

**FIGHT ALZHEIMER'S**  
**SAVE AUSTRALIA**  
**FIGHTDEMENTIA.ORG.AU**

**Submission to the Australian Aged Care  
Quality Agency (AACQA)**

**DISCUSSION PAPER:**  
***“LET’S TALK ABOUT QUALITY”***

**OCTOBER 2015**

## EXECUTIVE SUMMARY

This submission from Alzheimer's Australia is made in response to the Australian Aged Care Quality Agency (AACQA) August 2015 discussion paper *Let's Talk About Quality: Developing a Shared Understanding of Quality in Aged Care Services*.

The provision of quality aged care and support in a suitable environment is a central human right. The United Nations Principles of Older Persons states that:

“Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care, or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.”<sup>1</sup>

These principles should apply equally to people accessing residential and home-based aged care, including people with dementia.

The number of older Australians with dementia is growing exponentially, and the core business of both residential and home-based aged care services increasingly includes providing care to people with dementia. Alzheimer's Australia urges AACQA to consider and include issues relating to the safety and quality of care for people with dementia, throughout all standards and processes relating to quality and safety in aged care. As the prevalence of dementia increases in our community, it is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business.

Alzheimer's Australia also advocates the importance of ensuring strong consumer and carer involvement not only in the development of quality standards, but also in all of the processes relating to their implementation.

Alzheimer's Australia strongly supports the overall approach of the discussion paper, to shift from a narrow focus on standards and accreditation, to a broader focus on delivering real quality in aged care. Alzheimer's Australia also offers the following specific suggestions in response to the discussion paper:

- Informed decision making by all consumers, including those with dementia along with their carers, should underpin quality standards and processes for aged care services.
- Support for carers, including the provision of respite care for carers of people with dementia living at home must be included as a key part of quality in the aged care system.
- Measures of quality in the aged care system must seek to ensure access to appropriate, high quality care for the most vulnerable consumers, including those with dementia and especially those with significant behavioural and psychological symptoms of dementia; Aboriginal and Torres Strait Islander people, those from CALD backgrounds, older people who are lesbian, gay, bisexual, transgender or intersex, and those from other vulnerable minority groups; and low income/low wealth older people, including pensioners.

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<sup>1</sup> Cited in Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 8.

- Measures of quality in community-based aged care should be based around the provision of holistic care, in conjunction with other services, to enable people living with dementia to remain at home for as long as is feasible, if this is the person's preference.
- In residential care, quality involves ensuring the environment is as home-like as possible, and that there is a flexible approach to providing the best possible care for the individual resident. Key elements include resident-centred care with measures in place to cater for people with dementia; culturally appropriate care; involvement of relatives and friends; effective pain management; minimal use of restraint; and use of specialist supports.
- Consumers, carers, and appropriate volunteers such as Community Visitors, should be engaged as key partners in aged care quality and compliance processes.
- Consumer satisfaction with aged care services should be monitored, including through surveys administered by AACQA.
- Quality reviewers for home care services should conduct interviews with at least 10% of services users and/or representatives during the site visit, in line with the process for residential aged care.
- Quality standards should be continually strengthened to drive continuous improvement.
- The primary approach of accreditation should shift from planned visits to unannounced visits.
- Aspects of quality care which are essential and should never be compromised include person-centred care, informed choice by consumers, carer support, measures to prevent inappropriate use of restraint, and appropriate end-of-life care.
- To deliver quality care, aged care services must have adequate numbers of skilled, qualified staff, committed to providing person-centred care. Staff must be educated and trained in key aspects of care, including person-centred care; caring for people with dementia; and key aspects of care such as management of behavioural and psychological symptoms of dementia including alternatives to physical and chemical restraints, pain assessment and management, and end-of-life care. To attract and maintain the right workforce, improved pay and conditions and appropriate career paths will be needed.
- Funding arrangements must support the delivery of quality aged care, including to people with behavioural and psychological symptoms of dementia.

## CONTEXT: ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.<sup>2</sup>

Alzheimer's Australia represents and supports the more than 342,800 Australians living with dementia, and the more than one million family members and others involved in their care<sup>3</sup>. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information.

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<sup>2</sup> Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

<sup>3</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

Alzheimer's Australia is a member of Alzheimer's Disease International, the umbrella organisation of Alzheimer's associations across the world.

Our organisation advocates on the basis of evidence-based policy, promotes awareness of dementia, delivers national projects and programs under contract from the Commonwealth, and provides research grants to emerging researchers. We are committed to a strong consumer focus and have a number of consumer advisory mechanisms, which actively seek and represent the voice of people with dementia themselves, as well as carers. We participate on many Ministerial and Departmental Committees, and contribute to consultation forums and advisory groups. We are also a sponsoring member of the National Aged Care Alliance and are involved in other key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

## BACKGROUND: DEMENTIA AND AGED CARE SERVICE DELIVERY

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal and devastating condition that robs people of their abilities and memories.<sup>4</sup> It is cloaked in stigma and misunderstanding,<sup>5</sup> isolates people with dementia and their carers from social networks,<sup>6</sup> and carries significant social and economic consequences.<sup>7</sup>

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 340,000 Australians living with dementia, and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia<sup>8</sup>. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050<sup>9</sup>.

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum<sup>10</sup>. Dementia also has a profound social impact. People with dementia experience stigma and social isolation<sup>11</sup>, and family carers often find it difficult to balance work, life and caring responsibilities<sup>12</sup>.

Many of us will be diagnosed with dementia over the years ahead, or will have loved ones faced with the diagnosis. As our population ages, and as more of us survive the diseases of mid-life, more of us – both in terms of raw numbers, and as a proportion of the population – will experience

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<sup>4</sup> Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

<sup>5</sup> George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

<sup>6</sup> Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

<sup>7</sup> Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia. Available: [www.fightdementia.org.au/research-publications/access-economics-reports.aspx](http://www.fightdementia.org.au/research-publications/access-economics-reports.aspx)

<sup>8</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

<sup>9</sup> Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

<sup>10</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

<sup>11</sup> Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

<sup>12</sup> Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. (2015) Report for Alzheimer's Australia.

dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men<sup>13</sup>. The higher lifetime risk for women is mainly due to women's longer life expectancy.

Given the high and ever-increasing prevalence of dementia, and its correlation with age, it is critical that aged care services are equipped and motivated to provide high quality, appropriate care to people with dementia.

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.<sup>14</sup> Provision of comprehensive community based support, and appropriate, high quality residential care are therefore both critical to meeting the needs of people living with dementia.

Dementia should be core business for aged care, but there is evidence that the needs of people with dementia are not being fully supported through current mainstream aged care services. While the majority of people receive good care, unfortunately there are many instances where this is not the case. There are particular concerns regarding residential aged care, where Alzheimer's Australia receives reports from consumers about physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end-of-life not having access to palliative care.<sup>15</sup>

People with dementia will always need to be supported by mainstream services. However, it must be recognised that although dementia is a core part of aged care, it is not enough to rely on the provision of mainstream services to adequately provide for the needs of people with dementia. Instead there must be an approach that combines building capacity in mainstream services to provide quality care for people with dementia, along with the integration of specialist dementia services to support mainstream services where required.

## COMMENTS IN RESPONSE TO THE DISCUSSION PAPER

### Overarching comments

Alzheimer's Australia supports the broad intent of consumer directed care, which aims to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when. However, it is important to ensure a focus on

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<sup>13</sup> Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al, The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 2006; 37 (2):345-50; cited in Alzheimer's Association (USA) 2013 *Alzheimer's Disease Facts and Figures* p 19. [www.alz.org/downloads/facts\\_figures\\_2013.pdf](http://www.alz.org/downloads/facts_figures_2013.pdf)

<sup>14</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

<sup>15</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 4. [https://fightdementia.org.au/sites/default/files/20131112\\_Paper\\_37\\_Quality\\_of\\_Residential\\_Aged\\_Care.pdf](https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf)

*informed* decision-making, and the challenges and issues in achieving this in the case of consumers with dementia as the disease progresses.

Informed decision making by all consumers, including those with dementia along with their carers, should underpin quality standards and processes for aged care services.

It is also important to take into account the significant contribution made by carers to enable older people with dementia to stay living in the community. Support for carers is essential. Access to overnight respite care in these cases is critical to sustainability, helping to allow people with dementia to remain living at home for longer.

Support for carers, including the provision of respite care for carers of people with dementia living at home must be included as a key part of quality in the aged care system.

The discussion paper states (p 12): “New models of service delivery are needed to meet an increased demand for services, more complex care needs, reduced growth in funding and the expectations of consumers.”

It is important to recognise that demand is growing at a faster rate than the supply of aged care services. It seems inevitable that vulnerable, resource-intensive consumers, including people with dementia and especially those with significant behavioural and psychological symptoms, will lose out if we rely solely on market forces to drive access and quality. Measures are needed throughout the system to ensure that that does not happen.

While market forces have the potential to drive access and quality where there is competition, in many areas of Australia (and especially in rural and remote areas) there is little or no choice of service providers or residential aged care facilities. Most facilities are full, and there are waiting lists. This can make aged care consumers and their families afraid to complain about service quality, and unable to change to other services. Where there is no choice, there is no market to drive quality improvement.

Private aged care service providers, along with public providers, must be required to play their part in a holistic aged care system that caters to both the market-empowered and the vulnerable. It is critical that policy settings are in place to ensure an appropriate balance between profit and community responsibility. Quality standards and processes in the aged care system can play a part in achieving this.

Choice will bring about positive changes for consumers, but there will remain groups of people who could be disadvantaged by this approach – those with reduced capacity, those living alone and/or without a carer/partner or advocate to assist in decision making, those from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander people, and others who have faced institutionalised discrimination (eg LGBTI people). Changes to an open market approach with no safety nets in residential care could also put full or part pensioners at risk of being denied aged care places, in favour of those who are full fee paying or opting for additional services.

Measures of quality in the aged care system must seek to ensure access to appropriate, high quality care for the most vulnerable consumers, including those with dementia and especially those with significant behavioural and psychological symptoms of dementia; Aboriginal and Torres Strait Islander people, those from CALD backgrounds, older people who are lesbian, gay, bisexual, transgender or intersex, and those from other vulnerable minority groups; and low income/low wealth older people, including pensioners.

## Comments on key themes and responses to questions

Our comments on the five key themes of the Discussion Paper, and on the questions posed under each of those themes, are as follows.

### *Putting consumers front and centre*

#### **What do consumers look for in choosing an aged care service?**

We know that most consumers want to stay at home and live in their community. This has benefits for their own quality of life and avoiding or delaying admission to residential care, where this is appropriate, is also far more cost effective for the system. Alzheimer's Australia's experience is that consumers providing feedback express higher levels of satisfaction with home care services than with residential care. Community-based aged care services (in conjunction with other services, including general practice and primary healthcare) need to deliver holistic care that enables people with dementia to remain living at home for as long as possible, where this is the person's preference. This must include measures such as support for carers, support for social engagement including volunteering, and access to flexible respite care including overnight care.

Measures of quality in community-based aged care should be based around the provision of holistic care, in conjunction with other services, to enable people living with dementia to remain at home for as long as is feasible, if this is the person's preference.

In the case of residential care, the key to good care is ensuring the environment is as home-like as possible, and that there is a flexible approach to providing the best possible care for the individual resident. Alzheimer's Australia advises consumers/carers who are considering residential aged care for a person with dementia to look for a residential aged care home with the following attributes:<sup>16</sup>

1. An effective approach to care: This includes strong leadership by management and direct care staff; an adequate staff to resident ratio; a focus on individualised, resident-centred care, including the ability for the person to maintain their independence, preferences and chosen lifestyle as much as possible; dementia specific units or other separate areas, to be

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<sup>16</sup> Alzheimer's Australia Help Sheet: *Residential Care and Dementia 4: Good Care in a Residential Facility*. [https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare04-GoodCareInAResidentialFacility\\_english.pdf](https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare04-GoodCareInAResidentialFacility_english.pdf)

- used when separation is required; appropriate environmental design; individualised activity programs; quiet areas, etc.
2. Culturally appropriate care: The care approach should seek to know and understand each resident in the context of their culture and to communicate with the resident in their preferred language.
  3. Involvement of relatives and friends: This includes consulting and actively involving families/carers in care planning and review, as partners in caring; and providing opportunities for carers to participate in committees, support groups, etc.
  4. Effective pain management: Often when people with dementia are in pain they are unable to tell anyone; however, pain may trigger behavioural changes and any such changes should be investigated. Good pain management reduces confusion and distress, and reduces the need for psychotropic medications. Staff should have clinical skills in pain assessment and management, and should acknowledge and utilise the insights of families/carers in this area.
  5. Using minimal restraint: Best practice nursing care should mean that physical and chemical restraint (such as physical devices, isolation, tranquilisers and sedatives) is rarely necessary. The aged care home's policy on restraint should seek to minimise the use of physical and chemical restraint, and practice should match the policy.
  6. Specialist supports: Access to specialist psychogeriatric assessment and advice is important in providing good care for people with dementia. The advice of other allied health professionals such as physiotherapists, occupational therapists, speech pathologists, dietitians, and psychologists may also be very helpful.

In residential care, quality involves ensuring the environment is as home-like as possible, and that there is a flexible approach to providing the best possible care for the individual resident. Key elements include resident-centred care with measures in place to cater for people with dementia; culturally appropriate care; involvement of relatives and friends; effective pain management; minimal use of restraint; and use of specialist supports.

Consumers consulted by Alzheimer's Australia have also identified the following features they are looking for in an aged care service:

- Residential care services having **programs that engage and are tailored to the person's interests, capabilities and needs**. Boredom is a major issue for people in care and this can lead to issues with behavioural and psychological symptoms of dementia.
- Residential care services **engaging with the local and wider community**, to prevent people in residential care being isolated from the broader community. Programs that allow residents to be part of a larger diverse community of all ages are important.
- **Affordability**: Care in the community can be expensive and brokerage fees (often multiple fees if a provider has to get other services in) can reduce the funds available for actual care. To give just one example (a real life case study from a consumer) to illustrate how the system can fail to meet consumer needs:



*“A consumer currently receives a home care package. The provider is unable to supply some of the services requested by the consumer and brokers the services to another provider. A high brokerage fee is charged, which essentially reduces the amount of services available to the consumer. It is concerning that the consumer was assigned a provider that is unable to meet their needs and charges high brokerage fees, as opposed to the consumer being assigned a provider that can fully support their needs.”*

## **How do you measure whether one service is better than another?**

Measuring consumer satisfaction is a vital element in measuring service quality, and consumer involvement in the quality process is also critical. Consumers and carers should be engaged as key partners in aged care quality and compliance processes. Consumers have told Alzheimer’s Australia that they are keen to have a more central role in these processes. For example, involving care recipients, carers or former carers as part of assessment teams would utilise their expertise as well as give consumers more confidence in the system. There are of course questions to be explored around developing appropriate training and exploring how consumers could be equal members of the assessment team, or play an advisory role. Involving consumers in the quality monitoring process may assist to reducing the hesitation some consumers feel in providing honest feedback about the services they are receiving to a reviewer as well as provide the assessment teams with additional information to support the review<sup>17</sup>.

Alzheimer’s Australia also recommends that the reach of the Community Visitors Scheme in residential care should be increased, to include a role for volunteers in quality monitoring, possibly as part of the accreditation process<sup>18</sup> - as currently occurs in the health sector through accreditation processes including those conducted by the Australian Council on Healthcare Standards

Consumers, carers, and appropriate volunteers such as Community Visitors, should be engaged as key partners in aged care quality and compliance processes.

It is important that measures are in place to ensure that the consumer voice can be heard without fear or favour. The power imbalance between the service provider and the vulnerable consumer can make this problematic: Alzheimer’s Australia hears frequent feedback from carers indicating they are fearful of complaining or making negative comments about service quality because they fear retribution on their loved ones and have limited options to access alternative care. Alzheimer’s Australia recommends that as one means to address this, consumer satisfaction be monitored through surveys administered by AACQA.

Consumer satisfaction with aged care services should be monitored, including through surveys administered by AACQA.

As the number of home care packages increases over coming years, an increased and more robust focus on the quality of care provided in the community will be necessary to ensure the

<sup>17</sup> Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 16.

<sup>18</sup> Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

current standards of care are maintained and continually improved. The development of quality indicators for home care standards is a welcome move. Alzheimer's Australia has advocated that quality reviewers for home care services conduct interviews with at least 10% of service users and/or representatives during the site visit, to bring this in line with the residential process.<sup>19</sup>

Quality reviewers for home care services should conduct interviews with at least 10% of services users and/or representatives during the site visit, in line with the process for residential aged care.

### *Safety is essential but not enough*

From a consumer perspective, the accreditation process has served to reassure consumers that over time, aged care providers offering unacceptable levels of care will be dealt with. However, knowing that a service is accredited does not help consumers to ascertain whether the provider is delivering high quality care or just passing minimum standards for accreditation. In addition, many consumers believe that the accreditation process involves significant red tape which impacts on staff time for care of residents, and which does not necessarily focus on better outcomes for residents<sup>20</sup>.

Alzheimer's Australia supports moving away from the approach of accepting a minimal quality standard for aged care provision as this can lead to providers opting for a "lowest common denominator" of quality. The system should encourage a high standard of quality, underpinning the delivery of "supportive care", which involves:

"a full mixture of biomedical dementia care, with good quality, person-centred, psychosocial and spiritual care under the umbrella of holistic palliative care throughout the course of the person's experience of dementia, from diagnosis until death, and for families and close carers, beyond."<sup>21</sup>

The AACQA discussion paper notes (p. 13) that after 15 years of accreditation, almost all providers of residential care meet all of the accreditation standards both at full scheduled audit and at unannounced site visits, and that currently less than one percent of aged care homes have identified failures.

Given that Alzheimer's Australia receives frequent feedback about consumer/carer dissatisfaction with the quality of residential care provided to people with dementia, this begs the question of whether the standards set the bar at a sufficiently high level. As services have improved over the past 15 years to consistently meet the current standards, there is a strong argument for continual strengthening of the standards, to stimulate continuous improvement in service delivery.

Quality standards should be continually strengthened to drive continuous improvement.

<sup>19</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 7.

<sup>20</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 15.

<sup>21</sup> Hughes JC Lloyd-Williams M Sachs GM (2010) *Supportive care for the person with dementia*, p 301; cited in Hughes J (June 2013), Alzheimer's Australia Paper 35, *Models of dementia care: Person-centred, palliative, and supportive*, p 11.

Consumers have also expressed concern about notification of visits, and have expressed a preference for unannounced visits, to check the quality of care being provided. Alzheimer's Australia recommends that the primary approach of accreditation should shift from planned visits to unannounced visits to ensure that the everyday level of quality in service delivery can be more accurately assessed<sup>22</sup>.

The primary approach of accreditation should shift from planned visits to unannounced visits.

## **What aspects of quality care are essential and should never be compromised?**

### *Person-centred care*

Person-centred care is underpinned by a philosophy which “brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured”. Person-centred care means that people with dementia and their carers must be valued; they must be treated as individuals; the perspective of the person with dementia must inform our understanding; and the person’s social environment must be attended to because of the fundamental importance of relationships in sustaining personhood.<sup>23</sup>

Person-centred care must be the basis upon which all aged care services deliver care, including to people with dementia.

### *Informed choice by consumers*

Consumers must be empowered to make informed choices about the support and care they need, and their rights must be respected. Partnerships with consumers on their care must be underpinned by informed decision-making. Genuine consumer directed care for people with dementia can be delivered only when consumers and carers are enabled to be partners in the decision-making process, despite the challenges this may present. For people with dementia, as for those people without dementia, having a say in their everyday lives is a basic desire and underpins a sense of purpose and well-being. Many people with dementia have expressed a desire to feel that they are participating in decision making regarding their care but also recognise that their ability to do so is, and will be, compromised by the very nature of dementia.

According to the Australian Commission on Safety and Quality in Healthcare,<sup>24</sup> effective partnerships with consumers and carers exist when they are treated with dignity and respect, when information is shared with them and when participation and collaboration in healthcare processes are encouraged and supported to the extent that consumers and carers choose. The consumer/carer must be in a position to fully understand the proposed care plan and must have supportive information to make an informed decision. This is particularly important in the context of consumers with dementia and their carers from vulnerable groups such as those from culturally

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<sup>22</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 18.

<sup>23</sup> Hughes J (June 2013), Alzheimer's Australia Paper 35, *Models of dementia care: Person-centred, palliative, and supportive*, p 9.

<sup>24</sup> Australian Commission on Safety and Quality in Health Care. *Safety and Quality Improvement Guide Standard 2: Partnering with Consumers* (October 2012). Sydney. ACSQHC, 2012.

and linguistically diverse backgrounds, rural and remote areas, and Aboriginal and Torres Strait Islander communities.

### *Carer support*

Carers must be supported, listened to, encouraged and educated to play as full a part in the consumer's care as they wish. Links need to be made to support services and support should be provided to carers when a bereavement occurs<sup>25</sup>.

### *Measures to prevent inappropriate use of restraint*

The inappropriate use of physical and chemical restraint, particularly in residential care, but also in community settings, is a significant issue of concern for people with dementia and their families.

The presence of physical restraint in aged care facilities varies, and the evidence suggests prevalence rates from 12% to 49%. Physical restraint can cause a range of adverse psychological and physical effects, and research has shown that overall physical restraints do not prevent falls, and may in some cases cause death. Clinical guidelines indicate that physical restraints should be an intervention of last resort. Environmental, strength-promoting, surveillance, and activity-based alternatives should be considered first; and consultation with the carer and/or legal representative should occur wherever possible prior to restraint being applied<sup>26</sup>.

About half of people in aged care and about 80% of those with dementia are receiving psychotropic medications, although this varies between facilities. There is evidence to suggest that in some cases these medications have been prescribed inappropriately. Whilst almost all people with dementia experience behavioural and psychological symptoms of dementia (BPSD) at some time during their illness, the evidence supporting the use of psychotropic medications in BPSD is modest at best, with international data suggesting that only 20% of people with dementia derive any benefit from antipsychotic medications. Psychotropics have a range of serious side effects and are associated with increased mortality for people with dementia, and expert consensus guidelines recommend psychosocial interventions as a first line approach to behavioural symptoms of dementia. Psychotropics are best used only where there is severe and complex risk of harm, where psychosocial interventions have been exhausted, or where there are co-morbid pre-existing mental health conditions; and the principle behind their use should be "start low, go slowly". Informed consent for their use must be obtained where possible from the person or their carer/substitute decision-maker.<sup>27</sup>

Quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint. All residential aged care facilities should be encouraged to participate in benchmarking and self-audits on the use of restraints and

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<sup>25</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 32.

<sup>26</sup> Peisah C, Skladzien E (March 2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 7.

<sup>27</sup> Peisah C, Skladzien E (March 2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 8.

antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted.<sup>28</sup>

It is also important that the aged care complaints scheme escalates complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety of residents<sup>29</sup>.

### *Appropriate end-of-life care*

Being able to access appropriate care at the end-of-life is a critical factor in a more dignified death, and this is an important element of quality care, particularly for residential aged care services. Alzheimer's Australia has concerns about the current capacity of the aged care system to provide quality care for people with dementia at the end-of-life.

There are a number of factors that contribute to poor access to quality end-of-life care for people with dementia including:

- A lack of understanding that dementia is a terminal illness, which leads to delays or inability to access palliative care services.
- Poor understanding of the legal rights of people living in aged care by both health professionals and family members.
- A relatively low rate of advance care planning by people with dementia and their families which means that there may be uncertainty about the person's wishes for end-of-life care.
- Care providers not adhering to end-of-life care wishes due to staffing issues or concerns about legal implications.
- A lack of assessment and appropriate treatment of pain for people who have difficulty communicating their discomfort.

Important elements of quality end-of-life care include:

- Early planning and documentation of wishes, particularly for people who have progressive neurological diseases such as dementia. This is essential as the ability to communicate and make decisions decreases as the disease progresses.
- End-of-life care discussions with clinicians and family members.
- Planning for end-of-life care that is aligned with the consumer's wishes and goals.
- Shared decision making with the patient, substitute decision maker, family, carers and clinicians.
- Team work and coordination of care amongst various care teams such as health, community, residential and interdisciplinary care teams.
- Obtaining timely and appropriate support during end-of-life care.
- Care staff to have training in providing end-of-life care.
- Ongoing monitoring and evaluation of the effectiveness of end-of-life care systems and processes, including feedback from families and carers.

The residential aged care standards should require aged care providers to encourage residents to complete advance care plans as soon as appropriate. Providers should also work with residents

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<sup>28</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

<sup>29</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

and their families/carers to develop a palliative care plan; and support staff to receive additional training on palliative care supports, and on the legal rights of people at the end-of-life.

The period when the patient is approaching the terminal phase (death is likely in the next two weeks) should be recognised, and this information should be communicated to the family/carers. Medicines for symptom control in the terminal phase should be available in the home.<sup>30</sup>

Aspects of quality care which are essential and should never be compromised include person-centred care, informed choice by consumers, carer support, measures to prevent inappropriate use of restraint, and appropriate end-of-life care.

### ***Integration across the aged care experience***

It is important to note that integration needs to happen not just across the aged care experience, but between aged care services and other important services such as general practice, acute care, and community health services, among others. Effective collaboration and care pathways are critical, particularly for vulnerable older people such as those with dementia.

#### **What core aspects of quality care apply to both residential and home care services?**

All of the core aspects of quality care outlined above apply to both residential and home care services:

- Person-centred care
- Informed choice by consumers
- Carer support
- Measures to prevent inappropriate use of restraint (particularly but not only applicable to residential care)
- Appropriate end-of-life care.

### ***A quality culture that encourages excellence***

#### **What attributes and behaviours do you expect from staff providing care?**

First and foremost, the culture of the aged care service must be to deliver high quality, person-centred care for every individual accessing the services. The attributes and behaviours of the staff providing care must be based on this.

Dementia is an ever changing and progressive condition, often with complex physical comorbidities and potentially psychological and behavioural symptoms which require expert assessment by appropriately trained assessors, and care and management by appropriately trained staff. At present there are insufficient measures to ensure that these critical elements are in place.

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<sup>30</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 32.

Aged care services should have a skilled, experienced and adequate staff contingent to work effectively with people with dementia, and in many cases there is a great deal of room for improvement in this area. Facilities caring for people with dementia and particularly those with BPSD, must have sufficient staff and an appropriate skills mix to provide the care required.

Improved education and training for staff providing care is critical. This needs to be structured, ongoing, appropriate, and encouraged and funded by the employer.

Staff need education and training to build their knowledge and skills in dementia care and management of special needs, in order to provide good care. Education and training on person-centred care is critical, and staff should be educated about dementia and trained in management of BPSD including alternatives to physical and chemical restraints. Staff should have clinical skills in pain assessment and management, including for people with dementia who may be unable to verbalise their needs. Staff should also have education and training in appropriate end-of-life care.

Staff should have formal qualifications linked to both their initial education and training, and their ongoing continuing professional development.

To maintain an adequate, appropriately skilled and sustainable workforce, improved pay and conditions and appropriate career paths for workers in the sector are also needed. Some services may experience high staff turnover due to these issues, and high turnover can increase agitation on the part of consumers with dementia.

To deliver quality care, aged care services must have adequate numbers of skilled, qualified staff, committed to providing person-centred care. Staff must be educated and trained in key aspects of care, including person-centred care; caring for people with dementia; and key aspects of care such as management of behavioural and psychological symptoms of dementia including alternatives to physical and chemical restraints, pain assessment and management, and end-of-life care. To attract and maintain the right workforce, improved pay and conditions and appropriate career paths will be needed.

## ***Leadership and innovation***

### **What is an example of service delivery innovation that stands out to you?**

Alzheimer's Australia offers the following examples of innovation in aged care service delivery, in the areas of palliative care and respite care respectively. These are a couple of examples only and are not exhaustive: there are many other good examples of service innovation across Australia.

### *Home based palliative care: Clare Holland House, ACT<sup>31</sup>*

Dementia is a terminal disease, yet as noted above, achieving good end-of-life care is a major challenge for people with dementia. Clare Holland House, operated by Calvary Health Care ACT, provides specialist medical palliative care services to the ACT and surrounding region. The palliative care specialists are available 24 hours a day, seven days a week to provide support and advice to medical professionals.

As well as operating a hospice, Clare Holland House offers palliative care to patients and their families in the home, including residential aged care facilities. There is both a Home Based Palliative Care Team (for home based care) and a Specialist Palliative Care Aged Care Team (integrating specialist palliative aged care into residential aged care).

The Home Based Palliative Care Team consists of registered nurses, doctors, social workers, pastoral care, occupational therapists, and physiotherapists, all of whom specialise in palliative care. The team aims to improve the quality of life of patients and their families, and promote the comfort and wellbeing of people with terminal illness, focusing not only on physical comfort (managing pain and other distressing symptoms), but also the emotional, spiritual, and psychological wellbeing of patients and their families.

The Home Based Palliative Care Team achieves this by:

- Advising and supporting the primary health care team in the provision of palliative care.
- Managing distressing symptoms.
- Teaching the family how to care for the patient.
- Providing equipment to support the patients to stay in the home setting for as long as possible.
- Providing 24 hour telephone advice (and home visits if necessary).
- Providing support to the bereaved.

The Specialist Palliative Care Aged Care team - Palliative Aged Care Nurse Practitioner Nikki Johnston and Registered Nurse (Level 3) Clare Lovell, Calvary Aged Care - has recently undertaken a research project aimed at integrating specialist palliative aged care into residential aged care, to improve quality of life for residents, as well as improving the quality of their dying, by educating staff and holding case conferences with families and residents (if possible), GPs, and care staff at the facility. The aim is for all practitioners to really know the person with dementia and understand their experiences, so that an individual service can be provided to the person. Complex care planning specific to the person can then be undertaken, along with advance care planning. Goals of care can be discussed, including when staying at home might be the best choice, and when going to hospital may be the best choice, helping the person to die in their preferred place of death. Planning occurs at a time when the person is not in crisis, and helps to ensure the staff can recognise dying, put the plan in place, and achieve the preferred place of death. This is a proactive rather than a reactive intervention, which aims to improve the end-of-life experience for people with dementia and their families, and reduce avoidable hospitalisations.<sup>32</sup>

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<sup>31</sup> <http://www.clarehollandhouse.com.au/medical-services.html>

<sup>32</sup> Personal communication, Nikki Johnston, Palliative Aged Care Nurse Practitioner, 29 October 2015.



## *Alzheimer's Australia WA and Juniper Partnership to offer younger onset dementia specific residential respite services*

Respite provides an important break for the carer as well as an opportunity for social engagement for the person with dementia. Often for carers who maintain employment, respite can be an essential service. Unfortunately there is a lack of age appropriate respite options for people with younger onset dementia and often respite services will turn people away once they have developed behavioural symptoms<sup>33</sup>. This puts enormous strain on the carer and can lead to social isolation for the person with dementia.

There are examples where younger onset dementia specific respite services have been successfully developed and have had a positive impact on clients, such as partnerships developed with service providers through the Younger Onset Dementia Key Worker Program. In WA the Program has worked towards the development of a younger onset specific respite service in partnership with the Independent Living Centre and Juniper. The service is located at Juniper's Hakea House in Bentley and provides respite opportunities for up to six clients over week long or three day 'blocks'. The three day blocks are useful for clients that are new to respite and wish to trial the service in a shorter format.

The service provides opportunities for clients to engage in semi-structured, age appropriate activities in a supported environment while simultaneously creating avenues to build and maintain their social networks. Examples of activities that clients have recently engaged in include: mini golf, fish and chips in Fremantle, table tennis, Wii games tournaments, listening to a live cover band, planting a herb garden, etc. The service also provides carers with an opportunity to take a break from the often intensive support they provide to partners and/or family members living with Younger Onset Dementia. The program is modelled around fostering autonomy and empowering clients and takes a person centred approach in providing respite services that offer meaningful engagement for people with Younger Onset Dementia, are spontaneous and responsive to consumer needs, and encourage a strong sense of community and mateship in participants.

A short video on the project can be viewed [online](#)<sup>34</sup>.

### *Innovative models from the health sector*

There are also opportunities for the aged care sector to learn from successful innovations in the health system, for people with dementia. Examples include:

- **Peninsula Health**, the public healthcare provider for Victoria's Mornington Peninsula, has well developed consumer involvement strategies that ensure consumer experience and consumer engagement is central to their quality improvement processes. Their approach makes 'consumer engagement' everyone's business. The commitment to patient centred care and the consumer engagement 'culture' that Peninsula Health has built has been a significant contributor to making the health service a recognised leader.<sup>35</sup>

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<sup>33</sup> Howe A (2013). Alzheimer's Australia Respite Review: Policy Paper. Canberra: AA

<sup>34</sup> <https://www.youtube.com/watch?v=LSAKXjibewNQ>

<sup>35</sup> [http://ourhealth.org.au/consumer-rep-support/consumer-and-community-engagement/best-practice-practice#.VjASR\\_mqpBc](http://ourhealth.org.au/consumer-rep-support/consumer-and-community-engagement/best-practice-practice#.VjASR_mqpBc)

- **NSW Agency for Clinical Innovation (ACI) Care of confused Hospitalised Older Persons (CHOPs) program.** This program is a collaboration between the ACI and the NHMRC Cognitive Decline Partnership Centre. The program centres around seven principles to identify people with delirium, put in place plans for their management, ensure good communication and a person-centred supportive care environment. It recognises carers as partners in care and some very simple methods to help everyone in the care chain 'know the person'.<sup>36</sup>
- **Dementia Care in Hospitals Project (DCHP):** Hospitals can be confusing and dangerous places for people with dementia. The unfamiliar environment of the hospital can cause confusion and distress and may lead to an increase in behavioural and psychological symptoms, and poor communication can contribute to poor outcomes. DCHP is a national project based on a model developed by Ballarat Health Services in conjunction with Alzheimer's Australia Victoria and people with dementia and their families. It has been implemented in over 20 hospitals across Victoria, and is now being piloted at a further four hospitals nationally. This approach, based on staff education and cultural change linked with an overbed alert (a visual Cognitive Impairment Identifier), has been shown to improve staff and carer satisfaction with the care provided to people with dementia in acute care facilities<sup>37 38</sup>.

#### *International examples of consumer involvement*

There are good international examples of consumer involvement in the evaluation of health and aged care services. These have included consumer participation in auditing processes, audit tools designed to capture the consumer experience for those unable to verbalise their experience, consumer input into staff education and training, the grading of services, utilising consumer groups to improve services, and consumer driven ombudsman programs. There are opportunities to adapt and incorporate such processes in Australia<sup>39</sup>.

#### **What do you think is the greatest challenge for service providers in achieving quality?**

Service providers may be challenged to provide quality care at all times for people with dementia and particularly those with severe BPSD. Some aspects of this challenge might include:

- Challenges in recruiting and retaining an adequate, appropriately educated, trained and skilled staff contingent to provide quality care for people with dementia including those with BPSD.

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<sup>36</sup> [http://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0006/249171/CHOPS-key-principles\\_2014.pdf](http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0006/249171/CHOPS-key-principles_2014.pdf)

<sup>37</sup> [https://fightdementia.org.au/sites/default/files/08\\_Mark\\_Yates\\_The\\_Ballarat\\_Approach\\_The\\_Dementia\\_Care\\_in\\_Hospitals\\_Program.pdf](https://fightdementia.org.au/sites/default/files/08_Mark_Yates_The_Ballarat_Approach_The_Dementia_Care_in_Hospitals_Program.pdf)

<sup>38</sup> Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 13.

<sup>39</sup> Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* pp 22-27.

- Challenges in providing quality care within available resources including funding issues. Funding arrangements must support the delivery of quality aged care, including to people with BPSD.
- Challenges in accessing appropriate specialist support services for people with dementia, including BPSD.

Funding arrangements must support the delivery of quality aged care, including to people with behavioural and psychological symptoms of dementia.

## CONCLUSION

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, quality care for people with dementia must be core business for the aged care system, including both home-based care and residential care. Considerations of quality in aged care, including standards and assessment, must be fully inclusive of issues relating to dementia. We trust that the matters raised in this submission will be of assistance to the Australian Aged Care Quality Agency in the further development of a quality system for aged care that ensures the best outcomes for all consumers and carers.