

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
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**SUBMISSION TO NATIONAL SAFETY
AND QUALITY HEALTH SERVICE
STANDARDS VERSION 2:
CONSULTATION DRAFT**

OCTOBER 2015

EXECUTIVE SUMMARY

This submission from Alzheimer's Australia is made in response to the document released by the Australian Commission on Safety and Quality in Health Care (ACSQHC), *National Safety and Quality Health Service Standards Version 2: Consultation Draft* ("the NSQHS Standards").

Alzheimer's Australia is supportive of the intent to include safety and quality of care for people with dementia and delirium throughout the NSQHS Standards. As the prevalence of dementia increases in our community, it is critical that all hospitals and other health 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 involvement not only in the development of the NSQHS Standards, but also in all of the processes relating to their implementation.

This submission has been developed in consultation with Alzheimer's Australia's consumer representatives. In this submission we offer suggestions aimed at strengthening the focus on quality care for people with dementia, and on consumer involvement, within the NSQHS Standards. Specific suggestions are also made to enhance several detailed aspects of the standards.

CONTEXT: ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the national peak body representing people with dementia and their families and carers. Our vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia.

Alzheimer's Australia represents and supports the more than 342,800 Australians living with dementia¹, and the more 1.2 million family members and others involved in their care². 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 a sponsoring member of the National Aged Care Alliance and are involved in other key

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

² Alzheimer's Australia, (2011) *Pfizer Health Report Issue #45 – Dementia*, Pfizer Australia

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 in Australia

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.³ It is cloaked in stigma and misunderstanding,⁴ isolates people with dementia and their carers from social networks,⁵ and carries significant social and economic consequences.⁶

The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are now more than 342,800 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 dementia⁷. 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 2050⁸. Dementia is the second leading cause of death in Australia, and there is no cure.⁹

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 annum¹⁰. Dementia also has a profound social impact. People with dementia experience stigma and social isolation¹¹, and family carers often find it difficult to balance work, life and caring responsibilities¹².

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 men¹³. The higher lifetime risk for women is mainly due to women's longer life expectancy.

³ Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

⁴ George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

⁵ Blay, S., & Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

⁶ 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

⁷ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁸ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁹ Australian Bureau of Statistics (2015) *Causes of Death, Australia*, 2014: Cat no.3303.0

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

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

¹² 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.

¹³ Sehadi 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

Traditional responses to dementia based on residential care are becoming unsustainable due to high and steadily growing service demands. In addition, changes in community expectations are creating greater demand for community based, consumer-driven models of support and a broader range of specialist services, with 70% of people with dementia choosing to remain living at home¹⁴.

Dementia care in hospital and other healthcare settings

As the incidence of dementia is correlated with advancing age, and dementia is often co-morbid with other conditions, people with dementia, both those living at home and those living in residential care facilities, are frequent users of hospitals and other health care services.

One in every four people with dementia requires hospital services each year, which is twice the rate for people of the same age who do not have dementia. People with dementia have worse clinical outcomes including longer stays in hospital, higher mortality, and greater likelihood of readmission. Dementia often goes unrecognised or undocumented, which can contribute to the needs of the person with dementia not being met.¹⁵

There is room for improvement in the safety and quality of care provided to people with dementia. To illustrate, a 2013 AIHW report on dementia care in hospitals found that:

- Identification and reporting of dementia is often poor in hospitals: For 47% of the episodes of hospital care for more than 20,000 people with dementia in the study group, dementia was not recorded as either a principal or additional diagnosis.
- People with dementia generally stay in hospital longer and have higher associated costs of care.
- A range of strategies have potential to improve the outcomes of care and reduce costs. Strategies suggested by the AIHW report for implementation by hospitals included: the development of specialised positions for the care and management of older persons presenting to the emergency department; rapid assessment and response teams in the emergency department; the use of assessment tools to support the assessment and referral of patients with suspected cognitive impairment and/or delirium; online information and resource portals on dementia for hospital staff; specialised services such as liaison psychiatry services, and specialist wards and units; hospital education programs to inform and educate clinicians and staff about dementia; and better management of associated conditions, such as rehabilitation after falls, and identification and treatment of delirium¹⁶.

An expert symposium held by Alzheimer's Australia in 2014 identified the following urgent issues affecting people with dementia in the hospital system:

- The need for better identification of cognitive impairment in hospitals.
- Increased training for all hospital staff including how to communicate with a person with dementia, and how to respond to the behavioural and psychological symptoms of dementia.
- More extensive and systematic involvement of carers as partners in care.

¹⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹⁵ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, pp 4-6.

¹⁶ Australian Institute of Health and Welfare (2013), *Dementia care in hospitals: Costs and strategies*.

- Creation of appropriate physical environments to reduce confusion and distress.¹⁷

The symposium recommended the following strategies to improve outcomes for people with dementia in hospitals:

- Identify and manage dementia at hospital admission and plan for discharge from the outset.
- Involve family carers in the care and support of patients.
- Train staff to better understand dementia and communicate more effectively with people with dementia.
- Use alternatives to antipsychotic medication and sedatives, such as psychosocial interventions.
- Adapt the hospital physical environment to reduce distractions and help orient people with dementia.
- Reduce avoidable hospital admissions.¹⁸

Most of these strategies are also applicable to other healthcare services in addition to hospitals, and Alzheimer's Australia is pleased that these issues are generally well reflected in the draft NSQHS Standards.

Alzheimer's Australia has separately supported the development of national standards in acute care for people with dementia and delirium. Delirium is common in older people and will likely increase due to the ageing population and the greater likelihood of hospitalisation associated with older age¹⁹. People with dementia are at a five-fold risk of developing delirium during hospitalisation^{20,21}. Current evidence suggests that delirium may worsen the prognosis of dementia, alter the clinical course and trajectory of cognitive decline, and may also be associated with significantly worse long-term outcomes than in people without delirium. This can include longer stays in hospital, decline in physical and cognitive functioning, hospital readmission, entry into residential care and mortality^{22,23,24}. The proper identification of delirium is therefore the first step in ensuring effective treatment²⁵.

Overall, it is known that people with cognitive impairment who are hospitalised are at significantly increased risk of adverse events and preventable complications. Given the high and rising prevalence of dementia, addressing safety and quality of care issues for people with cognitive impairment must be core business and a high priority for hospitals and other healthcare services.

¹⁷ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 5.

¹⁸ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 5.

¹⁹ Travers C, Byrne GJ, Pachana NA, Klein K, Gray L. (2013). Delirium in Australian Hospitals: A Prospective Study. *Current Gerontology and Geriatrics Research*. <http://dx.doi.org/10.1155/2013/284780>

²⁰ Elie M, Cole M, Primeau F, Bellavance F. Delirium risk factors in elderly hospitalized patients. *J Gen Intern Med*. 1998;13(3):204-212.

²¹ National Institute for Health and Clinical Excellence. Delirium: diagnosis, prevention and management; Clinical Guideline. 2010. <http://www.nice.org.uk/nicemedia/live/13060/49908/49908.pdf>

²² Fick DM, Agostini JV, Inouye SK. Delirium superimposed on dementia: a systematic review. *J Am Geriatr Soc* 2002;50:1723-32.

²³ Rockwood K, Cosway W, Carver D et al. The risk of dementia and death after delirium. *Age Ageing* 1999;28:551-556.

²⁴ Inouye SK. The dilemma of delirium: clinical and research controversies regarding diagnosis and evaluation of delirium in hospitalized elderly medical patients. *Am J Med* 1994;97:278-288.

²⁵ Gagliardi JP. Differentiating among Depression, Delirium, and Dementia in Elderly Patients. *Virtual Mentor*. 2008;10(6):383-388.

COMMENTS ON THE NSQHS STANDARDS

Overarching Comments

Alzheimer's Australia is supportive of the intent to include quality care for people with dementia and related issues such as delirium throughout the NSQHS Standards, rather than having these issues as separate items within the standards, or an "add on". As noted previously, it is critical that all hospitals and other health 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 strongly advocates the importance of ensuring strong consumer involvement not only in the development of the NSQHS Standards, but also in all of the processes relating to their implementation.

As noted above, an Alzheimer's Australia expert symposium has recommended a range of strategies to improve outcomes for people with dementia in hospitals, including: identifying and managing dementia at hospital admission and planning for discharge from the outset; involving family carers in the care and support of patients; training staff to better understand dementia and communicate more effectively with people with dementia; use of alternatives, such as psychosocial interventions, to reduce the use of antipsychotic medication and sedatives; adapting the hospital physical environment to better cater for people with dementia; and reducing avoidable hospital admissions.²⁶ Alzheimer's Australia strongly advocates that the NSQHS Standards support these recommended strategies.

Alzheimer's Australia's consumer representatives have further suggested that all facilities covered by the NSQHS Standards should support the '10 Principles of care' as promoted by Dignity in Care Australia (available at <http://www.dcsi.sa.gov.au/services/disability-services/dignity-in-care-principles-home>).

It is also important that the NSQHS 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.

²⁶ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 5.

Comments on specific standards and actions

Alzheimer's Australia offers the following comments on specific aspects of the NSQHS Standards.

Standard GS: Governance for Safety and Quality

GS 11.1: The health service organisation has health care records systems that:

- a) *Make the healthcare record available to clinicians at point of care*
- b) *Comply with security and privacy regulations*
- c) *Enable systematic audit of clinical information*
- d) *Integrate multiple information systems, where they are in use.*

Alzheimer's Australia suggests the addition of another sub-clause e): "Enable prompt and accurate discharge information to be disseminated to relevant parties".

GS17.1a: The health service organisation designs the environment to maximise safe and high-quality care within the constraints of the existing facilities, where relevant.

Hospitals are busy, noisy, and often confusing places for people with dementia. The environment of the hospital can lead to increased confusion and disorientation for people with dementia, contributing to their distress. Recent research suggests that only 14% of hospitals have secure, safe, user friendly wards or areas for confused patients.²⁷

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.²⁸ 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.
- 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.

Alzheimer's Australia recommends that the NQSHS Standards and/or the processes relating to their implementation, refer all hospitals and other healthcare organisations to the Alzheimer's Australia checklists as a resource for making their physical environments more dementia-friendly.

GS17.2: The health service organisation provides clear signage and directions for locating services and facilities.

Alzheimer's Australia supports the inclusion of this new action.

²⁷ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 11.

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

Clear signage and directions 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.²⁹

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).

GS17.3: Where consumers are admitted, the health service organisation has systems that allow for consumer-based visitation.

Alzheimer's Australia supports the inclusion of this new action.

Standard PC: Partnering with consumers

Partnering with consumers is a critical element of ensuring safety and quality in healthcare. Healthcare organisations need to develop partnerships with *all* consumers, including people with dementia and their carers.

Standard PC: Partnering with consumers, needs to be inclusive of carers in the case of people with dementia or other cognitive impairments. There is significant anecdotal evidence that improving communication with carers, as advocates for patients and as participants in care planning, has beneficial effects on patient experience and outcomes, and can contribute to quality care³⁰.

Alzheimer's Australia supports the inclusion of the new criterion on health literacy and health information, which aims to ensure everyone involved in the partnership can give, receive, interpret and act on information in an effective way.

Alzheimer's Australia is also supportive of the inclusion of the new criterion on partnership with consumers in their own care, which aims to achieve a better care experience, which should lead to better adherence to treatment, better clinical outcomes, better consumer safety in hospitals, and less use of healthcare.

Often people with dementia and their carers have difficulty navigating the healthcare system and related health and care systems. Healthcare organisations need to consider providing care co-ordinators or navigators – such as an advocate or social worker who has education and training to

²⁹ https://fightdementia.org.au/sites/default/files/Business_checklist.pdf

³⁰ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, pp 12-13.

work with people with dementia – specifically to assist people with dementia and their carers. The NSQHS Standards should address this need.

PC 4.3: Clinicians provide consumers with information about health and healthcare that:

- a) *Is easy to understand and use*
- b) *Is in a format that meets their needs*
- c) *Includes information about treatment and options, risks and benefits, the care plan, what they need to do after leaving the organisation, and managing their medicines, where relevant.*

It is suggested that sub-clause c be expanded to read: "...*managing their medicines and other health monitoring routines, where relevant*". This will allow for consideration of issues such as the need for the health service to ensure that customers are competent to carry out blood glucose monitoring, and other health maintenance measures that may be required.

PC5.3: The health service organisation has systems to identify the capacity of a consumer to make decisions about their own care and provide informed consent.

Alzheimer's Australia notes that there are systems in place across states and territories to determine the capacity of persons to make decisions about their care and provide informed consent, and that any decisions or actions of health service organisations in this regard must be made within the legislative framework. This should be specified in the NSQHS Standards.

The legislation across Australia is based on the international principle of "presumption of capacity". An individual is assumed to have capacity to make their own decisions unless it can be proven that they do not have such capacity. A claim by a family member or non-professional person that a person does not have capacity is not enough for the person to be prevented from making their own decisions. In addition, capacity is decision-specific so even if a person has been diagnosed with dementia, they may still have capacity to make all or at least some of their own decisions, especially if the person has been diagnosed with early dementia.

PC5.4: The health service organisation has systems to identify a substitute decision maker if a consumer does not have the capacity to make decisions for themselves.

Again, any decisions or actions by health service organisations in respect to substitute decision making, must be made within the legislative framework, and this should be specified in the NSQHS Standards. In many cases, people with dementia choose to appoint an Enduring Guardian who can make decisions such as consenting to, or refusing, their medical treatment or other healthcare. If a person loses mental capacity and has not appointed someone to make healthcare decisions for them, the Guardianship law in all States and Territories sets out who can make the decisions.

Substitute decision-making gives the decision-maker complete legal authority to act in relation to particular types of decisions about the person who lacks capacity. The substitute decision-maker should act in consultation with the person to the extent that the person's remaining capacity makes this possible. Once the person has lost capacity, the substitute decision-maker must follow the person's written instructions if they have provided such instructions, or follow the person's verbal

wishes if the person has discussed their wishes with the substitute decision-maker. However, in some circumstances the substitute decision-maker may need to make the decision on their own, for example if they do not know what the person's wishes would be in a particular situation. In some rare cases it may be that the substitute decision-maker believes that they should make a decision in opposition to the person's views. In such a case the substitute decision-maker will need the authority of the relevant Board or Tribunal before they can override the person's wishes. Sometimes there is conflict between the substitute decision-maker and someone else, perhaps another family member or friend, and often the only way to resolve the issue is to make an application to the relevant Board or Tribunal, who will decide the matter.

PC 6.1: Clinicians work with consumers to plan, communicate, set goals, and make decisions about their care.

It is suggested that this be expanded to read: "*Clinicians work with consumers and/or identified support people to plan...*"

PC6.3: The health service organisation has systems to identify any support people a consumer wants involved in communications and decision making about their care; and PC6.4: The health service organisation has systems to ensure that carers are supported to participate in the provision of healthcare in accordance with the wishes of the consumer and the carer.

Alzheimer's Australia is supportive of these actions, as they align with the principle of "supported decision-making". Supported decision-making is a term that has arisen from concerns about potential lack of involvement between a substitute decision-maker and the person they are making decisions about. It is a more inclusive, consultative and shared way of making decisions that is generally viewed as being more in line with a person's rights. Supported decision-making may be based on a formal agreement between a person with questionable capacity and their supporter, or an informal network of people who support an adult to achieve their own goals and decisions that are based on their own views and wishes. This form of decision-making is in keeping with Australia's obligations under the United Nations Convention on the Rights of People with a Disability, to which our nation is a signatory.³¹

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 hospital 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 deterioration³². Alzheimer's Australia therefore strongly supports the intent of 6.4, that all health service organisations should 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.

³¹ The Queensland Law Reform Commission has recommended that the UNCRPD principles be adopted into guardianship legislation.

³² Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 10.

Standard CC: Comprehensive care

This standard is about creating a system for clinicians to identify a consumer's healthcare needs and work with them to identify shared goals for an episode of care. Alzheimer's Australia is supportive of this standard and its actions, and makes the following suggestions for enhancement:

- Professionals with specific education and training in dementia should facilitate care plans for people with dementia.
- Clinicians must consult and work with the person, their carer, and/or their substitute decision-maker as applicable, in all decisions regarding care, referrals, and transfers.

Standard RH: Reducing harm

Hospitals can be unsafe places for people with dementia, who are twice as likely as other patients to experience an adverse event such as falls, sepsis, or ulcers, when in hospital. Fractures and delirium are also experienced at higher rates. As a result, people with dementia in hospitals experience a five-fold increase in mortality rates³³.

Alzheimer's Australia notes that several of the actions under Standard RH: Reducing Harm are especially relevant to people with dementia, and our comments relating to this standard are as follows.

RH6.1: Where care is provided to consumers at risk of delirium, or with cognitive impairment, the health service organisation has systems that:

- a. Incorporate best-practice strategies for early recognition, prevention, treatment and management of cognitive impairment in a care plan*
- b. Recognise and minimise consumers' distress while they are receiving care*
- c. Avoid the use of antipsychotics and other psychoactive medicines, in accordance with best practice and legislation.*

Alzheimer's Australia is supportive of these actions, and our consumer representatives have further recommended that:

- The principles underpinning the *Dementia Care in Hospitals Project*, implemented across many Victorian hospitals and now being introduced in other jurisdictions, be promoted in the NSQHS Standards for adoption by all healthcare facilities. 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^{34 35}.
- Hospital staff must be consistently trained in dementia care. They must be able to help effectively with meals, toileting, and dressing, and be able to recognise the patient's needs

³³ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 8.

³⁴ https://fightdementia.org.au/sites/default/files/08_Mark_Yates_The_Ballarat_Approach_The_Dementia_Care_in_Hospitals_Program.pdf

³⁵ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 13.

and requests for assistance. It may also be appropriate to establish specialist hospital units for people with dementia.

The action relating to minimizing the use of antipsychotics and other psychoactive medicine is strongly supported by Alzheimer's Australia. Almost all people with dementia experience behavioural and psychological symptoms of dementia (BPSD) at some time during their illness, and these symptoms often worsen during hospitalisation. However, 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.³⁶

Use of psychotropics can increase the risk of adverse events in hospitals: for example, routine use of sedatives at night increases the chance of falling while trying to use the bathroom in an unfamiliar environment. Some alternatives to the use of psychotropics in the hospital environment might include working with the carer to understand and address possible underlying causes of the behavior (eg hunger, pain); providing familiar objects such as photographs to reduce confusion; or creating quiet areas removed from the over-stimulating hospital environment³⁷.

Alzheimer's Australia also reiterates its support for the Standards to reflect the recommended in-hospital strategies for improvement identified in the AIHW's report on hospital care for people with dementia, and the strategies identified through Alzheimer's Australia's 2014 expert symposium (both outlined above).

RH7.1: Where end-of-life care is provided, the health service organisation has systems to identify people who are approaching the end-of-life; and RH7.2: Where end-of-life care is provided, the health service organisation has systems to ensure that advance care plans:

- a. *Can be received from consumers*
- b. *Are documented in the healthcare record*
- c. *Are easily available at the point of care.*

Alzheimer's Australia is supportive of these actions which seek to promote better end-of-life care, including through reference to advance care plans. Unfortunately, many people with dementia have not put advance health directives in place that outline their wishes with regard to their care. Many also have other health conditions, and they may be repeatedly hospitalised and experience major medical interventions, when this may not have been in accordance with their wishes. Increased use of healthcare directives, relevant education for health professionals, and quality palliative care, can help people with dementia to have better end-of-life care, and reduce grief and trauma for families.

³⁶ Peisah C, Skladzien E (March 2014), Alzheimer's Australia Paper 38: *The use of restraints and psychotropic medications in people with dementia*, p 8.

³⁷ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, pp 14-15.

Alzheimer's Australia has concerns about the current capacity of the health and aged care systems to provide quality care for people with dementia at the end-of-life. Being able to access appropriate care at the end-of-life is a critical factor in a more dignified death. 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.

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 with dementia 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.

There is a need for more awareness and education for both consumers and health professionals about quality dementia end-of-life care. This needs to include education on issues around capacity, legal rights, pain assessment and management in people who have diminished capacity and difficulty with communication, and appropriate end-of-life care for people with dementia.

Advance care plans should be discussed/documented on admittance to hospital, and brought to the attention of the treating health professionals, so this issue is not dealt with at a time of greater crisis.

RH7.3: Where end-of-life care is provided, the health service organisation has systems that:

- a. Define the criteria and processes for clinicians to access help when managing end-of-life issues*
- b. Provide access to specialist palliative care advice that is readily available*
- c. Provide access to supervision and support for clinicians delivering end-of-life care*

- d. *Support organ and tissue donations*
- e. *Review the safety and quality of end-of-life care that is provided against the planned goals of care.*

It is suggested that an additional sub-clause f be added: "*Work with identified support people to assist them to care for the consumer if that is their wish*".

In relation to sub-clause b), it is important that palliative care services are routinely extended to people with dementia, as these are currently not always available. Alzheimer's Australia commissioned a national survey to investigate and document the experience of family carers and care professionals (including palliative care specialists, physicians, registered nurses, general practitioners) with end-of-life care for people with dementia. We had over 1000 responses to our survey, and the findings revealed stark differences in the experiences of consumers and the views of care professionals. The majority (75%) of care professionals believed that people with dementia have access to palliative care services. However family carers of people with dementia reported difficulty in getting access to appropriate end-of-life care for the person with dementia, including lack of access to palliative care specialists (58%), hospice care (68%) and support in the community (49%)³⁸.

RH 8.3: The health service organisation has systems to promote and maintain the sexual safety of consumers, the workforce, and visitors.

It is suggested that the wording be expanded to read: "*maintain the sexual and physical safety...*"

Standard CS: Communicating for safety

Alzheimer's Australia is supportive of the broadening of focus of this standard, to expand the scope from a focus on clinical handover, to communication more broadly.

Once cognitive impairment has been identified, hospital staff can still struggle to know how to communicate effectively with a patient with dementia. There are simple techniques that staff can learn which can improve communication with people with dementia, such as showing empathy, and adhering to simple communication protocols such as introducing themselves, maintaining eye contact, remaining calm, keeping sentences short, involving carers, and not presenting patients with too many choices at once³⁹. Effective communication with people with cognitive impairment should be embedded in the actions underpinning this Standard.

As noted above, when carers are able and willing, they can play a key role in providing support and care for the person with dementia in the hospital environment. Good communication with carers is essential to achieve this. It is critical that all hospitals are inclusive of carers and communicate effectively with them, and this should be fully reflected in the actions under this Standard.

Our consumer representatives have offered several additional suggestions regarding how hospitals and other health services could improve their communication, specifically in relation to people with dementia and their carers:

³⁸ Alzheimer's Australia (2014) *End of life care for people with dementia: Survey* Accessed 18 September 2015 at: https://fightdementia.org.au/sites/default/files/EOI_ExecSummary_Web_Version.pdf

³⁹ Alzheimer's Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 13.

- Healthcare organisations should allocate dedicated time to communicate, and have an advocate and/or social worker available to facilitate communication.
- Hospitals should advise consumers and families when the handover is taking place, so they can be involved; and should take time to introduce new staff to consumers and carers.
- Hospitals should let consumers know when doctors and other clinicians are on the ward, so families/carers have the opportunity to communicate any concerns and ask any questions they may have.
- Clinicians and health service organisations have an obligation to communicate their concerns regarding the clinical condition of the patient and clinical risks faced by the patient, and carers should be able to meet with the clinicians to understand these concerns.

Alzheimer's Australia recommends that the Standards reflect these suggestions.

Standard IP: Healthcare-associated infection prevention

It is recommended that all hospitals and health services should provide clear printed information to consumers and carers on how to prevent infection.

Standard MS: Medication safety

Alzheimer's Australia is supportive of the actions relating to documentation and review of the consumer's medication on presentation or as early as possible in the episode of care, noting that many people with dementia are on a number of medications, and these are often not reviewed but just added to.

Alzheimer's Australia recommends the addition of an action relating to the responsibility of the hospitals and other health services to communicate with the consumer, carer, family and/or the guardian to clearly discuss the consumer's medication and medication safety issues.

Standard RR: Recognising and responding to acute deterioration

Acute deterioration is a highly relevant issue for people with dementia in the healthcare system. Alzheimer's Australia is supportive of the proposed expansion of scope of this standard, to include deterioration in settings other than hospitals; to include deterioration in mental state; and to include acute suffering as an aspect of acute deterioration that needs to be acted on. It is critical that in situations of acute deterioration in a person with dementia, the consumer's wishes are followed and the legislative framework adhered to; hence the following actions are strongly supported:

RR7.1: If consumers are unable to participate in decision making about their care, clinicians use existing advance care plans, treatment-limiting orders, the consumer's previously expressed preferences, and other relevant documentation to guide decision making when responding to deterioration.

RR8.1: For consumers who experience a deterioration in mental state and require involuntary treatment, clinicians ensure that this treatment is consistent with legislation.

As noted above, carers may be best placed to recognise acute deterioration in a loved one with dementia, and effective communication with, and involvement of, carers is therefore vital.

CONCLUSION

Dementia is one of the major chronic diseases of this century. Alzheimer's Australia is hopeful that the National Safety and Quality Health Service Standards will contribute to ensuring that all people with dementia can access appropriate, high quality, safe, person-centred care through hospitals and other health services.

The approach taken in Consultation Draft of Version 2 of the NSQHS Standards is largely supported by Alzheimer's Australia, and we hope that the comments and suggestions put forward in this submission assist in the further development of the Standards. We are also keen to continue to work with the Commission on the implementation of the Standards, and more broadly on strategies to ensure that hospitals and other healthcare services are well equipped and motivated to identify and respond to the needs of people with cognitive impairment.