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SUBMISSION TO SINGLE
QUALITY FRAMEWORK DRAFT
AGED CARE QUALITY
STANDARDS CONSULTATION
PAPER

APRIL 2017

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide input on the Department of Health's Single Aged Care Quality Framework - Draft Aged Care Quality Standards (the draft standards).

Overall, we welcome the approach towards a single set of standards for aged care services to replace the multiple current standards. These standards will cover a broad range of services from entry level basic home support services to end-of-life care, and we are very encouraged to note the strong focus on consumer outcomes. 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.

However, we do note the remarkable absence of cognitive decline or dementia across the draft standards. This is very concerning given that 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 remains positive about achieving greater consumer choice and flexible services that will be available to consumers under the ongoing reforms, and as demonstrated through these draft standards. For people with dementia and their families and carers, these objectives are particularly important given the progressive nature of the condition which requires responsive and individually tailored solutions from service providers that will evolve over time to remain aligned with the individual's situation. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported.

Alzheimer's Australia urges the Department to consider and include issues relating to the safety and quality of care for people with dementia through these draft standards. As the prevalence of dementia increases in our community, it is critical that all considerations of quality in aged care, including standards and assessment, must be fully inclusive of issues relating to dementia.

In responding to this consultation paper, Alzheimer's Australia makes the following broad recommendations:

- Alzheimer's Australia recommends that Standard 3 include a specific mention and reference to Dementia and BPSD when discussing high impact and high prevalence risks across aged care service delivery.
- Alzheimer's Australia recommends that the quality standards should be continually monitored and strengthened to drive continuous improvement.
- 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. Alzheimer's Australia recommends that the single quality framework be extended to cover all assessment services across aged care.

- Alzheimer's Australia recommends the strengthening of crucial aspects of quality care across the draft standards, including person-centred care, informed choice by consumers, carer support, measures to prevent inappropriate use of restraint, and appropriate end-of-life care.

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.¹ It is cloaked in stigma and misunderstanding,² isolates people with dementia and their carers from social networks,³ and carries significant social and economic consequences.⁴

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. There are more than 410,000 Australians living with dementia. By 2025, the number of people with dementia is expected to increase to more than 530,000. Without a medical breakthrough, the number of people with dementia is expected to be 1.1 million by 2056. ⁵Dementia is the second leading cause of death of Australians² contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year.

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 annum⁶. Currently around 237 people are joining the population with dementia each day. The number of new cases of dementia will increase to 318 people per day by 2025 and over 650 people by 2056. Dementia also has a profound social impact. People with dementia experience stigma and social isolation⁷, and family carers often find it difficult to balance work, life and caring responsibilities⁸.

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 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 men⁹. The higher lifetime risk for women is mainly due to women's longer life expectancy.

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.¹⁰ Provision of dementia specialist comprehensive community based support,

¹ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

² George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

³ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁴ 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

⁵ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

⁶ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁷ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁸ 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.

⁹ 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

¹⁰ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

and appropriate, high quality residential care are therefore both critical to meeting the needs of people living with dementia.

COMMENTS IN RESPONSE TO THE DRAFT STANDARDS PAPER

Emphasis on care and management of Dementia

As detailed in the section above, 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.

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.¹¹

Alzheimer's Australia is therefore disappointed to note that the Standards do not acknowledge or consider the high risk and prevalence of Dementia and associated cognitive decline. We recognise that from the perspective of a service provider the concept of person-centeredness should mean the needs of each individual are understood and considered regardless of their unique situation. However as the peak organisation representing and advocating for the needs of people with dementia it is our role to ensure the needs of people with cognitive issues are protected. This is particularly significant around the discussion of *Standard 3: Delivering personal care and/or clinical care*. This concern was also raised by an anonymous query to the National Dementia Helpline :

"I am a quality assessor with the Australian Aged Care Quality Agency - the body responsible for the accreditation of aged care homes and the quality review of home care services. I would rather not use my name as I prefer to remain anonymous. I have been reviewing the recently released Draft Aged Care Quality Standards (see <https://consultations.health.gov.au/aged-care-access-and-quality-acaq/single-quality-framework-draft-standards/>) and would like to highlight for your organisation that, unlike under the current residential accreditation framework, there is no specific mention of dementia or the management of behavioural care needs. (The current framework has expected outcome 2.13 - Behaviour management).

While I applaud the focus on end of life care in the draft standards (in requirement 3.3) and the specific mention of "falls, pressure injuries, medication misadventure, choking, malnutrition, dehydration, pain and delirium" (in requirement 3.7), I am stunned and appalled there is no mention of dementia and the management of behaviour care needs. I did a word

¹¹ 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

search on 'dementia' in the document and found only one reference in a footnote; there are also no instances of the word 'behaviour'. And yet this is one of the key risk management areas for residential and home aged care providers AND one of the aspects of care where providers have the capacity to make a huge impact on a person's quality of life (and, sadly, often fall short). Note that the management of behavioural care needs often underlies all of the identified care issues in requirement 3.7!! I believe some specific mention of the management of behavioural care needs is absolutely necessary in any new set of aged care standards and I hope Alzheimer's Australia is able to promote this view strongly to the Dept of Health."

Alzheimer's Australia acknowledges that 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.

The Government has already recognised the need for dementia specialist service delivery, announcing the establishment of Specialist Dementia Care Units, which will provide one-on-one care for people who experience very severe behavioural and psychological symptoms of dementia (BPSD). This recognition of dementia specialist needs must be adopted across the development of quality standards and assessment processes for aged care.

Given the association between a diagnosis of dementia and high impact, and high prevalence risks in the delivery of personal and clinical care, Alzheimer's Australia's position is that it is essential that dementia be identified as a specific consideration.

Alzheimer's Australia recommends that Standard 3 include a specific mention and reference to Dementia and BPSD when discussing high impact and high prevalence risks across aged care service delivery.

Implementation of Standards and ongoing improvement process:

Alzheimer's Australia supports the broad focus on consumer outcomes and experience. We note and applaud the inclusions of statement outcomes for consumers which aim to provide consumers with greater understanding of service standards and control over their own health and wellbeing by allowing them to assess the quality of care and services they access. However, without a corresponding assessment methodology it is difficult to determine how these outcomes will be implemented, monitored and how they will feed into an ongoing improvement process.

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."¹²

As the Aged Care Quality Agency itself notes, 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 current 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 draft standards, to stimulate continuous improvement in service delivery.

Alzheimer's Australia recommends that the draft quality standards should be continually monitored and strengthened to drive continuous improvement.

Ensuring Access to Appropriate and Quality Services

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.

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 also 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. Measures are needed throughout the system to ensure that that does not happen, and these should be build into the standards as well.

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.

Thus Alzheimer's Australia recommends that that the draft Standards are explicitly inclusive of all potentially vulnerable groups with specific needs, including not only Aboriginal and Torres Strait Islander people, but also people from culturally and linguistically diverse backgrounds, people from the LGBTI community, people from rural and remote areas, homeless people, and other vulnerable groups. Each of these groups has specific and identifiable safety and quality risks which need to be addressed.

¹² 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.

Another objective of the draft system should be to support people with dementia to live at home for as long as possible, as this is the preference of most people with dementia and their family members, and is also more cost-effective for the aged care and health systems. We know that 70% of people with dementia currently live in the community, and over 90% of these people do so with the support of an informal/family carer. These carers often experience multiple negative impacts – psychological, physical and financial – and delays in access to the formal care and support which the person requires can only compound this situation.

Supporting the sustainability of the caring arrangements which allow people with dementia to live in the community for as long as possible must be a priority. Where it is known at the outset that a person's condition will inevitably deteriorate over time, as is the case for a person with dementia, measures must be in place to ensure seamless and speedy progression through care package levels as the person's needs increase. To underpin this, better assessment of cognitive impairment is needed in the aged care assessment process. Alzheimer's Australia is of the view that these standards should therefore be applicable to processes that determine assessment of consumer needs, such as Regional Assessment 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; Alzheimer's Australia recommends that the single quality framework be extended to cover all assessment services across aged care.

Essential aspects of genuine consumer centred care

Feedback from the Alzheimer's Australia Dementia Advisory Committee notes that the current standards still have a fairly narrow and predominantly medical model of care oriented view to determining consumer need. The following are some aspects that are essential to ensuring quality of aged care services:

Person-centred care and Dignity

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.¹³

¹³ Hughes J (June 2013), Alzheimer's Australia Paper 35, *Models of dementia care: Person-centred, palliative, and supportive*, p 9.

Person-centred care must be the basis upon which all aged care services deliver care, including to people with dementia, and this should be enshrined through the draft standards as well.

Alzheimer's Australia's consumer representatives have further suggested that all aged care services covered by these draft Standards should also support the '10 Principles of care' as promoted by [Dignity in Care Australia](#).

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.

Consumer-centred approaches and quality-rating systems are developed on the assumption that people can make informed choices, therefore the quality and simplicity of the information for comparing options is a key factor affecting their ability to 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 and linguistically diverse backgrounds, rural and remote areas, and Aboriginal and Torres Strait Islander communities.

Consumers in Alzheimer's Australia's networks have called for resources and toolkits for consumers, including information on the rights of consumers and the responsibilities of providers; consumer checklists for entering into care agreements; information about the Aged Care Complaints Commissioner; information on co-contribution and payments for aged care services; information to support consumers to compare and choose between providers including information on case management and what consumers can expect for this service; fees and charges; service availability; hours of operation; the education and qualifications of staff; the provider's complaints process; and provision of specialised services (eg for CALD, LGBTI, Aboriginal and Torres Strait Islander clients). Consumers also require accurate and appropriate information regarding the quality of care from service providers which should include consumer feedback.

Carer support

With the increasing reliance on home care, it is essential to ensure that there is adequate support for family carers. 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 occurs¹⁴. Respite plays a critical role in providing a break for carers as well as an important opportunity for social engagement for the person with dementia¹⁵. Often respite is essential to ensuring that family members can continue caring for the person with dementia at home¹⁶. The draft standards should therefore include a reference supporting a consumer by providing respite opportunities for carers.

Alzheimer's Australia further notes that when carers are able and willing, they can play a key role in providing support and care for the person with dementia in the residential care environment. Carers may be best placed to understand how to communicate effectively with the person with dementia, what certain behaviours mean, what the person's preferences are, and what their medication regime involves. They may also be best placed to identify when a person with dementia has experienced acute deterioration¹⁷. Alzheimer's Australia therefore strongly recommends that the draft standards make an explicit reference to carers, and ensure that all aged care organisations have systems to ensure that carers are supported to participate in the provision of care in accordance with the wishes of the consumer and carer.

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 applied¹⁸.

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.

¹⁴ Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 32.

¹⁵ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

¹⁶ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

¹⁷ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 10.

¹⁸ Peisah C, Skladzien E (March 2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 7.

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.¹⁹

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 antipsychotic medications to ensure that these are used appropriately, with consent and only when all other options have been exhausted.²⁰

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 residents²¹.

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.

¹⁹ Peisah C, Skladzien E (March 2014), Alzheimer’s Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 8.

²⁰ Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

²¹ Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 6.

- 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 draft aged care standards should require aged care providers to encourage consumers to complete advance care plans as soon as appropriate. Providers should also work with residents 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.²²

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.

²² Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 32.

COMMENTS ON SPECIFIC STANDARDS

Overall, Alzheimer's Australia is pleased to note the strong consumer centred focus that the draft standards take. But without supporting documentation such as interpretive guides, self-assessment tools etc. that can outline how these outcomes will be assessed and achieved, it is hard to determine their impact.

1. Consumer dignity, autonomy and choice

According to the Australian Commission of Safety and Quality in Healthcare²³, 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.

Alzheimer's Australia supports the broad intent of consumer centred 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.

Right now it is very difficult for consumers to ascertain quality of dementia care within residential care facilities. This makes the ongoing move to a more market-driven system challenging, as informed choice is not possible without good information. As noted in previous sections, it is important to ensure a focus on *informed* decision-making, and the challenges and issues in achieving this in the case of consumers with dementia as the disease progresses.

2. Ongoing assessment and planning with consumers

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 review²⁴.

²³ Australian Commission on Safety and Quality in Health Care. Safety and Quality Improvement Guide Standard 2: Partnering with Consumers (October 2012). Sydney. ACSQHC, 2012.

²⁴ Alzheimer's Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 16.

The National Safety and Quality Health Service (NSQHS) Standards provides an example on how this can be built into the draft standards. The focus in the NSQHS Standards on consumer involvement and data collection has led the states to release data on patient experiences surveys. For example, most states have publically available reports of patient experience data from specific patient groups and provides comparisons across hospitals.

It would be such a step forward in terms of transparency to have a national consumer experience survey of all Government funded aged care services which was released publically on an annual basis, and Alzheimer's Australia looks forward to working with the Aged Care Agency to progress work in this area.

3. Delivering personal care and/or clinical care

As highlighted in previous sections, dementia is a progressive disease and people with dementia require a range of supports and care. 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 community²⁵. Provision of comprehensive dementia specialist home based care, respite, and appropriate, high quality residential care, are therefore critical to meeting the needs of people living with dementia and their families. Given the association between a diagnosis of dementia and high impact, and high prevalence risks in the delivery of personal and clinical care, Alzheimer's Australia's position is that it is essential that dementia be identified as a specific consideration.

In revising and refining the draft standard 3 around clinical care, it can be useful to compare and the terms of measuring and promoting quality is the hospital system. NSQHS Standards were developed by the National Commission on Safety and Quality in HealthCare to drive the implementation of safety and quality systems and improve the quality of health care in Australia. The 10 NSQHS Standards provide a nationally consistent statement about the level of care consumers can expect from health service organisations.

The implementation of the standards has highlighted areas for improvement with most services being required to take at least one remedial action as a result of the accreditation process- often in the area of preventing infections or partnering with consumers. This is not a sign of failure on the part of the hospitals but instead a sign of the effectiveness of the standards in driving improvement. Importantly there are a range of resources including Guides for each standard to ensure a consistent understanding and implementation of the Standards.

The next version of the Standards which will be finalised in 2017 will include specific actions for recognition of cognitive impairment and action to improve dementia care. It will also include a clinical standard on delirium. The Commission has also embarked on an awareness and information campaign, *Caring for Cognitive Impairment* to encourage hospitals to improve quality of dementia and to help prepare health services for the anticipated requirements of the NSQHS Standard V2 and Delirium Clinical Care Standard.

²⁵ Australian Institute of Health and Welfare (2012) Dementia in Australia.

Alzheimer's Australia recommends that like the NSQHS Standards, the draft standards also include a reference to dementia, BPSD and cognitive impairment, especially when discussing effective clinical care.

4. Delivering lifestyle services and supports

Consumers want to have clear information about the quality of services being offered and the impact of those services on quality of life. Right now, there is not a single publicly reported measure of quality in aged care and as a result consumer choice is limited. The funding model within aged care is clinically focused with payments based on the level of clinical care required. While this approach recognises the costs of clinical care, it does not recognise the importance of a more social model of support and actually works to financially penalise services that improve the health outcomes for consumers. So besides these draft standards, work also needs to be done towards developing a new funding model which rewards facilities for quality outcomes or promoting wellbeing and independence. It is essential that key agencies provide guidance to service providers about new models of care which support people with dementia to live with as high a quality of life as possible.

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."

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. These attributes can be applied to service provision and organisations across the broader spectrum of aged care:²⁶

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 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.

5. Service environment

Residential Aged Care settings are often confusing places for people with dementia. The environment of the facility can lead to increased confusion and disorientation for people with dementia, contributing to their distress. Design of the physical environment is one important element in making an organisation dementia-friendly. Alzheimer's Australia has developed a set of checklists for creating dementia-friendly communities, including checklists for organisations on creating dementia friendly indoor and outdoor environments.²⁷ For example, just a few of the ways that indoor environments can be made more dementia friendly in accordance with the relevant checklist include:

- Steps clearly marked and lit, with guard and handrails on both sides, smooth non-slip non-glare surfaces, and nearby seating.

²⁶ 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

²⁷ https://fightdementia.org.au/sites/default/files/Business_checklist.pdf

- Doors with lever-type handles and no more than 2 kilograms of pressure to open.
- No areas of deep shadow or glaring light.
- Flooring in clear colour contrast and material to walls and furnishings.
- Colour contrast toilet seats with toilet bowls and floor, and provide consistent signage.

Signage and directions in the service environment should consider the needs of people with dementia and other forms of cognitive impairment. Signage should be simple and give clear and essential information only, and should be fixed to walls at eye level.²⁸

As well as words, signage should also include pictures (for example, a picture of a toilet makes more sense to someone living with dementia than the word). Arrows on the floor or wall for directions are better than written directions. When colours are used for signs they should be bright (eg red), and contrast with the background.

Pictorial signage and site diagrams will also be helpful for other groups in the community who may have difficulty with written English (for example some people from culturally and linguistically diverse backgrounds).

Alzheimer's Australia recommends that the draft Standards and/or the processes relating to their implementation, refer all aged care service providers to the Alzheimer's Australia checklists as a resource for making their physical environments more dementia-friendly.

It is also important to note that a better service environment needs to be ensured not only across aged care 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.

6. Feedback and complaints

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.

Alzheimer's Australia also recommends that the draft standards or supporting documentation include references that ensure:

- complaints being able to be made without fear of retribution or interruption of services
- the right of the consumer to nominate how, when and where they make a complaint including their key contact at the organisation

²⁸ https://fightdementia.org.au/sites/default/files/Business_checklist.pdf

- that there are various types of complaints that have to be handled in different ways e.g. criminal allegations, reportable incidents etc.

Often people with dementia and their carers have difficulty navigating the aged care system and related health and care systems. Aged care organisations need to consider providing care co-ordinators or navigators – such as an advocate or social worker who has education and training to work with people with dementia – specifically to assist people with dementia and their carers. The quality assessment process should also address this need.

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 process²⁹ - as currently occurs in the health sector through accreditation processes including those conducted by the Australian Council on Healthcare Standards care quality and compliance processes.

7. Human resources

Care for people with dementia is a core responsibility of all providers, and there must be clear criteria and expectations to support this. For example, all providers should be required to demonstrate that their staff are appropriately educated and trained in dementia care, and that this is maintained over time.

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.

A recent Alzheimer’s Australia focus group of carers of people with dementia has unearthed significant carer concerns about workforce trends in residential aged care. Changes to the workforce have been distressing for residents with dementia, staff and families. Carers in this situation report feeling trapped, as they worry a move to another facility would jeopardise the health and further upset their family member. Carers who were/are satisfied with the care received still report one their biggest concerns was/is a change in management or a shift to a “for profit” model happening around them. Carers have a high regard for residential aged care staff and would like to see them better compensated and acknowledged for the work they do. There is great unease regarding recent changes around removing standards regarding rostering of Registered Nurses and the repercussions on care.

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.

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

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 ensure quality care, management in aged care services must be committed to person-centred high quality care, and services must have adequate numbers of skilled, qualified staff. Mandated minimum ratios of staff to residents, and mandated minimum levels of qualified nursing staff, are required; including a requirement for all stand-alone residential aged care facilities to have a Registered Nurse on site at all times.

A comprehensive aged care workforce strategy is required to identify and address current and future workforce supply and quality issues. The strategy should include consideration of new models of care and innovative uses of technology. The strategy should include a focus on retention by protecting investment at the industry level rather than at the organisational level for care staff, and nursing and allied health professionals, for example through taxation incentives for staying in the sector.

8. Organisational governance

A cohesive, structured and integrated national approach to dementia education and training is needed, including minimum standards for education and training for those working with people with dementia. This approach should include a focus on leadership and cultural change at organisational level, to maximise opportunities to translate learning into improved practice. The approach should be supported by government and by the aged care industry, and focus on achieving sustainable changes to practice which lead to better outcomes for people living with dementia. Clinical and care related training, including care for people with dementia, must be part of the mandatory training schedule for residential aged care facilities. Backfill is a critical element to ensure staff attendance at training and needs to be allowed for, particularly given the challenges this can pose particularly in rural and remote areas where backfill personnel may not be readily available. GP education also needs to be addressed, including to ensure that GPs can implement a range of care options rather than defaulting to pharmacological interventions; and qualifications should be mandatory for lifestyle and leisure care roles.

It is also important to involve consumers at the organisational governance level to drive real improvement in quality and assessment processes. Another example is to study the

approach taken by the NSQHS around involvement of consumers. One of the ten standards in the NSQHS is Partnering with consumers. In brief, this Standard requires that:

- Governance structures are in place to form partnerships with consumers and carers.
- Consumers and carers are supported by the health service organisation to actively participate in the improvement of the patient experience and patient health outcomes.
- Consumers and carers receive information on the health service organisation's performance and contribute to the ongoing monitoring, measurement and evaluation of performance for continuous quality improvement.

The Commission has resources available to assist with partnering with consumers and has also run seminars on partnerships with consumers.

Right now, while the draft standards make reference to person centred care and consumer directed care, there is no mention of partnerships with consumers in terms of Governance or supporting consumers to be actively involved in quality improvement. Active involvement goes beyond a basic access to a feedback and complaint mechanism, and involved embedding consumer participation at the heart of designing, developing and implementing any effective quality and assessment process.

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 Department of Health in the further development of a quality system for aged care that ensures the best outcomes for all consumers and carers.

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.

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care. 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.

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 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.