)

Community Care
- Lack of consistency in staff

Residential Care
- Use of physical and chemical restraint

Respite
- Not able to access enough hours of care
- Need for respite services that can respond appropriately to BPSD or other high care needs

Workforce
- Staffing levels
- Training

Support for Carers
- Access to information and support services
- Need for better financial support
- Individuals separating in order to be eligible for carer payment
- Training and education for carers
Research

- Need for more government funding for dementia research

Quotes from Regional Queenslanders

Primary Care

My husband has a short stint of dementia, short because I couldn’t get anyone to diagnose my husband,

I have YOD Alzheimer’s. It took 18 months to get a diagnosis in Townsville even though we had genetic evidence this would happen to me. I have two children with autism and I can’t get any help, no one understands.

My husband was treated with Parkinson’s disease instead of dementia.

YOD, showed signs in 40s and 50, she didn’t get a diagnosis until she was 60. Awareness around dementia as a whole, issues around elderly and the younger generation suffering. If we had awareness around all the forms of dementia, the community would be aware; it would help to get a diagnosis. There is so much awareness and support around a diagnosis for cancer; but not for dementia.

GP was some support, but I was sent to the wrong person because he could not see anything wrong with my husband.

I took my mother to the GP, and he didn’t seem concerned. There was no suggestion to refer her elsewhere. A big problem in regional areas is we go to GPs for help. Unless they have had personal experience with dementia they take no notice of the carer and their concerns. There is a lack of medical professionals we have access to in regional QLD.

Information and Access

Only 2 or 3 geriatricians in QLD, I had to travel 620kms from Rockhampton to the Sunshine coast. It would be beneficial to us to have a visiting geriatrician.

We need a permanent geriatrician; the fly in fly out is not suitable.

We need to get emergency help

People here don’t know if they like white or black tea but the doctor will still give them a driving licence.

Residential – great for ageing but don’t cater for younger people. This should change with the higher numbers we will see by 2050

Reluctance of ACAT staff to provide EACH package

Community care

CALD: Helping people stay at home as long as possible is fantastic, but in Townsville there is not enough HACC. We need more resources put to that.

The longer you keep people at home means that when they enter full time care they have much more significant high care needs.

Food: They have sandwiches, this is culturally inappropriate. I am then provided with a bowel of rice and a sandwich.
Respite care

I put my husband in care and had to pick him up again because they couldn’t handle him. We need more short term accommodation.

Day respite is a waste of time

There is no respite for younger people with dementia. Respite couldn’t handle her being so active, she needed a secure environment. There are not enough carers, so she was sent home from respite. You feel social exclusion every day, from employment, education, Xmas, birthdays. We can’t do it because we don’t have assistance provided for someone with such high care.

Carer support

Funding for the carer

Not enough accurate information

Coming to Alzheimer’s group was a help. I came to ‘living with memory loss’ and was able to get a referral to a geriatrician.

We need more care and services in the home.

Comments

Primary Care

My husband has YOD. He wasn’t well, he was feeling tired and retired at 60 and we set out on travel. In London I did the administration for Brent memory clinic. The psychiatrics did it there, so it saddens me when I hear people say the psychiatrics can’t do it [memory assessments], we needs a geriatrician. It horrifies me about the diagnosis difficulties, 3 1/2 years, when the GP really needs to just to an examination and send it to a specialist. An assistant psychologist can do the testing and you pay them nest to nothing because they are dying to get the experience. Then you have an accurate diagnosis. I got 3 1/2 hours of cognitive testing. This was wonderful and priceless to have this at the YOD stage. I have copies of all the testing, all the reports and all the blood tests. That has never happened to me here

Information and Access

My husband is about to turn 70, he has had dementia for a number of years. His issues are mainly mental health. He has been diagnosed as psychotic. He had to go into residential care. Day care is not suitable as he tried to strangle staff. His problem is he believes he is in jail. It took a long time for me to find someone who is willing to take responsibility for him. The dementia unit would not take responsibility. The mental health people would not take responsibility. The suitability of the aged care is fantastic, but it costs me dearly. If it wasn’t for the wonderful staff that let him wash and clean and post letters, he would not have anything to do and he would go backwards. The staff are not trained. So my issue is who takes responsibility for mental health dementia sufferers?

I would like to see changes to building codes so with an ageing population people can stay at home. Like wider toilets, wider hall ways. Once someone can’t get into the shower they can’t live at home any more.
There is a patchwork in the inconsistency of services. You can’t make an
appointment. You wait 45 mins to be seen. It’s so simple to buy a house,
compared to the other stuff I was confronted with. I have a HACC cleaner, and I
can only get a basic service. They clean the bath room and can’t wipe the window
sill, that’s dusting.

Many ACAT teams are reluctant to give out EACHD packages. We went through
three providers before we got what we needed.

My husband is 74, he was misdiagnosed with Parkinson’s, and finally diagnosed
with Lewy body dementia. On the EACH program I get 12 hours a week. The other
150 hours I do myself. What will happen under the consumer directed care; will it
give me any more hands on help per week? What happens when the yearly
allocation runs out?

Will there be a review of the age care criteria for funding? I struggle if they are
under 65. We are younger and younger with dementia and other health issues.

Community Care

Different staff came in each day. I heard screams coming from passage, the
strange women came in to rip shirt off my father, she said ‘I have 20 mins to do
shower and I have to go’. This is not good enough. People with dementia need
time.

Residential Care

The whole of society needs to be made aware, what have we got that allows
people living with dementia to live their lives? In another life I inspected nursing
homes that is why I chose to keep my father at home. There are many that make
the minimum standards. I have seen people time and again drugged up ad tied up.
Some dementia units will put the least experienced person in to care.

Respite

My wife goes to Mater respite two days a week, and that is wonderful.

I get 1 hour respite Monday to Friday so I can take my daughter to school. It is not
enough.

Carer support

I care for my mum. I am 46 she is 76. Over night I was living in my home and then
I had to move out to care for my mum full time. I would like to praise our health
professionals and feel sorry for those in regional Australia. I have had to leave my
husband and family at home. I called Centrelink to get a carers pension. They
advised I am not eligible, as it is means tested. To get it I have to leave my
husband. I live on $50 carer’s pension. This needs to change very quickly.

I put my hand up, train me to I can transition with my mother. I would like to be
trained in first aid and how to shower her. So when she goes into high care I can
still help her. Please train me and financially support me.

There is a lack of information for me out there to care for my husband with
dementia. Will there be more funding, for carers like myself, who want to do more?
I devised my own program as there wasn’t anything out there to suit him. Is there
educational programs out there to help us? There could be programs out there to help new carers to keep them at home longer. We also need the help ourselves financially.

If my dad didn’t have dementia he would be horrified that I have seen him naked and have showered and wiped him.

Workforce

The home where mum is in is fantastic, it’s always clean and the staff bend over backwards. However they are understaffed, particularly in the dementia ward. The patients don’t have the ability to say “I need to go to toilet”. There are 2 staff between 20 patients. Mum also has cancer, but I am praying that mum’s cancer will speed up. I would rather die with a heart attack than live the journey with dementia. Mum was only allocated 3 nappies per day. When I questioned it, the staff said that your mum goes to the toilet too much. I kicked and screamed, and got it fixed but what about the other people. If that was a child we would take them off their parent. Mum can’t tell them she is dirty, we visit and we smell it.

I have been the carer of dad for 14 years at my home. It was a long journey. He showed signs of dementia in 50s, when mum passed away she said we need to look after him as he was not all that he appeared to be. He is the eldest of 10 and 7 of his siblings have passed away having dementia. We need to see dementia as a specialised area. Our carers receive basic training; cert 3 and 4 does not adequately prepare them.

There is a desperate need for education in allied health professionals. My father lost his denture plate and the dentist said if he has dementia the only way we can deal with him is give him a general anaesthetic. The police need extensive education. They told us we were neglecting him and we need to put him in residential care. I saw the security guards pull people with dementia aside and tell them to take off their buckles and shoes. People with dementia don’t understand they have shoes setting off alarms.

Research

I am as mad as hell. I have been caring for my wife who was diagnosed at 63. She has had every bit of medical attention we can get her. She participated in a drug evaluation at the UQ memory clinic. The results proved it was not a cure. We went to china, where she had 4 weeks treatment with stem cells, but it hasn’t helped. I spent yesterday trying to find out about the 60 minutes report. I then found out that the trials at Griffith University have been put back again. I assume it’s because they are having trouble raising the $100,000 to do it. How much money is the present government spending on Alzheimer’s research? The ageing section is the bandaid section. I would call you the minister for band aids. If you were to spend a billion dollars on research we might get somewhere. We can spend a billion dollars on schools and pink bats…

I am a carer for my husband with Alzheimer’s. I spent the previous 40 years as a medical researcher. I would like to emphasise that we need a massive amount of money for research. Cooperative research centres for Alzheimer’s.
We need to be proactive, research is key, we need to find a cure and sell it to the rest of the world.

Acute Care

My husband had a tumour and became psychotic and diagnosed with Lewy body dementia. No body knew what to do with him. We fought all the way. You don’t see one person, you see a range of people, and you’re at the hospital constantly. The left hand doesn’t know what the right hand is doing. You go from one to the other, its draining and costs a fortune. I had to sell my home. Every time you see another doctor you have to keep retailing the same retched thing you are living with.
Adelaide Consultation
25 October, Alzheimer’s Australia SA, Conyngham Street, Glenside, SA
Panel: The Hon. Minister Butler, Glenn Rees
Chair: Kathryn Cunningham
Number of attendees: 88

Main themes
Primary Care
- Difficulty getting diagnosis
Information and Access
- Too much information in the form of brochures
- Difficulty navigating the system
- Barriers between packages
- Wait list for services and need for more funding
- Use of brokers to decide on service
Community Care
- Benefits of CDC
Residential Care
- Lack of physical activity in care facilities leading to decline in physical function
- Uncertainty about quality
- Inappropriate use of antipsychotics
Respite
- Lack of services for individuals with high care needs
Workforce
- Student nurses having little interest in aged care
- Importance of overseas workers
Support for Carers
- Need for access to respite services for those requiring high care and for individuals with YOD
- Importance of Support and counselling services for carers
- Concerns about carers allowance
- Need for superannuation component of carers payment
- Concern about programs that lose funding
Research
• Need for more investment in research

Special groups

• Access to appropriate services for YOD
• Side by Side Project as an example of service that is working well for YOD

Comments

Primary Care

I would like to see more information out there that can help us identify someone with dementia. It takes a long time and a lot of money to get help.

Information and Access

My dad was diagnosed with dementia at 60, and he has passed away. The whole system really sucked. We were handed a pack of forms and all these brochures, but you are in a state of mind that you don’t care. All you want to do is fill out forms and get on with it. Because I was a nurse I was supposed to have all the answers, I had no idea. It’s hard to know where to go for help. Where is the source you can go to, to access all the information? You are swimming in a world of brochures and all you want is answers.

In the current environment we are encourage to navigate the system, and I get so confused. When you arrive in at crises point there has to be an easier way.

My husband has dementia; it started in June 2008, when he was diagnosed with frontal temporal dementia. His language had become muddled, he could not string 3 words together, and he had severe frustration. After 12 months I was offered 5½ hours from one service provider, and I thought this was great news as I was only getting 3 hours from another provider. Then I found out I could not get the 5½ hours help because I already had a package.

We need to take away the stigma and demystify getting support; it’s not because you have failed it’s because you care. We have a 6 month waiting lists, how can we support carers so they can have a rest, if our services are so pushed. We could expand our services tomorrow if we had funding.

We would all agree that the human rights of people with dementia are being ignored. Access to aged care is a nightmare; each aged care facility has a different form from to the next one.

I concur about everything that has been said about complexity of system. I ended up paying $800 to someone to find me somewhere for my husband.

Community Care

My wife has younger onset dementia. She had behavioural issues and stayed a year in a facility that had appalling conditions. I then was able to get on a trial for a consumer directive care project. It has made a huge difference. It has taken off so well, one comment from a man in the group was “first there was button up boots, then we had sliced bread, and now there is CDC”.

Residential Care
My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other people’s rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser. He was treated like a dog. I couldn’t get anyone to listen to me, finally I found a broker and I found a nursing home. My husband can no longer walk, can no longer talk. He has been in the home for 2 years; he has deteriorated so rapidly, the nurses were not allowed to walk him because of workplace safety for the nurses, so he was moved around with a shifter. The nurses learn to wash and clean someone but that’s where it ends. To converse with him or make life more pleasant for him, it doesn’t exist.

How do you know if a residential facility is good or bad? All I wanted to know was what facility was reputable and what is not. You put them in a facility and it’s the worst day of your life. When dad passed away I was left with overwhelming guilt as I was left with all the decisions.

My husband was turned into a zombie within a couple of weeks. He wandered into ladies rooms and was put on an antipsychotic. They increased the dose against my wishes. He has been put on four antipsychotics that should not have been put on together. He started falling. This is a serious concern because it has ended with my husband losing his mobility.

The lack of physiotherapy is unbelievable. I had a holiday and got the physio to come for twice a week for 3 weeks, so I paid $650. He is not allowed to be walked because the nurses might hurt their back. I do all the physio and I bring him home because I am not gain to leave him in that place, they leave them sitting in chairs for hours.

I think volunteers need to come in; there is an Italian man who has no one to talk to. There should be much more advertising for volunteers in aged care there is nobody and that is why I can’t have a day off.

My husband needs 24 hour care. We can’t say I am going to pop down to the shop to get a loaf of bread. I have a sick grandchild, I would like to go a visit her but I can’t do that. I visited another care facility, and I would not leave my dog there.

Two facilities we run have taken on a healthy ageing model. We focus on keeping people actively mobile until they die. The result has been amazing. Rehabilitation and recovery does not sit outside aged care.

Respite

Thank god for carer respite centre. They put us onto midway house; there should be one in every suburb. It gave me peace.

My husband was diagnosed 9 years ago at 55. It is horrendous trying to find respite for high care. [Service] is fantastic but that is low care. There are only 3 beds at ...; there are 17 people on that waiting list. These are all for four nights, I need more. So I am looking at residential care. It’s horrendous trying to find it. I did a seniors information scan on the internet and got listings for all the high care. Out of 140 there were 10 that had high care, pre booked respite. One facility told me because he can’t press the buzzer that he can’t go to that facility. I have been told by another facility he can’t go because he is under 65. Out of 10 there was one facility that was appropriate.
Workforce

I was in a class of 267 nurses at university; I was the only person who went into aged care. It was looked on as a terrible place. My training at uni did nothing to prepare me for aged care. We need to get the training right in universities. Older people go into hospitals and they are cared for poorly as their needs as an older person are not understood. When they act out the response from staff is restraint.

I am so grateful for people coming from overseas to work in aged care. It is up to us to train them better.

Support for Carers

It is important to have a support group for a carer, this needs to continue. The stress I have had has been extreme, and it is a long good bye.

I am 87, I am a relinquished carer. My wife died four years ago from dementia. Attending seminars and reading info does nothing to prepare you with dementia. I know. I travelled the journey with my wife. No one has developed a universal program as every person has different problems. The carer must be a path finder in the maze.

You can get an EACHD package that costs more than a carer’s allowance. I would like to see Centrelink payments going straight to the dementia care person.

I appreciate my carers allowance but it is .38 cents an hour. As carers we are on duty 24 hours a day.

I still work full time, my wife at 60 went into aged care. We have been married for 30 years, and due to funding we have had to separate.

Funding from dementia community grants are doing fantastic things but it does not continue. Where do the people go after 12 months to get ongoing social support and opportunities to contribute to society with their skills?

I am on board of carers support, most carers try their best but are heading toward poverty. It is not fair for someone on carer’s payment to earn the same as someone on the dole. They need respite and need to look after themselves and their own future. They need to have a superannuation component, who is going to look after them when they get older, all has been spent and no money for them.

Research

We have come so far with breast cancer research because of all the funding. We all know the stats of dementia and there is no cure. We need more money for research

Special Groups

Younger Onset Dementia

There is this artificial differentiation between aged care and care for the rest of us. So why not have disability assessment teams. Why the differentiation and why are we left out.

My wife was diagnosed at age of 57. When we needed help we were refused. We were told to keep away from the aged care homes. This is because it is only
available for people over 65. The PC Report on Caring for older Australians should be changed so it is inclusive of all Australians no matter their age.

I have recently started working with YOD, outcomes for side by side project are spectacular.
Melbourne Consultation
27 October, Alzheimer’s Australia Vic, Riversdale Road, Hawthorn
Panel: The Hon. Mark Butler, Glenn Rees
Chair: Maree McCabe
Number of attendees: 70

Main themes
Primary Care
- Difficulty getting a diagnosis
- Lack of assistance once diagnosis is received
- Family member being required to speak about problems in front of person with dementia

Information and Access
- Wait time for assessment
- CAPs level packages not appropriate for individuals with dementia

Community Care
- Admin cost taking up 50% of package
- Benefits of CDC

Residential Care
- Chemical and Physical Restraints
- Costs

Respite
- Need for more and higher quality respite services
- Need for high care places
- Difficulty getting enough respite to maintain employment

Workforce
- Staff training
- Staff Levels

End of Life Care
- Inadequate access to palliative care

Support for Carers
- Need to look after physical and mental health of carer
- Training for Carers
- Need for more information on managing behaviours
• Possibility of an insurance scheme to pay for care

Research
• Need for investment

Acute Care
• Poor quality care
• Lack of staff training
• Lack of interest in providing treatment to individuals with dementia

Special groups
• Financial difficulties for YOD
• Use of medication to control symptoms
• Need for YOD specific services that address the different needs of individuals with YOD.

Comments

Primary Care

My biggest issue is struggling with diagnosis. The doctors don't want to know you. When you finally get a diagnosis, you are put on the back burner. So I had to find a private person.

My husband now has Lewy body dementia. It took the doctor so long to give us a diagnosis. I had to explain everything to the doctors in front of my husband which was so hard, before he would send me to the geriatrician. She was wonderful. She would call me the night before an appointment so I could tell her what was going on and not have to say it in front of my husband. The GPs need better education and to just send you to a geriatrician.

We had to wait till we had catastrophic behaviour until we got a diagnosis.

Information and Access

I live in rural Vic, I chair a carers group. We have a lot of people trying to access the system. There is a long waiting time for ACAT. Once you have it there is a waiting list for EACHD even if you are classed as high care.

I am a case manager. From what I have observed, if one people are diagnosed with dementia they should automatically qualify for an EACHD package. Not go on an assessment of a CAPs package. This would decrease carers stress.

Community Care

I have been 6 months into the pilot of the consumer directed package. These gave greater transparency, and I am very positive about those.

My father has dementia for last 16 years, Community aged care packages. I can't get my head around the admin fees who take 50% of the package. It equates to about $250 a week, so he is getting half of what the package is worth. I don’t see how this is justified. We are struggling. He is at a very advanced stage. We keep
getting told there is nothing left there for you. A package is worth $50,000 but we get half than that is not sufficient.

Residential Care

There is willingness to sedate people with Alzheimer’s. There is a link to antipsychotic drugs leading to other illnesses. The nursing home wanted her to be manageable, and sedated her. I believe the longer the resident is in their own home the better. The bullying – there is no other word I can use. The bullying we have come across in nursing homes, from hospitals and doctors.

My mother had to go into a nursing home. She was a wanderer. There aren’t enough dementia specific nursing homes. She spent the last 15 months of her life wandering up and down saying I want to go home. In a dementia specific nursing home they can go in to the garden.

We are fortunate that my dad did well and my mum is in a private aged care facility. We have had to sell the home. The costs are huge. When returned to aged care, in high care, we were told by the medical professionals that we would need to employ a private nurse for $100 a day and $200 a night for extra care. Now we pay for extra physio. If you don’t have families that are there for you what happens to those people. I would like to see doctors practice, dentists, chemists, physios and practitioners interested, to give them a better quality of life.

I have an ethnic aged mother. I have ongoing issues with nursing home about her being ethnic. It took a year for the nursing to get it right.

My father went into a nursing home. He has always liked going for walks except now it is called wandering. Twice he walked out of the nursing home. It was a serious crime. So they whacked medications into him and he was like a zombie. Then I went in and he was trapped in a wheel chair.

Respite

There is no respite centre that have available rooms for us to send our loved ones too. I haven’t put my husband in respite because my heart won’t let me. We need to have good care in places that are more available.

I have taken care of my husband for 10 years. I have been receiving respite once every 3 months. I would like to know if it is possible to have it more often. After 3 months I am really dragging. During the respite we are taken away on trips for rejuvenation. I am blessed by Susie Nemo, the day she came to the door I asked for an angel and I really got one.

There is inadequate funding for carer respite. My husband is 46, and we have a 2 year old son. He needs extra medical help. The cost of everyday living means we are falling behind. I have had to find more employment, but I was told as a carer I was only allowed to be away from my husband for 25 hours a week. He has feeding problems and aggression. There is no hands-on support in the home. To find a respite facility to suit is very hard. My friend in Melbourne put her husband in respite to take her children away. He ran away from the nursing home because he was physically fit at 44 to build a ladder and escape. Where is the respite for these young fit people?
I suggest there is insufficient support for sufficient and supportive respite care. The outside activities that the person with dementia can do is great, tea parties. They look forward to it and they come home happy and tired. Then the carer and sufferer has a break that works but it has to be more often.

Workforce

There is a lack of training for dementia specific staff. From carers to nurses to people who run these places. I have had to sit there and explain to the staff. The lack of training includes all the staff.

The other thing is the staff ratio is appalling. I am constantly battling. My mother was locked in the toilet for 4 hours. No one cared to know where she was. I feel for the others that have no one to come in and look after them.

When they went into a nursing home there was no training in dementia, and now they are and they are using Alzheimer’s Australia for training, people in that home are now more aware of what they can do.

End of Life Care

I’ve been told that if my mother does not die fast enough in a palliative care setting she will be sent away. I am fighting for my mother to die in a palliative facility because I am told she is not worthy.

Many people don’t want to go into institutional care. I applaud the report that wants to keep people out of institutional care. I think people who are faced with institutional care, means that it is their time to die. A properly conducted sociological survey finding out the wishes of these people in an open minded way should be carried out

Support for Carers

The government should have a strong interest in the health of a carer. I had to reconstruct my professional life and look after my own health. Those who are carers have already suffered, to be means tested is a double whammy.

I am a past carer. Insecurity, boredom, depression and insomnia. These four issues are interrelated. There should be training for the carers as soon as the person has a diagnosis. Instead of walking out of the doctor with a script and saying what the hell do I do now, we should be given a sheet about a training session. The opportunities are there with the gateway system, and AA has courses, but people would be kept out of nursing by better support for the carer. we don’t know how to deal with sun dwonner.

I was guided to AA and to all the workshops that were available. As I go through the journey with my husband I am finding things that I didn’t learn from AA. I am struggling with sundowners at 2.30pm or 3.00pm. I didn’t even know it existed.

I have found that I have had to do the work that should have been provided to me. I have had to close my business to take care of him at home. I did it for 5 years until I got really sick. We are missing the knowledge about how to manage the behaviours of people with dementia. We need a system of carer coaches. Counselling services from Carer Vic has been particularly helpful.
I asked if what I had to pay for care had anything to do with the value of my house. If you have a good pension it is one thing. I saw a very nice place; it costs $400,000 per room. For two of us it’s close to a million. Then it is an insurance problem. So how do we get a fund to fund the nursing home? Simple. Superannuation. Take nibble of the trillions in superannuation fund that can only be used for the unlucky 6% to go into a nursing home.

Research

Both of my parents have dementia. I would like to ask is can we get more money for research. Everything comes down to research. I have been to many info nights, I thought I understood dementia as a carer, I don’t understand. I went into the wrong meeting, it was a meeting for a medical staff. I learnt more in there than in 5 years.

We need dementia research on the model of the courageous brilliant doctor in WA who hypothesized that ulcers were caused by infection and went on to win a Nobel Prize.

Acute Care

I have just had someone in hospital and the staff were not trained on how to deal and work with a person with dementia.

My husband walked into an emergency ward. He was not allowed to feed himself. After 5 weeks he was condemned to a nursing home. 5 days after he walked and 6 weeks later he came home with no more community aid than he had before.

I am the daughter of someone who has Alzheimer’s, my mother is currently dying. There needs to be a change of attitude, every time my mother enters a hospital they ask what is her quality of life? If I didn’t give an answer to please them they wouldn’t be interested in treating my mother. The health care system – if you have Alzheimer’s you are the lowest priority

There is no staff training in hospitals. If I didn’t go in to feed him he wouldn’t have been fed for two weeks.

If there is one thing that can change, is not the education of the carers but for the doctor especially in hospitals. The doctor at the hospitals asked my mother which hip is broken. My mother would have no idea what hip it was

There is also the stigma, my mother walks around with a teddy bear. That is her security.

I took my mum to see a professor at the hospital. A hospital staff was in the elevator with us and said what the hell is she doing with a teddy bear. Where is the dignity and respect for elderly people?

Special Groups

Younger Onset Dementia

We need people who can visit the home. And some coaching and mentoring for doctors and nursing homes. My husband has different needs to everyone else, and he is the youngest in the home he is in
I am 45 years old, I have 2 teenage children that my wife and I are trying to bring up on the pension alone. The pension doesn’t vary between someone who is in a nursing home and someone my age. That makes it hard trying to bring up kids and pay a mortgage. There needs to be more awareness of YOD as it is increasing. There has been mention made of medications. The more they get put on the more dopy they become. You don’t want to get to a stage you are put on so much medication that you can’t get out of the bed in the morning. Aged care facilities – there needs to be more emphasis put on places for younger people.

YOD, in terms of respite care and residential support, we have been trying to work and come up with a model that works for younger people. In England we saw a great service. It was specifically dedicated to YOD. I want to know if we could have it here, we have one in NSW, which is Hammond Care. But there is nothing here.
Tasmania Consultation
28 October, Bahai Centre, Hobart
Panel: Ellen Skladzien, Kim McGowen, CEO Hobart District Nursing Service and President of AA Tas.
Chair: Debbie Miller
Number of attendees: 29

Main themes
Primary Care
- Difficulty getting a diagnosis
- Lack of awareness of benefits of a diagnosis
- Difficulty accessing GP’s

Community Awareness
- Need for public education program (ideas included: pamphlets for doctors surgery, school programs)

Information and Access
- Need for integration of assessment for all services
- Question of if gateway would work well locally
- Need for higher quality assessment

Community Care
- Concern over the admin fees for community care packages

Residential Care
- Poor quality
- High staff turnover

Respite
- Importance of respite for carers
- Respite not meeting carers needs- too short or not available for those with BPSD
- Need for flexible respite that allows carers to stay and visit if they wish

Workforce
- Need for more training and supervision
- Concern about administration of medications in community care

End of Life Care
- Importance of palliative care and advance directives

Support for Carers
• Need for a consumer representative organisation specific for aged care consumers
• Need for better mediation options for disputes with providers

Acute Care
• Poor quality care
• Need for better education and staffing
• Concern about the closure of the Nell Williams Unit, a dementia specific emergency unit, at the Royal Hobart Hospital

Restorative Care
• Need to focus on what person with dementia can still do and help them to retain those skills.

Comments

Primary Care

There hasn’t been enough work done on enabling GPs to make this diagnosis. There is an attitude that if someone has dementia perhaps they are better off not knowing.

After dad passed away mum was diagnosed 2 months later. She had issues but I didn’t recognise them. It was too late then to put any care plan in place for mum.

GP access is one of the main problems. It is hard to find a new GP when the residents come to the residential care. And particularly after hours GPs are hard to get. For the aging problem, access to GPs across the country has to be addressed by the government.

GPs are not interested in people in nursing homes. My husband was in a nursing home, and the morning he was diagnosed to be dying and the GP didn’t arrive until 5 hours after he died to sign the death cert.

We went to endless GPs and could not get a diagnosis. Finally dad was diagnosed with a sinus infection, the locum then tested his memory and realised something was wrong.

Community Awareness

It took me a long time to get a diagnosis. I think there is a need for a public education program, so people can see the signs earlier, so it can be diagnosed and treated.

There is nothing in the surgeries to help people understand dementia. I am appalled; it was the same 10 years ago when my husband was diagnosed. Information should be put in every doctor’s surgery so the carers can find information to find help. I am happy to deliver pamphlets!

My husband has Alzheimer’s, when I started to say something was wrong to my 5 sons, they all thought I was going funny. So could we educate in schools? A lot of these young people with grandparents need to know well before it happens.

Information and Access
I would like to see one assessment for everything including respite and services. I have had direct experience that a person living alone in the community can’t get an EACHD package because their needs are too high. Cherry picking has always existed in residential care, people with mental health issues are completely rejected by providers because they are too expensive.

A better assessment should be made of the person before they go into care. A more professional assessment would be more appropriate.

The gateway system would be great but how will state and local government access that information? It will be hopeless and not work.

Community Care

We receive 34% of the package; the other 48% of the package goes to the administration of the package. The value of the package that I receive is about half the value of one residential care place. So there is room to make up for the funding for the providers.

I have concerns about the CAPS and EACH package due to the issues of accountability in terms of the funding. I wonder where the funding is going; because of the administrative costs seem very high.

Residential Care

Mum is in the lodge (high care) they are slowly understanding her. None of the homes will be perfect, but there is a big turnover of staff, you get someone that finally understands that finally understands your mothers mind, then there is a change in the shift or manager, this is hard for someone with dementia. Mum wears glasses, and she doesn’t wear them until I go in and put them on for her. She is incontinent, she has trouble walking, I had to tell them to not feed her too much or she won’t be able to walk from overweight.

Dad was left in a chair, he couldn’t walk or feed himself, but mum is encouraged to feed herself, and she paints, knits, and joined the choir, this isn’t mum, this is someone else living another life. But she really enjoys her life in dementia. It is important to have the people to do all those things with them that they can’t get in home care.

Respite

We can support anyone in the community but we can’t do it without family carers and they can’t do it without respite. We all know the stories for the carers going before the client, and that is due to carer strain.

I have used residential respite unsuccessfully. I go away and when I come back my husband and mother have deteriorated considerably. My mother is not able to walk and we have to invest heavily in physiotherapy, so I try not to use residential respite so that leaves me with no break.

There is so little time for me to do anything. The respite was too short.

I could come with my husband to respite, that to me was a perfect model for respite. If the daughter or wife or carer can be admitted it is a perfect model.
We need more secure dementia areas, specifically built. There astronomical figures for people with dementia in the future. When people go into respite they can escape. The relatives had to be called at mid night because of behaviours and the only way it could be solved is to take the person home.

There should be a health maintenance focus – I prefer community based care as we have control over it. When my mum came out of hospital she couldn’t walk. Doing therapy at home she started walking at home. This makes my job a lot easier. It makes me annoyed that with the 12 different respites we have used, only one she has come home walking.

My mother and father have dementia. My dad was very aggressive and the system couldn’t cope at all. We couldn’t get respite care. Every respite dad went to he came out not walking.

Workforce

In the community there is lack of staff supervision. We have had many carers over the years, they are poorly skilled.

Only 15% of health care workers recognise it is a terminal illness, so we need to change the focus of their training. The managers of the aged care facilities want to train their workers but can’t afford it.

We need more money put into training GPs.

There are many incidents with medications. In the community in Tasmania the legislation is that community based support workers can do what they like. They can give any narcotic, or any type is substance according to the … act. For residential support workers it is better.

End of Life Care

There is a need for advanced care health directive at the time of diagnosis so the person can be still involved in how they die. I cared for my aunt and you wonder would she have wanted to die like this. If she had directives would it be like this?

Early diagnosis is important, so the person can make their own decision particularly about palliative care

Acute care

All the work being done is completely undone once a client goes into acute care; they come home in a much worse condition than when they left.

There are things happening in acute care that are purely for the convenience of the hospital, not the client.

Acute care policies need to be overhauled, there needs to be better education and staffing to deal with what Alzheimer’s and dementia patients need.

My husband was taken to the hospital and moved into the Nell Williams unit. At 9pm the nurse said don’t worry about you husband I will look after him. The nurse assured me he had been dealing with dementia for many years, so I was appalled when the Nell Williams centre was closed.
The Nell Williams Unit was a specifically designed aged care emergency unit in the Hobart Hospital. It won an international award. Within 12 months they closed it down, for no reason other than bed pressure.

Support for Carers

I am a carer, I have been for 8 years, and I am looking to be heard. We don’t have an affective advocate for us to be heard in Tasmania. There is no organisation that represents consumers of the aged care system.

By 6pm I feel like sitting in the corner and having a cry. There is no body who can help me. The AA people are absolutely fantastic. That gives me a couple of hours, but you feel so awfully lonely. Because you lose the person you have lived with for 50 years.

There should be a provision for external mediation where appropriate. A peak body in aged care might be able to fulfil that. Too often people with dementia have a problem with a service provider and they are still upset. It is not adequately solved; it is a provision in the act that is very vague.

Restorative care

I looked after my mother for 7 years. Two years after she was sent into nursing home I was diagnosed with frontal lobe dementia. When I was caring for my mum I didn’t know there was any support out there. The only time I found out there was support was when I found out I had dementia myself. What programs are there to retain the skills of people who have dementia? Creative programs are good but there should also be availability of programs to do everyday things to care for themselves. Is there any thinking out there to try to help the person with dementia to care for themselves? Then they can stay in the community longer and more meaningfully.

There needs to be services for people in the early stages of dementia who want to maintain themselves in the home and their social contacts. When you get a diagnosis and it can take over your whole world. But people want to remain as a social person and continue all their activities. Not just the person with dementia.

Carers have no idea about how to take a therapeutic approach to activities. I get mum to do up her buttons and feed herself and engage herself in whatever way possible and her mood is so much better when she has carers that use those approaches.

I work as an advocate for people with dementia. My role is to allow people with dementia to make their own decisions. It is supportive decision making. I am constantly amazed at the degree to which people with dementia can communicate their desires and decisions. That makes me passionate about the therapeutic approach.

I had to fight to keep my mum at home. Even though they have dementia, they don’t have it all the time. Give them more empowerment about what they want.
Darwin consultation
31 October, Darwin Airport Resort, Darwin
Chair: Sue Bradley, President Alzheimer’s Australia NT and past carer of her mother
Panel: Ray Norman, Education Consultant Alzheimer’s Australia NT, Ruth Leslie Rose, CEO of Alzheimer’s Australia NT
Number of attendees: 41
Special guest: Peter Styles, Shadow Minister for Senior Territorians

Main Themes
Primary Care
- Length of time to get diagnosis
- Difficulty in getting services without a diagnosis
- Doctors not listening to family carers
Community Awareness
- Experience of stigma and avoidance
- Need for awareness and information about prevention
Information and Access
- Lack of services in regional areas and high cost of travelling to services
- Desire to stay in local community
- Need for more flexible hours (after 5pm and weekends)
- Need for simple information and case management
Residential Care
- Behaviours provoked by inappropriate care
- Importance of environmental design (including outdoor areas)
Workforce
- Better training required- 3 months course is not sufficient
- Difficulty recruiting staff
- Pay inadequate
End of Life
- Concern about end of life choices in NT
Research
- Need for more funding

Special Groups
Younger Onset Dementia
• Lack of appropriate services
• May have increased numbers as diagnosis happens earlier
• Aboriginal and Torres Strait Islander Need for culturally appropriate services for Aboriginal and Torres Strait Islander communities

CALD
• Lack of services for CALD people
• CALD groups not wanting formal services

Comments

Primary Care

My mum was an extremely intelligent women, she was in a facility and never properly diagnosed, just old and forgetful.

My father has other things, such as Parkinson’s disease, but it took a long time to get a diagnosis of dementia. When we got it I wasn’t shocked at all.

It took a good two years to get a diagnosis; we knew there was something wrong with her. The family carer knows that things are not quite right, you want a label put on it and work from there. I was of the understanding that doctors in the early stage only get it right 50% of the time. The doctor said its ok you are just getting older and forgetful. Then when we did get a diagnosis she was in the moderate stage of dementia.

Firstly my husband was diagnosed with depression, when he was finally diagnosed with dementia it was too late for medication.

You have to be careful of diagnosing someone who doesn’t have dementia. A mild cognitive impairment doesn’t always necessarily mean dementia. So you are a little bit weary of giving people a diagnosis, but then you have difficulty accessing services you need if you don’t have diagnosis, catch 22.

I knew my mother in law had dementia when she couldn’t find anything in the kitchen. It took me 4 years going back and forth to the GP who I wasn’t allowed to talk to because of privacy issues. My father in law hadn’t been a good husband, and wouldn’t admit anything was wrong. He would take her to the GP and say everything was fine even though she slept with a knife under her pillow. I ended up having to sit in the GPs office and refuse to leave.

I would have to pay for two consultations so I could talk to the doctor privately. People with dementia can answer all the questions from the doctor, and it looks like nothing is wrong. That’s why the doctor needs feedback from the family carer.

Community Awareness

There is stigma associated with dementia. It is very hard. Over a period of time my mum’s circle of friends drifted away because of her behaviour.

As people get older, they accept everything. We need to change this attitude of a person, that it is not just old age, we need to start making it a public health issue.
Excessive care sometimes hurts people, don’t be over protective, and give them the information they need.

Getting my dad into a memory clinic is impossible because he doesn’t have the problem, it’s everyone else.

Community, education and awareness. People should be aware that there are things you can do in your lifestyle to help the prevention of dementia. Good awareness will reduce stigma, and make early diagnosis easier. This will result in less denial and more discussion about end of life etc. We won’t get it unless we get an overall good community awareness program going.

Information and Access

There are many people we can’t access due to the cost of travelling and funding we can’t get. This has not been addressed fully and needs to be addressed.

Although people with dementia are on high level community care packages it only equates to $100 of care a fortnight.

The isolation that people experience is great, from being a carer and also where they live. A person who has lived in the bush all their lives wants to stay there. There is a lack of integration between service providers and a caring community. This is important around the NT.

We have a lot of situations of people living outside of Darwin who have used neighbours for support and when the service provider came they didn’t acknowledge that person as a carer and had strange people come into the house which is distressing for the person.

People with dementia don’t operate from 9.00-5.00. I have one client who would love to watch his grandson play football on the week end and as he can’t drive he can’t go. We need to look outside the square. Because of the sundowning 8am isn’t helpful but maybe 7pm is. Woolworths is open till midnight, so we should look at that as an industry. We need to get the community involved, make them aware that person still wants to participate.

There should be flexibility of hours. Why can’t we have it over the weekend? Have people on board to do the evening shift when family members are busy making dinner.

We need funding for NT to develop a geriatric evaluation unit (GEM). Memory clinic is a new initiative that is working really well.

We go down to Kathryn; there is a lack of services for people of dementia in places like Kathryn. Up here in Darwin there are carer’s groups, in Kathryn you are lucky to get it every 3 months, and there is very little respite.

There needs to be more packages in the Territory for all those elderly people who are living on their own.

The gate way – I would really like to think that it is not some corporate glossy thing that provides minimum standards. I want to know, what will this provider give me? I want to know if they have an Italian speaker, if they have vegetarian days. I want
to know what these services specialise in. I want simple instructions about how to get in the system.

People often have to be in a crisis before a service can go out to make a difference.

There are a lot of services, but we need to narrow it down, so the person with dementia is dealing with one person, like a case manager. The case manager can’t be changed over too often because the person with dementia gets upset with changes.

Residential Care

I have to stay with my husband till early ages in the morning as the staff kept coming back asking questions. They need one electronic record, instead of someone sitting by them having to repeat over and over he has dementia, he can’t remember.

I had a call in middle of night as they were kicking my mother out of the facility because she bit someone. I flew to Sydney, to get to the bottom of it. My mother was woken at 5am in the morning; my response was I would bite you too. The staff were picking on people with dementia.

150 beds cannot create a home like environment. We need a range and diversity of services. That might mean a 6 bed place, or a fire place for people to sit around outside. There should be diversity in how care is provided.

My mum passed away with Alzheimer’s. She was in a brilliant nursing home. It was built with a circuit with hand rails and people always got exercise. There should also be a communication wall. So you can pin up photos of what you have done in the day.

The environmental design for residential homes is important. Such as patterns in the landscape, particularly for indigenous people, the built environment, such as yellow is easier to see as you get older. There should be somewhere to go for sunlight and a sheltered area out of the wind. Art and horticultural therapy is also important.

When I go into a home I want an aged care service that will listen to me, that doesn’t look like a motel, where I can access the outside.

Every aged care facility should be designed around dementia.

When I get old I want an aged care facility that is a happy place. Art and creativity has to be there.

Workforce

Aged care is my passion, I am not in it for the money, I have it in my heart. I pay for training out of my own money. You have got to have the training and you have to have the heart to do it.

It is getting more difficult to get workforce. We have to bring in overseas staff. This has a cost attached to it. Or we bring in short term contract staff that can’t stay here long enough to build a relationship with the clients.
The turnover of paid staff, the government has to bite the bullet on this. It’s a shame we are not giving the level of pay suitable for the level of care needed. Spend money on training them. Maybe not have it free, and reimburse it if they successfully finish it, give them some incentive.

Wonderful thing about NT medical program, it is hex free, so applications of people coming into program is great. Rehabilitation or Comcare payments for traditional healers – need money put towards people in community working with the traditional healers – working in tandem with the medical practitioners.

The training of staff in facilities is inadequate. There is lots of willingness and care, but it is not professional care. I believe only 3 months training is required for staff in residential care. I don’t know any trade that can provide professional service in 3 months.

Training is very close to my heart. I believe whole heartedly about what you’re saying with 3 months not being long enough for training. I would like to see students coming back and renewing their knowledge and improving on it.

We do not value workers in aged care because we don’t pay them enough. Well paid and trained staff is really important.

In every facility I have been to in the last 3 years, the major comment is the pay, recognition and understanding the value of people working in aged care. At least make the pay equal and value of recognise what they do.

I loved working in the dementia ward, but people need to be trained properly. You don’t say “you silly old women you don’t need to milk the cows”.

End of Life

There is nothing in place to allow us, once diagnosed, to make the decisions that are important to us. We need the force of law, which is available to every Australian citizen except those in the NT.

Research

We desperately need more research. Dementia is the third biggest killer of all diseases in Australia. We get 1/10 of research funds that goes to other diseases. To stop this epidemic we need to push for more research.

Special Groups

Younger Onset Dementia

The aged care criteria is 65 and above. I am concerned about Younger Onset Dementia (YOD), those people fall through the cracks.

I have a concern about YOD. We are diagnosing people earlier and earlier we don’t fit in the aged care system.

One client was 57 years old, clearly demented; he was in dire straits and dehydrated. He was only 57 and not getting appropriate care.

People with YOD can access aged services, but it is not appropriate. Often we struggle with respite services, YOD wouldn’t fit in. It’s not that they can’t access it, it’s that the services are not appropriate.
Aboriginal and Torres Strait Islander Have you got any idea about how you will go about developing culturally appropriate services for the indigenous community? The numbers still at home are much greater than those in services.

There are very few services for remote and indigenous communities. Workforce, access and costs of travel are issues. These costs are not recognised by our government funding.

CALD

Not just indigenous people, but services for multi-cultural people. They have difficulty understanding all the information. They need more information in their own language to help them understand the processes and getting information.

For CALD groups, we need people to accept services.

GLBTI

I want to talk about the difficulties that GLBTI members face when they enter aged care facility. The feel vulnerable and want to move in somewhere that they feel safe. Key priority is training and education of service providers and sensitivity around awareness and sensitivity.

There are a number for Gay men who have HIV. One impact of their drug therapy means they get YOD. Stop talking about aged care, the minister should be the minister for care. If we just have care you can get things to fit together. These young men need to be able to talk to one another. About what they want for the future, including advanced care planning.
Perth Consultation
3 November, Cambridge Conference Centre, 350 Cambridge Street, Wembley, WA
Chair: Ellen Skladzien
Attendees: 26

Main Themes
Primary care
- Time to get a diagnosis
Community Awareness
- Need to increase awareness of dementia services through AA
- Experience of stigma and avoidance
Information and Access
- Use of a broker to find a suitable service
- Difficulty getting meaningful and reliable information about services
- Multitude of different forms to fill out
Community Care
- Need for continuity across levels of care
Residential Care
- Not enough physical activity in care services
- Lack of engaging activities for person with dementia
- Importance of relationship between carer and person with dementia and valuing the ‘human touch’
- Overuse of medication
Respite
- Concerns about cashing out in terms of responsibility and potential for exploitation
- Day Centre model works well
- Informal respite through activities with friends
Workforce
- Training for staff
- Difficulty implementing best practice because of systems and policies in place
- Staff are leaving because of better pay in mining
End of Life Care
- Importance of getting legal affairs in order early in the disease
Support for Carers
• Need to know what to expect  
• Benefits of AA services  

**Special Groups**  

**Younger Onset Dementia**  
• Difficulty with getting a diagnosis  
• Lack of appropriate Services  

**People with Dementia**  
• Frustration of being aware of losing memory and language skills  
• Importance of continued involvement in hobbies  
• Benefits of community awareness and support  

**Comments**  

**Primary Care**  

_The early intervention can only occur if the family doctors recognise the early onset. My wife went for 6 years without a diagnosis seeing a psychiatrist and psychologist. So we weren’t able to get support early in the disease. We were not aware of AA. Then when we went to them we followed their advice and now we have no problems._  

**Community Awareness**  

_Friends are important. Once you didn’t speak about cancer and now you talk. At one time people would never sit like this and admit they have a problem. Fortunately we are going forward. We went to a lecture this morning with a professor and it was excellent. I think we are lowest on the low line for any charity._  

_When we first went to AA people were afraid and embarrassed to say anything. Now days we can all have a joke about it. It should be open, for the government and everything._  

_There are a lot of people out in the community who don’t know where to go for the starting point, and where to go to get a diagnosis. I have heard from some clients who have said once they get a diagnosis their friends drop away._  

_We found AA at the point of diagnosis. We were told to contact them. Someone I know whose husband has dementia she had no idea that AA existed, so the is a need for public awareness._  

**Information and Access**  

_My father is in care in Melbourne, we hired a person who was responsible for recommending a choice of 3 facilities. We are very happy with it, centrally located and it is staffed by every possible person in the world, white and black. What sold it to us was that over 80% of the residents are male. My point is we employed someone to do the searching for us, it costs $500. It shouldn’t be necessary to employee someone to find somewhere for you and to make sure you get the basic level of care._
A facility might be rated 5 stars for me but might only be rated 3 stars for you, as you might not like swimming.

The government puts out a general form for applying for all the services, then each place has their own form, it becomes a mess.

Difficulty in finding good solid reliable information.

Community Care

A friend had a perfect community package. Last week her carer came in and said I have bad news. Our company that has been going for 10 years has not had its contract renewed. Now my friend will not have personalised care, it will be on a roster and they will not know who will come into their house. There has to be something about the relationship between the carer and the consumer.

Residential Care

What degree of training do carers get that go into nursing homes? My wife is in a nursing home, they move her with a lift, and she sits in a chair all day, with her clothes all screwed up after they have taken the hoist away. They don’t care.

My father has Alzheimer’s and is in residential care. They are quite often bored. They have crafts and a bus trip but there is not enough staff to provide extra activities. Even something as simple as a newspaper reading in the morning, they can only do it once a week, it is not enough for them.

My husband went into a privately run home. It was great, so many activities. Then it was sold an all of sudden money counted, staff deteriorated. It is sad that money is overriding the care.

I would like to see a link between the accreditation of the facilities and the quality of education of the training of the staff that are providing the care. There is no emphasis on this; staff are rotating through the facilities. The care given depends on the knowledge of the staff that they receive that day.

We go visiting people who are in facilities, you think wow a lovely clean place, and seem to be very efficient. And yet when you talk to someone you buddy up with, they want to get out, they don’t want to be there. There are terrific and awful places around, but to me there shouldn’t be bad places, there should be a government authority that checks on these places. If you are looking at a facility for a loved one do they need to be rated?

They have a list of all the activities, and when you go up there is no activities and no variety. It doesn’t seem right.

So many facilities are working so hard to meet the accreditation and they forget the human element. There should be more emphasis placed on the feedback from the residents in the facility. That way the feedback is coming from the residents, not the staff.

Basic care just is not there. And good training. If you start from empathy and caring then you get good care and more of it, and more choice.

Humanness, friendly smile and ‘are you ok?’ this is driven by the culture of the organisation, not accreditation. Get back to basics.
My husband was being over medicated at one stage, I knew he was difficult and loud, so I knew the medication was for benefit of other patients and I had to accept it.

More continuity of care, chopping and changing between different stages of Alzheimer’s and also when you change between packages.

Some places only do low care, then they need high care and have to move to a different facility and it causes more trauma.

Respite

In England the disability services, my friend gets a paraplegic, she get money to employ who she wants, and I think I wouldn’t like that responsibility.

There is a danger of exploitation for services.

I have a minor bit of respite. After a day or two, the staff who was treating him in respite couldn’t cope and he ended up in hospital because his blood sugar levels were all over the place. So in the future I would like someone to just come in and replace me. I think that would suit a lot of people.

I think to be able to cash out would be of assistance for us as we live out of the city.

I did it for a friend, and it was a very rewarding experience. We had a lovely couple of weeks. No real problems, I just looked after her and made her meals for her.

Even now when my father is in residential care, I visit him every day. I feel if I go on a holiday that he will miss out. I can’t access respite care but I still feel I can’t go away for a long time.

When Val needed respite, friends took me down the coast to go fishing, I feel comfortable and enjoy myself and feeling in a family type situation.

It’s awkward, I love being with Judy, I don’t want to go anywhere and be without her, I will take her with me.

I have the benefit from a day centre at AA, there is a lot of companionship and the carers are terrific. It makes the world a bit better.

Workforce

Sometimes the trainees are frustrated because they hear about good practice but the systems and staffing in the facilities is inadequate to allow them to do good stuff.

When you go around facilities, and given 10 minutes, how do you asses the care is good? It’s almost impossible. Staff ratios which I thought mattered don’t matter. You can get inflated numbers as some places include receptionists.

All the staff are evaporating to work up in the North West for $200,000.

End of Life

One of the first things they told me was look into the legal aspects of representing my mother. Everyone treated my mother as an individual, but a number of times I had to force my way in and override my mother. We had to go to the tribunal and
get court orders so that service providers had to listen to what my sister and I were saying.

We have power of attorney, but I can sign it but it feels like I am giving all of me away.

You need to do it so fast, it we did it and then a month later my wife would not have been considered competent.

My father is 97, he went into care last year without handing power of attorney to anyone, because no one bothered to ask him.

After workshops with AA, and the attention brought to legal requirements. We having enduring power of attorney but we haven't gotten around to advanced care directives.

Support for Carers

I would like my husband to know where to go to find out what stages I am with dementia and what to expect. He has brought a clock so I know what day it is and don't ask it 50 times a day.

I think when they get to a bad stage, and you are stressed that's where AA and south care help.

Special Groups

Younger Onset Dementia

YOD is creating lots of problems for early diagnosis; they don’t fit into the aged care mould.

There is no places for younger people who have to go into care; they get dumped into care with older people.

Experiences of People with Dementia

I have 51 years that someone has told me what to do. I don't remember things, I forget your name, and mostly you don't remember those things. And you just have to think, that's what I have got. Even when I talk to you, I'm thinking things but I can't say them to you. I have semantic dementia.

I think having AA is great. It has helped me immensely, I said no way! Do you know what my nick name used to be in school, I had such a good memory. In my mothers generation if they couldn't remember something you didn't go around them. But the doctors are kind and caring, and it is not a joke. I think it is important for us sufferers and the carers. If you like your gardening do your gardening. I love cross stitch and I still do it.

I was at shopping centre and couldn't remember how to get out. You get panicky. I just walked to one of the guys and said I have dementia and I can’t remember how to get out. He was so kind. I keep doing that.

I got the disease 5 months ago, I am frightened. I am learning and listening. I wish there was someone who would help me with my memory. I forget where I put things. It comes back to me after a while.
Responses to Q&A sheets

Canberra

What are people living with dementia looking for in aged care reform?

- Recognition that their mix of life-threatening diseases need to be treated holistically, as one illness reinforces the malaise of another (e.g. diabetes and dementia). Referral to specialists will not suffice.
- A stronger voice
- A skilled workforce
- More consistent care options in CAPS packages, need continuity of carers
- More flexible respite to help partner keep people at home is needed
- Simple assessment
- Ongoing support
- Funding to maintain a better standard of furniture and cleaning in nursing homes
- Loss of control of peoples’ property
- Needs a better system to ensure privacy and dignity
- Consumer directed care
- Option to stay at home with EACH D package
- Opportunity to use services across the board (more than one service provider)
- Consistency
- Responsive to need
- Quality care
- Easier access to services. Better transparency of the system. Staff who are better able to deliver the services in the home and consistency of that service.
- Being able to stay at home longer or until they die

What concerns you most in access to community and residential care services that meet your needs?

- Lack of training for staff and access to professionals
- Little coordination of services – government and NGO.
- Once in care all the outside activities offered by CAPS and EACH (D) drop off. Need a crossover of services, and more activities in residential care.
- Assessment is too complicated
- Lack of information before the event
- Little option to try alternate services
- Lack of high care – dementia specific beds
• People need to be able to access services when they need them. Current wait list, service availability prevents this. Services for aged and those with disability are too complex for most charts and carers. The idea of a main ‘gateway’ is good but it needs to be provided/staffed by very skilled clinical people. My concern is that this ‘gateway’ will just be another service which refers and provides info but no service, and will not be staffed by the right people.

• The length of time it takes from diagnosis to implementation of a service or help and the frustration and tangle of red tape to get the help.

Do you have particular concerns around access to information and assessment for access to care services?

• Need for plain English explanations on forms.

• Diagnosis is problematic – sent off on side issues, and when diagnosis is made you’re just sent home without knowing what to do next.

• ACAT is too crude: there is intermediate level between high and low and the assessment does not go into enough of the more subtle behavioural issues.

• Assessment by relatives needs to be considered as part of initial signs of dementia

• Lack of information to potential clients in regards to what services are available

• People currently receive different information from different services, i.e. some GPs provide info, some provide nil. People are given inaccurate information. Time needs to be taken by people providing advice and information to ensure that their information is accurate.

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

• Home and respite care

• Need more places for short term respite (including overnight, such as The Cottage (Carers ACT)

• Designers of some residential care facilities should consult experts in dementia. E.g. Space to pace, shady outside areas, small groupings.

• Services for those with behavioural issues

• Services should be flexible and many current services are flexible, but there are always gaps. Needs to be capacity within system to fill in these gaps.

• Respite or day care services for EACH/EACH-D packages. Service providers aren’t able to supply the trained staff to be able to do this so these clients need a place to go for a few hours or overnight.

• Better trained staff within acute care settings around behaviours.

What types of support and services do you need to assist you in your role as a carer?

• Access to health professionals

• Access to up-to-date information on all aspects of dementia care
A case manager would be good – someone who keeps tabs on all services available/accessed, and who knows the client and carer

Better training for staff in acute care setting

Day care/Day respite service for community clients. There needs to be more available especially for high care clients as they miss out. Indigenous support is very rare and no places available for indigenous clients that suit their particular needs.

Are there health issues that need to be addressed in the reforms?

More employed in age related conditions that need early diagnosis – complex chronic conditions, co-morbidities and population level approach

There is no ‘in between’ health advice about dementia and what to expect – i.e. between the GP and the geriatrician – I need someone else to advise me on what I observe, and give ongoing comments on how my partner is going.

Health of carer – particularly depression

Clearer diagnostic/assessment of dementia pathway

Specific training around dementia and services available to people – for GPs

Better communication between services about medical conditions and behaviours

Better understanding of services available for clients for the GPs

At senior education levels, public health should be part of the curriculum.

Are there any other concerns you have about dementia care or the aged care system?

Need to engage with producers of medical equipment e.g. people living with dementia need support for using their insulin injection device. Patients cannot remember whether they delivered their injection dose.

Dementia needs to be a permanent national level priority for the nation

Need earlier diagnosis than present. This will need better screening tools for use by GPs

Need for better referral

Need more research, not only about cases of dementia but also development of diagnostic tools

Funding models often do not really accept that the spouse is often still in the home. Taking on complex loans and/or prescriptions moving house to smaller place is hugely stressful when dealing with a partner with dementia.

Lack of funding, lack of staff

Currently both community and residential care is poorly staffed. Needs to be concentration on ensuring skilled, well paid staffs are looking after needs of older people

Lack of appropriate education for staff

Registered training organisation provide inadequate training for staff
• Wages need to be reflective of the job that carers do
• Training concerning behaviours/activities to counteract behaviours

Sydney
What are people living with dementia looking for in aged care reform?
• Real ‘person centred care’ – not just rhetoric
• Early diagnosis and support for cognitive impairment
• Intervention. A ‘buddy’ to see them through the life stages
• More funding
• More information
• Streamlined service provision

What concerns you most in access to community and residential care services that meet your needs?
• Inappropriate staffing – underpaid and underqualified
• Lack of understanding of dementia and mismanagement of behaviours. Too quick to use drug intervention, not other therapies
• Education to carers, support for client and carer
• Lack of information available in the community. In particular reluctance or ignorance on behalf of service providers to give information to families.
• Not enough beds or help
• Guardianship needs to be looked in to
• Physical layout/security suitable for very physically active people with YOD with challenging behaviours/wandering issues

Do you have particular concerns around access to information and assessment for access to care services?
• Difficult to navigate your way through the system – need central resource point
• Receive conflicting advice from different sources
• Awareness
• Choice
• Support for isolated clients and depressed clients
• Access point – GPs to direct/white pages/Google
• Centrelink – re-train/awareness with YOD
• Information is sparse, people need to have someone who can physically do the referral for them rather than expecting the family to do the ‘leg-work’. Also encouragement to people to access services early rather than waiting for a crisis.
• Awareness of community services – currently in centre based day care centres are not at full capacity, but carers are unaware of services. By the time they access the service, they are on a waiting list for a nursing home.

• Awareness/promotion needed in the community

• “Gateway” proposal – will it be face to face assessment or phone assessment? Assessing persons with dementia over the phone is an absurd idea

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

• DBMAS

• Non-pharma alternatives

• Debriefing and counselling

• People with YOD need age appropriate services that meet their need for physical activity and community engagement

What types of support and services do you need to assist you in your role as a carer?

• Case management/support – navigating my way through on my own

• Support for working carers and younger carers

• Informal support

• Someone to advocate, to assist in the navigation of the service system.

• Consistent service – e.g. bathing – ensures that the same person attends each time

• Services that can be opened for longer hours.

Are there health issues that need to be addressed in the reforms?

• Depression

• Grief

• Generational gap

• Diagnoses acceptance

• Enabling client to accept diagnosis and receive help/support

• Education of workers in residential/respite services. Minimum standard of cert III is not enough. Also, information and education for workers on YOD and their needs in the care system.

• Attitude of neurologists when diagnosing dementia in younger people – they offer little support, no referrals to care services etc.

Are there any other concerns you have about dementia care or the aged care system?

• Accommodation bonds and interest: difficulty selling the house, and losing money

• Services to be flexible – especially in facilities

• Education and debriefing for care staff
• YOD-specific services
• Continued thought that ‘aged care’ providers are the best suited to provide care to younger people – people with YOD do not want to be part of the aged care system
• Many carers hurt themselves, especially their backs, in their role and usually not offered manual handling training specific to their needs
• Many residents with dementia in RACFs are given questionable ‘pain management’ to get the ACFI ‘points’ – system needs cleaning up
• Ensuring that people with YOD are accommodated within the care system. These people can’t sell the house, can’t access superannuation, and can’t leave work. They need to be respected, provided for and not made to justify their needs for service. Recognition of the impact of dementia on children and young people who have a parent with YOD.

Brisbane
What are people living with dementia looking for in aged care reform?
• Further funding for research
• Dementia friendly services throughout society e.g. banks, shops
• Increase HACC services to slow any move to nursing homes
• Hospitals need to be dementia friendly. Delirium is common post surgery yet medical specialists and nurses do not know how to manage the situation, therefore there is a need for bench top and clinical research and training.
• Need for dedicated ward and appropriately trained registered nurses.
• Improved training of GPs, nurses and other health/aged care workers.

What concerns you most in access to community and residential care services that meet your needs?
• Staff to patient ratios
• Lack of information available. The information is there but it is hard to find.
• Community care is inappropriate for people who live alone. Packages only work where a partner supports the person.
• Access to exercise/mobile programs for clients

Do you have particular concerns around access to information and assessment for access to care services?
• (No comments)

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?
• Respite care in aged care facilities. It is impossible to access these at present
• Timely aged care assessments

What types of support and services do you need to assist you in your role as a carer?
• More training for support and in home care

Are there health issues that need to be addressed in the reforms?

• Need for more geriatricians who visit aged care facilities – to train/advise the GPs who don’t seem to understand people with dementia. This could be done via telemedicine if necessary.
• Nurse practitioners are urgently needed in aged care facilities
• More information from GPs after initial diagnosis

Are there any other concerns you have about dementia care or the aged care system?

• Dementia initiative scrapped by government
• Staff in aged care sector have poor understanding of dementia
• GPs need training on assessment and management
• What about implementing a work for the dole in aged care scheme?

Adelaide

What are people living with dementia looking for in aged care reform?

• Meaningful care with affection
• Flexibility, consumer directed care packages
• Cottage style respite (short term overnight stays)
• Facilities to encourage mobility
• Acknowledgement of status as a person of value.
• Knowledge that carers are being taken care of
• A clearer, simpler system
• Correct information from Centrelink.
• Training for carers in handling residents, especially in personal care.
• Aboriginal and Torres Strait Islander: to be on homelands, to have an aged care home in the community, to train the community as workers

What concerns you most in access to community and residential care services that meet your needs?

• The need for flexible, individualised support and services
• Availability and entitlement
• Support for family carers – carer payment should be equal to minimum wage
• Access to services is too complex
• Case workers
• The huge difference between day care and residential care in terms of activity and intellectual stimulation
• Dementia residents are ‘locked in’ unless relatives take them out
• No aged care home available for Aboriginal and Torres Strait Islander community member to stay in away from land/family and community

Do you have particular concerns around access to information and assessment for access to care services?
• Better information
• Concern about ‘gateway’ idea – people may still end up on wait lists they know nothing about
• Everything including assessments done over the phone – not face to face
• Need to ensure assessors explore all areas of concern and are able to refer to any organisation/service for support, not just ACAT, CACPs, EACH but all lower level programs too – including carer respite programs
• Difficulty of finding services – high care respite almost impossible to find, booked out or unable to book in advance
• ACAT assessment understaffed
• Difficult to receive an assessment
• Should respite be moved out of residential care?
• Aboriginal and Torres Strait Islander: have the age limit changed for communities and packages
• Cottage respite works on a wellness model

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?
• Emergency residential respite services – often people with dementia end up in hospital setting if there’s no room in respite services
• Short-term respite, especially weekends
• Cottage style respite
• Day centres with meaningful activities
• Dementia units in residential care that are not prisons
• Regular staff – you rarely see the same carer’s faces twice.
• Doctors who do not prescribe antipsychotics to stop residents from ‘wandering around’
• Family members should be welcomed and involved in residential care – some centres think they own residents
• To keep client at home with a decent care package and care available

What types of support and services do you need to assist you in your role as a carer?
• Transport
• Carers want appropriate respite options that mean their loved ones are involved in meaningful occupation/activity
• Home maintenance
• Available respite
• Health services, First aid training
• Consistent day care – often day centres can only offer 2 days, and people with dementia get confused going to multiple centres.

Are there health issues that need to be addressed in the reforms?
• An annual health assessment
• Carers’ health
• Respite is vital
• Residents are being drugged unnecessarily, leading to falls, dizziness, and a broken hip leading to hospitalization
• Lack of EN/RN
• Lack of training for staff, especially migrants coming into aged care homes and hospitals

Are there any other concerns you have about dementia care or the aged care system?
• At aged 87 years – relinquished role as carer. A one-two week respite stay would be great for those living in their own homes
• Have meals prepared and company
• Education for communities to support a person to stay at home
• The baby boomers will soon retire with minimum superannuation, and will need aged care
• Perhaps the National Disability Scheme should include a levy for aged care
• Really concerned about the impact of changing governments, impact of inconsistent, often short-term approach. Investment in DTSC – training for health professionals should not be limited to several years, as service needs to build identity and reputation with health professionals and workers
• The cost e.g. Demands for $300,000-$400,000 deposit making a massive hole in carer’s super funds. Self funded retirees or partners still working can pay up to $52,000 per year from their super fund while those who haven’t saved pay less than a pension i.e. there is no incentive to work and save.
• Drugs can be very expensive and not on PBS
• Not enough workers in Aboriginal and Torres Strait Islander communities
• Respite is a big issue in all communities
Melbourne
What are people living with dementia looking for in aged care reform?

- Reform not just aged care – needs to include younger people under 65
- More reliable criteria for ‘dementia specific units’ – not just a locked door, but dementia trained staff, activities, interaction etc.
- Better understanding by health services – e.g. hospitals (especially private)
- Need better care to support those with dementia in their homes for as long as possible
- House maintenance
- Whatever it takes to enable them to have the best life possible in their older years
- Dementia specific nursing homes
- Funding for nursing homes – treat as an insurance problem with a levy on super contributions. Will need to be supported by taxpayer funds until the Aged Care Insurance fund increases its capacity.
- A voice
- Dignity and respect
- To stay in their own home (safe and familiar) for as long as possible.
- Acknowledgement by healthcare system of people suffering from Alzheimer’s disease and dementia
- Choice rather than being dictated to by the government/health care system
- Removing the stigma associated with dementia
- Steps to ensure that “care” really is what it means
- Acknowledgement of the varying needs of people of different multicultural backgrounds

What concerns you most in access to community and residential care services that meet your needs?

- Limited access to respite in remote/rural areas
- Community care staff not dementia care trained
- Unless you are on Centrelink you are not covered
- Self-funded retirees need help
- Takes too long to get ACAS team and then EACH-D package
- Packages should be more flexible and person centred
- A lot of staff in residences come from overseas and have limited training in English. No matter how well intentioned they do not understand the care needed especially with associated behaviour concerns.
- Sedation is not an appropriate solution to behaviour problems
• The withdrawal of outreach workers from CADM clinics.
• Need for an enquiry into the non-transparent and farcical sums of money demanded by some nursing homes
• Getting access to information when needed e.g. how do people with language and literacy issues access the information they need?
• Quality of care
• Limited availability of government support – particularly daily respite centres
• The unpredictability of who is entitled to what. Everyone should have the same rights and access to services.
• Lack of quality care
• Insensitivity to different cultural attitudes/ beliefs

Do you have particular concerns around access to information and assessment for access to care services?

• Limited in rural/remote areas – too far from education services
• Many rural GPs are foreign trained so problems in communication, understanding of dementia
• Long waiting times to get diagnosis
• Will re-assessments include ongoing assessments of carer’s needs and capacity to manage?
• Takes too long
• Need more support to keep patients home longer
• Respite for dementia sufferer and career needs more time allocation, accessibility and support
• Don’t want an intrusive assessment process or one that keeps people from getting access to the help they need
• A means test could be counterproductive
• Don’t need a comprehensive assessment – a doctor’s certificate and healthcare card should be sufficient
• Facilities for younger people with dementia
• Adequate staff ratios
• Training of staff
• Special needs
• Local councils are not equipped to handle enquiries
• Assessment for access to care services can be time consuming and exhausting due to its complexity
• Information can be difficult to access
• Information needs to be interpreted & in some cases, simplified

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues?)

• Option of 9 weeks/year respite to be provided in the person’s home or in a small home style setting
• Aged care facilities for respite are not appropriate for a person with dementia who wants to live and die at home
• Training of staff dealing with patients needs
• Dignity and respect when dealing with people
• Behavioural issues not to be treated just by sedating
• Adequate education of staff
• Respite, especially in the home
• Would like an overnight service from 7pm-7.30am to clean, feed, occupy the person with dementia
• Home care help - Gardening, handyman
• Residential care (24 hrs)
• Home care is preferred when the alternative is to send someone into residential care
• Behaviour management (without medication)
• Community services e.g. social groups (locally)

What types of support and services do you need to assist you in your role as a carer?

• Recognition of the carers’ specific medical etc needs
• Respite when needed at reasonable cost
• Quality residential care at reasonable cost
• Palliative care in the home
• Greater access to daily respite centres
• Annual training updates
• Career needs to have their needs assessed as well as the sufferer.
• Training in what is available/entitlements
• Education on management, dementia, services and how to access them
• Education
• Support and respect from all professionals in the health care system
• Doctors to use interpreters where possible

Are there health issues that need to be addressed in the reforms?
• Palliative care for dementia sufferers – ‘end of life care’ and support with dignity is essential. Following directives of patients’ own wishes.
• The bond (?) system in low care residences is horrendous
• Users need to know what is available (e.g. there is a mobile dental service but it isn’t widely known)
• Listen to carers about medical treatment
• Need information on ways carers can acquire and improve their caring skills
• Adequate funding for medical research on dementia to stop the disease from progressing and help prevent it occurring.
• Everyday health issues – teeth, hearing and incontinence.
• Greater availability of daily respite centres would be of significant benefit to the health of carers
• Over prescribing medication
• Illnesses/health issues due to poor care
• Review of current diagnostic tools

Are there any other concerns you have about dementia care or the aged care system?
• Greediness of service providers in their use of the EACH packages to empire build.
• Younger onset dementia requires more respite specific for younger people
• Will there be sufficient capacity?
• Consumer choice should motivate service providers to do better.
• The salaries of staff who work in nursing homes require a review; for the work they perform their salaries should align more closely to registered nurses
• Mark Butler stated that the average stay in residential care is about 1.3 years? This would be because: the family has removed their loved one due to compromised care or the resident has passed away. Both reasons are a real reflection of what is wrong with the system.
• Inequity- people of CALD backgrounds have a harder time accessing all the appropriate information & services

Hobart
What are people living with dementia looking for in aged care reform?
• More access for people living in rural areas, e.g. at present people cannot access packages like EACH unless they travel
• More secure and purpose-built dementia facilities
• Better informed medical practitioners
• Support services to remain effective, active and informative
• Flexibility of choosing their own carers and allied services, similar to the consumer directed package

• To be heard, every carer’s forum I have been to is swamped by approved providers, union reps and employees in aged care, they all have their own agendas

• A stronger emphasis on psycho-social activities that keep them connected to the community

• For all aged care staff from cleaners to Directors of Nursing and CEO’s to be properly trained on how to deal with people with dementia

• For all dementia education providers to be properly qualified i.e. to have the experience and capability to deliver the course content

• For all nursing homes to have more staff qualified to be willing respond to calls for assistance. Due to staff pressures, the waiting times are far too long.

• For aged care accreditation to be more than the current "tick the box" exercise. There should be the option for residents and their representatives to be able to directly contact the ACAT team to arrange off-site appointments.

• For the accommodation rules to be changed to allow couples to both enter aged care when one needs to enter aged care

What concerns you most in access to community and residential care services that meet your needs?

• Appropriate residential care for YOD

• After giving your loved one 24 hour care you realise that depth of care is not available in a residential care facility

• ACAT assessments more accurate and realistic

• Duplication and complex means of access to services

• Service providers making decisions to place clients in aged care facilities and withdrawing packages without consultation with the client or carer

• Service providers being very judgemental, each person is unique with different circumstances

• Safety issues in community care- adequate training required

• Access to a reasonable amount of the package (70%-80%) currently on CDC and access it is about 48%

• Getting information about the overall system

• The unmet need of overnight respite care

Do you have particular concerns around access to information and assessment for access to care services?

• People in the community who have advanced stages of dementia, do not have access to community services which results in carers coping with reduced respite

• More information on services that are currently available
• A telephone number in times of crisis
• General public are not aware of support systems for carers
• GPs not always aware of who or how to access services
• Expectations placed on aged care facilities are unrealistic
• Duplication-One focal point of access is needed both in print and on internet
• Provide policies, guidelines and what to expect from the care services
• Focus more around the individual care plan
• One assessment please, for packages, respite, day centres etc.
• Providers need to track our records
• More involvement for the person with dementia in ACAT services
• ACAT teams need to involve relatives when undertaking assessments, particularly when the person being assessed has dementia
• The refusal of GPs to do anything about the early diagnosis of dementia of their clients

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

• Medical services accessible 24 hours a day
• Allocated aged care services in the acute care setting
• Funding must reflect 24 hour care provision and not the current 2-3 hour care through community packages
• Hope care – assistance with gardening
• Respite care – day and holidays
• Medical advice when needed
• More in home respite. This will reduce anxiety for clients.
• Involve them in discussions with what they would like to enable them to remain at home
• Provide family with sensitive information like palliative care
• In home respite for my two care recipients
• Residential respite which is suitable for people with psychosis, delusions and complex physical needs
• Afternoon day centre support as this is the most difficult part of the day, at the moment services are only available between 10am and 1pm

What types of support and services do you need to assist you in your role as a carer?

• To support people to stay at home support for services in required
• More staff, funding and education
• Supportive case manager
- Family support group
- Offers of medical support
- More respite beds for married couples in southern Tasmania
- More support from services providers and allied health. I.e. education, assist with updating care plans, IT support for carers that are housebound (paying bills on line etc.)
- When injured in home there should be in home respite
- Overnight respite once or twice a month
- Trade residential respite for home respite
- Staff that meet my needs, at the moment they don’t turn up and they are unskilled or affected by substances

Are there health issues that need to be addressed in the reforms?
- A wellbeing issue and an aspect of managing behaviour: providing caring touch (a gentle massage) for people living with dementia, this could also assist carers with respite.
- More GPs who will visit nursing homes and be available on weekends and public holidays
- GP access for residential aged care facilities
- Recognition and education of dementia for everyone start by educating the youth in school
- Put nursing education back into the hospital system, much more prac time needed in acute, aged care, mental health and palliative care
- Community education on the early signs of dementia
- Prejudice issues
- GPs educated to assist in early diagnosis
- Non- bullying from state government departments – i.e. guardianship board
- Access to appropriately skilled GPs
- Access to skilled mental health professionals
- Restorative care
- Skilled palliative care workers
- Therapeutic activities versus care workers sitting and reading magazines

Are there any other concerns you have about dementia care or the aged care system?
- The person diagnosed should be part of designing a long term care plan whilst they are still able
- Real consideration to be made in relation to specialised funding for people with dementia
• Increased research into cause and treatment of dementia, particularly neuronal placidity
• The maintenance of dignity
• The exploitation that can occur financially
• More focus on aged care plans – develop electronic care plan which includes specific like and dislikes. Allow all allied health professionals to access it.
• Cultural diversity to be included in social settings
• As a person’s condition deteriorates their support and access to community care diminishes
• Services are designed to try and force residential care on consumers who wish to remain in the community
• People with dementia admitted to hospital for medical or surgical procedures are not well treated. The use of chemical restraints is widespread.
• Dealing with people who have dementia is made more difficult due to the lack of a comprehensive health record.

**Darwin**

What are people living with dementia looking for in aged care reform?
• Not to be discriminated against
• Feel safe
• Have respect and dignity
• To live a life they know
• Familiar surroundings that are homely
• Welcoming environment
• Entitlement to feel safe
• Appropriate and adequate level of care and understanding
• To be able to remain living at home for as long as possible
• Early diagnosis
• A case manager to guide you through the system and journey
• Access to information and knowledge of where to go to get the information
• Recognition of dementia as a disease with increased needs, not normal aged care
• Provision of around the clock care, available outside of standard work hours.
• Individualised care

What concerns you most in access to community and residential care services that meet your needs?
• Culturally appropriate
• Home like environment
• Language barriers between residents and carers
• Getting someone to give the right medications and to notice the side effects
• Getting appropriately trained staff
• Not enough staff for the number of residents
• Conflicting information
• Lack of resources – insufficient staff to appropriately care for dementia residents
• More specific and diverse care facilities with appropriately trained staff

Do you have particular concerns around access to information and assessment for access to care services?
• The general community need to be more educated.
• Information needs to be more accessible and easily accessed.
• The ACAT service in Darwin is good, friendly and full of information.
• Need a case manager to help with accessing the correct information.
• Lack of services in remote areas.
• Need more comprehensive assessment to ensure timely recognition by doctors.
• More current information on the latest breakthrough research available.

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?
• More opportunity for support services and counselling
• More couple accommodation
• Renewal of certificate (staff to re-do training over a period of time)
• More funding for dementia specific in-home care – we need at least double the amount that the EACH and EACHD package provide
• Increased places for respite care
• All of these services are required through the various stages of dementia

What types of support and services do you need to assist you in your role as a carer?
• More culturally appropriate services
• Education more accessible
• Adequate respite
• A day therapy centre, so I can go to work and know my parents are okay during the day
• Better training
• Support from services to assist with care
• Simplified and coordinated services and information

Are there health issues that need to be addressed in the reforms?

• Timely for diagnosis
• More help should be available to assist with dementia and elderly people taking the correct medication at the correct time, this could prevent hospitalisation
• Recognising dementia as a chronic disease
• Health of carer’s
• More support for carers – having a transient population means that family is not always nearby to help
• Increased funding for research and specific care requirements of people with dementia

Are there any other concerns you have about dementia care or the aged care system?

• More research
• We run a high care house, which has five elderly and dementia clients sharing the home. They have carers to provide assistance and home management and they all seem very happy. I would be happy to share this model of home care with other interested parties
• Support to recruit and retain staff
• Funding systems that are realistic
• Not enough training for staff
• Not enough compassion from staff
• Pay needs to increase in aged care to retain the good staff
• Need for centralised, consist and familiar contact (case manager) for a person with dementia and their family

Perth

What are people living with dementia looking for in aged care reform?

• Access to information about quality of care and costs to the family
• Early diagnosis of dementia
• GPs that have interests in and ability to address the needs of people with dementia.
• Security of funding for service providers
• Access to future planning
• The provision of sufficient funds, by the federal government, to allow the continuation of successful programs which are managed by recognised organisation like Alzheimer’s Australia
• The allocation of funds must budget for the increased number of people in Australia who will get dementia
• Accommodation rating system
• More connections so I can make friends with similar problems
• More care in the community
• Be able to access information in an easily accessible, comprehensible format relevant to their level of the disease and relevant to the level of receptiveness/readiness for the information
• Knowledge that services are quality and affordable

What concerns you most in access to community and residential care services that meet your needs?

• Uniformity of level of qualification. Certificate three, for example, having specific level of personal care
• Access is too complicated
• Short term contracts for funding of community care e.g. we received excellent services and had a good relationship with the organisation, but it did not have its services refunded
• By following the advice from Alzheimer’s Australia we have no concerns.
• We use the recommended facility South Care
• I need to know the costs, availability and types of residential care.
• Families need help to find the correct services
• Seeing the right people, and being able to change if you want to see a different person
• The non-streamlined approach – having to tell and re-tell history to everybody who requires information each time a different service is provided
• Poor quality and low knowledge of care staff regarding dementia

Do you have particular concerns around access to information and assessment for access to care services?

• While Alzheimer’s Australia provides good information, I feel their services should be broadened into one central website and centre through which all information is accessed. A gateway which leads to all paths that may be required
• Waiting times
• Labyrinth of detail and information
• Lack of knowledge and support from GPs – they are not aware of support services such as Alzheimer’s Australia
• Funding for aged care services in state hospitals must continue
• Social workers are able to provide very good information
• It is very difficult to know what is available when faced with a diagnosis. It would be beneficial to have a “one top shop” for information e.g. Alzheimer’s Australia.
• GPs, neurologists, gerontologists need to be armed with information to hand over when providing a diagnosis

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?
• I will need respite to ensure my ability to continue as a carer
• Respite care should not be in a long term care facility, so it is in a more positive and less threatening environment
• Residential care
• Home care

What types of support and services do you need to assist you in your role as a carer?
• Cay centre
• Support worker once a week
• Continuity of care across service packages
• General sympathy
• Streamlined, continuity of care with staff that have been taught to deal with patients with a high level of empathy and knowledge

Are there health issues that need to be addressed in the reforms?
• A focus is necessary on the different types of dementia i.e. younger onset dementia and semantic dementia
• Dementia and ageing to be de-stigmatised
• Services that adequately meet the needs of people with dementia
• Early onset dementia does not fit into aged care services – eligibility etc.
• Promotion of ‘self’ and protection of independence and autonomy

Are there any other concerns you have about dementia care or the aged care system?
• Gaps between packages to give consumers and their carer’s continuity of care, rather than changes which add to distress
• Meeting the needs of younger onset dementia clients
• Culturally appropriate care
• Accreditation of the carer linked to the tasks – not their experience of giving the service
• Need more than ticking boxes. There needs to be more quality, humanness and relationships.
• Yes – the training of doctors (GPs) to recognise the symptoms of dementia/Alzheimer’s to allow diagnosis and early intervention
• I am concerned that when things get worse I will not have the care needed for my husband
The knowledge of care staff is low or not present in relation to dementia issues – a certificate three is not consistent in its content or delivery and I feel staff in a dementia specific unit should have mandatory knowledge.

Responses to Online Survey

General
What are people living with dementia looking for in aged care reform?

- Bring back the caring in how we fund our elderly; they are being preyed upon by business and the Government we elected.
- To remain a respected member of the community. To remain involved for as long as possible, to have others treat them with dignity & respect & patience. To have activities & opportunities available to match their ability.
- Being cared for by qualified and caring professionals, who help them maintain their independence and dignity.
- To be treated with dignity and an understanding of their individual needs. To have access to appropriate medical care. To have access to appropriately trained staff who are aware of the need to provide a variety of therapies, whether in a one-one situation or a in a more formal situation. There is much training available and apart from the staff, the family carers need to have access to short training sessions so they understand the various problems presented by those with dementia.
- Autonomy, respect, individuality, and enablement. To be able to afford this. Support from streamlined, consistent and available services.
- Pleasant surroundings/friendly, well trained approachable, patient, compassionate, CONSISTENT and caring staff. Activities to give them meaning and pleasure, end of life managed well and compassionately. Light, well designed rooms and surrounds to help minimise confusion, accessible garden with perfumed plants, my mother was a resident at the Pines Lodge Southern Cross Care North Plympton SA and it was excellent.
- Quality of life and assurance. Constant contact with loved-ones and in particular with carer if he or she is a spouse or child. That their condition is given more recognition and professional staff, both medical and nursing, be adequately trained to deal with patient with dementia. This has to be treated as a condition different to any other form of illness or disability. Those carers themselves are made properly aware and receive the necessary guidance, instruction and support in their role if they were to perform efficiently. In doing so it could ease the burden placed on others.
- Confidence that help sought in home will actually assist.
- Personal care with dignity.
- Good quality care close to home at an affordable cost.
- The community to be informed, people are so ignorant to the words "dementia" and "Alzheimer's" this is a difficult question for me, my mother passed away one year ago from Alzheimer's, but she never acknowledged there was anything wrong with her "my
memory is as good as when I was a teenager" were my mother’s words, therefore there is nothing as far as she was concerned that she wanted or needed.

- Improved care.

- Flexible, caring support.

- Specific training for the aged care industry to support staff caring for patients with dementia and to support the families visiting their loved ones having dementia. Action to combat.

- To be treated as a person.

- A stimulating personalised environment.

- More services relating particularly to dementia. More beds in respite for those living with dementia and their families.

- Quality care and trusting staff. Ongoing professional support.

- Easy access to information about services. There appears to be a "maze" which is hard to navigate without help. Clarify! Flexible and increasing support to enable one to care at home for a longer period. The amount of "time" allocated is insufficient compared with programs offered in early stages of the disease. An hour a day is not nearly enough to allow the carer to cope with 24 hour care.

- Residential care suited to needs - e.g. younger onset have a place where patients are not all elderly and are able to use a computer and have rooms with internet connection.


- People who support family members with dementia need to have more facilities available for in home care. Dementia patients need to have a consistent carer in order to develop trust from both the patient and the family carer. They also need access to overnight care in home.

- Care. More dementia specific low care places to be available. Earlier diagnosis especially of Non-Alzheimer’s dementias. Doctors to be better educated about Non-Alzheimer’s dementias. Nurses in general hospitals to have more awareness of needs of dementia sufferers, leading to less confrontations and trauma for the patient with dementia. Better and simpler access to information. It was very difficult to access government health and Ageing information. The web site was incredibly difficult to wade through to find how to access information about low and high care places, rules for finances, etc. Some common sense to be applied to ACAT dealing with a dementia sufferer living alone and waiting for assessment. To only deal with the dementia sufferer because of privacy issues meant ACAT just closed their file because each time they tried to make an appointment the person said "No, thanks". ACAT didn't consult with the referring Dr or with the family member whose details they were given. VERY FRUSTRATING.

- More overnight care in small community establishments day respite out of the home.
• Increase in sensitivity and support from General Practitioners, both for the person with dementia and the carers. Awareness/early diagnosis. Improvement of Aged Care facilities.

• Confidence that there will be quality care available, either residential or community based, when it is needed.

• Aged care staff that are better trained to look after those with dementia. Better funding to enable training of aged care staff. A better understanding of aged care dementia issues by those responsible for aged care accreditation, to enable better assessment of aged care facilities.

• Support both in home and in residential care that allows the patient to have quality of life. Support for the carer to allow them to remain their own person while attending 24/7 to their loved one. Security –financial and physical–for the family as they have been looked after by the aged person and they need guidance to help them cope with now doing all the things their partner did in addition to what they normally are now doing. Easy access to any information they need - the one stop shop is essential and needs to have ALL the answers including such simple things as where the nearest Caring group meets. It is essential that all questions can be answered.

• Genuine Care. Resident focused care not a staff focused environment.

• Warmth in residential care; more focus on comfort food and dining; more entertainment and company.

• That the dementias are NOT included as part of Aged Care. It is a DISABILITY and all services along the continuum-of-care should be reflective of this. It is NOT a ‘nursing’ problem, - and for a lot of the time, it is not even a medical problem, in terms of managing day-to-day living. The challenges of everyday living for most of the ‘journey’ are related to the various manifestations of the condition as DISABILITIES, needing an astute and well-informed understanding of cognitive / perceptual impairment and how that directly changes the person’s capacities to manage the myriad of tasks/activities of every-day life! It is NOT a problem of the ageing process!!!

• De-mystifying the process of getting information and practical help for the person we care for. If the proposed Australian Aged Care Commission serves the needs of older people and their carers it will be a good thing. If it reduces the running around for different information and assistance then it will be an asset. I commend Alzheimer's Australia for their tireless efforts in advocating for people living with dementia, but there are other aspects to aged care, such as developing a capable workforce and training for that workforce. People with dementia want to know that the professionals looking after them are proud of their work and find it rewarding. They do not want to feel they are getting the leftovers of healthcare.

• Good quality care for basic everyday living e.g. making sure they eat well, are clean, have clean clothing. That their toilet needs and personal hygiene is attended to most importantly they are treated with respect and not patronized are made to feel afraid.

• A feeling of being safe and cared for.
• Access to quality care. This means having sufficient facilities and staff available to meet the needs now and in particular to meet the rapidly expanding need. It also means access to appropriate facilities for people under 65.

• Access to quality services when and where they are needed.

• Individualised care which meets that person's needs. Reflects more home based care rather than institutionalised care. Community care which is 24/7 similar to the model for some people with disabilities. Quality of life, quality of care and quality of death!

• Dementia research funding advocacy. Recognition of the shortage of nursing home facilities and the costs. Maybe a new model for home based care.

• Ease of early access to services.

• Easier pathway through services equitable system.

• Respectful, caring and informed staff and safe pleasant facilities. Staffs need to be well trained in managing the frustrating behaviours of dementia patents and not become rude and rough. It is bad enough to worry about the deterioration of a loved family member without being concerned they may be being treated disrespectfully. One nurse I overheard referring to patients as the "Vegies".

• Access to immediate help when they need it

• Funding for research and aged care facilities. Support with preventative measures such as nutritional advice and exercise. Support networks when they, or one of their loved ones, is faced with dementia. Access to expert advice and care.

• Flexible respite care. Both in home and also for residential aged care facilities.

• People and carers want diagnosis as soon as possible to develop management strategies and plans for the future while the person with dementia is capable of making independent and rational decisions. Carers need help to negotiate the system. Informal carers who do not live with the sufferer feel powerless and especially need assistance.

• Access to dementia-appropriate services with a guarantee of lifelong care, regardless of progression of illness.

What concerns you most in access to community and residential care services that meet your needs?

• Government Policy and Funding.

• Currently accessing Elsie Salter House - Day care - in Ashburton concerns: Ideally there would be some opportunity for one-on-one interaction. The clients' abilities - physical & mental varies a lot - ideally there would be a little more time to be able to interact with each client on a one-to-one basis - even if only for an hour or two per week.

• The waiting lists are a problem, particularly with the 'diagnosed' elderly who have surviving spouses. Often the spouse is initially happy and convinced about the need for supported care, but as time goes by their resolve is undermined by the delays.

• The increasing co-contribution that people are required to provide.
• Rigidity and inflexibility in the top management and board members of many age care homes. And the ability for them to become blinked by 1001 new health safety.

• My parents are both living together now and have been for 62 years. I hope if one goes into residential care that the other one does too. The oldies hide an awful lot of issues because they are scared the sickly one will be put in a home. More education for aging population would be great. I think Centrelink could be much more compassionate, they cause a great deal of stress.

• The complexity for baby boomer children of today's elders in finding suitable services to support them.

• Lack of available beds WHEN NEEDED, I managed to get beds for both parents in the same facility, but we were very lucky!! INFORMATION. Not enough HOURS OF CARE in the community to meet the needs of people with dementia, and their carers especially as the conditions worsens. My father had total breakdown and needed hospitalisation and I had to give up work to care for them both (he is legally blind and 93yrs), this was over a period of 10 years and I'm lucky my marriage didn't suffer as well. It is ridiculous to expect people to manage with 3-4 hours/week if they are lucky. Respite both home and residential is hard to get. I didn't claim any Centrelink benefits as Dad was getting the Carers allowance.

• Lack of adequate funding is often the excuse in shortcomings in services provided. Common excuse that there is a lack of trained staff or otherwise, and shortage of equipment and facilities.

• It's a maze - especially for elderly people to negotiate - they are not confident searching online for example.

• Reluctance of Residential Care providers to allow full inspection of premises, food preparation and staff qualifications.

• The unfairness in costs of care. I don't see why I should be penalised for working hard during my working life, being careful with my money. Not wasting my money gambling, drinking and smoking only now to find I have to subsidise people who have. Robin Hood is alive and well in the age care industry.

• When people are diagnosed a parcel with all information of places and people to help and services available should be given to families and this should also be an adult child when there are two parents and one parent is the patient, as I found it impossible trying to access information as privacy laws said I couldn't.

• Ensuring that my mother gets the stimulation she needs to arrest the progress of her dementia.

• Limited choice.

• We were very lucky that our father was well supported by the system through in-house care, respite care and ultimately, a good nursing home with caring staff. An earlier nursing home that he lived in for some months was of all lower quality with staff who were over worked.

• I fear that having my Mum put into high care will have her deteriorating more rapidly without as much stimulation.

• Not enough accessibility. Residential respite is not offered enough.

• Red tape slow processing.
• Information is hard to get about resources available. As dementia increases there is a lack of programs available and carers to provide some "time out" for the carer. It is hard to get regular carers and thus a familiar person for ongoing care.

• A case worker should be provided to families attempting to manage patients at home at diagnosis - because resources are scattered, info fragmented, there are many bum steers that waste already depleted energy. OH&S has gone mad. Paper quails are overvalued - the average 50s style woman is what is so often needed, she no longer exists. Teach everyone they’ll have to do some caring one day because there just are not enough carers to go round, equip them with the necessary common sense, strengthen community bonds - it takes a village to look after a frail person. Re-evaluate how much life lengthening drug therapy is offered.

• The quagmire of information in many places not easily deciphered.

• There is no consistency with the carers provided which causes more confusion to the dementia patient.

• Lack of easily available information in an area where one suddenly finds oneself needing to be an 'expert'.

• I have been very impressed with the residential care for my mother at Bay Side Cottage and Hadden Place Day Therapy and Respite Centre.

• The lack of available, appropriate residential care facilities and the complex issues involved in securing a desirable placement. Misrepresentation in marketing to Seniors who may not present as having dementia but do not necessarily have the legal capacity to enter into contracts for aged care housing. Affordability.

• The fragmented approach to assessment, the limited supply of quality operators which means that good services have long waiting lists which often means that families have to go to extra services operators just to get a bed in a half decent home. The extra services only offer flasher accommodation when what is really needed is quality care, not upmarket buildings. Currently there are limited places for people needing high care with few new beds being commissioned other than extra services beds. Government needs to establish and provide baseline high care accommodation as many families do not want to use extra services due to this high care. Also the current system whereby bonds are 'negotiated' seems unfair with some people who have organised their affairs or never having saved, paying little and others being required to pay significant sums. It would be better for homes to set bonds, to let the public know their price, and to allow families to choose the accommodation level that the home is to provide. From what I can gather the care and other services will be the same in whatever home the person ends up going to. Competition can only be a good thing for families seeking better access to services to meet their needs.

• That I would not be happy going into any of the aged care facilities that I know of. Will there be any better alternatives?

• How do you find out about them? It has taken me 8 years to get my head around how the system works. The worries about financing our old age. We have saved money but how do we know how much we need? How can I be sure that the care we receive in a nursing home is appropriate? It makes me feel insecure to know that the family home is to be included in assessment of our finances. There are so many implications involved here. How can you sell the home if the Government owns half
of it? How can you trust nursing homes to charge a reasonable entry fee? That will not work.

- That the words spoken by senior management and nursing staff just do not relate to the attitudes and behaviour of the resident's primary carers, the PCAs. That the PCA's run their own systems in the corridors of a facility. They are unsupervised and unsupported by Div1s because the Div1s are consumed by completing regulatory paper work and huge amounts of general administration. The Div1s are glued to a computer screen.

- That my concerns about food have been denied by the Manager of the Aged Care facility.

- There is a chronic shortage of relevant, appropriate, timely dementia-specific services in the community. As they are mostly delivered through the Aged-Care system at present, they are often inappropriate and insufficient. Same points apply to Residential Care services!

- We want assurance that if mum ever has to go into residential care, we won't have to "sell the farm" to find her a place. She has an adult daughter as her fulltime carer, and expressly wants her daughter to be able to live in the family home for as long as she wants. We are fortunate in that mum is a veteran and Veterans Affairs actively advocate for their clients. But not everyone has the benefit of their advocacy.

- That there is enough staff in residential care facilities. That the staff are well trained to be able to manage and understand the needs of those that do not have their own voice.

- The lack of residential facilities. This means long waiting times (the carer often tries to keep going until they "hit the wall") or having to take a place at a facility you think won't give proper care. Good places are few and have closed waiting lists or waiting lists of at least 6 months. If there are places they tend to only be available at inferior places. Residential Respite places are limited and require booking several months in advance. Even worse the current funding limits how often you can get residential respite (even if you are prepared to pay). This is likely to drive carers to put a person into care earlier than would otherwise be the case.

- That 'dementia friendly' too often means 'lockable facility' and doesn't mean person-centred care that is designed to minimise the impact of dementia and maximise quality of life.

- That it meets my needs rather than a one size fits all. My biggest fear is low quality of life or neglect.

- The sheer cost to a family The standard of care and staffing ratios in nursing homes The question of the current wage structure in residential care (low wages -poor quality staff (in many cases).

- Paid carers have a lack of understanding of what people are paying for and how this affects their family carers. Lack of respect by paid carers for peoples remaining abilities. Lack of knowledge of ageing in residential care and moving of residents because management won't support the additional staff required to provide higher levels of care.

- Inadequacy in client to carer ratio in aged care facilities appear to be penalised for having private health care-once ACAS do assessment, ready to start charging for bed per day as assessed as not rehab.
• That there will be enough good quality respectful humane services. Also that staff are resourced to do the job without too much strain.

• Timeliness and the service you need aren’t always available and the services make you what they want you to have.

• I am worried that services will not be well funded and that staff will not have an expert understanding on how to deal with dementia cases. I am concerned that those living with dementia will not be able to do so with dignity due to underfunding of care facilities.

• Poor training of the staff in meeting the needs of frail aged people.

• Alzheimer’s patients seem to be having few options apart from a “secure facility”. This is very frightening. There should be facilities for patients who are one of a couple to go into together.

• That people with dementia who are entering care services are not assessed adequately or provided with appropriate care for their condition. That there is little capacity to plan for the inevitable deterioration of the person’s condition. That challenging behaviours associated with progressive dementia are then seen as too difficult to cope with in the aged care setting or even in dementia-specific settings.

Do you have particular concerns around access to information and assessment for access to care services?

• Family members who have relatives in aged care need to be empowered and educated to ask and receive regular info on pain relief used for their family.

• It is essential to have access to the internet - I think those who don’t would find it much more difficult to access information. Overall - the availability of information & the support services are phenomenal. I am certainly very appreciative for what is available & what I have been able to access.

• I know that the Alzheimer’s Association provides superb support services - but the public generally is in ignorance. I am especially concerned that carers should be much assisted in terms of communication. The old ‘I told you yesterday’ is still around - as a retired ‘helpline volunteer’ one call that sticks with me was that of a daughter who, with her sister, visited their mother in a hostel, and each day the mother would ask ‘When are Mum and Dad coming to see me’ - to which the other daughter always replied ‘Oh Mum, I keep telling you that they’re dead’ and of course the mother grieved every day, only to ask the question the next day when she would get the same answer!

• Yes. Especially regarding home care packages. the government hands out a sum of money for each “case” but the actual care delivered rarely correlates with that sum, recipients and their carers are not given details of what is available to them and often requests for extra services are treated evasively.

• My concern is that there is no information in GP surgeries or health clinics about dementia. Many other topics are displayed but there nothing on dementia found in any surgery. This glaring omission. GP’s are busy and if a carer/potential carer or friend armed with the areas into which to look, much time will be cut in doctor’s surgeries. A carer suspecting that their partner/relative/neighbour should surely be able to have access to a nurse educator with qualifications in aged care and dementia care to make useful observations and give advice to the potential carer/family member before the final diagnosis. In this way financial, enduring powers of attorney and can be put in
place when the prospect person with dementia understands what it going to happen in the future.

- Well that was a nightmare. My mum has dementia and I had to pursue this with her Dr He was not helpful at all. He should have picked it up first especially with all her medical history. She had a very serious staph infection which caused the dementia and he never followed it up. Having medical staff supporting you makes a huge difference. The person who finally helped was a social worker who pointed me to the right organisation but you still have to do it all yourself and I have a family of my own and no other family to help me.

- I have lived the nightmare with my father until his death in April. He had a formal diagnosis of vascular/mixed Alzheimer’s from a geriatrician but the rural Palliative care nurse was completely ignorant of this a few weeks before his death. What a blessing that was. I will have to do this all over again with my mother. Please address communication between the services and provide a continuum of care based on consumer choices.

- Information WHEN you need it!! Which is often on the weekend when a crisis occurs! Over assessed and not enough services at the end of it! How many times do we have to say this??????

- Access to information is not such a problem. But again it is the cost-cutting that affects the satisfactory services being provided or sought. To be put point blank, it often results in "third grade" service.

- As hinted above - most information seems to be online.

- Too much glossy handouts that are not easily readable.

- Yes I found it hard to access information.

- Getting access to information is difficult, particularly when you are in the middle of looking after someone with dementia.

- Hard to find the right information and to work out what it means for us

- No.

- Gaining access, not enough places.

- I have no idea of the process that awaits my mother.

- Information is hard to get without contacting either Alzheimer’s or Carers. Assessment can take too long.

- Unite resources, including voluntary, into a one stop shop, design care systems from patient and primary carer point of view e.g. you shouldn’t find your disease and location dictate what you get.

- Yes. We need better and simpler access to information. It was very difficult to access government health and ageing information. The web site was incredibly difficult to wade through (and I am highly computer literate) to find how to access information about low and high care places, rules for finances, etc. We need some common sense to be applied to ACAT dealing with a dementia sufferer living alone and waiting for assessment. To only deal with the dementia sufferer because of privacy issues meant
ACAT just closed their file because each time they tried to make an appointment the person said "No, thanks". ACAT didn't consult with the referring Dr or with the family member whose details they were given. VERY FRUSTRATING.

- The wait time for assessment.
- Lack of information from General Practitioners. Lack of willingness of GPs to be involved and recommend assessment, or denying requests for assessment/services.
- There are long waits for ACAT assessments, from both initial assessment and from low to high care. This is due to the limited human resources that states and territories provide for the ACAT program. This delay impacts on families and people with dementia with often long waits especially if they are waiting in their own home. The only way to short circuit this long wait is to get the person admitted to the local hospital and refuse to take them home until an assessment is done. The hospital then leans on the ACAT team to undertake the assessment as they want to free up the acute bed for other admissions.
- It is virtually impossible to get any idea of care offered by a home from outside. When high level care is required, there is little choice available - it is usually a take it or leave situation. Aged care accreditation is a tick the box exercise - it should be done more frequently on a surprise basis, with more emphasis on what is actually happening, rather than worrying about whether all the paperwork has been completed.
- Definitely. There is a real problem at present finding out information. It took me 8 years to find out. It becomes just too hard for people and they just cope without getting services they really need. The Gateway idea is good but it must have the answer to every question any one can ask. Family doctors must also have that information as it is the first place people go to when something is amiss. There are so many agencies that can help and they include church ones, local government, State government and Federal Government and private organizations. Many of these double up and it takes a long time to find out what is available. It is essential the Gateway is very well thought through, very well advertised and easy to access.
- Not in particular
- Well, in a way. It is nigh on impossible to get an accurate feel for a place when they are using a rotating shift between 4 sections, when the staff are changing 7am-3pm, 3pm-11pm, 11pm-7am. Actually a good measure is to note how many staff are using different "voices" when speaking with residents. If they are not confident that their everyday "voice" is effective for communication then perhaps you need to look more closely.
- Yes, information in a timely manner as you go through the stages - we were flooded with brochures on a few occasions but it's too much at once, carers need to be given the information again in a timely manner
- There is information out there, -but it is more of an issue about where is it? - How do you find it? - What information are you going to need at different stages as the disability continues to change? - Who are the best-informed people out there to help with specific problems? - How do you access them / find out where they are.
• Yes, in Brisbane, the Queensland Health ACAT services from the north side did not share information with the Southside ACAT last year when we had occasion to access emergency respite care for mum. So the district who completed an emergency ACAT while she was in respite, did not make it available to the district whose catchment area she normally resides in. But in the end it was a good thing, because when they did the emergency ACAT report in a north side nursing home, they put her down as someone who wanders, when in fact all she was doing was looking for a toilet in an unfamiliar environment. Fortunately we were able to have another assessment some time later when mum returned home and a more accurate picture of her behaviour was gathered. I believe that all older people who have several health conditions (it's impossible to define an age without sounding ageist) should think about their future needs, discuss those with their family and appoint an enduring power of attorney. Decision making is easier when you have a clear idea of the person's wishes.

• No.

• Yes - no one seems to want to help – overloaded.

• Information of services and facilities suitable for younger people is almost non-existent. For residential care there is an extra problem in that because of long or closed waiting lists, facilities are very reluctant to provide information and especially allow visits.

• It is a maze, a frightening, unfathomable maze. Everyone who starts on the journey seems to have to find their own way - depending on the care their PWD needs, depending on what services are available in my area compared to services in the next suburb or municipality, depending on whether they know where to look.

• Needs to be coordinated in a one stop shop delivery model.

• Not really. I have been interviewed by assessment teams when reviewing a home's accreditation. Outcome then posted on a web site.

• No.

• Very frustrating, waiting list for assessments. A lot of information on internet, but how versed are older persons on seeking information.

• Not enough is really known about dementia and it would be good to see it prioritised in research.

• You have to wait for assessment and then wait to get the care. And then the care is the care they want to give you, not what would really help you.

• Yes; there is no long term view to assist me to face the issues that arise with my mother's care i.e. I need to know what services I can access along the dementia journey.

• My concern is for a relative who is a widower and lives alone. Organising an assessment by an Aged Care Assessment Team seems to be a step, yet I think some form of assessment and care service is required to keep him living independently and to help him plan for the future.

• Yes - there seems to be little support for families when a person with a diagnosis of dementia is entering care about the best options for lifelong care. It seems to be more about the "vibe" of a place or how nice the furnishings are.
What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

- Currently we have access to & utilise 3 different services: - 2 hours through Ashburton Support Services - Wed - 4 to 5 hours thru Elsie Salter Day Care - Thur - 3 hours in-house respite Fri. The service I would appreciate would be a much more compassionate & understanding & caring Alzheimer’s specialist. To date we've had 5 appointments with two different specialists. Their 'bedside' manner certainly has much scope for improvement. Someone to talk to at various times - to ask questions - what do I do now? How do I resolve this? Is this the right decision? Are there other medications? i.e. SME (subject matter expert) availability for Q&A

- Residential care in my aunt's case.

- Home care and support.

- My husband died in June 2011. I would have appreciated more day care visits when he was still living at home, not just short 2-3 hour sessions one of twice a fortnight. This did not give carers enough time to wind down to feel 'normal' again. I believe that those with difficult behaviours can live in secure dementia units, but staff must be specifically trained to help with these often upsetting behaviours to themselves and to other residents. Art and music therapy can do wonders to help those in the advanced stages of dementia and an understanding of the behaviour so they may be defused. It is essential that residents to be able to walk through the grounds of the establishment without hindrance, to enjoy the sunshine which gives them a sense of purpose and freedom.

- To be honest I had to struggle very hard to get care for my parents they both should be in residential care but I want them in their home as long as possible but there are lots more aged people and no help we need lots more services all of them.

- Individualized consumer directed services. Care can create dependency instead of providing enablement

- RESPITE/showering/dressing/cleaning/incontinence pads/laundry/assistance with medical appointments/recreation for the sufferer/counselling for family carer/advice and support available WHEN you need it NOT 2 weeks away! /It is not rocket science so please do not over complicate the care or the assessment.

- ALL of these!

- Home care.

- To understand the When and How to use the available services.

- At the moment I am managing to care for my wife using two days respite at the Brisbane Mater Hospital where she gets excellent care. We also get good quality support from Alzheimer's Australia at the Gabba.

- More home care would have been a better option, and respite care more accessible.

- Residential care.

- Home care.
• Understanding of carers needs and accessibility to services without waiting lists. More staffing in residential care for those with dementia.

• Home care, residential care.

• Flexible respite care for hours/days at a time instead of a rigid block of a week or two. More centres that offer respite that are/become familiar to the client. A place that is secure and offers a variety of stimulation/activities as well as occasional (or more) overnight care.

• Home care and suitable respite care i.e. younger onset, catering for FTD not just Alzheimer type dementia.

• Can’t say enough!!!!!!!!!!! More young onset dementia places and services in all of above.

• Home care.

• Have a progression through services as symptoms become more severe and as families become unable to care for the ill person at home. HACC package was excellent once we had access to it. Then more was needed and a low care dementia specific bed was hard to find. There seems to be a lot of pressure on Nurses and Nurse Assistants who are poorly renumerated for difficult, important work.

• Short term residential care and outside day care.

• Access to home care services would have made a huge difference to minimising the progress of dementia, dignity and independence.

• After the early stages of dementia the persons level of confusion becomes so much that others find it difficult to lead manage their care while leading their own lives. At this stage families begin looking for some form of residential care service. Often these services are limited, especially if the person has a severe behavioural issue, including wandering or absconding from the home. Many homes don’t want a person that has such issues so finding an appropriate place is often difficult. With the growth of community based care it would appear that people with dementia are entering residential care later so it would seem that this is the only area that government should focus on as at least 4 out of 5 residents in care these days are people with dementia. So new services should be encouraged to provide care for residents with those types of needs and let those that don’t have these needs continue to be cared for at home through community care programs.

• Residential care services.

• All of the above. We are lucky to now have home care, respite care and a package with assistance. The Daily care is wonderful. We are involved with Carinya which is a Villa Maria establishment where people can have day care with wonderful people in charge, a bus pick up service, and very appropriate activities. We can access respite stays of up to 2 weeks. This takes the pressure off for a few hours on a regular basis and it is wonderful. There should be more of these types of support. We also really appreciate respite care in our own home. This is a wonderful service and should be available to all who need it. If the Carer goes under then there are two people for the
health system to cater for, so this type of service allows the carer to be a normal person and it recharges their batteries.

- To be able to support family members in their or our home.
- Better residential services and advocacy for residents with dementia and Alzheimer’s.
- Home-based Respite care for my husband, to enable me to go to work. Needs to be able to take him out and provide varied, community-based, stimulating, 'normal' activities. There is also a need for full-day 'Day Centre' type care, i.e. working hours which is dementia specific, but providing something other than a programme for 'geriatrics'. All services need to be provided by highly trained well-educated professionals in the condition of dementia. NOT NURSES!!!

- In home care is a necessity for us; it would be great if all carers had a sensitive, reassuring manner, but some are quite gruff, which can be off-putting to an elderly lady who is very shy. So more training in handling the complexities of aged care for paid community workers would be great. Training for workers in recognising unmet needs rather than seeing only challenging behaviours is a must. That is not to deny that some people have psychiatric illness that needs attention, but not all behaviours are mental health problems, some are caused by undiagnosed physical conditions, loneliness or too much stimulation (too much noise, too much visual stimuli).

- I believe that a multi-faceted approach is ideal - encompassing all listed options. A one size fits all does not support the fact that people have different needs and also the people's needs change as the Alzheimer’s journey progresses.

- Respite care - residential care.

- Currently residential care. On my caring journey of nearly 8 years, the needs varied. Initially it was help taking my wife out, keeping her occupied and giving me time. Later it was that plus periods of residential respite. Occasionally it was access to advice on challenging behaviours.

- In-home respite care with a carer suited to my husband's needs and personality.

- Residential care-secure dementia unit.

- Service for severe behavioural issues.

- Respite care and residential care.

- At different stages all of these have been needed.

- Care and support. Home help for the household to relieve some of the burden. This is not always available if a person is not the usual person who does the chores, but if the carer does them they are hard to fit in amongst the caring and the exhaustion.

- Respite care, residential care services for behavioural issues.

- I believe my brother needs assistance with activities of day to day living. An example is that he is losing, or has lost, the ability to use ATMs for banking. I believe he also needs help with attending appointments and other activities that require planning, problem solving and organisational skills.
• I am particularly concerned about the provision of lifelong care, regardless of evolving behavioural issues - with an emphasis on continuity of caregivers and care environment.

What types of support and services do you need to assist you in your role as a carer?

• I am confused at how the government has made available funds for pain management in dementia and elderly patients in care, when it drives managements into a frenzy, we are now ignoring skills of staff and driving ever increasing use of medication, now each behaviour must be pain related and you must provide proof medication was accessed, don’t care if there was a trigger, don’t care if you managed to remove cause of behaviour. Morphine patches are now in vogue as is Endone up to twice a day with a patch and let’s throw in Panadol 4 times a day, this accesses good revenue. And threaten staff with their job if they do not agree, that removes their advocate? Is this a backdoor attempt at euthanasia reform with no debate, and no policy changes? Check your death rate recently.

• My uncle in his role as carer is not sleeping, and is finding the drive from Rosanna to 'Peter James' in East Burwood increasingly adding to that tiredness. As in most or all cases of serious illness it is what Elizabeth Kubler Ross the 'next person' who needs equal care & support.

• Respite, assistance with personal care.

• I am no longer a carer as my husband died in June 2011. But I spent much time in my husband’s dementia unit talking, dancing, laughing and playing music with (not to) residents. Some, but not all, carers seemed to have no imagination or were not capable of empathise with the residents and were happy to just sit and read a newspaper. Carers need more training in diversional therapy and only those with a natural bent towards working with aged care residents must be selected in the first place.

• Understanding from the general community and especially the medical profession and most of all Centrelink they are the worst you feel like you’re a criminal trying to rip them off for the few dollars they provide as an allowance. Heavens sake I gave up a part time job to take care of my parents. The forms they have you fill in are ridiculous they certainly weren’t compiled by a carer because the questions they ask are so unfair. For example you can’t count the hours that you take to help shop, there are no questions about how much work you do arranging every appointment, organising meals on wheels etc etc no my biggest beef is Centrelink. Now that we are in the system the different agencies are great.

• Communication between the services.

• Respite, both residential and home based.

• Most importantly meeting with other carers in support groups that are provided by some organisations as with Alzheimer's Australia. These are handled by professionally trained staff. Often meeting in a social atmosphere and involving or participating in group activities is of very valuable and positive assistance.

• I am not a carer - but my mother is, and she is hearing that getting help is not worth the bother even though she is not coping. She does not have the confidence and
wherewithal to research and reach out for support. She has to initiate everything (we are not allowed to) and she hasn’t really the capacity to do so. GP doesn’t seem to have time- even though we have alerted her to the problems.

- Access to gerontologist, podiatry, physical /Body care. Home safety advice
- Nothing more at this time. I would like to see the government spend more on Alzheimer's research rather than the pittance currently spent. The government should realise a cure for Alzheimer's would be the best way to overcome future care problems. I sometimes wonder if the staff of governments, support and care organisations are more interested in a cure not being found.
- Home visits from aged care support on a more regular basis than we ever had would be a start.
- Extra people to visit my mother.
- None.
- A plan of the processes involved with going from one facility & when this will happen. By typing this I will now ask the Aged Care provider to give me a typed plan. It needs to be on paper so that I can properly process things when they happen. I want more consultation.
- Quality trained staff.
- Respite and programs for the client to participate in while they are able. These seem to close down when there are issues.
- A case manager from day of diagnosis - who protects the carer from breakdown? Should the diagnosis be a double sentence?
- I think every carer needs a "case worker" experienced in the local area and who knows every place /service available and referrals to them. Someone to help say "this thing might occur and you may need e.g. a wheelchair soon". Especially useful for rarer forms of dementia.
- Guidance with dealing with dementia patients. How to provide them with the respect that they deserve and manage any outbursts that they may have.
- I have found Alzheimer’s Australia an incredibly helpful source of help by way of information, support group, library, counselling and more. This has been in an absence of any other help for family carers.
- The type of support currently offered by AASA is invaluable.
- My family member has been in residential care nearly three years and I am the only person who regularly visits, usually 3 times a week or more. As her informal carer I would appreciate having the opportunity for some counselling from time to time as the dementia takes more and more of my family members 'person' away and I need to come to terms with this. Also other family members, while related, leave the care, decision making and management usually to just one person and it would be good have a service that can listen and help carers put this responsibility into perspective.
- Psychological support. Alzheimer’s Australia has been very helpful here. A local carer's group where likeminded people can give support to each other and have a bit
of fun. Respite care in the home and out of the home. ‘Time out’ for the carer makes it work. Information about everything freely available when I need it. Financial certainty so we can plan our futures. We should feel secure in our own home knowing it is always here for us. Financial and psychological security. Somewhere to ring when immediate assistance is needed. Information about the disease. Knowledge is power. The Alzheimer's Association is great at providing this. We need to know what is normal within the disease and how to cope with it.

- Education!!!!!!!!!!!!!!!!!!!!!! A real person to contact for information and suggestions of where to gather more advice. Feel that this is a collaborative journey.

- Paid leave to go and feed my mum.

- Home / Community based, suitable Respite Services, provided by people who are highly trained in the condition of dementia. Of sufficient quality and quantity to enable the carer to participate in the paid workforce, if necessary.

- I believe all adults should complete an advance health directive and power of attorney, and should update those every five years or sooner if necessary. It makes the job easier for the person who must make decisions when a person has lost their decisional capacity. So a staged campaign in each of the states with say, the Public Trustee sending a postcard or flyer to persons aged 60+ inviting them to discuss the matter or to contact a justice of the peace might be an idea. I would really love to see a public education campaign aimed at eliminating discrimination against people with dementia and ageism in general. Similar campaigns for disability and mental illness have been successful in the past so it's time to let people know that just because someone has dementia or even early dementia, they retain many of their abilities and still want to be part of society.

- Someone to talk to about coping with the day to day issues. The confidence that when I cannot get to the facility that my mother is being well cared for in all respects.

- Information on availability of respite care, residential care - tried many times but to no avail.

- Assistance such as cleaning services, while appreciated, are so minimal that they are really of minimal assistance. Overnight in-home respite care so that I can go away for a break. My husband is not suited to external respite care - the staff have phoned me on previous attempts and asked me to take him home because he is so distressed and therefore this lovely, gentle man is also too disruptive day and night to the staff and to other residents.

- Education about the disease and other health care issues, information about where and how to access care/services, connected services, case manager who walks with you on the journey, time for me and my relationship with the person rather than always being in a caring role.

- When my wife was at home I accessed through local government and church groups their respective day care facilities. Found this most helpful.

- Ones that fit around my work and family needs.

- Home care, activity groups, home nursing, respite, local doctor.
• Breaks from the role where care of the relative is good quality so you don't worry while you are gone.

• Support at home with the chores (cleaning, gardening etc.) Someone of my choice to come in and do some respite while I go out occasionally. Training for the whole family and friends about behaviour and what to do about it.

• Funding and training. How to fit in looking after myself as well.

• A guide to working out how to assess the level of difficulty the sufferer is having and what type of assistance would be helpful and appropriate. It is difficult to work out when it is appropriate to intervene and how much to leave responsibility with the sufferer when they are living alone and are concerned about their independence.

• My father passed away with an Alzheimer's -related illness in April 2011.

Are there health issues that need to be addressed in the reforms? (E.g. timely diagnosis, care in hospitals, dementia risk reduction and dementia research)

• Fund the elderly and we will not have to stone them till they fall off the perch.

• Absolutely - all of the above.

• All of the above - all my working life I worked with cancer patients, and when I started my training in 1958 the word 'cancer' was whispered, and I'm finding the same thing is still occurring with the word 'dementia' - in many ways this is the barrier to improving the first three of the above - and incidentally money would be caused to flow more readily for the research section.

• G.P.'s need more training. If a patient has some cognitive impairment, the G.P. may say "are you cooking for yourself?" the patient may reply yes and the G.P. accepts it, instead of asking what the person cooked the previous evening. Answer would probably be baked beans on toast.

• Health issues. Many illnesses could have been caused by poor dental treatment. Attention to teeth at the early stage of dementia is essential as very poor dental hygiene can lead to future infections and many discomfits to a resident who can no longer explain the nature of his/her pains. Early Diagnosis is essential. This gives the PWD and their carers to put family matters in place before the PWD becomes too confused to understand what is happening. I believe it is important that potential sufferers should be part of the diagnosis process. GP's need to be trained to recognise dementia and with the help of an appropriate trained practice nurse or a specially designed clinic with appropriately trained staff to help both the carer and the PWD. Guidelines to dementia diagnosis are difficult.

• It was my own persistence that saw my Mum get the diagnosis and help she needed. There's too much hysteria around dementia maybe it's the name but my Parents are still in denial. The biggest problem for my Mum was when she was very sick in hospital when she withered away and needed rehab it took so long to move her to Hampstead and this caused her to get very very depressed because she wasn't getting any services that she needed. The truth is if you don’t have family to come in and help you eat she physically couldn’t do it then she didn’t eat. Great nursing why can’t they get volunteers at least.
• Good medical services for the elderly with dementia. It is a disease not a death sentence. We all die and so should all receive the best medical advice until death. This means advice that a treatment is no longer a viable option. Let the people with the money and knowledge provide the services and allow individuals to take responsibility for diagnosis, research and risk reduction.

• Yes timely diagnosis with directions about what to do in the future, well educated GPs and other staff. Hospitals do not cope well with people with dementia, e.g. after surgery following fractured NOF my mother was left with her lunch untouched in front of her, still untouched at 2.30pm, staff just standing around talking and laughing!!!!!!! I am opposed to FOR PROFIT agencies being allocated funding for this care, and see the whole funding process as overly complicated-too many providers! Care workers are poorly paid, for the work they do.

• Again, ALL of these with emphasis on timely diagnosis, followed by the rest.

• GP education.

• Timely advice realised by education provided by radio, television, and newspaper articles.

• More DEMENTIA RESEARCH NOW.

• Absolutely, timely diagnosis, referrals immediately from GP, and totally dementia research.

• Letting the right hand know what the left hand is doing.

• Timely diagnosis - my mother could not get my father's GP to realise that there was a problem and by the time it was diagnosed, he was a long way gone.

• More dementia risk reduction. Knowing what I can do to help my mother.

• Acute hospitals and emergency departments have NO understanding of dementia and patients are often treated badly in these situations.

• Timely diagnosis is vital. Any hospital admission is fraught as the environment is totally unfamiliar and staff often do not have an awareness of the needs/behaviour of a person with dementia. General awareness of the benefits of exercise, diet, social interaction is fine but should not be portrayed as the way to prevent dementia but simply to enhance well-being for all in the community. Continued research involving consumer input is needed to enable the needs of dementia sufferers and carers to be addressed.

• quality of life over quantity when designing research - prolonging life isn't necessarily 'progress', more emphasis on care system design rather than brain function until we get it right i.e. very practical and applied.

• Let's get all of the above happening and certainly research into it, let's get this cure!

• The current research being conducted in America where arthritic drugs are being used should be fast tracked to Australia by the government.

• Yes. Lack of help during the incredibly draining and confusing time when trying to find a diagnosis. Drs who say some memory issues are normal and dismiss family concerns was very disappointing in an otherwise excellent GP. Three years with
annual visits to a neurologist with a final report saying, "There is something wrong but I don't know what" without thought of referral to other help was very disappointing. Doctor's comments of "She just didn't concentrate hard enough during the test" were very dismissive (and incorrect) and unhelpful. After numerous calls to hospitals at night for me, the next of kin, to come to calm the patient down there is an obvious need for nurses to be more aware of ways to deal with confused, disorientated patients who are frightened. Getting a bigger, 'bossier' nurse to deal with them is NOT a solution. Education about challenging behaviours (and this is not extreme behaviour) would hopefully help.

- Care in hospital needs to be addressed. Mum's stays are stressful for all concerned.
- Timely diagnosis. Gradual re adjustment from independent living e.g. not being admitted to hospital from independent living unit - to rehabilitation - to directly going into secure dementia based on one staff member's recommendation. Dementia was exacerbated by the confusion of moving from one facility to another, unnecessarily, in a short time span. Care in hospitals was negligent in terms of the lack of understanding of dementia related issues e.g. Person with dementia was tied into a chair with 'apron' and left alone with a plate of food resulting in the person attempting to eat the plastic cover over food. This is distressing for the carer to witness and takes away the dignity of the person with dementia. Patient being discharged from hospital too early because staff unable to manage difficult behaviours. Doctors in hospitals talking about the patient as if they weren't there regarding issues of palliative care. Lack of dementia specific wards. Dementia patient left for hours in Emergency with no support person. Ambulance officers lack of respect towards dementia patient. Dementia risk reduction and research are vital.
- Yes - dementia prevention and risk reduction public awareness programs would be useful. Dementia research into familial links would be a good area for government funds to be targeted to.
- Hospital staff are not dementia trained. Carers need to be able to advise hospital staff of dementia of patient as soon as possible and have it noted on the records. So that other staff are aware of this. In addition, carers need to be with the patient at all times, similar to a young child being accompanied by a parent. Dementia research needs to be accelerated. Diagnosis needs to be much better and earlier. GP's need to recognise those with dementia and make appropriate referrals.
- Timely diagnosis definitely. Especially with Alzheimer's. Doctors MUST be better educated about the early signs so they don't say "It's only the ageing process happening", when you go there with a concern. Thus research must be supported. Professor Woodward is doing a fantastic job in this area. He needs more financial support so his work can continue. Care and respect of patients is so important in hospitals. Nurses need education on how Alzheimer's and other diseases work so they can understand and assist the patients. Wages of nurses in nursing homes needs to be GREATLY improved. They are doing the work families can no longer do so they need to be encouraged to stay in nursing homes where there is a great need for them. There should be a set minimum ratio of nurses and patients set by the Government – not just decided by nursing home owners as private owners will set the minimum they can because of the profit line of their establishment.
• Timely diagnosis absolutely! Being able to have an advocate if hospitalized.
• anything to reduce the incidence and improve the care available would be welcome.
• All of the above points. Urgent attention is especially needed to change the way we care for people with dementia in Acute Hospital care. It is horrifying!
• Timely diagnosis would be good, as long as it is accompanied by sensitive and supportive counselling that life is not over for the person with dementia. Support for people with dementia in acute care is also important, and it seems that education of hospital staff is the answer. We need to value the family carers, and Alzheimer's Australia really honours that concept, but more public awareness is needed. I would venture to say that at each stage of life, we care for each other. Whether it is parents raising children, spouses sharing the workload during middle age, or someone caring for an older relative or friend. Likewise with professional carers, they need to be both fiscally rewarded for their genuine service to people living with dementia and respected for their ability to provide care for people with complex needs. Thank you for the opportunity to provide input.
• Yes a better process for early diagnosis. Better training for GPs and the way in which the ACAS process works.
• All of the above.
• Dementia research is grossly underfunded compared to other diseases even through the burden is very high and expected to become the most significant.
• More information in hospitals to carers on why my husband is being taken off some medications and onto others instead of treating me as though the only one that needs to know that is the specialist. Why do GPs treat dementia as a taboo subject? Surely it is a disease that needs to be fully diagnosed, fully addressed and discussed with carer and/or patient, and a pathway laid out on possible treatments - not to mention the need for things like Power of Attorney, Advanced Care Directives etc. which I had to find out for myself.
• All of the above....timely and supported diagnosis, better care in hospitals for people with dementia, dementia friendly environments in both acute and primary care.
• Yes 1-Training of hospital emergency staff when a person with dementia is presented 2-Education/awareness of the general public about dementia 3-Where there is an evidence base push preventative programs.
• All of the above.
• Delirium, depression, dementia.
• All of these as again they are all interlinked and part of the continuum of experience with many dementia patients.
• Care in the home.
• Yes proper diagnosis and medication trial if possible. Dementia risk reductions. Fall preventions.
• Timely diagnosis would be helped if all people over a certain age (65 years?) were given Alzheimer's pre-screening through a short memory assessment tool organised,
or administered, by their GP. Over 65's are given free flu and pneumonia injections, so why not memory assessments? Almost all of us over 65 are aware of some word-finding or memory difficulties, so why not take advantage of this to encourage awareness and preventative health care? If time is an issue for GP's why not get psychologists to do the tests under the Enhance Primary Care program (or something similar)?

- Plans for care for people with advancing dementia which specifically limits their placement in mainstream acute care health facilities. Adequate palliative services for people with advancing dementia. A better system of assessing people with advancing dementia within their own environment, rather than moving them to another facility. Provision of appropriately-trained nursing staff (not patient care attendants) in dementia facilities - a professional recognition of the importance of this work and efforts in the community to publicise the great work these nursing staff do in maintaining quality of life for people with dementia and their families. It would be great to see more qualitative research examining the experience of people suffering dementia and their carers and families.....with a view to improving care for these people and support for their carers.
APPENDIX B – CALD CONSULTATIONS

Minutes from consultations

Sydney CALD consultation
21 October, Fairfield RSL, Fairfield, NSW
Panel: Ellen Skladzien and Lynn Silverstone
Chair: Pino Migliorino
Number of attendees: 49

Main themes
Primary care
- Misdiagnosis
- Timely diagnosis

Information and access
- Desire for verbal info instead of pamphlets
- Wanting recommendations rather than just information
- Need for better access to information- and language appropriate information
- Need for culturally appropriate services
- Wait for assessment
- Need for better funding for existing services
- Artificial boundaries between what services can provide

Community care
- Needs to be more flexible

Respite
- Need for longer hours of respite
- Respite staff requesting carer help to respond to behaviours
- Concern about cashing out option

Workforce
- Staffing levels and training
- Lack of culturally appropriate staff
- People not seeking help from the workforce due to stigma
- Concerns about how staff treat people with dementia in hospitals
- Lack of funding

Support for Carers
• Counselling and support groups for carers
• Interpreters for carers who cannot speak English
• Problem of programs that do not have ongoing funding ending suddenly

Consumer comments

Primary care

I am a carer for my husband who was diagnosed with YOD. I had to quit work. I have no income. Our GP told him that he was depressed. He was given depression tablets. It was only when he suffered a seizure at home did we get referred to a neurologist. He found nothing. He had epilepsy and I was referred to a hospital. The next neurologist diagnosed him.

I think the GP needs more training to recognise what is depression and what is Alzheimer’s because there can be a misdiagnosis.

I am very upset with GPs. I had to have a panic attack for my GP to understand, I haven’t had a holiday in 20 years.

Information and access

I had a lot of trouble about not knowing where to go. I ended up with Catholic Care, which I found through Lynn (dementia advisor). When mum was diagnosed I got a pile of advice in papers, but I want someone to talk to me. I want them to tell me what we need to do. I will never read that.

Centrelink gave me pamphlets, told me to choose, but I can’t choose, they know better and what is best.

It is hard to access interpreters.

People don’t understand the system. They only find out about the packages when they are in a crisis.

We need one number not 101 numbers. Carers are suffering a lot.

I work for Baptist community services. We provide EACH packages. We have packages available but clients cannot get them because they are waiting to be assessed.

There are not enough facilities; there is no place for my mum. She has to be assessed first, it is so hard. Many people who don’t talk English are in big trouble because even when you are highly educated, when you have Alzheimer’s you will only talk your native language.

In our Arabic social group we have 5 clients with dementia. But they could not move into the specific dementia group because of funding. We can have staff around that are trained, but if we don’t have the funding we cannot fulfil their needs. There is not enough funding! We have funding for 12 months and then we are back to square one. This puts our clients through more trauma.

My mother was in a hospital, in a psychiatric ward, it was very inappropriate. We had to take the first dementia specific place that had a spare bed. We had to take it
because it was an emergency. How nice it would be to have options. The gateway is a fantastic idea, but it will not work unless the resources are there.

My question is about activities for YOD. There is only one program for people with YOD. The government don’t talk about the YOD, nor does the PC report.

As a carer I can’t think clear because I am so busy, it is so hard to find information.

Community care

Because mum and I live together, [the community care provider] cannot supply food, or clean. If someone lives by themselves they can do this. So what they were doing is not a great help. I have depression but my culture does not let me leave my mum to put her in care.

Respite

For emergency care, you can have a few hours respite. But I work 4 hours a day, not 2 hours a week. I have depression. I worry I will end up with dementia soon.

Physically my mum is fine, mentally, she makes you crazy! They sit at home with her, but she is an active lady. I have to stay at home too with my kids, and she just follows me around. They can only take her out once a fortnight. I can’t find short respite. They give me number, and then I am told ‘no sorry we don’t have it’.

I am a carer for someone with Parkinson’s and Alzheimer’s. Access to services is restrictive. As a younger carer I don’t have the ability to not work. When you find a [respite] facility they are managed by staff who don’t know the person, you are up there every day continuing in a carer’s role, this is not possible.

I am concerned about cashing out for respite. We have to try and encourage CALD to take up services. With cashing out, it will make the problem even bigger. This will be even harder if the person isn’t skilled.

The government is putting in a new front end, why can’t the money just go to the Commonwealth Carer Respite Centre. They provide good services but just don’t have enough money. We need more money for the services that are already in place.

I didn’t know where to go for culturally appropriate respite. The GP should tell us where to go.

Workforce

If service providers have Korean clients, they need a Korean coordinator.

My preferences are to have a worker that is bilingual and bicultural. This is not possible as there is not enough staff in aged care. I am interested in self managed care. Is this an option in aged care?

Does the PC address training culturally appropriate staff, encouraging people to take on these roles?

Thankyou to Lynn, she was a great help to me when my mother had dementia. We tried to put her in a nursing home, so we could have a bit of rest, she didn’t want to go in. We have Italians coming to give us service, now they can’t come because it costs too much. So we will get Australian’s but my mum does not speak English
There are problems in employing culturally appropriate staff. It is important to create pathways. Where I work people work with the local TAFE and they target nationalities and languages. There is interest in getting in the aged care industry, but you have to create special pathways, it’s about access and equity.

We have a lot of staff from cultural backgrounds, but it is not enough, so we have to be culturally sensitive.

I have been working in dementia for the last 10 years. The training is important; however you have to have places for the workers to work. In the CALD communities people are hiding and coping by themselves, they stay in their friend and family circles because they do not speak good English. They don’t know where to go to find services so they go back to Honk Kong or China where they can have cheaper labour. They must reach into the CALD community. Every culture and community has their own beliefs and ways of seeking help, those aspects must be recognised by the Government.

Hammond care – for us recruitment is a huge issue for community care. We struggle giving staff enough hours. We can’t give staff a guaranteed income. We need bilingual staff, especially because they take a lot of directions over the phone. We are getting more people saying I only want Arabic or Vietnamese speaking people in our home.

We have clients who say we don’t want anyone from our speaking language because their community is so small. They don’t want their business going into their community.

We have compliance and quality assurance issues. The requirements of the job can be technical and you need someone who has certain skills. When using brokerage, you need to look at the additional costs. MCCS has lot of bilingual staff, and it would be great to tap into that. You should take into account tapping into these workers at a better rate.

I have concerns about how people with dementia are treated in hospitals. The staff can’t deal with people like that. There is a lack of care and communication between relatives, nurses, and doctors.

We do need to have workers that have training. This is my concern about having cashing out services. You then have people giving respite who don’t have any knowledge. They need education and support for that sort of system to work.

Support for Carers

We need to address the issues psychologically for the carers, so then the carer can make the right decision.

I recognise the work of the carer as being exhausting and emotional. The carers need opportunity for counselling and debriefing.

If the person supplying care does not speak English, they do not have the capacity to interact with the system. The system does not cater for linguistic diversity.

Most carers cannot speak English very well, and we need a free telephone interpreter service.
Catholic Care carers meeting (dementia café) were very helpful. I needed information, and now it has stopped. I can’t get in touch, it is hopeless. When it starts and then it stops after 12 months [because the funding was not continued], it is devastating for a carer.

We are all used to physical care issues, but the emotional aspect around dementia has not been addressed by the PC. Where do you go for services at the point of a personal crisis?

I called Catholic Care; they give me two hours a week of support. It is not enough.

Among Koreans it is still confusing about how to care for people with dementia. They thought the symptoms of dementia were depression
Melbourne CALD Consultation
27 October, University of Melbourne, Hawthorn Campus
Panel: The Hon. Mark Butler, Glenn Rees, George Lekakis: Chairperson of the Victorian Multicultural Commission and Maree McCabe: CEO Alzheimer’s Australia Victoria
Chair: Marion Lau, Deputy Chair and Chair of the Aged Care Policy Committee, Ethnic Communities Council of Victoria
Number of attendees: 143
Demographics: Afghan, Turkish, Vietnamese, Chinese, Sri Lankan, Indian, Lao, Finnish, Romanian, Arabic, Greek, and Maltese.

Main themes
Primary care
• More stigma in some cultural groups can make it harder to seek a diagnosis
• Difficulty getting a diagnosis from mainstream providers
Community Care
• Need for specific supports for refugees
• Preference for community care
Residential Care
• Need for funding for help with volunteer training and transport for community groups
• Lack of consistency in cost of care
• Small providers not being successful in ACAR
• Poor quality- not even protecting basic human rights
• Accreditation System not working
Respite
• Concerns about cashing out and how people from non English speaking backgrounds would manage funds
• Lack of CALD appropriate respite
Workforce
• Concern about staff wages
• Exchange program with Holland to get student workers who are bilingual
Support for carers
• Non ongoing funding raising community expectations
CALD Specific Services
• Impact of change in regulation about cultural plans
• Need for CALD specific Community Care and RACF
• Need for bilingual staff

Consumer comments

Primary care

I would like to touch on the stigma associated with dementia. I belong to small Tamil community. If a member in our family had dementia they would not divulge. GPs should be able to identify if the person has or is likely to develop dementia. It is necessary to get the GPs to take more interest in identifying people who have dementia. Because of the social stigma these people should be treated in their homes.

My mother passed away 3rd February. Symptoms started in late 2007 when she turned to me and said “who are you”. On a Qantas flight she said “who are you and why are you sitting next to me? I am going to call the police” We touched down in Melbourne and I went straight to a GP. We found it a struggle just to get my mother diagnosed. Then she was put on a wait list. I did not know how neglected or isolated the Turkish community was until I experienced it. We need trained staff that caters to people from all backgrounds. I had to get the diagnosis done privately because I was confronted with a dead end wall.

Community Care

Afghan community aged people stay at home and they don’t go out at all. These people need to stay together and they have a lot of problems like depression because they lost everything in the war time. There is no place for them or any funding for a program to help these people. These people have special needs and need to be able to stay together to talk and get support.

The Vietnamese community prefers community care. When we assess people for aged care packages we see that the level of care needed is quite high. Children look after a mother who has dementia. They take turns. So their mother moves from one place to another so they can cope.

People are happy to look after them at home but it is quite costly. The language spoken at home must help maintain the quality of life for people at home. Is there a study to be done comparing the costs home care and the amount that you pay to the nursing homes?

We need much more funding if we want people to stay at home. We don’t want them socially isolated.

We came to Australia in 1969. I feel like we were victims of a system that did not want to acknowledge my mother at all. I have lived it for three years and I went to hell and back. In the last 6 months my mum did not know how to take her clothes off. She had no sense of hunger. I showered her. I chopped up her food and put it in her mouth. The only thing she could use was a spoon. I had a service provider who was supposed to help but they wouldn’t. Someone is going to pay for what I went through with that service provider. You don’t know even 10% of what it is like to live with someone with Alzheimer’s disease. Living in isolation and alone.

I am one of the volunteers that represents 300+ Lao members from all of Victoria. We are grateful for the funding we have received for our programs, but I would like
to see more support to resource our community in education and volunteer training and staffing to ensure continuity of awareness of issues happening in our community.

Residential care

I have had a very bad experience in a nursing home. There is a lot I have seen that makes me wonder about human rights protection. Will the Australian Government have laws to protect basic human rights of residents in nursing homes? From what I see it is just terrible.

When you go into a hostel and a nursing home- why is there such a difference between the costs of putting someone in a nursing home. It can vary so much between different places. Is this dependent on who owns the place or is it the Government? What about someone who does not own their own home. They don’t have the money for a bond. Is it true that nursing homes have to have spots for those people?

I am a past President of Aus Finnish Home. We are short of places and don’t have the funds to rebuild.

I am from Hampton Park (Turkish group). We apply for nursing home places and community care through the aged care approval process but have been rejected.

In nursing homes the accreditation requirements are good but as soon as the accreditation team leaves it changes. Unless you have a house or you have money you can’t get into a good nursing home. Why? Is it because they are private businesses? It is really important to have quality for all older Australians regardless of where they are coming from.

I am from Hampton Park Turkish Seniors. We have a wonderful crowd, including people with Alzheimer’s disease. Our problem is transport. We are willing to fundraise to raise the money because I would like to take everyone out at least once a month, but we are having a problem with getting funding to use a small bus

Respite

I don’t recommend cashing out because it will be useless for our community.

I support the gentlemen talking about cash out. I don’t think cash out is suitable for the Vietnamese community at this point in time. Maybe sometime in future, but our first generation has no language to understand the system. If you have cash out how are you going to manage it? If they need nursing care then the nurse should come around and the community can support family. That is what we really need at this point in time. Next 15-20 years their needs may change but that is what we need now.

I have been asked- why are you crying why do you have so much difficulty putting your mum in respite? My mum doesn’t speak English. There were no services available that met her needs. She didn’t fit into your equation or policies. I am sure I am not the last.

Workforce
I want to know, who sets the benchmark for the payment of carers who work in nursing homes? The people who are working in these areas should be admired, and I wonder if they are really compensated.

There is an agreement between Holland and Finland that we can use the students in their final year in the university in the appropriate colleges. We have about 12 students. They bring their language skills and culture and the clients love them. Maybe you can extend these agreements? Most of the nursing homes do not know about these agreements. We should be teaching languages at school. If we have people with language skills here in Australia then it needs to happen at school.

Support for carers

I was involved in a project this year educating carers to how to live better with a person with dementia. The project was excellent, but it raised hope in the community, then the funding finished. We need more programs like this funded for more time.

CALD specific Services

I work for Vic Arabic social services in the aged care sector. Organisation and service providers were asked for a couple of years to submit cultural plans to make sure they are meeting the cultural needs of older people. For the past 2 years, service providers were not obliged to do so. We as an ethnic organisation have found that there is a drop down of interest in main stream organisations taking up opportunities to educate or train their staff, or provide ethnic communities to information. How will the Government make sure that the needs will be addressed appropriately and how will they measure that they are addressing those needs? Will we be seeing more funding to ethnic organisations to make services more available?

The Turkish population is ageing. We are an ethnic non-profit association. What we want the PC to look at is how to find smaller ethnic agencies to provide CAP packages to help people age at home. Our project under the community partners program is to raise awareness of Turkish community of services available, how to access them, to train service providers to make them more relevant, and to have more bilingual workers. There is a lack of carers and volunteers trained. We have not been able to get funding in the aged area (our organisation). We would like PC to look at smaller groups that don't have the infrastructure established.

We need culturally specific facilities but the government does not favour this. I believe that every nursing home should be multicultural – we are a multicultural society.

The Australian Vietnamese Woman’s Association provides diverse services including aged care packages and community groups. The Vietnamese community is ageing very fast. I can see the community getting frailer and the number of people with dementia increasing. We have only one nursing home in the country. It does not cater for people with dementia. How will government help build more facilities?

I am from the Sri Lankan community. Although you say diversity is looked at, how can it realistically be practiced in the nursing home? If you go into a nursing home
or hospital, getting someone to speak your language can be very difficult. Unless you have some way to make this work the person with dementia is going to be suffering. One person speaking the language in the nursing home or hospital is the least we can do.
Responses to Q&A sheet

Special Groups: CALD Sydney

What are people living with dementia looking for in aged care reform?

- Appropriate, quick and flexible assessment and services
- No long waiting lists
- Consistent staffing
- Variety of choice – that means services available and no waiting list
- Information available for all services
- Accreditation of the services
- Have someone who cares and understands their personal needs
- More dementia specific services
- Workers trained specifically to work with dementia clients
- A better assessment to identify their needs
- More advocacy by workers for people with dementia and their carers
- Support in a crisis
- No stigma in the community
- For their condition to be understood by families and friends
- Help for people with younger onset dementia
- Not having to change services as needs increase
- Dignity
- The right to stay in their own home
- Continuity
- Have individual needs addressed
- Holistic approach (personal care, domestic assistance, respite)
- More packages
- More hours
- Services that address the loss/grieve associated with having a family member with dementia
- Security, care and safety
- To get help from home if possible
- Able to get information from home and know how to get it
- More help and company
- Love
• Better community care/support and advice on how to deal with challenging behaviours with people with dementia
• Services tailor to individuals with different ethnic backgrounds
• Diagnosis—difficulty in communicating with GPs
• Emotional costs of people with dementia and carers
• Government needs to get serious about aged care as a whole

What concerns you most in access to community and residential care services that meet your needs?
• Staff not trained
• Understaffed, not meeting client's specific needs – carer continue to be carers even when their loved ones are in the nursing homes
• Currently there is NO CHOICE – you have to take the first place available
• Lack of interpreters
• The role of the carer even after the person is placed in residential care, mostly due to staffing levels
• Languages and cultural barriers
• Need workers who speak my language and understand my culture and beliefs
• Skilled workers
• Quality of care
• Cost
• Lack of funding to address needs
• Accessing needs of Early onset dementia
• Cost, honesty and determinism
• Consistency
• The chance to meet together and share with others about concerns
• Long waiting lists
• Distance
• To provide more respite care for short time
• Ethnical group service by staffs with the same nationality
• Choice of bilingual/bicultural staffs
• High turn-over rate
• Funding for training of staffs

Do you have particular concerns around access to information and assessment for access to care services?
• Phone numbers do not work – issues must be addressed face to face so that emotional issues can be addressed
• There should be a DVD of all services in the area that the client can take home and view
• Access to information
• Access to more community based services and to decrease wait lists (12 months for EACH packages, 2 years for agencies in western Sydney such as BCS, Southern Cross etc.)
• There needs to be one access point into the system so there is less confusion about where to look for help.
• Language and cultural aspects – mainstream services use interpreters to help but it is not effective, people are reluctant to ask for help because it is too much trouble.
• We are unable to access a lot of services in our community.
• More information for multilingual communities
• A list of services needs to be sent to all GPs and medical centres.
• CALD communities need education about dementia
• Culturally appropriate counselling
• Long waiting lists
• Why have central points? There are no resources to provide services through service providers
• Translators and interpreters
• The system is difficult to navigate
• Diagnosis—bilingual/bicultural
• Always struggling with funding
• Vacancies available?
• Confusion about where the patients can bet the assessment team
• More multicultur sel carers
• Information that is available in different key languages and needs to be clear and easy to follow
• Staffs who understand the system of age care
• Sustainability
• Too many papers and information is not available in other key languages.
• Outreach to people with dementia and carers who are isolated and/or have troubles with the languages.

What kinds of services do you need most? (E.g. home care, respite care, residential care, services for those with severe behavioural issues)
- In home respite and day centre respite
- Respite care that is individually tailored
- Personal care
- Help with behavioural problems
- Transport
- All of the above when needed
- Support for carers with kids (child care services?)
- Lower worker to client ratio
- Staffs and services need to be person centred rather than just “baby-sitting”

What types of support and services do you need to assist you in your role as a carer?

- Support - Many are elderly and have difficulty coping
- Counselling and debriefing
- Respite - appropriate allocation, more hours available, good quality.
- Flexibility
- Help to understand the role
- Good quality support from service providers
- Financial help
- Information on where to find help for all types for difficulties
- Education
- Regular training
- Contact with other carers – carer support groups such as memory lane cafés
- Someone who will listen
- One stop shop for information
- Longer hours of services
- CBDC—often not used/not preference for many clients/inappropriate (I don’t understand what it means so I just type it down)

Are there health issues that need to be addressed in the reforms?

- Dementia
- Counselling for carers – if not addressed carers cannot address their emotional issues, this leads to depression and other medical issues
- Mental health issues affecting people with dementia
- Funding for younger onset of Alzheimer’s
- Respite for younger onset dementia
- Carer stress
- Care for carers
- Safe workplace in aged care facilities
- Co-morbidities and management of medication and cost

Are there any other concerns you have about dementia care or the aged care system?
- The high costs of diagnosing dementia. Could the government subsidise this?
- CALD services for dementia need to be placed in high priority
- If “cashing out” is introduced will training be provided to the paid carers?
- Financial support
- Address Younger Onset Dementia
- Social activities like at the dementia specific Orange Blossom Cottage at the Hills Shire District

> Orange Blossom Cottage provides social support and friendship to clients through mentally stimulating recreation and social interaction

- More education to CALD community (clients/carers/workers) through ethnic newspaper/TV, ethnic radio etc.
- Lack of communication between hospital staffs and patients and carers. There needs to be more education for hospital staffs in dealing with people with dementia.
- Bigger budget for research to help to prevent early onset dementia.
- Issues around access to the system and the quality of aged care, maybe there should be better training and pay for aged care workers so that quality of care maybe improved
- Stigma with dementia, there are people with dementia refuse to find help because of the stigma associated with dementia
- More social activities
- Financial issues
- More energy and attention should be spent on prevention rather than dealing with issues when it is at the crisis point
- More facilities

**Special Groups: CALD Melbourne**

What are people living with dementia looking for in aged care reform?
- Compassionate, skilled staff to deliver a suite of services that are both consumer directed and block funded
- People with dementia in the Romanian community are isolated and neglected, this is due to us being a smaller community and not having enough services to provide to our community
• Educational support for Turkish speaking community (awareness and understanding)
• Community service and support for senior citizens (especially ethnic groups)
• Increased activities and support/resources for senior citizens e.g. home care and aged care for Turkish people
• Training programmes
• Care places for all nationalities (one for Sri-Lankan)
• Quality home care
• More written materials (lack of Turkish resources)
• Information sessions about the disease in their first language, instead of interpreters
• Responsive services
• Support for carers
• Research into a cure or means to modify the impact of the disease
• Appropriate services that can be addressed in the community, rather than residential
• Staff who are considerate and caring of their needs
• Better and quicker access to assessment
• Staffs need to be better compensated to keep the sector alive and recruit people into it
• The needs of training and educated workers who speak the language of the patient (Arabic) and not interpreting only
• Culturally specific services

What concerns you most in access to community and residential care services that meet your needs?

• Poorly skilled work force that needs to be paid in accordance to their duties performed
• The Romanian community needs a lot more attention from the Government.
• Need to make the Romanian community more aware about the services available for them
• Well trained Turkish speaking aged care and home services
• Transport services and carer community activity (increased social community activity)
• Promotion of activities in the Turkish community
• Services more culturally relevant, for example food, staff who can communicate in the appropriate language, interpreter services – these are not issues considered at all at the moment
• Care places for older Sri-Lankans, with family around, familiar landscape and surroundings
• Most residential care places are not culturally appropriate
• Turkish people only have one ageing nursing home – Ottoman nursing home. We applied for one in the South Eastside but it has been rejected.

• Different councils have different policies

• Lack of CALD responses to dementia

• Lack of access to support services that anglo-Australians have come to expect

• There is no national strategy on care for the CALD aged

• Interpreter service is not used friendly

• Wait lists for CACPS, EACH and EACHD, there are not enough packages to meet demands

• Huge gap for social support funded through federal government money

• Costs of residential homes are far too expensive

• Not everyone has a carer so they miss out on social services as they are not eligible for NRCP funding

• There are no elderly residential services for Arabic ethnic groups. We need funding and support for Arabic groups to help us maintain this service.

• It is hard to decide what care facility to go to in a short amount of time

Do you have particular concerns around access to information and assessment for access to care services?

• GPs are critical in the patient’s journey. Additional funds need to be directed to up skilling GPs

• Not enough information available for the Romanian community

• Nursing homes don’t provide Romanian speaking staff

• Staff are stressed due to language barriers

• Promote seminars and training for volunteers

• Training volunteers and service providers in different languages

• Yes, there should be better updated information for people needing aged care services e.g. home care services, information and residential care services and information

• Current systems don’t work well at the moment – there is lots of missed information and communication

• Not using interpreters or interpreter services

• Not enough Turkish interpreters

• Information needs to be in more community languages. There needs to be language dedicated phone numbers such as those used by Centrelink.

• Yes, there is a huge lack of funding from the government to assist in assessment and better care coordination for CALD people from hospitals as a main provider back through the community
• Better coordination between GPs, hospitals and community is needed
• People who don’t have a carer can’t access NRCP services
• Many elderly people don’t have access to information in their Arabic language
• Bring in students in their final year of studies in health areas from specific countries. An agreement is in place with Finland and Holland.

What kinds of services do you need most? (E.g. home care, respite care, residential care, services for those with severe behavioural issues)
• Funds need to be directed to keeping people at home with additional care and support 4-6 hours per day
• Romanians like to grow old in their homes, so home care is most needed
• Asian community prefers in home care
• Home care, appropriate with quality and relevance
• A carer in their first language
• Culturally sensitive services
• Immediate services when people need them
• Consideration for people’s religions
• Greater variations of respite care e.g. homes for Greek people
• All! Home care, respite care with more social activities, and more affordable access to residential care
• More seamless entry between HACC and Federal services
• Better culturally specific residential services
• Residential care services for people who speak Arabic

What types of support and services do you need to assist you in your role as a carer?
• Funding for staff training
• Counselling services to avoid burnout
• Training programme and seminars for support
• Financial support
• Support from the government to employ quality carers at home (culturally and linguistically relevant)
• Look into what the Turkish community need
• Respite in the home with bilingual trained carers
• A GP to come to the home
• More respite for family carers
• Access to information and support through a helpline
• Services to keep carers healthy
• More flexible services that fit within a carer’s life and work
• More funding should be put into social support and carer holidays
• Carers shouldn’t be punished for working more hours
• Funding for carer respite
• Social support for client and carer
• Support services so we don’t have to care 24/7

Are there health issues that need to be addressed in the reforms?
• Mental health issues of the carers
• Preventing dementia and Alzheimer’s
• Early diagnosis
• Turkish community is one of the fastest ageing populations
• The government needs to look at each ethnic group instead of the population
• Chronic disease – more preventative health measures
• More information on the prevalence and cost of dementia
• Chronic health conditions and people with complex care needs as these people don’t fit easily into services for the aged
• Aged services should work better with other services
• Hospitals need to be better funded for interpreters to be more culturally appropriate

Are there any other concerns you have about dementia care or the aged care system?
• That this consultation doesn’t result in ‘real change’
• Services need to be flexible and sufficient in terms of hours of care
• Remuneration to satisfy good quality dementia carers
• A care place for the Sri-Lankan community
• The aged care system is very complex at the moment, there are many different agencies doing the same thing
• I am concerned about the nursing homes. Most of them are not suitable for dementia patients. I am concerned about dementia residents sharing a bathroom.
• For the government to look more closely into the Arabic community, and provide quality nursing homes, as we are ageing
• Don’t put all dementia clients together, mix them in with low care clients
• The overall planning of CALD care is woeful
• No national strategy on the care of the CALD aged
• No minimum data sets maintained by Alzheimer’s Australia or carer groups
• CALD care unduly reliant on small grants through CPP and dementia grants
• Cashing out or vouchers does not fit for people who are complex, don't have carers or who have cognitive issues
• There needs to be good links between CALD agencies and mainstream services
• Senior citizen groups should be better supported to provide support to members who are ageing or have dementia rather than kicking them out.
• Police and communities should be more aware of ageing and dementia
• Experienced trained workers for dementia are in high need for all multicultural groups, especially Arabic ethnic group.
• Why not use innovative ideas from overseas by working with companies in other countries? We use Finish technology companies by trialling their equipment.
Responses to Online Survey

CALD responses from Survey Monkey:

What are people living with dementia looking for in aged care reform?

- Person-centred care - staff who are TRAINED in dementia care, better staff ratios in High Care, in facilities with a concentration of people from a specific cultural background, some staff who also speak that language.

- More of a group home setting than a larger institution, so that there will be more one-one care. More places for people with dementia. More Readily available support for families, esp. those whose cultures are used to having their dementia affected family member at home.

- Truth in advertising. Glossy brochures with information on services available often fail to state that there can be long waiting lists - consequently this means that these services are NOT available when needed.

- Reforms that will enable them to live as long as possible in their own homes or with family carer if possible. Increased respite care for the Carer.

- Being treated with dignity

- People want to stay in their own homes or to live in home like environments. Investment needs to be made in these areas. Also early diagnosis and link to services

- Community education for people from non-English speaking backgrounds. Culturally responsive support services.

What concerns you most in access to community and residential care services that meet your needs?

- Lack of commitment of some staff + those who are simply "skimming the surface" in their work instead of being committed to the residents. The control & power play of those in senior management/administration roles, who at times feel threatened when "challenged" with any queries and who will also make it difficult for dedicated and committed staff to stay in a particular workplace.

- There is not enough government funding and placements for people with dementia. No proper training and encouragement for those that work with dementia persons. No or little after service care, and too much red tape in getting dementia people into places. More priority should be given to those who suffer more rather than the onset of dementia.

- Long waiting lists.

- Depending on where one lives, I find living in a city one has better access to care services than in a regional or rural area, where there is a lack of services.

- Knowing what services are available and actually using them without feeling you are not living up to your responsibilities.

- Services that are people focused. People need choice, but not to be overwhelmed with having to administer their care.
• Lack of culturally relevant activities and services. Lack of use of interpreters. Social isolation caused by lack of contact with people who speak the same language. Ethnic aged care volunteer services such as ethno-specific Friendly Visiting Programs not received well in residential care facilities

Do you have particular concerns around access to information and assessment for access to care services?

• I continually need to resource the information myself & become informed in order to feel sufficiently equipped for any new transitions.

• Yes - there seems to be too many chiefs syndromes, and too many different/conflicting answers from far too many people who are supposed to be in charge.

• We need ONE information station via which we can access all other available services. First good point of reference is the Carers Association; this needs to be regularly advertised (local papers e.g.). Try to avoid 'overlapping' of services occurs - this is confusing.

• People now are shoved from one service provider to another to access care services. Service users who are not happy with service are reluctant to complain as they fear that they will lose the service which they currently have.

• No the info is there. Knowing where to look is probably the big problem.

• I have high concerns about ACAT assessment waiting periods. They are basically the gate keepers to packaged care and residential care. The fact that in hospital assessments have stopped takes away the option for someone to be cared for in their home while still being supported by appropriate services, the option then narrows down to residential admission or no support in the home. Also, there seems to be great deals in assessments by ACAT.

• Misdiagnosis at assessment due to insufficient use of culturally competent dementia assessment tools such as RUDAs especially by GPs creating lack of trust in the aged care and dementia support system by CALD background people living with dementia

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

• Previously Respite Care Residential Care Services

• Respite Care, especially from those people with dementia who are still at home. Also, after hours and more overnight/week-end care.

• Services needed are many and vary according to health of person with dementia, what stage of dementia has been reached, health of the carer (most often that is steadily decreasing).

• In the beginning home care is useful for the carer, but when dementia is well advanced it would be getting be residential care and respite care so the carer is not so stressed out.

• Home care is good at early stages. Respite care is absolutely essential, but I didn't take it enough because my mother (the dementia patient) didn't like it.
• There is a great need for flexible respite. Services that suit clients and carers, not just providers.

• same-language, same-culture social support and respite, culturally relevant activities in residential care great understanding by staff of traumatic pre-migration experiences leading to behaviours of concern when dementia sets in.

What types of support and services do you need to assist you in your role as a carer?

• More communication and for this to be undertaken with honesty. Activities for residents (as per compliance) to suit their stage of dementia.

• A better balance of those dementia people with other forms of disability and ageing. More support from all the government bodies - not just each fobbing off excuses and blaming the others.

• In-home help - to give carer some 'time-out'. Carer needs time to attend seminars, or information sessions to assist with giving care 24/7. Sometimes carer needs transport to be able to attend educational sessions. Carer needs to attend to their own medical appointments. Assistance is needed with home cleaning and gardening. Overnight assistance may be needed when person with dementia reaches end-of-life stage; help with home-nursing can become a necessity.

• House cleaning and maintenance, minor modifications to the family home to make it more wheelchair friendly, social support, transport, counselling services.

• Same-language, same-culture social support and respite. Translated information about aged care and dementia support.

Are there health issues that need to be addressed in the reforms? (E.g. timely diagnosis, care in hospitals, dementia risk reduction and dementia research)

• Education of GP's and Division 1 staff that are usually "not on the floor" and involved in direct care of residents. Dementia Research.

• Yes, all of the aforementioned.

• Yes. All of those mentioned.

• Early diagnosis, dementia awareness and education, preventative education with community groups and families.

• I think, just from watching Mum deteriorate, that I do not want to go through that. So I am all for dementia risk reduction and education on what to do to minimise the risk as far as possible. To do this more research is definitely needed.

• Training and education for hospital staff. The treatment of the elderly by both medical and nursing staff can at times be appalling.

• Better and more widespread use of RUDAS and culturally competent assessment tools e.g. RUDAS. Better use of interpreters in hospitals. Culturally relevant community education for CALD communities for dementia risk reduction. More CALD inclusive dementia research.
APPENDIX C – GLBTI CONSULTATIONS

Minutes from consultation

Alice Springs GLBTI Consultation
Wednesday 2 November, Kunghas Can Cook, Larapinta Drive, Alice Springs
Chair: Judy Buckley

Main Themes
Community Care
- People hiding sexual identity from carers
Residential care
- Desire for more choice and innovative care models
- Need for privacy
- Staff and residents responding negatively to cross dressing
- Concern about response to GLBTI in catholic facilities

Workforce
- Need for better training and wages
- Staff can assist GLBTI people by connecting them to their community

End of life care
- Unique legal issues in NT
- For GLBTI people families sometimes ignore wishes

GLBTI Community
- Desire to be cared for by other members of community
- Family having a different meaning for GLBTI people
- Importance of respect
- Generational Differences

Discrimination
- People move away from communities after coming out
- Double discrimination based on age and sexuality
- People losing contact with family members
- Person with dementia being open about sexuality which had been kept quiet
- Staff refusing to provide care based on sexuality

Sexuality
- Behaviours related to sexuality and dementia
• Lack of recognition of sexuality in aged care regardless of sexual identity

HIV
• Discrimination/lack of understanding
• Higher probability of getting dementia

Intellectual disabilities
• Need for an integrated system

Comments

Community care

*When some people receive home care they sanitise their homes, hide magazines and take pictures down so they are not found out. They are frightened. There would be stress; what happens if I forget to do that one day?*

*Awareness building is there. I am concerned about the engagement generating and continuing to generate with service providers and policy makers.*

*I was a support worker for people for year. I met a couple who said they were sisters, but I knew straight away there was a relationship there. About 6 months later she told me and I said “yeah I know”.*

*Freeing up modes of service, so people can be more innovative, people will be able to get the care they require, not the care that is part of their package. That is a pretty important thing.*

Residential care

*I have seen an improvement from institutionalisation; now we have diversional therapy. We have changed our attitudes; some people don’t want to shower every day. The rights of people have improved.*

*The GLBTI retirement village being set up…little units that people can buy into. It’s a fantastic concept. Having survived the whole HIV issue, I started thinking, what happens to older gay men and lesbians? There are lots of people who won’t be in the position to self-fund their accommodation.*

*Sitting at a table at a residential facility and someone is in drag, and then the wig gets knocked off, everyone screams, how demeaning.*

*There are instances with people being forced to dress in clothes that match the sexuality that they look like, rather than what they choose to be. Refusal is seen as misbehaviour.*

*Carers need to knock on the door before they go in, it’s their home, and they need their privacy.*

*Catholics are still so anti-gay and lesbian; it would be very difficult for them to go into a Catholic home.*

*I was nursing a dying HIV patient, the man had just died, and his partner was there with him. Another nurse came into the room and said “I want this body out, we need the bed”. I said just because they are a gay couple it does not give you the*
right to change the code of conduct of nursing where the family members can stay for as long as they like.

Two men have been together for 40 years but the partner feels he cannot show any affection in the residential facility.

Workforce

Need to assess the assessors. Training is very old fashioned.

Staff will do other things; they can work at McDonalds for more than $17 an hour.

Aged care is not an easy job. It is physically demanding. It’s almost degrading some of the lifting techniques we use. Putting people in slings, everything is exposed for females. There is a lack of nurses, so we have had to bring in carers.

Lack of training is a big issue.

Need to educate and train workers to look after these people. You may need the specialised care, just like indigenous people. It’s all about education and saying lets have the whole spectrum of people being carers.

Carers may not have enough education to be able to care for you in an appropriate way.

Having carers identify as GLBTI, there are very few.

If the carer does not know then they can’t hook the person into their community.

Half the carers are not qualified in any way.

End of life care

There are legal issue for us in the NT because you can’t be an adult guardian before a person is incompetent. We need a way in advanced care planning to say this is the carer I will want. This could be a bigger issue to the GLBTI people, as families will try to step in after they have had nothing to do with the person.

I recently went to hospital and I was asked ‘do you have an advanced care directive’ and then I was asked ‘where is it’? This is one area that the NT government needs to consider.

GLBTI community

We don’t know how many people are living here and intend to stay in the NT as they get older. How many people are we talking about who will need the aged care system, community or residential care? We don’t know. I think this is really important.

We need to give people the opportunity to be cared for by members of the community.

The term family to GLBTI has another meaning; it is not just about the blood connections.

It takes a whole village to raise a child; it takes a whole village to look after the other end of the spectrum as well.

I think it is just a fact that you have to have cross generational communication, within the gay and lesbian community, if you are going to have caring.
We want the same respect.

There are videos on YouTube, and research papers, where people are looking at the issues and recognise that there are different issues for GLBTI people who are ageing. Particularly people who are in the 70 or 80 aged group. They have grown up and come through a very different social environment than there is now. I think this is a problem as younger people growing up now don’t understand the issues and concerns of their elders, such as concerns about ‘coming out’.

In the GLBTI community we do not talk about ageing enough.

Getting messages of safe sex into Aboriginal and Torres Strait Islander communities is difficult as it’s not really totally recognised or culturally appropriate to be gay or lesbian.

Discrimination

Behaviour is tolerated but orientation is not, it would be difficult to stand up and say I am a gay aboriginal man. They move away from their community so they don’t feel the shame.

Ageism is the issue. You have to come out as an older person.

When a man and his partner first moved to town they had to pretend they were step brothers. When the gay scene emerged in Alice Springs, he was blown away. He burst into tears as there were other people there that felt like him.

Males married because they were expected to. I knew a gay man who didn’t come out. Then, when his wife found out, he was cut off from his children and he was an incredibly lonely man when he was ill.

I have a friend who does not identify with the Gay community, he is a cross dresser. He is elderly; his family has become estranged from him. I worry how he will cope when he ends up in aged care. Helping people like this will be a huge side issue.

I met two young aboriginal girls who called themselves sister girls.

There is a personality change with dementia, they are not the person they were before, so you and your partner may have kept things quiet, and all of a sudden your partner has Alzheimer’s and will yell out “that’s my boyfriend!”

A carer bathed a woman, and when she found out she was a lesbian she left, it was discrimination. She was suddenly left without a carer.

Partners who have been together forever get separated as families refuse to understand.

Loss of identity for GLBTI is more important than the general community. A lot of people take so long to accept themselves, by the time they start losing control of their life, it is even more intense. Someone who is GLBTI with Alzheimer’s is going to experience a whole other level of issues.

Sexuality

Some behavioural issues can relate to sexuality.
You can’t control your sexuality and feelings when you have Alzheimer’s. Carers need education and training to say this may happen and this is how you deal with it.

Sexuality doesn’t exist in old people’s homes.

Heterosexual facilities – males and females can’t mix.

There are huge challenges around gender and sexuality issues, in the home or in a residential setting.

HIV

There is a lot of discrimination and myths and false feelings that shouldn’t be there when nursing GLBTI with serious illnesses, such as HIV.

Dementia for people with HIV. People on antivirals are more likely to get dementia. That will be their next wave as people with HIV are living longer.

A lot of people think that they don’t want to go near someone with HIV as they might catch it.

Intellectual disability

The transition between aged care and disability can be stressful as the two don’t mix; it comes down to education of the carers.

Since my cousin was 18 she has been in an aged care facility. She has never had a boyfriend, a job or travelled. She was diagnosed as being intellectually disabled. Her whole life was stolen from her. That is what happens to young people when they are put into these sorts of facilities.
Responses from Q&A sheet

What are people living with dementia looking for in aged care reform?

- Continuity of care
- Safety – no restraint as ‘behaviour support tool’
- Carer support – adequate, responsive, adaptive, flexible
- Maintain community living, rather than placement

What concerns you most in access to community and residential care services that meet your needs?

- That community support cannot be increased to maintain a person at home, the only option is placement in residential care
- Too many agencies involved
- Partners often have to separate after years together one enters residential care
- The trend towards large institutional care – 150 beds plus does not equal a home like environment or the capacity to provide support that meets individual needs

Do you have particular concerns around access to information and assessment for access to care services?

- Access is often too slow
- Information overload
- Unable to find the relevant information, it is overwhelming
- Services can be discriminating based on age (under 65), culture (GLBTI etc.)
- If you can pay, you get access quicker
- Need to remove heterosexual subtext to information, access, entry (e.g. wife/husband unless the law changes)
- Would like to see a senior’s gateway website identify aged care service providers who are trained in LGBTI sensitivity

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

- Continuity and consistency
- Care more than three times a week
- Respite support
- Prompt access to assessment
- Education and training to increase sensitivity and awareness of staff and residents of facilities to the entitlements of GLBTI people (both home and residential care)
- More variety in both community and residential care e.g. 6 bed homes, GLBTI specific, culturally sensitive, more integration with the community
• Environmentally sustainable, low maintenance buildings
• Home care should allow for couples to stay together if they wish, after a lifetime together

What types of support and services do you need to assist you in your role as a carer?
• Rapid respite is and when it is needed (not just planned)
• In-home respite for breaks
• Flexibility and choice
• Access to equipment quickly

Are there health issues that need to be addressed in the reforms?

Are there any other concerns you have about dementia care or the aged care system?
• GLBTI community – there is prejudice, discrimination, bias and no understanding
• Culturally appropriate services needed
• Fear of discrimination based on sexual orientation or gender identity

**Response to Online Survey**

What are people living with dementia looking for in aged care reform?
• More support in the home financially, extra access to professional carers and resources, less paperwork.
• Security, empathy and socialisation.
• Person centred care; more funding so that staff can be educated and have time not just for tasks but for social engagement, activity etc. People with dementia, in my view, would prefer to stay at home for longer but this causes significant burden for carers. Aged Care services must provide more in home support and respite. This is particularly important for the younger-onset group.
• Ongoing care and support in a safe environment and by people who understand what dementia care is about and what is necessary for the best outcomes for the person with dementia.
• Safety, dignity and dependability. To have around them whom they have chosen.
• Culturally appropriate care for GLBTI older people
• More training in the area of diversity whether that be GLBTI or for persons with younger onset dementia, cultural sensitivity training. Overall client need specificity training.

What concerns you most in access to community and residential care services that meet your needs?
• Not enough support packages available for each community. Not enough home support available unless you are financially able to personally pay for extra services. Overworked care staff due to shortage of trained aged care workers whose wages are a pittance for the work and responsibility they undertake. MORE TRAINED AGED
CARE WORKERS ARE DESPERATELY NEEDED as most of the staff I have encountered are women of an age close to retirement age and they don't see too many younger people coming up behind them to fill positions they will leave in the not too distant future. Residential services seem to have the same problem of staff shortages and lower wages than other nurses not doing aged care. Not enough funding for activities especially in high care. Not enough if any support for relatives who are transitioning putting their loved ones into permanent care. Not enough consultation with family of care recipients as to how a facility is or could be designed or working from their perspective. The cost of residential care for someone who has financially provided for themselves and their partner/family is so high that someone who has younger onset dementia requires a large financial commitment leaving the surviving partner/family to struggle financially.

- Skill of the staff, range of activities available and stimuli, access to family and friends.
- ACAT is very difficult to access before the time of crisis. There must be a better way to streamline that service so that support is available when needed.
- Lack of training of people involved in care who have no understanding of the needs of gay, lesbian, transgender, HIV people, who are possibly homophobic, who will behave in ways inappropriate to the care of people with somewhat different needs from people who are considered heterosexual as the norm.
- That those services will recognise me for who I am and allow me to express myself openly. That they will support me in loving myself and those whom I choose to love. That they will support all my friends who care for me, making their life easier as is needed. Services need to be responsive to local conditions but the idea that "local" follows State boundaries is ludicrous. Local may be geographically or culturally defined. As a gay man I need services that understand me being gay and with whom I can feel safe and with whom I can have some chance of understanding their reactions to me. If we cannot express our deepest feelings openly, honestly, without shame or fear, in our old age, then we are a failed society and there is no care, just service.
- That the industry will be homophobic and not understanding of my needs as an older gay man.
- The scarcity of appropriate services in rural and non city areas. In particular non institutional care and staff training to particular well being issues to clients.

Do you have particular concerns around access to information and assessment for access to care services?

- I have found that some carers in my support group have not been aware of some services that are available. I have found that due to the privacy act, concerns for my partner's health were not being acknowledged or were unable to be discussed by health professionals, thus making a diagnosis a very delayed process. This is a very common situation for family carers. Once my partner entered the system I would have thought that medical professionals and care facilities would be consulting with each other but this is not so. I would support a central computer file which could be accessed with appropriate permission for medical reasons. The amount of paperwork that carers have to deal with is complicated, stressful and emotionally draining.
Yes - is it a formalised referral process?

There are a number of excellent services, but so many different numbers! Services such as Dementia Link Workers are very helpful for pulling all of this information together. Perhaps a ‘one number’ system might be useful.

My concerns are about the lack of training of people doing care in environments which are difficult enough without having dementia as an added component, and with having no idea of how to handle groups of people in categories about which they know nothing and in many cases, haven’t even heard of.

The aged care system is complex and in some ways mysterious. None of us take easily to talking about and planning for things that may be required as we age. The issue is bigger than aged care and services; it is about on-going conversations, public conversations and private conversations. There need to be positive role models and champions making ageing and caring more about people and normality than it is about health and care. Accessing information needs to be in a culturally safe environment where the risks of self-exposure are less than the immediate benefits. For gay people, dealing with others who are gay may not always be the answer but it is a great start.

No.

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

All of the above are essential.

Behavioural.

Respite is very important, and support for behavioural issues are needed for family and professional carers.

At the moment I don’t need any services, but my partner is 89 and I am 85 and we live in our own home without as yet needing care of any sort. This may change suddenly and dramatically if one of us becomes ill and we need home care or other types of care.

I don’t know the answer to that, but people should not be left alone to deal with it, whether they are the person with the behaviour, their carer or their service provider.

Home Care.

What types of support and services do you need to assist you in your role as a carer?

More home care. Financial advice and awareness of future cost for residential care. More information on what to expect as the illness progresses and how that progression will impact on the carer/family/friends. Suitable respite facilities and more of them made available for people with dementia.

Strategies and skills of managing difficult and challenging behaviours.

Education! We need time to learn about the needs of people with dementia.

As we care for each other without external assistance at this stage, we do not know what support and services we will need, but we would like to feel that our local council had a register system of ageing people in the community who may require home care.
and who should actually be monitored on a regular basis. As far as we know, no Victorian council has such a data base, and this is a disgrace in a country which has an ageing population.

- Recognition that I am not the only carer and that carers like me also need support. I don't want to be a burden to them.

- Sensitive support.

Are there health issues that need to be addressed in the reforms? (E.g. timely diagnosis, care in hospitals, dementia risk reduction and dementia research)

- Timely diagnoses essential. GP education about dementia, our GPs have been fantastic but admit to not knowing a lot about dementia. DEMENTIA RESEARCH ABSOLUTELY, the government needs to know this is not going away. Facilities to be designed for residents living with dementia not dying with dementia and not solely for economic reasons. Care in hospitals needs to be specialized for people with dementia to make their stay less traumatic for them, their family, hospital staff and other patients.

- Risk reduction.

- Dementia risk reduction, I believe, is a hugely important area.

- Health issues that need to be addressed in the reforms are those based on education, training and support from doctors, hospitals and local government, including mental health monitoring for dementia risk and dementia research. So far all this enquiry is doing is putting dollar values on health care for the ageing community without regard to the personal issues of each individual and/or family.

- I guess all of these but there must seriously be more research into the affects of positive experiences on people with dementia and on the ways in which this can be used to the benefit of those with dementia and for their carers, whether they are non-professionals or professionals.

- Timely diagnosis definitely but probably equally as important is the need for a higher profile in regards to aged care in general, as well as, in particular the diversity with respect to needs of the aged population and those people who may be afflicted with issues generally associated with the aged but who may not be physically or mentally aged.
MEETING WITH ALZHEIMER’S ASSOCIATION, 3RD NOVEMBER 2011

Alzheimer’s Association WA Inc., 9 Bedbrook Place, Shenton Park WA 6008

Thank you for the opportunity to discuss the needs of and issues faced by GLBTI people relevant to the services of the Alzheimer’s Association.

By way of a loose agenda, we would like to discuss the ways the Alzheimer’s Association can:

- be inclusive of GLBTI clients, clients’ relatives and friends; and AA staff
- be aware of and actively protect clients against homophobia/transphobia and intersexophobia
- be understanding of possible client confusion if a transgender/transsexual client loses memory of their transition
- be prepared for HIV+ve clients with early onset dementia
- engage in training (staff and management) for all of the above

Also, we would be interested to explore ways we might work together, perhaps to assist in:

- making/maintaining community connections for GLBTI seniors
- helping AA establish LGBTI carer support groups?

We congratulate the Alzheimer’s Association for being pro-active on the issue of GLBTI people. We also commend Alzheimer’s Australia for their excellent paper by Heather Birch, ‘Dementia, Lesbians and Gay Men’ (Paper 15, October 2008), which provides a comprehensive discussion on the issues.

GRAI welcomes any suggestions of ways we can work together with the Alzheimer’s Association in the future. If we can be of assistance, please contact me at j.comfort@curtin.edu.au or 0422 654 244.

Yours sincerely

Jude Comfort

Chair, GRAI.

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1 There are a number of issues around disclosure: GLBTI clients may avoid disclosure in an uncertain environment; inadvertent disclosure may be problematic for family and partner; on the other hand, non-disclosure may result in loss of intimacy and partner rights.

2 Alzheimer’s Australia are to be commended for their work in this area and their excellent Help Sheet, AIDS Related Dementia. [http://www.fightdementia.org.au/understanding-dementia/aids-related-dementia.aspx](http://www.fightdementia.org.au/understanding-dementia/aids-related-dementia.aspx)
APPENDIX D – ABORIGINAL AND TORRES STRAIT ISLANDER CONSULTATION

Minutes from the consultation

Alice Springs Aboriginal and Torres Strait Islander Consultation
Tuesday 1 November, Kunghas Can Cook, Larapinta Drive, Alice Springs
Chair: Judy Buckley

Main Themes
Community awareness
- Education for people early in the disease
- Community awareness is important because of prevalence of stigma
- Education in Aboriginal and Torres Strait Islander and Remote context is different
- Former carers should be involved in providing support and education

Information and access
- Lack of services for remote areas
- Services provided by shires which results in less community control
- Need for better coordination
- Lack of consistent aged care services in remote areas
- Need for mobile medical centres

Residential care
- Importance of Choice
- Safety rules and regulation make service providers unable to provide choice
- Lack of Staff

Respite
- Like idea of being able to pay family but there is a need for protections
- Case manager model might work well

Workforce
- Staff levels, training and pay
- Need staff experienced in working in the bush
- Need for a career path
- Need for more Aboriginal and Torres Strait Islander workers

Younger Onset Dementia
• Younger onset dementia prevalent in Aboriginal and Torres Strait Islander communities
• Age barriers should be removed from the aged care system
• Aboriginal and Torres Strait Islander Importance of country
• Community spirit
• Different understanding of dementia
• Reverting to first language

Consumer comments:
Community awareness

We need more education. My sister is in the first stage of Alzheimer’s, she is in so much denial it is not funny. She argues with people about who they are. It is really important that there be more education and proper support. Not to feel embarrassed or that it is an unmentionable disease.

Families say ‘she doesn’t know me anymore; I don’t want to talk to her’. It needs to be demystified.

It’s basic education. We need to go to the community and let them know that you’re not going mad if you have dementia.

We have identified that community education is important, but to do it well in a remote and indigenous context, requires a lot more effort. Special skills and more money needed.

I am 70 now. My first introduction to dementia was when I was 8 and my grandmother became ill. She had 10 children but no one visited her, because they wanted to remember her how she was. It was never talked about; it was as though she vanished.

Education is such an important issue, mainly because I see that the values of the Aboriginal community are changing. In the past Aboriginal cultures would try and retain the elder for culture and language. But now their values are changing, they see the elderly as a burden in an ever increasing way. I can’t see why these issues are not in the curriculum. The children will then start to value the older people in their community. And see them as a resource. These type of concepts need to be embedded in curriculum – primary and high school.

We are looking after an old sick dog. We are thinking what will we do palliative care wise and that it’s good that owners don’t have to see this. It’s a bit like when you put people in a nursing home. There is lacking a capacity among white fallas, it is hard to see people get sick. There is an element of wanting to put people away so we don’t have to deal with them. Indigenous people have a better capacity than some of us to deal with it. It needs to be out there and demystified. I think people have the capacity to deal with it but we need to give them social support.

There is not enough on media, we don’t see enough advertising. Spend the money and put us out there in the media, not just the research and the one ad we see a year of AA.
Take the children out to the old peoples homes, rather than the basketball court. Just because your parent dies, it doesn’t mean that 18 months down the track you don’t want to talk about it. It could be useful for people who are walking that path to be educated by people who have already walked that path. These people are educated to help other people.

Information and access

For indigenous people in remote communities, if they need particular levels of care, they have to come to Alice Springs. I wonder about their issues, and how it fits with wanting to be with families.

Most aged care services out bush are provided by the shires. This means people have less control in their communities about aged care services.

The shires have control. As long as the shires are working with the community in a way that the community is in control.

Once someone is in a nursing home, no one is allowed to support them anymore; the funding from Alzheimer’s is not allowed to support them.

If our community had resources to look after aged people, we might be able to get coordination around service providers and people in the community who want to help out.

Why can’t we have mobile medical centres, like the mobile dialysis unit?

If the facilities were in town, there would be more social interaction for people concerned. It wouldn’t be hard to get a school to visit etc.

Dementia service coordination needs a lot of attention.

The aged care services out bush go up and down, they can be dysfunctional and people leave. We need to support the aged care services to ensure they can run.

Residential care

We have to treat people as people. Cut out expectation and regulations that prevent us from supporting people.

We have to back off on safety stuff. We had a patient that prefers to eat outside. And staff said no he can’t, in case flies get in his food. Crazy OHS rules.

Staff have to follow a photograph of how to set a meal out. But my mum would only eat with a tea spoon.

Aged care is a regimented institution. Everyone has to be showered by 6, dinner and 7. But someone might want their shower only every 2 days.

Due to the lack of staff, it’s easy to sweep people with dementia under the mat and forget about them.

There was a great place in England, the people could eat when they want, there were falls but there was nice padded carpet. It was energy draining for the staff, as they had to run after people who didn’t want to wear their continence pads; they need to be paid well.
If people have a happy experience, it stays with them. They may forget why they are happy, but they are still happy. When people have choices, they cost less to manage. You shouldn’t fight with someone who doesn’t want to wear the continence pad.

Respite

I would love to be able to pay family for the services they do.

Cashing out – will this work for people who are vulnerable and marginalised around their money.

You need a case manager, talk about what you want to do for you money for the next 12 months.

It will need to be a very easy system to use.

Workforce

Staffing is a huge issue, and resources and social inclusion.

It's all about education; the staff don’t know how to deal with people who have Alzheimer’s.

It would be great if we constructed aged care as a career path that young people want to go into.

People are motivated to stay if they are recognised for the hard work they do.

Opportunities in the community to train staff, we need to get away from the silo funding approach.

You get people that are not used to working with people in a town camp setting. You need someone with experience out here to do it, not just an expert from Melbourne.

Carers and nursing staff need education, as so many of them have no idea about Alzheimer’s. It’s so easy for them to provoke bad behaviour.

It’s not a career path, and that is a huge issue for indigenous people. If you were in the police force, you would be a sergeant after 10 years.

Is there enough staff available for people who come in from the bush and need respite?

Some staff are incredible, but they get burnt out and move onto a better paid job.

Would the aged care training package be appropriate for Aboriginal people who have English as a 2nd language? We want to encourage more aboriginal people into the aged care career path.

Younger Onset

Maybe age shouldn’t come into it, whatever age you are you should get whatever support you need.

Person support – not aged care. It is prevalent in indigenous people that they get YOD. If it is an aged care thing then they shouldn’t be getting support.

Aboriginal and Torres Strait Islander culture
When aboriginal people leave their community there is a huge void. Country heals people, it is their medicine. When they are back there their whole being, and essence of what makes them Aboriginal is healed. People desire to get back as soon as possible.

We have had remote area nurses in clinics feel nervous about allowing people to come here; we are worried the person might pass away as we don’t have the medical treatment. But when they get there they are better because they are on the land again.

Indigenous people take responsibility, much better than we do in our culture. When you have that community spirit, it could be much better to have the people out in the community because the whole community would become involved in looking after someone.

Living in our Aboriginal community, it is all under one thing, if you assigned a mental problem; you are just seen as ‘mad’. Now there are differences and that needs to be explained to people.

They revert back to their original language after dementia.

If you look at the rapid ageing of Aboriginal populations, they are ageing quicker and younger.

The prevalence is higher, 5 times higher, than in the non-indigenous population. We don’t know the causes, but it is thought to be the link from other chronic diseases.
APPENDIX E – REGIONAL CONSULTATIONS

Minutes from consultations

Merimbula Consultation
Monday 17 October, Sapphire Room, Club Sapphire, Merimbula, NSW
Panel: Glenn Rees, Rosemary Oats (Aged Care Business Manager, Anglicare NSW South Coast and Snowy Region)
Chair: Barbra Williams
Number of attendees: 41

Main Themes:
Primary Care
- Waiting time to see a specialist
- GPs not listening to carers concerns and relying only on standardised tests
- Length of time till getting a diagnosis

Community Awareness
- Stigma associated with taking on a full-time caring role
- Similarities to the stigma associated with mental illness
- Avoidance by friends and family

Information and Access
- System is complex and difficult to navigate even for those who have a professional health background
- Importance of local networks in finding out information about services
- Role of AA as first point of contact
- Reluctance to call a national hotline and preference to talk to local people who know about regional services
- Wait time for assessment

Residential Care
- Different facilities suit different personalities
- Residents are worth more to providers if they are unwell

Respite
- Quality inconsistent (e.g. staff unable to administer medication)
- Need for better environmental design
- Importance of flexible respite to meet carers needs

Workforce
- Training
- Staff level/ratios
- Need for a career path

**Comments**

**Primary Care**

When I took my wife to the doctors it was 18 months before I could see a specialist. He gave her tests one after another and we were told there was nothing wrong.

Tom was 66 when I noticed things in the wrong place around house. I told the GP and she said we all age and get absent minded. Two years later he was wandering and the GP said still did not listen to me that there was something wrong. A couple of months later he went on a 9 hour walk. Bells rang, and GP did tests. One friend said it took 10 years to get her husband diagnosed.

I knew there were things wrong with my husband. I couldn’t convince anybody, he would drive on the wrong side of the road, go over speed bumps and he nearly knocked us both out of the car. I went to local doctor in QLD and asked if the GP could assess him, I wanted him off the road. He did a test and past it with flying colours, there was not a thing I could do. We moved and I went to a local GP. I said there is something dreadfully wrong, he takes the car and he is going to kill somebody or himself. He was referred to geriatrician and after the first test they said sorry he has Alzheimer’s. Doctors need to be informed that if the partner has a fear they need to look into it, until someone will diagnose it.

Diagnosis is extremely difficult and common., I talked to two doctors, one of them would not acknowledge I was talking, he ignored me, I went back and said this time I am laying the law down and when I got to specialist in Canberra she said why didn’t you do something about this two years ago.

I would like to let people know how we got into the system. The experience several of you had with doctors not understanding the problem, people were dismissed or brushed off. But my experience was all good with a local doctor. The memory loss is such a gradual process you don’t notice it. But the doctor gave Val a memory test. All this happened quickly, it didn’t go on for years. Service was good and started with our local doctor.

**Community Awareness**

Family member has YOD. Friends do not understand why a young person has stopped working to be a full-time carer. They think we should just get a job. We try not to let others know about the illness and to keep it quiet. We are proud of what we do but the way we are seen outside is a different perspective.

My husband was 68 when he was diagnosed. He was early onset. Once it was general knowledge we noticed the social stigma. We were stopped being invited out. When we went to barbeques it was obvious people felt that they couldn’t interact with my husband.
When someone has breast cancer or an accident, everyone feels sorry for them. But if it is a mental illness or dementia people try to avoid you and they don’t know what to say. People do not understand it.

This all brings back memories, my first contact with dementia goes back 15 years when my mother was suffering, and we put it down to memory loss. We had to sell her house and move her into a home. She lost her friends, they didn’t desert her, she pushed them away. The local council sent around cleaning ladies and she accused them of stealing. She was difficult in later years, contrary to what she used to be. Present day – I was able to recognize the loss of memory [in my wife] we are going through now. I am proud of being a carer. We let people know our problem so they can understand if she does not understand the conversation or forgets. It is important to let your friends know so they understand and don’t go away saying ‘what is wrong with her’. We are happy but we are in early days. Lovely ladies from Bega are most supportive. I look forward to our meetings; we are one big happy family.

The stigma is caused by our generation who look on people as weak. If we do anything about it we need to educate the kids. My great grandson looked at me and said to his mother ‘he is old’ and we were not much better.

People down the street say how your mum is, they say we will visit her but they never do. It pisses me off.

Information and Access

This area [Merimbula/Bega] has an outstanding service to dementia care compared to Melbourne. We are way ahead from a nursing perspective.

If I wasn’t in health industry it could be difficult to know where to go, but once we make contact with one service they then recommend the next services. Good networking. The aged care industry struggles with staffing. This can impact on a persons stress levels. One gap could be for carers who work full time and finding support groups that are flexible, such as evening times.

When my husband was diagnosed, we were given no referrals to anywhere or anything that would help us. I said to a speech therapist that we were moving to Bega, they said you won’t get anything like you get in the city. We have had more care here than anywhere.

I had a gentleman in to do the bathroom fittings and survey to see what I needed, another man to see where they can be put in. But you have to pay for them, and I just don’t have the money to pay $300-$500 to have them supplied and fitted so we don’t have them.

When we moved here [Merimbula] everyone told me I was stupid, it is the best thing I have ever done. It is wonderful, all the facilities that are here.

My mother is living at home alone, and she is on an EACHD package, it is a life saver for me. She has plenty of services, up to 17 hours a week. It covers home modifications.

All I know is I speak to you (Barbra Williams, Regional Manager) and it happens. I contacted AA after I saw the sign and walked in.
I visited the GP in Sydney; he gave me the AA number and said to do the ‘living with memory loss’ course. I went and did 10 sessions, then contacted AA in Bega, that’s how I found out how to get services.

Even though I work in system it is still confusing. I rely on community members knowing, services are confusing and they change yearly.

I found out at markets, with the memory van. I knew something was wrong with my mum, people just said she is getting older.

We have been here for 30 years, no close family (started crying) if it hadn’t been for AA who started the ball rolling, access to home care, and I get respite every week, it has made such a difference to our lives.

My mum was independent; dad never did anything for himself. But he is now learning to cook; it’s a load off me. He will not take meals on wheels. But sunshine centre has been very good for mum.

Merimbula nursing girls terrific and Bega girls are terrific. You do not know what is around the corner. There is only one thing that I wish for. I wish that my wife was home with me.

The waiting time involved for assessment! Why does it take so long?

We were in Sydney but moved here to get better treatment and support. To get an ACAT assessment in the city there was a 6 month wait, this came and went, and after 7 months they sent a sociologist instead of a medical person. When I was assessed again I was told the first assessment was not worth the paper it was written on. The first hospital we went to we were treated with care, but we were ignored at the second one.

The aged care assessment team are not pushy enough. They are too easily convinced it is fine, don’t worry about it now, rather then them saying we will come out and make suggestions for you. There is a need for more staffing and people available to perform these functions.

Residential Care

Different nursing homes suit different people with different personalities. Mid way through the disease, the home was too big. It was heavily staffed with fully trained RN nurses. I then put him into respite in Marina Park. There are two main cottages with dementia, no more than 12 people in each cottage. Three staff on all the time. Fully secure. There is a lot of one on one with patients. Each patient had a primary carer. They had movies playing. Music playing. At one point he was pacing so much he wasn’t eating. So every time Tom passed the desk they gave him a piece of food. You need to asses the personality and choose the home that suits this personality. When it was time for him to pass away they bought palliative care to his room. I would like to see this type of set up in more nursing homes; it is more conducive to the patient.

At the moment the system operates that your worth more to the providers if something is wrong with you than if they try to rehabilitate you. The lower mum got the more money the government provided. There was a quick jump to antipsychotics. Took me six months to find out what we could do for mum. You
trust the system but somewhere along the line the system is trying to get their little bit.

Respite care

We use respite care but the quality is inconsistent. The environments can be worked on to support people with dementia, e.g. photos to show where people can go. But it does not happen. Some staff are well trained and some aren’t inconsistency again. There should be programs around for people in residential care, and consideration needs to be given to how the buildings are maintained and kept going. There needs to be a lot more reform in residential care, and what is going on in there, staff levels, education for staff and how the buildings are built.

Within the last few months my husband went into respite, paid by the government. But there are no registered nurses at the weekend so I had to bring my husband home for the weekend as he required medication. There was no one qualified to help at the nursing home. I found this a bit weird. I had to bring him home give the medicine, so I didn’t have my full break. The nursing home was also ringing me every so often because they couldn’t handle him, so I didn’t get my respite at all.

Services in the community make a great difference. Merimbula home nursing came out three times a week which enabled me to go out and get my hair cut. Respite is critical to just lay down and have a sleep. I would have persevered further but (started crying)

For respite we waited 2 weeks. No trouble getting him in. When going in for full time care there was one vacancy and then transferred into totally secure cottage. Most of the time there are usually one or two rooms available. But there are more and more people getting dementia.

The ladies from Merimbula nursing did respite with my husband once a week for 2 hours, but this is not long enough for someone like me who needs to go out. I can’t get anyone to sit with my husband while I go to Bingo, my one day a week. It is not as flexible as it could be. Two hours sounds a lot but it is not.

The mobile respite team have been wonderful. Sunshine club is wonderful (dementia specific service).

Workforce

Nurses don’t really know how to handle people with dementia. Is there training in their courses these days? And the same for doctors? The scheme at Bega hospital has been much successful. I would like to see that spreading around the country; it has been a wonderful innovation.

My husband has been in respite and they didn’t seem to be able to deal with his sundowning. They didn’t have the time and when he had behaviours they were calling me for help. Staff are not trained to cope with sundowners.

Why isn’t more money put into training carers on how to deal with dementia? It is glaringly obvious from what I have seen for the last 12 months. We all know people in nursing homes are not trained in dementia. The number of nurses and carers in some homes in relation to the number of residents isn’t enough. There
should be more training put to carers in nursing homes, we need to have nurses but generally we need trained carers.

Volunteers on boards need more training so they can be passionate about it.

I have concerns about staffing ratios.

People have been saying we need more carers. I don’t care how much training you have, there is still that special person that can deal with it. There are only a certain few people that have the special quality to be a carer.

I have been looking after mum for more than 10 years. [When my mum was in respite care] the nurses were wonderful; she got looked after very well. Then I got a call and my mum had been assaulted, the ambulance got called, taken to hospital, mum was very much traumatised. We have no hard feelings towards the person who did this to mum as he has dementia. He had never been away from home before. At the coroners inquest I made a few suggestions: aged care could do with more staffing in dementia care. There should be more supervision, we have childcare centres, and there is one person to 5 children. In the dementia wing there are 20 residents and there are just 3 people in there to wash, shower and handle all their needs.

I found it difficult to understand diversional therapy.

My mother got frail at 98. Staffing – we need more and not paid enough. There has to be a career path.
Geelong Consultation
26 October, Geelong yacht Club, Eastern beach Road, Geelong, Vic
Panel: Glenn Rees, Ellen Skladzien, Jack Sach
Chair: Darren Cheeseman MP Federal Member for Corangamite
Number of attendees: 84

Main Themes:
Community Awareness
  • Lack of community awareness of dementia
  • Suggested TV program or school education program
Information and Access
  • Regional differences in access
  • Requirement to switch service provider because changing package
  • Importance of social activities
  • Barriers in what packages will provide
Community Care
  • Importance of staff consistency
  • Need for exercise programs
Respite
  • Importance of emergency respite
  • Respite that provides social interaction for person with dementia
End of Life Care
  • Importance of setting out advance directives
  • Concerns about wishes not being respected
Support for Carers
  • Importance of AA support programs including living with memory loss and memory lane cafe’s
  • Carers allowance concerns
  • Size of bond and need for reassessment
Acute Care
  • Person with Dementia not being listened to because of having a diagnosis

Consumer comments:
Community Awareness
I am concerned that the average person has very little understanding of Alzheimer’s. I find that when I go to the shops with Carol, I talk to someone and get confused, and the lady behind the counter doesn’t quite know what to do. If only the average population had an idea, there needs to be a much stronger approach to the average population to help us.

The majority of people with dementia typically look normal. It is difficult looking at them realise there is something wrong.

I have had to explain that a people need to have more tolerance and understanding of the person of dementia. It was just because they didn’t understand; they thought they were just being stubborn. So obviously it is not getting out to people that you need tolerance and understanding.

I would hope to over come this problem of making the public aware would be for television to show the average person what it is, how it is and what to do. There would only be two stations that would cover such a thing, the ABC and the SBS, but that is far, far better than nothing. It gives an opportunity for people to talk to other people, and you discover people you can help. In other words spread it around, not only to politicians but to everyone, to help us.

I would love to see some form of information taken to high schools, because when patients go somewhere people don’t recognize that they have Alzheimer’s. They don’t realise he has something wrong until they come to the home. Our children would also love to learn more about their father too, they are used to learning and having professional people to learn from.

Information and Access

Recently got a community care package with a multicultural care service, they have been great. Access to that isn’t easy, we were lucky.

We lived close to Coffs Harbour. It took us 12 months before we got to speak to anyone in the hospital system. Now we have come back to Victoria. I immediately contacted the memory clinic here. It took until 4 months before Coffs Harbour responded to Geelong to send down my husbands details. We have had a fantastic experience here in Geelong.

After our first ACAT assessment, we had house cleaning once a fortnight, I had a gardener, and I had an OT come out. I felt the OT had too much on her plate. We had a second aged care assessment. He was then classified as an EACHD. Then I had to wait for another service provider. They couldn’t tell me how long it would take because there was a waiting list. The service providers just run down the list and take who they want, its not first come first served. I want to know why there is a discrepancy that people have to wait so long.

When I first found out that I had Alzheimer’s I just drifted along and was in a form on denial. When I did become aware of it I became a real mess. It was Ruth who gave me the professional support and the understanding.

Because the behaviours are not following in a particular format or time of day, the support we need depends on the time of day.

We need more social engagements, so they can look forward to going out.
It's just the floors and the toilet and the shower that is it. They won't do any heavy things, where old people can't get at. It's only an hour and a half so they can't do that much.

In the past they would only do half a mirror because she can't reach any higher. She won't vacuum under the chairs, there is no consistency.

Community Care

I would like to see the same person going to the same client. The client finds it very frustrating to have to explain where everything is. One person to one client.

Exercise programs for older people. My mother is 88, she has no incentive to get up and do anything. She will loose the use of her legs.

I was diagnosed with Alzheimer's about 2 years ago, one year, lucky I have a carer! I was told to keep exercise up, I go to a gym. I think it is very helpful. I think it helps my strength. I was concerned I wouldn't have the strength to sail any more, we started again and so far so good.

It's not rocket science, we just need more support.

Respite

I was taken to hospital with an asthma attack. The help from Southern Cross care to help care for my husband was absolutely amazing. It gave me confidence that if anything happens to me that David will be cared for.

I got stuck out of down due to a car problem. I called Carers respite, I dialled the 1800 number, they got all my information, they relayed it to Geelong where my partner was, and it was terrific.

One of the best things I have started to do with two of my mates is we go out with Mercy Care. We have a wonderful time. We have a stroll and have lunch together. Our wives have a decent break from us.

There needs to be day care centres, where it gives us respite, but it gives the person with Alzheimer's something they look forward to going to. To be with other people that have the same problems themselves.

End of Life Care

My husband and I have our wishes on record on the computers here in Geelong and I feel comfortable knowing they are.

My daughter is high up in emergency in the hospital. From the staff point of view, if they know your wishes are on record they can make a hard time easier for staff and family. I would advise anyone here to have a medical advanced care plan.

I heard on TV- on the program about organ donation- that family can override any decisions.

Support for Carers

My husband was diagnosed with dementia. Through an advertisement in the paper I saw living with memory loss program. That is how I became involved with AA. We would go every week and the carers would learn from one another. That was the basis of my knowledge from learning from those people. I learnt more from that
than I have from any literature or anything else. We were a family from the start and right to the end.

My husband had Alzheimer’s. I felt so alone. Through Alzheimer’s I get help, I am not so alone anymore.

It is important to have someone to talk to, listen to you, and not be judgemental.

It is very important for us as a group to get together, Memory Lane Cafés are important.

I am a carer for my mum. I recently tried to get carers allowance and I discovered that because my brother is there on the weekend and I only do 5 days, and don’t live with my mum I can’t get it. There should be better access to carer’s allowance.

How you are asset tested, is that going to stay the same? Given that you can’t get carers payments if you have too many assets.

We haven’t got any money left, it doesn’t seem fair. When people go into aged care they are either paying a bond because of low care or paying accommodation fee and people find it difficult as there is no reassessment. It is means tested at the start but not in the interim. Clients are finding it is difficult to survive at home.

Acute Care

I was told to be quiet and behave myself. The hospital was aware I had dementia but I was only diagnosed a couple of weeks before hand. They treated me as though I was a child.

Ambulances – I had to call the ambulance for the first time in my life. When they arrived I had to draw their attention that I had dementia, they couldn’t wait for me to get someone to help so I told them to get lost and drove myself to the hospital.
Mandurah Consultation
4 November, Offshore Fishing and Sailing Club, Mandurah, WA
Ellen Skladzien and Frank Schaper
Number of attendees: 22

Main Themes:
Primary Care
- GPs need more information or training
- GPs lose interest after diagnosis
- Doctors not willing to visit nursing homes or do at home visits

Community Awareness
- Need to Raise Awareness
- Stigma

Information and Access
- Lack of centralised information
- Waiting list for services
- Need for a key worker
- Desire for verbal information instead of brochures
- Waiting Time for ACATs

Respite
- 6 week wait for respite care
- Staff not listening to advice from family regarding behaviours

Workforce
- Inexperienced, unsupervised staff
- Staffing levels and wages are inadequate

Research
- Need for more research
- Desire for feedback after participation in research trials

Acute Care
- Hospital staff unable to handle dementia symptoms and calling family at all hours to provide care- even showering

Consumer comments:
Primary Care
Information needs to be given to the GPs. The first GP I went to said ‘what do you expect at his age’?

The doctor does not want to see my husband any more, he is just floating.

When I got my husband diagnosed I was told it was just old age. When they called Fremantle hospital they didn’t want to see him again.

My husband is suffering with Alzheimer’s. I would like a doctor to come to the house, to have his check up, so he doesn’t have to leave the house.

There was not one doctor that would go to the home so I had to change doctors to visit him. I am told the doctor will have to cut down on the homes he will visit. There does not seem to be the availability of doctors to give this service.

You need to shop around for doctors. You have to think long term. You don’t want to have to change doctors, make sure you ask at the surgery if there is a doctor that is prepared to visit the nursing home and do home visits, there are some.

By accident we had a medical problem, and the nurse asked what was going on. We are now on an aged care assessment waiting list.

Community Awareness

When you think of the amount of publicity for breast cancer, depression, men’s diseases, you don’t get the same awareness for Alzheimer’s. The whole outlook of society needs to change. Its not happening with Alzheimer’s like it is with other.

Your friends drop you; people don’t know how to handle it in a social situation. People don’t talk to him they talk to me. We need to change the community’s reaction toward it.

Alzheimer’s has to be a more popular topic to talk about. Most people do think it is just an old person’s disease, but its not. We need to make sure people have respect for those people. We lost a lot of friends, they think its catching. We need a voice out there for more money.

Information and Access

We came here, it was such a maze and we felt swamped. I wrote to the doctor, and didn’t hear anything.

I am concerned about having choice; we should be given a list of places that we could go to.

We have nothing that can give us step by step of where we might go. No list of possibilities that can be given to us. We would like a person we can talk to individually, about what is troubling us.

Through everyone being helpful and kind things are beginning to move. I have addresses galore and places to contact. There is no central set of information like a childcare centre that you can go. People get all sorts of problems and all the services are split up.

Other illnesses such as diabetes have a full time nurse available who is responsible for particular individuals. They provide help with the next step, where
to go and how to achieve what you are looking for. At the moment we don’t know what we are looking for as we don’t know what is available.

A big brochure came in the post yesterday and now I have more to read and work out. I just want someone to tell me what needs to be done.

I have learnt more about Alzheimer’s from reading, such as those about Hazel Hawke. You have to move into their world as they can’t move into ours. It makes life a lot easier when you understand how Alzheimer’s is affecting them.

I have organised the end time, but the in-between what do you do because the nursing homes can’t look after them then.

Respite

Carers cope with a hell of a lot. There is very little consideration. How do you get respite when it is not available until six weeks down the track.

It wasn’t until he went in for respite that things need to be changed. They complained that my husband walked around all night but he was looking for the toilet, but there was no sign on it. I took a little light and fixed it so it would shine it the door and explained that was where the toilet was. Until one night they didn’t turn the light on and he went into the lounge room and thought it was the toilet.

Workforce

I have had experience with different carers coming to the house who were not even trained. For example, a young girl about 16, trying to do a good job came to the house but she was not even supervised. But what could happen if I went out. There is not enough money given to the care staff for them to be trained.

I have a dream where there were special carers, so the families would know the person. It would be that person that could come for a weekend and let you have time off, a bit like a social worker.

The Nursing homes my husband is in has only 2 staff for 16 patients. How can they attend to them all? They have to go around and give medication and help to toilet people. No one is attending if someone has a fall or needs to eat. It should be 3 staff for each person not 8 to 1.

Staffing is a main concern in all nursing homes. I know one place has 1 staff member to 11 people with dementia but that might be over the weekends. It’s not enough.

There are a lot of people out there with empathy and care, but if they can’t get paid for it they don’t want the job. It all comes back to finances and wages.

There is not enough money to employ the staff that are needed. In the 90s when I was working I would be the only carer for 10 dementia people for 6 hours, and I was given a 10 min coffee break. We need to move on from that.

Research

I would like to know what research is being put into the Alzheimer’s. I want to know what type of dementia my husband had, if it was gene related and if it could happen in the future. You wonder where it will end up and there is no answer.
My husband did research for 9 months at the hospital. He got fed up after 9 months as he didn’t want another MRI. I never got any feedback in those 9 months as to what came out of it. As he was having all sorts of things like blood tests and MRIs.

Acute Care

My husband went to hospital; he is advanced with Alzheimer’s. I get phone calls at 2am in the morning from the hospital to sit with him to make sure he is not running around. They need a nurse that knows what Alzheimer's is about. He falls, next thing I get a phone call to come over.

I had my husband in hospital and they expected me to look after him during the time he was there. I went home that evening and they had transferred him to another hospital and he had not rung me. They need to have someone in the room at all times with the person who has dementia.

A friend whose husband has Alzheimer’s was in hospital and was running amuck. It was by god’s grace they rang the daughter and not the wife. She was getting blasted on the telephone. His wife had to go in to the hospital for 10 days to sleep in a recliner, and do the showering. She had no time to herself.

My husband was in a private hospital, and they were still waiting for me to wash him. That is disgusting, as soon as they see Alzheimer’s, that’s it, it frightens everybody.

My husband was in and out of hospital. Every time he had a catheter put in he had an infection and I would have to nurse him. It is so distressing.
Responses from the Q&A sheet

Merimbula

What are people living with dementia looking for in aged care reform?

- More professional carer’s
- Improved residential services – trained staff, environments that support people with dementia, buildings environment, staff interactions
- Flexible packages for support in the home
- Case management model
- Problem solving helpline
- Quality care – staff training at a certificate IV requirement
- The ability to be independent for as long as possible
- An atmosphere where they can make their own decisions as they are able The resources to keep people in their home – i.e. community care
- The availability of occupational and divisional therapy
- Contact with children, gardens and pets – simple things which give life meaning
- Services that enable people to stay at home longer
- Early assessment and diagnosis

What concerns you most in access to community and residential care services that meet your needs?

- Too early to need help, but would like to think that current service may be extended
- People don’t know how to access the services
- It’s confusing, as each facility has a different way of assessing and funding requirements
- Poor levels of staffing and knowledge
- Indifference in residential care – management needs to be passionate
- Need access to ACAT assessment as early as possible. This area needs an acute care facility instead of having to transfer clients to Goulburn with acute mental problems.
- Staffing levels and pay levels in nursing homes
- Full disclosure of facts, costs and help
- More community infrastructure at the local level – foot paths, seats, covered areas, meeting places and transport
- GPs are generally not helpful and some do not recognise carers concerns, such as changes in behaviour
- Different types of care packages can be confusing
Do you have particular concerns around access to information and assessment for access to care services?

- The waiting time involved for assessment
- Case management model would be useful
- All GPs need more information and the ability to empathise when dementia is diagnosed. GPs are ignorant about early signs and testing.
- Concerns about use of privacy of an individual as an excuse for lack of transparency
- Glossing over crucial places of information e.g. power of attorney does not give the right to see your parent’s care plan
- Need to state facts as they are, not pretend all is rosy in the wood pile
- Nobody needs so much choice they can’t cope with the fine print, at the moment a lot of advice and explanation is provided with smoke and mirrors
- Information about facilities which provide respite care
- There are too few financial advisors and professionals that can provide information about residential care costs and income and asset assessments

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

- More respite that makes the person in care happy
- Home care for mid-range dementia needs
- Early stage: cooking meals, socialisation, and gardening
- Next stage: personal care, shopping support and respite with appropriate programs.
- Acute mental health facility (residential)
- Residential respite

What types of support and services do you need to assist you in your role as a carer?

- Dementia specific ongoing training
- Respite – needs to be quality
- In home support
- Better recognition of the carer role through Centrelink
- Should abolish means testing for carers
- Support for fulltime workers who are carers
- Information, education and advice
- Knowledge about community services available
- Information available from Alzheimer’s Australia is comprehensive

Are there health issues that need to be addressed in the reforms?

- GP education – it’s a struggle to get referral and support that is ongoing
• Early diagnosis
• I am concerned about how many urinary tract infections in women are caused by them sitting in set, soiled incontinence pads
• Vascular problems caused by no mobilisation
• The cocktail of drugs given that affect the system of 90+ year old people.
• No privacy when the doctor visits
• The volunteer program at Bega hospital is very successful, preventing infection, falls, maintaining hydration. Perhaps a similar program could be trialled in surrounding areas.

Are there any other concerns you have about dementia care or the aged care system?

• Staff ratios are too low
• Availability of information for families and carers
• The unknown is an ongoing worry
• All people should have an assessment every 5 years, similarly to other health checks (cancer etc)
• Support for residential care to make that changes that will benefit people with dementia
• Need more special carers in nursing home, not just more staff in general. More funding would help keep staff
• Concerned about the extreme to which OH&S appear to be taken, at the expense of care
• The use of antipsychotics to ‘control’ anxiety. Anxiety occurs because people feel threatened or fearful. Reassurance may serve them better.
• Restricting people’s freedom by not allowing them to mobilise
• Refusal to let families comment on care plans
• Litigation should not be a basis on which decisions are made
• Meals on wheels delivered frozen are not suitable as people with dementia cannot prepare and reheat them
• Consideration of residential care that is suitable for people with challenging behaviours

Geelong
What are people living with dementia looking for in aged care reform?

• A system that helps the person with dementia to stay independent and is their home for as long as possible if not indefinitely
• More support
• Services, especially to support carers and families when difficult situations arise
• Lots of love and care
• Secure in the knowledge that a place will be available when the need arises.
• More nurses and carers
• A sustainable system that doesn’t penalize other family members
• The individual with dementia has their needs met appropriately and with dignity
• Need a book with a listing of all available services – maintenance, cleaning etc.
• Early diagnosis
• Case management
• Quality carers
• Training for aged care workers
• Aid when troubled
• Help to live at home comfortably

What concerns you most in access to community and residential care services that meet your needs?
• There are services available but no-one to co-ordinate what is required and by whom
• The cost of care
• The time it takes to get a package after being assessed
• It’s hard to figure out the care packages. There should be a central waiting list
• No facilities for couples in nursing homes
• Inequity between rural access to specialist services and city
• Aged Psych services don’t specialise in dementia care and won’t give a dementia diagnosis

Do you have particular concerns around access to information and assessment for access to care services?
• Information needs to be readily available – especially to young people and the general public
• Mother was assessed by ACAT in early 2011 but no follow-up since.
• Earlier diagnosis
• Not enough publicity
• Time to get a package after being assessed
• Cost of assessment for driver’s licence Occupational therapist should be claimable on Medicare

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?
• Home care, aged care services, gardening services, home maintenance
• Respite care for emergencies
• Carer holidays
• Day-care is really helpful
• Trained people to give home assistance and mental assistance for the patient and assistance to the carer managing difficult behaviour
• Residential care services – alarm system for people at home (to detect gas etc)

What types of support and services do you need to assist you in your role as a carer?
• Better access to carer allowance/pay to allow dementia person to stay in their own home, living by themselves with the aid of a carer
• More respite and social activities for patients
• 2 Days of day care – currently only has 1 day
• Knowledge
• An emergency back-up in case the carer becomes ill
• Advanced care planning and palliative care
• Socialisation for the elderly living alone with dementia
• Carers allowance is difficult to access
• Quicker access to EACH-D packages
• Home help – OHS rules impede usefulness of this
• Counselling
• Interesting day centre activities – music, exercise, social, ‘men’s shed’ etc.
• Support to encourage patients to accept and utilize respite services

Are there health issues that need to be addressed in the reforms?
• Transport and support for when licences are taken away
• More opportunities to keep physically fit
• Cash support
• The health of personal carers
• Timely diagnosis – earlier assistance
• Keep people in their homes longer
• Physio to keep elderly agile
• More knowledge in the community, other diseases have visible signs, dementia clients are not easily recognisable
• Education of health care workers
• End of life guidelines should be uniform across Australia
• General health care education on dementia or general TV
• Regular reviews every 6 to 12 months, e.g. from a geriatrician
Are there any other concerns you have about dementia care or the aged care system?

- Geriatricians to provide medical services in rural areas
- Reduce overlap of assessment – aged health service, ACAT, CDAMS.
- Dementia care in high level care nursing homes seems to take away independence and lock dementia patients in
- More training for doctors who treat dementia patients
- The cost of accommodation
- The system is too complicated
- More nurses trained to care for dementia patients
- Need more residential homes designed for dementia, with day staff to keep the patients busy
- Driving assessment is too expensive
- Need more empathy/less regimented care

**Mandurah**

What are people living with dementia looking for in aged care reform?

- A drop in centre to carer’s free time during the day.

What concerns you most in access to community and residential care services that meet your needs?

- There are no specialist consultants in geriatric medicine to provide all round care in a clinic situation and when liaising with the hospital.

Do you have particular concerns around access to information and assessment for access to care services?

- Too fragmented

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

- Respite care

What types of support and services do you need to assist you in your role as a carer?

- Caring for me as well

Are there any other concerns you have about dementia care or the aged care system?

- We need more care workers in the nursing homes

**Responses to online survey**

What are people living with dementia looking for in aged care reform?

- Firstly - some recognition. There is no mention of dementia in the Aged Care Reform. There needs to be more awareness of symptoms, early diagnosis, respect for people with dementia, less stigma, more funding to improve the care of the person and more
funding of research into the disease. We need to halt the increasing numbers of people being diagnosed with dementia. This will not happen until the government treats the matter seriously!

- With both my mother and father having dementia and myself caring for them we need a simpler form of diagnosis and care plan so they can remain in their home retaining their life skills. Once they are put into full time care they lose their identity and many other daily chores they would have happily continued in their own home.

- Age appropriate motel style accommodations at hostel level, single large bed/sitting room at nursing home level. Care workers trained in all aspects of handling people with dementia. Time out of nursing home with a subsidised carer for the under 70's. Hostels should be in their own grounds and have areas to have meetings with families both inside and out in the grounds. Theatrette and age appropriate movies for younger onset residents. Normal activities like cooking with assistance, gardening, outside activities like hiking for those who are physically able.

- * A more federally consistent approach * a less ad hoc and multifaceted system * better support for spouse carers of dementia patients * easier access to good respite care * easier support for transition from home/hospital care to permanent aged care * more support for organisations that support seniors with day care and home help/making the home safer for the patient * less paperwork for entering the permanent aged care system.

- More in home support for them and carers.

- Compassionate, flexible, responsive, supportive care for both patients and carers. Affordable access to neuropsychology for early diagnosis of dementia. Destigmatisation of dementia, improved community recognition. Evidence-based and innovative care. Research on how to better care for people with dementia, so that we can look after the ones who have it, as well as research on how to prevent and treat it.

- Skilled staff and whole of facility responsiveness. Requires more resources in staff ratio. Have currently been to facilities where there is one staff to 16 in high care. How can person centred care be activated with that ration.

- A safe place to live with caring and compassionate staff.

- Flexible, appropriate services and support. Less complexity (and/or more assistance to navigate the aged care system). Greater understanding about the impact of dementia on the person with a diagnosis AND their families and carers.

- Continuity of service. Easy access to service in a timely manner. Better standards in residential care setting.

- Respect and safety and recognition that not all people with dementia have Alzheimer's and are old.

- Quality of Care and Dignity - Correct staffing to meet their needs.

- Better trained nurses.

- Trained staff with a clear understanding of the disease and how it affects people. Family members want consistent, responsive care for their loved ones and to be able to support their loved ones when they are in care. Family members want to be part of
the caring decision process and want their concerns and suggestions listened by those working in aged care. Better choices for their loved ones and a more responsive system which takes into account an individual's needs, interests and background.

- access to appropriate services including community services and residential care
- Affordable options especially for respite in caring for someone with dementia at home. Accessible day respite programs. GP and medical people who diagnose early signs of dementia
- People with dementia prefer to live at home, however depending on their health and going into middle or advanced dementia, this is not possible and they need residential care. As dementia is affecting younger people, residential care should be separate from the aged care cottages.
- Development of prevention methods/drugs to reduce symptoms. Early diagnosis and education, support and elimination of social stigma.
- The ability to stay in their own home for as long as possible and have support services to enable them to do this comfortably.
- Improved pathways to services, improved services, money to be spent on the person, not swallowed by providers, and improvement in Residential facility.
- Respect and a safe environment - to be treated as a person with a disease not a nuisance.
- The easy access to 'best practice' care in a timely manner.
- My husband is in the early stages of dementia and does not accept the fact that there is anything wrong with him so that he resents almost anything that intrudes on his daily routine. This makes it difficult to involve him in some of the programmes available.
- More funding from the federal government to increase the ratio of trained nursing staff to residents in residential aged care.
- The best care possible that is as close to living at home as possible.
- Consultation, consultation, consultation. Absence of private interests such as BUPA and devolution of government services and Medicare, etc.
- Respect, understanding, flexibility in policies, so that they can live close to how they have most of their life, i.e. married couples regardless of their classifications i.e. high or low care, together.

What concerns you most in access to community and residential care services that meet your needs?

- Lack of funding - particularly to regional areas.
- Trained staff with adequate safeguards for patients, better accreditation
- The paper work is too complex and the differences between ACAT, service providers and residential aged care means one system would not work. The packages available never fit the needs of the person who needs them the most.
• The time it takes to get help. I was "qualified" for an EACH package but never got it as by the time my husband really needed the extra help (he could no longer stand and walk) he was past the stage where he could live at home. If we had got the extra help when we needed it he would still be at home now.

• Transport * good quality care *

• Residential care standards and support from family.

• Unresponsive, inflexible, ignorant of different varieties of dementia, and the importance of a correct early diagnosis.

• Inflexibility.

• The lack of spaces in residential care for both high and low care.

• Timeliness and appropriateness of services. This is especially true in relation to people with younger onset dementia, who have such different needs. It is also important that people are supported better to access services that are near their homes and families - not shoved off to facilities hundreds of miles away just because that is where there is a space.

• Lack of individuality, risk prevention gone mad- why can we not continue activities we have always done that make us feel worthwhile- cooking, gardening cleaning etc.

• That the whole system is geared to aged frail people and not those younger than 60 who may well be active and physically well.

• No balance between needs and wants.

• Just not enough places.

• There are never enough places available to support families and carers in maintaining their loved ones at home. Also when the time comes for their loved one to move into residential care, choices are limited and often not available when needed. Dementia sufferers need consistency and stability in their surroundings and also the people who tend to their needs. Often care providers change regularly which can unsettle someone suffering with dementia and this means that the care giver cannot enjoy the respite which in home care should be able to give to them.

• Safety at home, training of staff, carer stress, equity of services to rural areas.

• Availability, not enough appropriate facilities. Concern that carers don't have a good enough knowledge base about dementia to care for appropriately. This is often evident especially with community workers. Direct carers do not get an adequate income considering their work.

• In residential care we need a balance of carers and nurses. We are aware that dementia patients and in my case, Alzheimer’s, the disease is driven by the personality of the patient, therefore dementia trained carers are better suited as nurses are more medical driven and appear indifferent especially in hospitals.

• Too many people with dementia have late intervention and assessment, making it difficult for community service providers to be accepted and provide early guidance and education. Television advertising campaigns may publicise the help that can be accessed.
• Provision of continuity of care from people who know and understand all types and stages of dementia care.

• Emergency respite, short term respite, staff lack skills, not suitable or not trained, not knowing where to access information.

• Assessing community and residential care services can be a complex and confusing process. This process can become horrific when conflicting advice is given by medical and other professionals. In our rural area access to sympathetic doctors is severely limited.

• Services and service providers do not provide for people with YOD, challenging behaviours or BPSD. This includes when living in the community and residential care.

• As pensioners, the cost of services is a worry.

• Encouraging the person with dementia that the services are worthwhile and non-threatening.

• Lack of equity in pay for registered nurses in aged care facilities. Lack of recognition and value of the specialty area of aged care in the health system.

• Residential care is restricted in what it can offer because of staff ratios. There is a greater need for occupational / diversional therapy. The best kind of respite or residential care is where there are small numbers in accommodation and staff have a better opportunity to meet individual needs.

• Lack of consultation and presence of huge non-profits.

• No flexibility & lack of housing resources. Lack of information easily found. Government departments trying to get every cent they can from the elderly.

Do you have particular concerns around access to information and assessment for access to care services?

• Yes - more information is needed especially for people from regional, rural and remote areas.

• My partner and I had difficulties and wonder how those without younger, IT savvy people can manage the system until they are faced with a crisis, nobody notices.

• Communications at all levels should be upgraded. My husband was in hospital and I was not told he was having seizures or had had a mild heart attack until just before discharge, the communications need to be "as it happens" not "at discharge" for the carer to know what services are needed.

• There is plenty of information out there but it comes from too many different sources.

• Absolutely. Neuropsychologists are currently the best assessors of the changes in early dementia, but there are less than 400 in Australia, there aren’t enough training places, and their services aren’t covered by Medicare. Too many doctors make diagnoses of dementia without arranging appropriate education and other services for patients if they diagnose at all. People with dementia are often not diagnosed, missing out on the opportunity to plan for their futures and access suitable carer and patient advice and support.
• Still too complex. Difficulties for younger onset who are still square pegs in round holes between disability and aged care services.

• There is plenty of information around, but it takes too long for an assessment to happen in country areas.

• Navigating the system is very complex. We need a one-stop-shop, staffed by people who understand the impact of dementia and how/what services are available. Don't push us from place to place! The trauma and stigma of diagnosis is bad enough without crushing families further with bureaucratic processes. Help us to break through!

• It isn’t clear; so many adverts break up the information in the DPS guide it makes it difficult to follow.

• Care services? Near none existent in rural areas outside of the large towns.

• It seems shrouded in darkness - no transparency in actual care needs - always an overview until you actually get in there.

• Family members and carers often do not know where to start to get the information and support they need when they first notice that something is 'not quite right' with their loved one. Many doctors are not able to give a diagnosis and are not aware of what resources are available in the community.

• Yes. We need more education.

• Very difficult to get a review by a psycho geriatrician or neurologist especially in rural Australia to determine competency when making decisions about the future. Or to determine dementia if undiagnosed. ACASS will often have the symptom i.e. memory loss, without the diagnosis. This isn't helpful for early diagnosis and management. Memory clinics are also difficult to get into.

• The health system is lacking in directing and offering information on dementia. After being referred to a specialist, I received a prescription and an explanation of the CT scan at my request and my husband given a counting and reading test, a telephone number for the Alzheimer's "Living with Memory Loss" and a request by the specialist to see my husband in twelve months. This may not be the answer to the above question but Alzheimer's Australia is a private company picking up the slack from the health system.

• A/A - Need broader publicity about services available. Costs of residential aged care - too few professional advisors know about the complicated method of assessing assets/income fees which are encountered by self-funded retirees going into care. At university level accountants, solicitors and other professionals should be educated for their future need to advise in practice. A requirement for updating this education should be mandatory. Carers spend too much time (and money on insufficient advice from professionals) sorting out financial costs. This becomes an extra emotional and financial burden at an already difficult time of separation.

• Yes, once a diagnosis is made the 'labels' that are associated with it.

• No - it should be freely available and particularly to the person and their carer or next of kin.
• The assessment process and occupational services systems worked very well for us. The main concern regarding access to information is that information can be inconsistent or not "tell the whole story". It is possible, for example, to gain an overview but not situation specific information.

• Yes, it is a very complicated web you need to get through before you are eligible.

• No. The local Alzheimer's Australia NSW group is always very helpful with any information we require.

• Just that it is very difficult to get the person on-side for the formalities.

• Access to hospital records and information is lacking in residential aged care.

• I live in Launceston Tasmania and I am very happy with the availability of information and support from the access services. Some time ago I was part of a survey for the gold book that provided information of services for people with dementia. I think that information booklets like this should be available in all Drs Surgeries and hospitals and staff and diagnosticians should be encouraged to give them to clients and carers.

• Yes

• Assessments are too rigid. Facilities are too rigid. Lack of funding provides elderly (in my case) with unsatisfactory living arrangements. Parents married for 62 years separated due to high & low classifications, causing further health problems, resulting in unnecessary medications & healthy issues costing even more to live day to day.

What kinds of services do you need most (e.g. home care, respite care, residential care services, services for those with severe behavioural issues)?

• All of the above.

• Flexible home care. When asking for an additional service under a HACC program, I had to justify why, mum had to be visited and confirm she wanted the service.

• Home Care, Convalescent Care, Respite Care, Residential Care, Home Modifications, A.C.A.T. and O.T.

• My mother, who lives alone, refuses to acknowledge she has a problem, which makes caring for her very difficult. For my family, our greatest need at present is support to cope with her changing behaviours and aggression, and to manage our feeling of guilt or worry that we are not permitted to do more for her. No doubt that as Mum's dementia progresses, we will need in-home care and assistance with managing her aggression and risky behaviour (e.g. she believes she is invincible and climbs trees and tries to scale cliffs, as she used to do when she was a child). The only problem is that now she is 76 and weighs a little over 40kg.

• OT available every day in residential care to help with sundowning.

• Availability of adequate respite services.

• All of the above - with qualified staff - not just AIN's

• Respite care especially for dementia clients who all have special needs.

• Competent and consistent respite care which is available when it is needed.
• More trained care workers. People need to be trained in the skills to care for someone with dementia. This applies not only for paid workers but unpaid ones too.

• All of the above services during the progress of the disease.

• Home care, respite care, residential respite care occasionally.

• In-home respite care - in order to remain in familiar surroundings and access to emergency in-home respite.

• Home - personal, more hours, respite.

• A sympathetic doctor.

• Respite and those with BPSD and YOD.

• Home care, respite care and because my husband is disabled I will soon need some help with showering him. Up until now I have only had to use the services of a carer for a day when I had to go to Canberra for specialist services for myself. I could use some respite but my husband would be unhappy away from his own environment.

• Respite care services.

• Medical practitioners who will take residents in residential aged care.

• In home nursing care from a dementia team - showering, advice, encouragement, information as to other services. In home respite. Day centre respite. Residential respite (as a last resort). Linen service for incontinence consequences. Help with lawns, cleaning etc.

• Psychological services and respite services.

• Residential services with more staffing to carry out better care servicing.

What types of support and services do you need to assist you in your role as a carer?

• In home help - especially at night when the person will not go to sleep as I, the carer, gets no sleep either. More respite. Assistance with laundry – incontinence

• In my personal experience and with my work, if carers were able to place their “dependant person” into respite overnight or overnight stay, this could be every night or maybe one night a week. Carers need to have a life too, a major reason for putting their “dependant” into a permanent nursing home is because the carers cannot get enough sleep, and also needs this social time for themselves.

• As a full time worker, I found it difficult to have services that covered the time while I was at my employment. In afternoons there were little or no services. We were too far away for most services to collect my mother to take her to day care centres, although she only lived 30 km from CBD. It was easier for me to attend each morning to get her breakfast, supervise tablet taking, suggest appropriate clothing for the day and leave her for a time until a carer arrived for 2hrs in the morning. I would not get home until at least 8pm at night, doing the caring and cleaning that possibly a service provider could help with. I could have left my employment and gone on the dole which is something individuals have to decide on. But I had to support my partner and 1 child so that was not an option for me. Weekends were spent catching up on washing and all other household duties whilst trying to get out for a coffee etc.
• I now need help with transporting my husband from nursing home to doctor’s appointments, but such care is not available.

• Day care facilities, transport, home care, respite care.

• My mother is in denial of how bad my father's condition is. His life would be more comfortable if she were given education and support so that she doesn't do things that agitate him. E.g., taking him out when he's drowsy, overstimulating him when he's confused, dressing him up and sitting him in his chair in a different room each day when staying in his own room would probably be better.

• Flexibility. It is a hard to find commodity for all our talk. Consistency of staff and matching staff to client successfully - consumer directed care would suit us but where do I find that in my area.

• More of what's available and a quicker service.

• Education, information and support.

• Respect and recognition that I am a carer and not be treated as a dole bludger because outwardly my wife does not show that she has disability.

• Correct Education - availability to make education accessible to all communities.

• Support NURSES. People trained in caring for people with this ILLNESS. These people are sick!!!!

• In home respite care and support given by well trained staff. Responsive staff who develop a rapport with the loved one and their carer. Also keeping the same one or two people who provide the in home care.

• More time!! I do case management with community aged care packages. It would be good to be able to spend more time with carers and clients in providing them with skills and tools to care for their loved one.

• Respite care and home care as the carer needs emotional support as dementia is a lonely life. The carer needs a window of time to shop, have their hair cut, go to the dentist etc. There is very limited help one can expect from family or friends as the general public have little knowledge of dementia or patience in the process of ageing.

• Already receiving EACH package, this is an enormous help.

• Care that you can rely on i.e. same carer(s) at same time, so you can plan.

• Celebrate Dementia week, get it out there - has gone by for previous years with no acknowledgement. Packages not sufficient - Providers greedy.

• Our situation changes weekly. Currently, as the primary carer of my father who is still nominally running a business, I have had to employ two part time carers and another person who can both help with the care of my father and assist in the business. We have excellent respite care one week per month. It has taken considerable effort to put all of this into place. The big gap for me and for my Dad is that there is no choice of doctor in our rural area and I do not find our family doctor approachable in discussing my father's multiple illnesses. Certainly we have not discussed the dementia element which comes with the Parkinson's disease. I would also like to see the cancer
specialist using Skype to discuss blood test results instead of us having to travel for two hours for a two minute consultation.

- I am very pleased with the level of care I access at present.
- Specialist services such as mobile X-ray and skin specialists who will visit aged care facilities so that residents do not have to undergo the traumatic journey and long waits in public hospitals.
- I have valued the support of the dementia team. Their early intervention after diagnosis offered good advice, familiarity with the client and the ongoing support has been invaluable.
- Behavioural assistance and respite.
- Visiting services. Transport services. Medical diagnosis services.

Are there health issues that need to be addressed in the reforms? (E.g. timely diagnosis, care in hospitals, dementia risk reduction and dementia research)

- Yes - all of the above examples. Specific training for current GP’s as well as the student doctors. More caring and understanding workers are needed in both low and high care residential homes. Nurses and doctors in hospitals need education on behaviours associated with dementia as they seem to have no idea and cannot handle situations. Significant funding is needed for research into dementia so that the care is improved and finally a cure found. We need to follow the example of France in this area.
- Research.
- I think the main health issue is educating the public on how to understand a person with dementia. Both mum and Dad were different and my belief is only the family can interpret their needs successfully. When they go into a home with many changes of staffing, it is impossible to care for them as you would have cared for them. Behavioural changes are most important but I believe can be dealt with appropriately. I would be happy to give written feedback on every visit of my mum, but where are the staff to assess and update these issues and to take action on them!!!!!!! Timely diagnosis is very important so you can understand what is happening to your loved one, in both cases of Mum and Dad it was too late once I realised they had dementia. A person with dementia can cover up what their issues are, I think they know something is wrong, but cannot understand what it is and the community as a whole don’t recognise dementia.
- Timely diagnosis and appropriate referral. Dementia should not be used as an excuse for failing to give PT, OT and other services in hospital. Putting patients all together in a "Dementia Ward" and treating them all as if they have advanced dementia whatever their stage is ridiculous. A person with dementia should still be treated as a patient with heart disease, who has had a stroke, has cancer etc. not as if they are all geriatrics and beyond medical help. Carer as a resource person. Carers are often not used as the resource person they are and if over 60 are often talked down to by hospital staff. We need a new campaign to highlight the knowledge Carers have and a checklist to see that all medical personnel have taken some time with the carer.
• Care in hospitals - nursing staff treat the dementia patient as having normal mental ability. They assume that the dementia patient can convey their wishes and ask for assistance (e.g. Just ring the bell if you need anything) the dementia patient will 1. not remember that there is a bell and 2. cannot indicate what their needs are.

• All of the above.

• Care in hospitals is always a problem. Many times the ladies in my care have been treated badly within the health system.

• Absolutely. Getting a diagnosis can be very difficult, especially if GPs don't have the time to spend on assessment, or if they refuse to actually make a diagnosis - which happened in my mother's case. I am also very worried about the impact on people with dementia who find themselves in hospital, which I know from the experience of other family members was absolutely horrendous and added to their very rapid decline on returning home.

• Dementia research and education for care providers as to how to deliver a person centred approach and make residential homes real homes!

• Mental Health workers being taught that early dementia is not a mental illness that needs the person locked up.

• Timely diagnosis. Gradual re-adjustment from independent living e.g. not being admitted to hospital from independent living unit - to rehabilitation - to directly going into secure dementia based on one staff member's recommendation. Dementia was exacerbated by the confusion of moving from one facility to another, unnecessarily, in a short time span. Care in hospitals was negligent in terms of the lack of understanding of dementia related issues e.g. A person with dementia was tied into a chair with an 'apron' and left alone with a plate of food resulting in the person attempting to eat the plastic cover over the food. This is distressing for the carer to witness and takes away the dignity of the person with dementia. Patients being discharged from hospital too early because staff unable to manage difficult behaviours. Doctors in hospitals talking about the patient as if they weren't there regarding issues of palliative care. Lack of dementia specific wards. Dementia patient left for hours in Emergency with no support person. Ambulance officers lack of respect towards dementia patient. Dementia risk reduction and research are vital.

• Yes all of the above

• Hospitals are dangerous places for people with dementia - especially those who are mobile and/or seriously disorientated in unfamiliar surroundings. Staff need to be well trained in caring for those patients with dementia. Preferably there should be a secure ward for such patients - ideally with staff who want to work in that area and have had sufficient training. Diagnosis is also an issue as some people are waiting up to 3 years or more to get a diagnosis. This obviously has detrimental effects as they may not be able to take advantage of the medications available which may have helped, especially in the earlier stages of the disease.

• All of the above.
People with dementia are poorly managed in an acute hospital setting. They often come out with new symptoms such as pressure areas, increase in behaviours, and decrease in mobility to name a few. Discharge planning is often very poor.

More education and research into the health system for timely diagnosis. Care in hospitals to include further education by both doctors and nurses in understanding that patients with Alzheimer’s, for example, are not always off with the fairies but process information more slowly and over a longer period. This time is seen as the silent period when the patients can be sitting quietly or pacing. At this time, and after caring for my husband with Alzheimer’s, I don't see any current dementia risk reduction available which would help my husband.

Increased research into causes and prevention requires more funding than allocated at present. Extension of volunteer program started in Bega Hospital to all hospitals, to prevent people with dementia at risk of delirium and consequently at risk of injury.

Care in hospitals, dementia risk reduction, and dementia research.

Early diagnosis and better understanding within community. Health professionals don't understand Dementia. Many health services don't know what is available in their own area; there should be a clear pathway.

We need much better care in public hospitals.

There are a number of issues of concern to me as the carer of my father while he was a patient in the surgical ward at the regional hospital. They are: 1. given my father's underlying health issues, he was not cared for appropriately and this led to further injury. In particular, it did not appear to me that nursing staff were aware of his sight impairment or sensitive to the fact that the unfamiliar surroundings would make him more confused than usual. He did not know how to contact staff during the night. I observed that his buzzer was not always put in the same place during his stay in hospital. 2. There was a long delay before my father was seen by a doctor after his fall. 3. Apparently a doctor had discharged my father from hospital without having examined any injuries arising from the fall. 4. My father was discharged without consultation with me and without any discussion about how he could travel to his home whilst in pain. 5. After my father suffered a fall, there was a general lack of communication about his condition and no appropriate follow up or consultation. Comments from staff about my father’s general condition in his hearing but without acknowledging him were disrespectful.

Care in the community to prevent transfers to hospitals. Includes when living in your own home and or a nursing homes. There needs to be roving teams, specifically educated on dementia and delirium.

I don't think we see a specialist often enough to assess his progress on the medication.

All of those mentioned in the question.

Staff to resident ratios in residential aged care has not been addressed at all.

Obviously, as much research as possible into the different causes of dementia should continue to be an important priority of governmental planning because of the increase
of dementia in society. Ultimately the cost of prevention or early diagnosis and treatment will cost society less.

- Consultation processes.
- Timely diagnosis. Dementia risk reduction services. Medical authorities to realise that quality of life near the end is of paramount importance and not just the thought that because someone is old they don’t matter anymore.
Transcript – DVD from regional QLD

Interview 1

My name is Joan Hood, my husband is Edward but he is known as Rob. He is 84 years of age and he has had dementia for 8 years. Well I am just thinking of little basic things that are not there which are terribly important to us and terribly important to our loved ones there. The basic cleaning is not adequate including: pants not being changed (often bad smell), not cleaning their teeth (particularly twice a day as recommended by dentist who visited), not always clean shaven and shirts are sometimes not changed. There have also been incidents of dentures being worn by the wrong person.

Interview 2

My name is Graham Radell, my wife Susan has had Alzheimer’s for 5 years and mother in law for 15 years. My question is that funding for carers and people with dementia is an absolute disgrace. Apart from pension, the carers get $110/fortnight. You have to work 24/7, 365 days. You work out the math! When the person is then transferred to a nursing home, the pension is gone, however you still have to provide the running around for things like medication, shopping, doctors visits, incontinence products etc. It is just not worth it. We need more funding.

Interview 3

My name is Peter Forbes, my wife Rhonda is the carer for my mother in law who has been diagnosed with Alzheimer’s for 5 years. My mother in law has recently become more aggressive and we experience a demonic episode which was unnerving and very upsetting. It is out of control. Our concerns are that there are not enough avenues or accurate information to get emergency help. Day respite is a waste of time because she doesn’t want that. Emergency respite – we need something we can access because nothing is available.

Interview 4

My name is Melinda Tulan, I live in Townsville in far north QLD. I would like to raise some issues regarding the difficulties associated with people from non-English speaking backgrounds. I have been caring for my elderly parents for roughly 12-13 years – they have been in a low care facility for approximately 7 years and during that time a number of things have come to mind. I think the initiative to help people stay at home for as long as possible is great but I don’t think there are enough resources up here for HAC (home and community care packages) and generally there is a bit of a wait list so more resources need to be put towards that. The consequence of leaving people at home for as long as possible means that once they go into care facilities, they are likely to have much more significant care needs which facilities often can’t cater for up here. My issue is regarding food – they have a lot of, for example, sandwiches. And for my parents who are Asian, this is not culturally appropriate. When I enquired about other foods, the only thing they could offer was to provide a bowl of rice with the sandwiches. This again confused my parents because sandwiches and rice is still
not appropriate. The staff then stopped serving the rice because my parents were not eating it.

Interview 5

I am June Wilkinson and I live in Townsville. I am no longer a carer because unfortunately my husband passed away after a short stint with dementia. A short stint, in as much as I couldn’t get anyone to diagnose him. I knew – he was frail – to begin with he had a lot of medical problems and was just classed as ‘frail’ at the age of 70, and he died at 75. Diagnosis is the hardest thing to get. I had rails set up in the place and feel very humble that I was able to care for him myself and didn’t have to put him into one of those places.

Interview 6

I am Trisha Henwood, I’m 44 and I have younger onset Alzheimer’s. I live in Townsville and it took 18 months for me to get a diagnosis even though we had genetic evidence that this would happen to me. I have 2 children with autism and I find it very difficult to get services to help them in this situation with a mum deteriorating with Alzheimer’s and nobody seems to understand the grief they are going through. I try to be proactive about educating people about Alzheimer’s and I enjoy doing that.

Interview 7

I’m Madeline Duffy from Rockhampton. I have a husband with early onset dementia. My problem was trying to get help early on and to get my husband onto the drug Aricept. Coming to the Alzheimer group here in Rockhampton was a help because I came to a seminar called ‘Living with Memory Loss’ and I was then able to get the name of a geriatrician. I wished at the time to get a position where my husband was at. My GP was some support and did send me to someone in the Brisbane area but it must have been the wrong person because he could not see anything wrong with my husband and told me to go home and there’s nothing wrong. I felt like I was hitting my head against a brick wall. Since coming to the Memory Loss, I have been put onto a geriatrician. I believe there is only 2 or 3 in the whole of QLD. I have travelled to the Sunshine Coast to see this lady who then did proceed to give Darryl brain scans which showed there definitely was a problem. We travelled by car, the 620km to the Sunshine Coast. As I’m getting older it is getting harder to do. I just feel it would be beneficial to have a visiting geriatrician. I think most in our group use psychiatrists.

Interview 8

I’m Gwen Simpson from Rockhampton in the regions and over the past 8 years that I have been down to the Alzheimer’s CQ I have ascertained some problems. Number one thing is there is no geriatrician in Rockhampton. There is funding in Rockhampton to pay this geriatrician but we need a building to base this person permanently because the fly-in, fly-out system is not suitable. There are also issues with the doctors – for example, I have had people here who don’t know whether they need black or white tea and then the doctor just gives them a driver’s licence. There needs to be the development of a tests or additional tests to give the doctors a better idea of what they can or can’t do – therefore more training for
doctors and in the nursing homes. And more services for carers to keep people with Alzheimer’s at home but with the appropriate resources and training.

Interview 9

I’m Margaret Rosenberg from Rockhampton. Allan’s had dementia from about 67 years of age. He had a major stomach operation - I think the morphine and other drugs bought this problem on. He was treated for Parkinson’s disease for 3 years and it wasn’t until the last couple of years that they’ve diagnosed dementia with Lewy bodies. My problem is getting into short term care – a lot of places have long term care but not say 3-4 weeks. About 18 months ago I had a rather unpleasant experience when I went to take him into a home but I had the doctors tell me he was very high care. They put him into a motel-style accommodation and after about a week they told me to come and get him because they weren’t coping. I lost a bit of heart after that and felt that if there are more safe places for short term care that would be helpful. There is often also a long wait for short term care.

Interview 10

My name is Barbara and I live in Rockhampton. I was a carer for my mother. She began having very noticeable problems with her memory in 2005 and I was very concerned. I took her to her GP and he asked her some very simple questions which she answered ok and therefore he didn’t think there was any problem. There was no suggestion of referring her anywhere, despite Rockhampton not having those services anyway. One of the big problems in regional areas is that people go to GPs and unless they have had personal experience with dementia in their own family, they don’t tend to take any notice of a carer and their concerns. My biggest concern is the lack of medical professionals in regional areas of QLD.

Interview 11

My name is Nadine Hedger. I’m from Brisbane. My mother has younger onset dementia which she started showing signs in her late 40s/50s; however she didn’t get a diagnosis until she was 60 due to the constant diagnosis of depression. The behavioural change in mum was dramatic – anywhere from aggression to violence to complete loss of memory and speech. The main point that needs to be changed in aged care reform is the awareness around dementia as a whole including the issues around the elderly suffering from dementia but also those of a younger generation. Just because of how different the behaviours are of a younger generation. If we had awareness of the different types of dementia then the community would be more aware, early diagnosis, more research, structured treatment plans etc. We don’t have the required agencies for people of the younger generation in terms of respite services. My mum was excluded from care because they catered for the elderly and m because my mum was younger she tended to wander a lot and was more active. I needed her to be in a secure place, which most of the homes are, but because there was an inadequate staff to patient ratio, it couldn’t cater for my mum. So all in all she had half a day of respite before being told she was ineligible for the services within Brisbane. In home care was extremely supportive however because she was high care high needs sometimes we only had 2 hours of care which is not enough time to do shopping etc. It is the everyday level of social exclusion that you feel as a family and because of this
disease you are excluded from employment, further education, Christmas, birthdays – everything any other citizen is entitled to you aren’t because you don’t have the assistance there for high care patients. There are stunning residential facilities for elderly care, but a lot of them wouldn't cater for my mother because of her wandering. I believe there should be more facilities for younger onset dementia patients.
APPENDIX F - ALTERNATIVE MODELS OF HOSPITAL BASED CARE

During consultations consumers told of two regional models of dementia care in hospitals which were thought to be successful.

Research into practice: volunteers improving person centred dementia care in a rural hospital

This program at Bega Hospital aimed to establish and train a group of volunteers in a person centred care approach to support people with cognitive impairment. Patient outcomes were compared to Moruya Hospital, which did not have a volunteer program. Both staff and volunteers at Bega Hospital perceived positive patient outcomes especially related to hydration and nutrition and improved patient safety and emotional care. There was strong agreement by both staff and volunteers that the program was worthwhile and should continue. Based on study findings, the model is replicable with minimal resources in other sites and is particularly suited to rural settings.

Detailed information of the study can be found at:

Nell Williams Unit - a dementia specific unit at the Royal Hobart Hospital

The Nell Williams Unit at the Royal Hobart Hospital officially opened on 21 January 2010. The unit was created in response to Tasmania’s ageing population, recognising the need for people with dementia to have a dedicated and appropriate space when they enter the emergency department of a hospital. The objectives of the unit are to assess, evaluate and treat older people, specifically those with dementia. Special features were introduced into the unit to lessen anxiety. These include coloured handrails, medical equipment hidden from view and comfortable recliners for families, encouraging them to stay with the person with dementia. The unit won the International Design Innovation of the Year award at the University of Stirling’s International Dementia Excellence Awards in London. During the consultations in Hobart consumers expressed concern that the unit had been closed.

More information about the unit is at:

A media release with detailed information is at: