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**REVIEW OF THE
COMMONWEALTH
GOVERNMENT'S REGULATORY
ACTIVITIES APPLYING TO
QUALITY OF CARE IN AGED
CARE RESIDENTIAL FACILITIES**

**SUBMISSION FROM
ALZHEIMERS AUSTRALIA**

JULY 2017

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide input to the Government's Review of regulatory activities applying to quality of care in residential aged care facilities (*the Review*).

The Australian aged care system is generally considered by stakeholders and international peers as providing high quality services. Recently, however, there have been a number of examples in the media of the aged care system providing poor care and failing to respond to the needs of consumers.

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

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

These principles should apply equally to people accessing residential aged care in Australia, including people living with dementia. More than half of all people in permanent residential aged care have a diagnosis of dementia.²

Although Alzheimer's Australia hears many reports of quality service delivery and support in residential aged care settings, we also hear from consumers with far less positive experiences that span 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.

These stories paint a disturbing picture of a care system under strain and ill-equipped to manage residents with dementia, especially in instances where behavioural and psychological symptoms of dementia (BPSD) may be present.

Alzheimer's Australia urges the Government to consider issues relating to the safety and quality of care for people living with dementia as they assess the adequacy of our regulatory processes. As the prevalence of dementia increases in our community, it is critical that all aged care services are well equipped and supported to provide safe, high-quality care for people living with dementia as part of their core business.

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

² Australian Institute of Health and Welfare (2015). *AIHW National Aged Care Data Clearinghouse*. Accessed 5 July <http://www.aihw.gov.au/media-release-detail/?id=60129552716>.

Recommendations

Recommendation 1: More closely link aged care compliance systems with quality systems to ensure they drive service improvement.

Recommendation 2: Increase consumer consultation throughout the accreditation process, including providing consumers with accessible information about the accreditation findings.

Recommendation 3: Data on performance and quality of aged care services should be routinely collected, analysed, and made publicly available to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.

Recommendation 4: Quality indicators should be published on the 'My Aged Care' website and should include relevant information to aid informed decision-making about use of restraint, psychotropic medications as well as information about staffing and skills mix.

Recommendation 5: A dementia focus should be embedded across the aged care regulatory framework and accreditation processes in order to provide consumers with more information about the quality of dementia care of individual providers.

Recommendation 6: Consumer satisfaction should be monitored through surveys of all residents in aged care facilities administered by Australian Aged Care Quality Agency.

Recommendation 7: All assaults, including assaults perpetrated by a person with a cognitive impairment, should be required to be reported within 24 hours.

Recommendation 8: All direct care workers in both residential and community aged care should be required to undertake more extensive background checks analogous to Working with Children Checks; and mandatory reporting of physical and sexual abuse should apply to all aged care services, whether in receipt of Commonwealth funding or otherwise.

Recommendation 9: The scope and reach of the Community Visitors Scheme in residential care should be increased to include a role for volunteers in quality monitoring, possibly as part of the accreditation process.

Recommendation 10: Compliance and complaints processes should be strengthened to ensure consumers or their carers and representatives can report issues without fear of retribution. The draft aged care quality standards should include partnerships with consumers so that they are supported to be actively involved in quality improvement.

Recommendation 11: All staff in residential aged care facilities need to receive high quality training in dementia care, including a social model of care and alternatives to physical and chemical restraint. Quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint and provide information to consumers about their use; and the Aged Care Complaints Commissioner should escalate complaints which relate to use of restraint or assault.

Recommendation 12: Residential aged care facilities should undertake an internal environmental audit to identify issues that may be contributing to behavioural symptoms and should take reasonable steps to address the issues which are identified in order to improve care. Such an environmental audit should be a formal part of the accreditation process.

Recommendation 13: Specialist Dementia Care Units which can provide one-on-one care for people with severe behavioural and psychological symptoms of dementia, which were announced in the 2016-17 Budget, should be established as soon as possible.

Recommendation 14: There should be improved access to information and support for advance care planning for people with dementia, their families and carers, as well as improved access to palliative care and pain management in aged care.

Recommendation 15: To ensure quality and safety in residential aged care, funding arrangements should support appropriate staff ratios and skill mix.

Recommendation 16: 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.

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 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 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 2056.⁷ Dementia is the second leading cause of death of Australians, contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year.²

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum.⁸ 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 isolation,⁹ and family carers often find it difficult to balance work, life and caring responsibilities.¹⁰

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, a growing number 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 men.¹¹ 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.¹² Provision of dementia specialist comprehensive community based support, and appropriate, high quality residential care are therefore both critical to meeting the needs of people living with dementia.

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, 586-87.

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

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

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

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

11 Sehadi S, Belsler A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al. (2006). The lifetime risk of stroke: Estimates from the Framingham Study. *Stroke*, 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.

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

COMMENTS IN RESPONSE TO TERMS OF REFERENCE

The Terms of Reference of the Review broadly seek to address the following questions:

- *Why, prior to its sanction on 17 March 2017, Commonwealth aged care regulatory processes did not adequately identify the systemic and longstanding failures of care at the Makk and McLeay wards documented in the Oakden Report?*
- *What improvements to the Commonwealth aged care regulatory system would increase the likelihood of immediate detection, and swift remediation by providers, of failures of care such as those identified in the Oakden Report?*

While this Review has been triggered by the issues reported in the Oakden Report, it is important to note that there is a broader context. The implementation of incremental reforms across the aged care sector, including in residential aged care, has created a level of complexity around aged care regulatory processes. Consumers and stakeholders have been increasingly concerned with the burdens of the current regulatory framework and although aged care reforms have begun to address some of these issues, the scale and pace of change is itself a challenge.

Alzheimer's Australia will address the questions raised in the terms of reference for this Review by responding to issues across three crucial elements of our aged care regulatory framework, namely:

- Accreditation and Quality;
- Investigation, Monitoring and Review; and
- Complaints and Compliance.

Accreditation and Quality

The Accreditation Standards against which residential aged care providers are assessed have been criticised by a significant number of our consumers. From a consumer perspective, the accreditation process has served to reassure consumers that, over time, aged care providers offering unacceptable levels of care will be dealt with. However, the Standards only establish the minimum acceptable level of service for accreditation, rather than providing any insight or guidance into whether a provider is delivering high quality care. In addition, many consumers report to us that the accreditation process involves significant red tape, is highly administrative and focuses on paper-based assessment – which not only impacts on staff time for care of residents, but does not necessarily focus on better outcomes for residents.¹³

Demonstrating Compliance vs Quality Assurance

Numerous submissions made to the Productivity Commission as a part of the 2011 report underscored the burdensome nature of administrative processes in the current system, with the Council on the Ageing (Australia) (COTA) contending:

'... the accreditation process should not require substantially more paperwork than is required for normal business, clinical and care management needs. We have some sympathy with the view that quality accreditation processes in the health and aged care sectors have placed too much emphasis on excessive paper trails rather than on actual outcomes being achieved'. Productivity Commission p. 128, 2011.14

¹³ Alzheimer's Australia (2013). Paper 37: *Quality of Residential aged care: The consumer perspective*, p 15.

¹⁴ Productivity Commission (2011). *Caring for Older Australians*.

The current accreditation process incorporates self-assessment, administrative and resident 'sampling' (a minimum of 10%) and scheduled re-accreditation audits (every 3 years). While the many consumers we have spoken to agree that accreditation should not be overly burdensome for providers or take away from care of residents, some have noted the shortcomings of a system that focuses on scheduled, well-publicised assessments that largely occur during business hours rather than out of hours (when staffing levels may vary).

Consumer Views on Accreditation

"In another life, I inspected nursing homes, that is why I chose to keep my father at home. There are many that make the minimum standards. I have seen people time and again drugged up and tied up."

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

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

"I realise the importance of "paperwork". I realise paperwork is part of the care process. But it should not be considered to be more important than interaction with the human beings who are being cared for."

"The involvement of family or representatives in my parents care was problematic. Although the Accreditation Standards states that the physical and mental health of residents should be promoted and achieved at an optimum level in partnership between the resident (or his or her representative) and the health care team, this never really happened. There was a lack of discussion regarding issues including appropriate pain management, a lack of care plans (at least available for me to view), lack of notification regarding residents' meetings, and no notice from the facility that accreditation audits were being conducted."

As a result of this highly targeted compliance approach, a number of consumers have told us that they feel quality improvement is focused on in the lead up to accreditation but ceases to be as dynamic a force once accreditation has been achieved. The current system appears to provide no compelling regulatory or funding incentive to seriously drive continuous quality improvement between these periods, especially in relation to quality dementia care. Indeed, as the Aged Care Quality Agency itself notes, almost all providers of residential care meet all of the accreditation standards both at full scheduled audit and at unannounced site visits. Compliance and quality improvement are not, it would seem, operating in tandem and one system is not necessarily driving performance in the other.

Recommendation 1:

More closely link aged care compliance systems with quality systems to ensure they drive service improvement.

What Alzheimer's Australia's consumers make clear to us is that there is a need to better link compliance with quality assurance.

The ongoing development of national quality indicators may assist in the comparison across residential aged care services. There may also be a need to develop an interlinked and more

nuanced approach to accreditation in conjunction with the quality system, such as including whether a facility has met or exceeded the expected outcomes.

Another example of how this might work is provided in the health care sector by the Australian Commission of Safety and Quality in Healthcare (ACSQHC), through the development and implementation of the National Safety and Quality Health Service (NSQHS) Standards.

The National Safety and Quality Health Service Standards

The primary aims of the NSQHS Standards are to protect the public from harm and to improve the quality of health service provision. They provide a quality-assurance mechanism that tests whether relevant systems are in place to ensure expected standards of safety and quality are met. There are 10 NSQHS Standards, which cover high-prevalence adverse events, healthcare associated infections, medication safety, patient identification and procedure matching, clinical handover, the prevention and management of pressure injuries, the prevention of falls and responding to clinical deterioration.

Importantly, these NSQHS Standards have provided, for the first time, a nationally consistent statement about the standard of care consumers can expect from their health service organisations. The implementation of the NSQHS Standards in hospitals and day procedure centres has contributed to significant improvements in patient safety. The NSQHS Standards have provided the impetus for new activities and they have led to increased priority being given to existing activities that aim to improve patient safety. Examples are an increased focus on the effective and appropriate use of antibiotics, better documentation of adverse drug reactions and medication history, and an increase in the number of hospitals reporting information nationally so that blood usage can be better monitored.

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. In addition, the Commission has 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.

Increasing Consumer Engagement and Involvement

The Accreditation 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.”¹⁵

According to the Australian Commission of Safety and Quality in Healthcare,¹⁶ 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.

It is clear that we need a new approach to the accreditation of aged care in Australia that gives consumers greater input into the process and results in outcomes that can then be

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

16 Australian Commission on Safety and Quality in Health Care (2012). *Safety and Quality Improvement Guide Standard 2: Partnering with Consumers*.

reported to consumers in an accessible form. We should strive for an accreditation system that focuses not only on identifying facilities that have fallen below minimum standards, but also a system that provides incentives for continuous quality improvement and results in better quality of life for residents.

Too often, families of people living with dementia in residential aged care have reported to us that their feedback (and that of the resident) is not actively sought, so that consumer experience is only ever represented in formal complaints. Most consumers have little involvement in governance of a service and residents may not have access to an impartial advocate (consumers have reported to Alzheimer's Australia about families having to use Elder Rights Advocacy, Senior Rights, etc., with formal advocates sometimes meeting with resistance from residential aged care staff).

Five Star Rating System in the US: Publicly available Quality Assurance Data

Besides the NSQHS Standards mentioned above, we can also look overseas for other accreditation systems. In 2008, the Centres for Medicare and Medicaid Services (CMS) implemented a five-star rating system of nursing homes in the United States. The assessment process provides a good example of how outcome measurement can be used to provide consumers with information about the quality of facilities. Information on measurable outcomes for each facility is made publically available through a website and each facility is given a 5 star rating based on their performance in health, staffing, and quality measures. This system provides consumers with important information beyond whether a facility meets a minimum level of service and also provides incentives for facilities to provide higher levels of care.

It is therefore clear that there needs to be greater involvement of consumers in the accreditation process. Consumers should be provided with the opportunity to give confidential input throughout the assessment process and the outcomes of the accreditation process should be provided to consumers in an accessible form which can inform their decisions about care.

Recommendation 2:

Increase in consumer consultation throughout the accreditation process, including providing consumers with accessible information about the accreditation findings.

Transparency and Information

Although the accreditation status of a residential aged care facility is publicly available, consumers often report to us that they find the documents difficult to interpret and that there is a lack of transparency as to how that relates to quality of care.

Alzheimer's Australia has long focused on consumer-friendly (and indeed, dementia-friendly) language in the aged care sector, which includes publicly reported quality indicators. We note that a voluntary quality-indicator program has commenced as part of the aged care reforms but that the initial indicators included as part of this program are clinically focused. Ultimately, it is vital that accreditation and quality mechanisms span consumer experience and quality of life within aged care services and that they are reported in a way that is both accessible and meaningful to consumers.

Recommendation 3:

Data on performance and quality of aged care services should be routinely collected, analysed, and made publicly available to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.

The My Aged Care website has been established to provide consumers with up-to-date information about aged care and assist consumers navigate the aged care system as well as provide referrals for assessment and service provision. Although the system was (and is) intended to include a range of indicators to support consumers making informed choices based on transparency and comparability of such elements as price and quality, currently, none of this important information is available to consumers.

Recommendation 4:

Quality indicators should be published on the 'My Aged Care' website and should include relevant information to aid informed decision-making about use of restraint, psychotropic medications as well as information about staffing and skills mix.

Consumer Views on Transparency and Information

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

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

"Yes, information in a timely manner as you go through the stages – we were flooded with brochures on a few occasions but it's too much at once, carers need to be given the information again in a timely manner."

"We have nothing that can give us step by step of where we might go. No list of possibilities that can be given to us. We would like a person we can talk to individually, about what is troubling us."

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

Dementia Specialist Focus

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011. Provision of comprehensive dementia specialist and appropriate, high quality residential care is therefore critical to meeting the needs of people living with dementia and their families.

However, 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 more complex care needs, will lose out if we rely solely on market forces to drive access and quality. Vulnerable groups, such as those with severe behavioural and psychological symptoms of dementia, Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse backgrounds are likely to be adversely affected unless there are specific measures throughout our regulatory frameworks and accreditation systems.

Dementia should be core business within aged care, but there is evidence that the needs of people with dementia are not being fully supported through current mainstream aged care services. Although quality should encompass individualised care, no matter what the requirement or how specialised the care need, Alzheimer's Australia is concerned that dementia is not being adequately addressed through our current and draft regulatory/quality

systems. For instance, we were disappointed to note that the draft aged care quality standards¹⁷ do not acknowledge or consider the high risk and prevalence of dementia and associated cognitive decline, despite more than half of all residents in residential aged care having some form of dementia and despite the clear need for providers to have specialist capacity to manage dementia appropriately.

Anonymous input from Quality Assessor

"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-acag/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 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.

This loss of a dementia specialist focus was also reported in the Oakden Report, which notes:

"In 2012, the Australian Government released Living Longer. Living Better an Aged Care Reform package. This was in the context of the cessation of certain elements of the National Dementia Initiative in 2011. Since that time it has been recognised that severe and very severe BPSD has begun to fall between the cracks of the Commonwealth Aged Care system and the State funded Mental Health Care system, with the need for both levels of government to cooperate in the development of programs that cater for this small group of highly disadvantaged people and their families and carers."¹⁸

The Oakden Report

¹⁷ Department of Health (2017). *Single Aged Care Quality Framework - Draft Quality Standards Consultation Paper*.

¹⁸ Groves A, Thomson D, McKellar D and Procter N (2017). *The Oakden Report*.

A recent analysis noted calls for cultural change in parts of the aged care sector, so that dementia capability, including behaviour management, is accepted as part of core business and an essential in-house capability, rather than a discrete expertise or specialty area.¹⁹

A Senate Community Affairs Committee Review of the Aged Care Workforce has also recommended that *“the government work with the aged care industry to develop scholarships and other support mechanisms for health professionals, including nurses, doctors and allied health professionals, to undertake specific geriatric and dementia training”*.²⁰

These recommendations are not surprising. 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 under the aged care regulatory framework as well as its important aspects such as quality standards. Therefore, in the accreditation process of aged care facilities it is important to consider how cognitive impairment impacts different aspects of care and residential aged care providers should consider these specialist needs as part of their quality assurance processes.

A dementia focus in the review of Aged Care Standards, accreditation processes and development of quality indicators could also be utilised by consumers to make improved choices about what facilities provide the best dementia care and could also be used to focus on improving the quality of care in facilities that fall short.

Recommendations 5

A dementia focus should be embedded across the aged care regulatory framework and accreditation processes in order to provide consumers with more information about the quality of dementia care of individual providers.

Investigation, monitoring and review

Currently the investigation, monitoring and review processes in residential aged care have a more reactive rather than proactive or preventive approach. While a reactive response to the reporting of complaints has a necessary and legitimate function in any monitoring regime, systemic issues require a proactive and preventive approach that does not rely upon vulnerable older people to identify, articulate and progress a complaint in circumstances in which they are likely subject to a significant power imbalance.

In the case of people living with dementia, this power imbalance is further exacerbated as these individuals may also face issues such as lack of understanding of complaint mechanisms, limited capacity to engage with such mechanisms, communication difficulties and fear of reprisal.

Consultations Alzheimer’s Australia has held with consumers show divergent experiences across the sector. The majority of families we interviewed were satisfied with their level of participation, inclusion and resolution of minor complaints or incidents. Conflicts were often resolved swiftly with positive, if only short-term, outcomes for the person living with dementia. However, it was noted often these discussions and decisions were made in isolation, without leading to structural or fundamental improvements in the organisation’s

¹⁹ KPMG (2015). *Analysis of dementia programmes funded by the Department of Social Services*.

²⁰ Commonwealth of Australia (2017). *Future of Australia’s aged care sector workforce*.

dementia care. Many families identified what they saw as a system-wide failure to engage in quality improvement.

Consumer role in monitoring

Consumers and carers should be engaged as key partners in aged care investigative, monitoring and compliance processes. Measuring consumer satisfaction is a vital element in measuring service quality, and consumer involvement in these processes is also critical. 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 review²¹.

As noted earlier, the National Safety and Quality Health Service (NSQHS) Standards provide an example on how consumer engagement can be built into aged care regulatory processes. 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.

A firm commitment should be made to develop and implement a consumer experience survey. While indicators can, and should be, chosen and promoted on the basis that they measure both clinical care and quality of life much more needs to be done to understand the consumer experience and views of the services they receive. It would be a tremendous 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.

Recommendation 6

Consumer satisfaction should be monitored through surveys of all residents in aged care facilities administered by Aged Care Quality Agency.

Physical Assaults within aged care

In 2015-2016, there were 2,862 notifications of 'reportable assaults'. Of these reports, 2,422 were recorded as alleged or suspected unreasonable use of force, 396 as alleged or suspected unlawful sexual contact, and 44 as both. This represents an incidence of reports of suspected or alleged assaults of 1.2% of people receiving permanent residential care during that period.²²

As with community settings, there have also been concerns raised about aggression by people with dementia towards staff and other residents in aged care facilities. There is significant concern from consumers about the lack of requirement to report assaults and the impact this may have on the safety of other residents within an aged care facility. This relates to broader issues around appropriate care and support for people with dementia who have very severe behavioural and psychological symptoms of dementia. In some cases, to ensure the safety of other residents there is a need to provide a short-term placement in a specialised psychogeriatric facility. But this option is not always available.

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

22 Australian Law Reform Council (2017). *Elder Abuse- A National Legal Response, Final Report*.

Case study: Assault by another resident

“My mother-in-law [who has dementia] has been assaulted four times at a residential care facility... One of those occasions required stitches. It appears to be the same person (another resident) who is the offender. My husband is now writing letters but whilst there is correspondence, there isn't much action in preventing these episodes from reoccurring...”

A 2015 member survey by the NSW Nurses and Midwives' Association (NSWNMA) found that aggression towards other residents and staff by people with dementia is common, and poses a serious dilemma:

“It would be inappropriate to criminalise people with cognitive impairment for committing acts of physical or verbal violence as they are essentially ‘blameless’ being affected by a brain disease rather than carrying out intentional ill will. However, there must be an effective system in place to keep both aged care residents and staff protected from physical or verbal attack.”²³

Alzheimer's Australia agrees that aggression exhibited by people with dementia does not constitute criminal abuse; but the challenges posed by these situations are acknowledged. We recommend that all incidents of assault, including assaults perpetrated by a person with cognitive impairment, should be required to be reported within 24 hours.

Recommendation 7

All assaults, including assaults perpetrated by a person with a cognitive impairment, should be required to be reported within 24 hours.

Adequacy of current Monitoring Mechanisms

In the case of Oakden, it was reports of abuse and over-medication that sparked an Inquiry by the South Australian Health minister. While physical abuse of residents is clearly a criminal matter that requires serious review and consideration, these incidents could also be seen as symptomatic of a system that is not working. Even where blatant abuse may not be occurring, there are often issues relating to quality of care which arguably constitute abuse. Poor quality residential care which does not offer dignity, comfort, and meaning, can equate to psychological abuse of residents, as illustrated by the following case study.

Case study: Inadequate care in residential aged care

“My mother was diagnosed with Alzheimer's around 50. Family members placed her in a ... complex for geriatrics; the youngest resident. Mum remained a resident of the complex for 9 years until her death in 2014. Mum's first ward was a lock-in facility for dementia, with no stimulation or meaningful activities. The place smelt like shit and had a vibe of death; dingy and dim. She wandered the hallways all day, bored out of her brain. Mum was soon put into a wheel-chair and moved to a palliative care unit where she remained in bed for the next 5 or 6 years, in a dark room with the curtains permanently drawn and an old arm-chair covered in black mildew, which no-one ever dared sit on.

If Hell exists, this was it. The hallways echoed with moans and outcries from patients, begging nurses to come change them, crying from the humiliation of having to sit in their own muck and faeces for hours on end: “Help me! Please! Can anyone hear me? Please! This is no way to be!” It was horrifying. My mother's hygiene was not attended to by staff and nurses treated

her like an inconvenience and a lifeless corpse. They had no respect for her well-being and treated her without dignity.

On many occasions, staff spoke about my mother as if she were already dead. One nurse had the audacity to discuss DNR options with others, in front of my mother, as tears rolled down mum's face – ignoring my mother's stress and trauma at hearing this. Another time, when my mum was suffering terribly from aspiration pneumonia, a nurse took no regard when suctioning mum's throat and said to me, "She's got no fight left in her. It won't be long now. When MY husband died..." and proceeded to tell me about her husband's death, as my mother moaned and groaned in pain, coughing, spluttering and crying out in pain. I was so over-come by grief and trauma that I had no response but to bow my head and cry a waterfall of tears, silently with a deep pain in my chest. The undignifying and inhumane way that my mother was treated within this 'care' facility will last with me forever."

The family member who provided the case study above has suggested the need for more vigilant spot checks of residential aged care facilities, including on weekends (including Sundays). It was also suggested that the spot checks should include reading the resident's case notes and inspecting the resident closely: for example, checking for hygiene, scabies, dermatitis, decaying teeth, neglected cleanliness, and so on, with penalties including closure for repeated breaches.

Consumers and some stakeholders have also raised suggestions about implementing 24/7 monitoring within aged care facilities to enforce monitoring and compliance. It is the view of Alzheimer's Australia that we need to address the fundamental issues in the aged care system, rather than simply creating a system of compliance and monitoring which could violate the privacy of residents.

Another way to ensure better quality of service is to address issues across the workforce. While there are broader issues discussed later in this submission, issues such as the suitability and minimum standards of employment should be part of the regulatory framework. Australian research has identified a lack of mechanisms to ensure that professionals such as personal care workers are fit for the responsibilities of working with the aged, and has suggested a need for licensing of these workers and a way of conducting background checks analogous to the Working with Children Checks that are required for people who work with children. The research also highlighted the fact that no statutory reporting obligations apply in aged care services that do not receive Commonwealth government funding.²⁴ Alzheimer's Australia supports action to address these matters. While workers in aged care are currently required to undergo police checks, we believe more extensive background checks are required, and that these should apply to workers in both residential and community aged care.

Recommendation 8

All direct care workers in both residential and community aged care should be required to undertake more extensive background checks analogous to Working with Children Checks; and mandatory reporting of physical and sexual abuse should apply to all aged care services, whether in receipt of Commonwealth funding or otherwise.

Such a requirements will not be any different to other sectors providing 'public good' services and /or services to vulnerable groups in the population (for example childcare workers; general practitioners).

24 Cited in Kaspiew R, Carson R, Rhoades H (2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report no 35, pp 11-12.

Significance of Community Visitor Scheme

Volunteers within the Community Visitors Scheme may also play an important role in the assessment of aged care services' accreditation standards. In a similar vein to a 'mystery shopper' role, a volunteer within the Community Visitor Scheme should be provided with information on the expected standard of care from a service and should be encouraged to provide feedback to both the service and the Australian Aged Care Quality Agency with regard to the adherence of quality accreditation standards. As recognised in the Oakden Report, concerned family and carers of consumers in the Oakden facility had first raised the alarm through the Principal Community Visitor, who further escalated the matter which eventuated in the Oakden Inquiry.²⁵

Thus Alzheimer's Australia has recommended 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 process²⁶ – 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.

Recommendation 9

The scope and reach of the Community Visitors Scheme in residential care should be increased to include a role for volunteers in quality monitoring, possibly as part of the accreditation process.

Complaints and compliance processes

As a degenerative disease that affects cognitive skills and decision-making ability, dementia makes people living with the disease vulnerable participants in any consumer instigated compliance process. Their cognitive impairment may make it difficult or impossible for people experiencing unsatisfactory service or even abuse to report their experiences through the appropriate channels and to be in a position to provide irrefutable evidence in the instances of abuse. People with dementia may also be reluctant to complain because they are often highly dependent for their care on those providing it, whether this be family members, or staff of aged care facilities.

These concerns may also be felt by carers of people living with dementia. Families have told Alzheimer's Australia that they are reluctant to raise concerns out of fear of repercussions for their loved one, even though the Charter of Care Recipients' Rights and Responsibilities²⁷ stipulate that residents have the right to make a complaint without fear of reprisals or disadvantage. A lack of anonymity left families feeling especially vulnerable.

It is important that measures are in place to ensure that the consumer voice can be heard without fear or favour. A power imbalance between a service provider and a vulnerable consumer can make this problematic.

As noted earlier, some families felt that because resident outcomes are not measured or reported on, the sector lacks incentive to improve. Regular feedback is not sought from residents and family, so performance and resident experience is measured only in terms of incident reporting. This is seen as a lost opportunity to prevent failures from occurring and continuously improve quality. As noted in the previous section, Alzheimer's Australia

²⁵ Groves A, Thomson D, McKellar D and Procter N. (2017). *The Oakden Report*.

²⁶ Alzheimer's Australia (2013). Paper 37: *Quality of residential aged care: The consumer perspective*, p 6.

²⁷ Department of Health (2017). *Charter of Care Recipients' Rights and Responsibilities – Home Care Aged Care Act 1997*.

recommends that as one means to address this, consumer satisfaction be monitored through surveys administered by Aged Care Quality Agency.

Additionally, many families report not wanting staff members to be held personally responsible for errors they believed were due to organisational or managerial failure. Many families have a strong sense of loyalty and duty to facility staff and do not wish to jeopardise their employment.

It is thus also important to involve consumers at the organisational governance level to drive real improvement in quality assessment and compliance processes. Again an option 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.

While the draft quality standards for aged care make reference to person centred care and consumer directed care, it should be noted that there is no mention of partnerships with consumers in terms of governance or supporting consumers to be actively involved in quality improvement.²⁸ Active involvement goes beyond a basic access to a feedback and complaint mechanism, and involves embedding consumer participation at the heart of designing, developing and implementing any effective quality and assessment process.

Recommendation 10

Compliance and complaints processes should be strengthened to ensure consumers or their carers and representatives can report issues without fear of retribution. The draft aged care quality standards should include partnerships with consumers so that they are supported to be actively involved in quality improvement.

Alzheimer's Australia also recommends that the draft quality standards 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;
- there are various types of complaints that have to be handled in different ways e.g. criminal allegations, reportable incidents etc.

ADDITIONAL COMMENTS

More than 50% of people in Commonwealth-funded residential aged care setting have dementia.²⁹ Although many people with dementia receive good care in residential aged care settings, 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.³⁰

28 Department of Health (2017). *Single aged care quality framework: Draft Aged Care Quality Standards Consultation Paper*.

29 Australian Institute of Health and Welfare (2012). *Residential aged care in Australia 2010-11: A statistical overview*. Cat. no. AGE 68.

30 Alzheimer's Australia (2013). Paper 37: *Quality of residential aged care: The consumer perspective*, p 4.

Alzheimer's Australia has highlighted some of the most concerning elements below and note that although they may lie outside the precise scope of this review, they nevertheless have an impact on poor quality and care outcomes (as were highlighted by the Oakden report).

Better management of behavioural and psychological symptoms of dementia (BPSD)

Behavioural and psychological disturbances are often an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear).³¹ Environmental factors can also contribute to BPSD, including too much stimulation, lack of privacy or an institutionalised like environment. Staff practices may also provoke behaviours. In many cases BPSD can be prevented through effective management of these contributing factors.

Individuals with severe BPSD who are ambulant often require specialised care. The care required by this group overlaps considerably with older individuals who have behavioural and psychiatric symptoms related to mental health conditions. Both groups require access to specialised 'psycho-geriatric care', although the underlying cause of their symptoms may be different. The National Health and Hospital Reform Committee³² identified access to psycho-geriatric care as an area that needs reform. "As a matter of some urgency, governments must collaborate to develop a strategy for ensuring that older Australians, including those residing in aged care facilities, have adequate access to specialty mental health and dementia care services".

The report of the Psychogeriatric Care Expert Reference Group was also considered by the Ministerial Conference on Ageing in 2009.³³ It carefully documented a framework for service planning and care delivery for people with psychogeriatric disorders. The framework included:

1. Integration at all levels within the broader health care system with appropriate facilities to assist older people with BPSD and/or mental health issues.
2. Ongoing access to and utilisation of specialist clinical expertise and care.
3. Appropriate assessment mechanisms and placement to ensure best 'client fit'.
4. Appropriate staff levels and skills mix across the continuum of care.

The Ministerial Conference endorsed that framework.³⁴ However this endorsement has not resulted in many practice changes on the ground level.

Case study

"My dad was over medicated with strong medical drugs that were not being monitored by staff at the nursing home or the doctor. This went on for years across two different nursing homes, no matter how much I tried getting my voice heard no one ever listened - they said they would address things but when I'd leave and come back things were never changing only worsening."

31 Algate, D, et al (1996). Need-driven dementia-compromised behaviour: An alternative view of disruptive behaviour. *American Journal of Alzheimer's Disease & Other Dementias*, 11(6), 10-19.

32 Mental Health Coordinating Council (2009). *The National Health and Hospitals Reform Commission - 'A Healthier Future for all Australians.'* Accessed online at <http://www.mhcc.org.au/media/8935/nat-health-hospitals-reform-commission-submission-03-09.pdf>.

33 Report by Psychogeriatric Expert Care Reference Group (2010) to the Ministerial Conference on Ageing.

34 Communiqué issued on 15th December 2010 by the Ministerial Conference on Ageing in 2009 endorsed framework for service planning and care delivery for people with psychogeriatric disorders.

There is emerging evidence that restorative and rehabilitative approaches to care for people with dementia may assist with BPSD.³⁵ Active restorative and rehabilitative activities, such as recreational and daily living activities have been associated with improvement in mood and behaviour.³⁶

In Alzheimer's Australia's view, comprehensive assessment and a focus on learning the language of dementia – observational techniques to assess how the person communicates pain – are required across the regulatory framework to ensure better management of BPSD.

Inappropriate use of restraint

Some aged care facilities are taking appropriate steps to provide quality care for individuals with BPSD. Many are not. As a result there are still numerous reports of physical and chemical restraint.³⁷

The inappropriate use of physical and chemical restraint, particularly in residential aged care, but also in community aged care settings, is a significant issue of concern for people with dementia and their families. Physical restraint may include methods such as bed boundary markers, deep chairs, lap belts, hand mitts, seat belts, or leg, wrist or ankle restraints; removal of mobility aids; or restriction of the person to a locked area/secure ward. Chemical restraint refers to the use of psychotropic medications to modify the person's behaviour.³⁸

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 applied³⁹.

It is estimated that 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. The evidence supporting the use of antipsychotic medications is modest at best, with international data suggesting that only 20% of people with dementia derive any benefit from antipsychotic medications. These medicines 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.⁴⁰

35 Camp, CJ, Cohen-Mansfield, J, & Capezuti, EA (2002). Mental health services in nursing homes: Use of nonpharmacologic interventions among nursing home residents with dementia. *Psychiatric Services*, 53(11), 1397-1404.

36 Galik, EM, Resnick, B, Gruber-Baldini, A, Nahm, ES, Pearson, K, & Pretzer-Abhoff, I (2008). Pilot testing of the restorative care intervention for the cognitively impaired. *Journal of the American Medical Directors Association*, 9(7), 516-22.

37 Alzheimer's Australia (2012). Consumer Engagement in the Aged Care Reform Process.

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

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

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

The legal framework in relation to regulating and monitoring the use of restraint is under-developed in Australia.⁴¹ However, all persons essentially have the right to live in a “restraint-free” environment, with restraint only to be used if other strategies or interventions have failed. Restraint should only be used as a last resort, to prevent a person from harming themselves or someone else. Restraint can only be used lawfully without consent of a Guardian or Attorney with legal authority for this decision, in situations of immediate high risk or emergency.

If a person with dementia is living at home, anyone, including family members or carers can only restrain the person in the case of an emergency, and only for as long as the emergency lasts. Then the family member or carer needs to seek an assessment of the person’s health and service needs, to ensure the person’s safe care in the community. Even if the family member or carer is also the legal decision-maker it does not mean that they can indefinitely restrain the person or lock the person in.

Similarly, aged care facilities require consent from the individual, or the legally appointed or nominated person or agency, to make accommodation and restraint decisions, such as placing a person in a locked ward. While this decision can be made against the person’s will, it still must have legal authority, so the Attorney or Guardian needs to consent on the person’s behalf.

The use of medication to treat behavioural disturbance should be consented to either by the individual, if they still have capacity to make healthcare decisions, or by the substitute healthcare decision-maker, except in an emergency situation.

Consumer Stories - Restraint

“My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other people’s rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser. He was treated like a dog. I couldn’t get anyone to listen to me, finally I found a broker and I found a nursing home”.

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

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

“I was shocked that my father had been put on a sedative without his or my knowledge despite our request that his not be done”.

“My girlfriend was concerned that her mother’s appetite had waned and her mother was losing her strength. The antipsychotic had turned her mother into zombie. The situation culminated in my girlfriend’s mother collapsing and being unable to be roused”.

41 Alzheimer’s Australia (2016). *Dementia and your legal rights*. <https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Dementia-and-your-legal-rights.pdf>

"In the nursing home, residents with dementia were administered drugs and sat like zombies in a circle around the t.v. from nine o'clock in the morning where they were supervised by one staff member

The Commonwealth Government has produced a booklet on the use of restraint in residential aged care facilities, which provides useful guidance on this matter. This guidance includes:

"A person-centred approach is a restraint free approach – a way of thinking that preserves the human rights of any person... With a restraint free approach, the use of any restraint must always be the last resort after exhausting all reasonable alternative management options... The application of restraint, for ANY reason, is an imposition on an individual's rights and dignity and, in some cases, may subject the person to an increased risk of physical and/or psychological harm. The inappropriate use of restraint may constitute assault, battery, false imprisonment or negligence. Staff need to identify, in a proactive approach with management, how to prevent situations that may lead to a perceived need for restraint."⁴²

Despite these legal protections, consumers have told Alzheimer's Australia that it is often the case that in practice informed consent is not obtained for restraint, particularly with regard to the use of antipsychotic medications. Where families do provide consent, often no alternatives to restraint are offered, and the family may feel obliged to provide consent as they may be concerned that the person with dementia may otherwise be asked to leave the facility.

To address the issue of inappropriate restraint of people with dementia in the aged care system, staff need effective education and training on person-centred care and on alternatives to restraint. Consumers and carers need to understand and be able to advocate for the legal rights of the person with dementia.

In addition, the regulatory framework for aged care services should aim to end inappropriate use of physical and chemical restraint. All residential aged care facilities should participate in benchmarking and audit 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.⁴³ Reporting of the use of physical restraint has been included in the Voluntary Quality Indicator Program in Residential Aged Care, but this should be extended to also include the use of antipsychotic medications as a form of restraint. Information on quality of care for people with dementia should be provided through the quality indicators on the My Aged Care website and further consideration should be given to how quality care can be linked to resourcing and other incentives.

Consideration should also be given to how the Aged Care Accreditation process can be strengthened to ensure higher quality care for individuals with BPSD. It is important that the aged care commission can escalate complaints which relate to use of restraint or assault to a manager within set timeframes to ensure the safety of residents.⁴⁴

Recommendation 11

All staff in residential aged care facilities need to receive high quality training in dementia care, including a social model of care and alternatives to physical and chemical restraint.

⁴² Department of Health and Ageing (2012). *Decision Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*. https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf

⁴³ Alzheimer's Australia (2013). Paper 37: *Quality of residential aged care: The consumer perspective*, p 6.

⁴⁴ Alzheimer's Australia (2013). Paper 37: *Quality of residential aged care: The consumer perspective*, p 6.

Quality standards and assessment processes for aged care services should aim to end inappropriate use of physical and chemical restraint and provide information to consumers about their use; and the Aged Care Complaints Commissioner should escalate complaints which relate to use of restraint or assault.

Service Environment

Residential aged care settings are often confusing places for people with dementia. Design of aged care facilities can play an important role in preventing the escalation of BPSD.⁴⁵ Facilities should be designed to reduce noise and other unwanted stimuli and reduce confusion. Other design features such as signage and cues, single bedrooms, secure indoor and outdoor areas for wandering and a homelike, familiar atmosphere can be helpful in providing a dementia friendly environment.⁴⁶

The facility environment can also trigger or exacerbate BPSD, such as crowding, noise, lighting, poor interior layout, or temperature. The task-oriented nature of daily life in a facility can also increase these symptoms. Understandably, people with dementia, particularly people with limited ability to communicate, may respond to being rushed, staff frustration, or lack of empathy.⁴⁷

This is also true for many of the families Alzheimer's Australia has consulted with. As previously mentioned, conflict and misunderstandings often appeared to be due to facility staff being inadequately trained or resourced to identify or address dementia-related changes to the person. Some families also noted that facility staff, when encountering BPSD, did not assess the person for underlying causes such as pain, contrary to the recommended first line approach.⁴⁸

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.⁴⁹ 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.

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.

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

45 Australian Government Department of Health and Ageing (2008). Report to the minister for ageing on residential care and people with psychogeriatric disorders.

46 Fleming, R (2011). An environmental audit tool suitable for use in homelike facilities for people with dementia. *Australasian Journal on Ageing*, 30(3), 108-12.

47 James, A (2011). *Understanding Behaviour in Dementia That Challenges: A Guide to Assessment and Treatment*.

48 Guideline Adaptation Committee (2016). *Clinical Practice Guidelines and Principles of Care for People with Dementia*.

49 Alzheimer's Australia (2014). *Creating Dementia Friendly Communities- Checklist*. Access online at:

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

wall for directions are better than written directions. When colours are used for signs they should be bright (e.g. 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).

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.

Recommendation 12

Residential aged care facilities should undertake an internal environmental audit to identify issues that may be contributing to behavioural symptoms and should take reasonable steps to address the issues which are identified in order to improve care. Such an environmental audit should be a formal part of the accreditation process.

Appropriate use of secure units

Consumers have also raised concerns regarding the placement of people with dementia in secure units, often without due process, including lack of alternatives and lack of informed consent. Placement in secure units generally occurs in response to behaviours being exhibited by the person, such as agitation, aggression, or wandering behaviours. As noted earlier, in many cases such behaviours may indicate that the needs of the person are not being met – for example, they may be in pain, hungry, thirsty, or bored; or they may simply feel a need to move about, which in itself can be a positive in terms of maintaining the person's physical health and fitness. The needs of the person should be explored and alternative approaches to restraint should be exhausted, to ensure placement in secure units is undertaken only as a last resort.

In some cases, placement in a secure unit may be required for duty of care reasons and may be in the best interests of the person, and indeed may even reflect their will and preferences if they were in a position to express these. Where placement in secure units is unavoidable, informed consent should be obtained, and measures should be taken to ensure the welfare of the person who is being detained.

But it is important to note that autonomy and safeguarding are not mutually inconsistent, as safeguarding responses also act to support and promote the autonomy of older people. For example, confining a person to a secure area is likely to be more acceptable where the area is of sufficient size, comfort, and quality to make it a relatively pleasant place to be – for example, a wing of a building including some outside space, rather than simply a solitary locked ward. Safe walking areas to accommodate wandering can also be extremely beneficial.⁵⁰ Further consideration is required of how to protect the rights and ensure the welfare of people with dementia who are placed in secure units.

Grafton Aged Care Home in NSW provides a positive model of good practice in addressing residents' needs and protecting their rights.

50 Department of Health and Ageing (2012). *Decision Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*.
https://www.dss.gov.au/sites/default/files/documents/09_2014/residential_aged_care_internals_fa3-web.pdf

Grafton Aged Care Home (GACH)

GACH is an aged care home constantly improving service delivery through innovative policies procedures and staff education programs. Following participating in the Alzheimer's Australia NSW project *Moving into Care*, GACH developed a strong focus on improving care for their residents with a diagnosis of dementia.

GACH ran a workshop in June 2015 to educate members of staff and equip them as leaders within the areas they work. The 6 hour workshop focuses on understanding dementia, the needs and wants of those with dementia, and how to best apply person centred care practices.

As a result, GACH has made the decision to maintain an 'open doors' policy in their secure dementia unit which led to the development and implementation of the afternoon café and friendship morning. The afternoon café provides an opportunity for residents to participate in meaningful activities while assisting staff workloads. Meaningful activities are provided in the café depending on the residents present. Consequently, staff members have witnessed a reduction in wandering and an increased appetite in residents when involved in the preparation of food.

Following the success of the afternoon café, the 'Friendship Morning' initiative was implemented. The 'Friendship Morning' provides 4 hour one-on-one meaningful activities for residents to participate in, run by recreational activities officers and assistants in nursing with a sound knowledge of dementia care. GACH has also shifted from using plastic cups and plates to china crockery for tea, coffee, and meals.

GACH also makes use of STAR charts as a tool designed to provide staff with important information about a resident's history in order to help staff better engage with the resident. As part of the 'Resident of the Day' initiative, staff regularly review and update STAR charts, which has proved to be helpful for staff and of benefit to the residents.

Establishment of Dementia Specialist Units

As noted above, there are instances where placement in a secure unit may be required for duty of care reasons and may be in the best interests of the person. Residents who cannot be managed in mainstream facilities can be accommodated in the special care facilities, sometimes called psychogeriatric or aged-care neurobehavioural units, for a defined period of time until behaviours abated before returning to mainstream care.

Alzheimer's Australia has recommended the establishment of specialised high care dependency units which are designed to meet the needs of individuals with severe BPSD and individuals with severe mental health concerns, which has also been identified as the preferred approach.⁵¹ These units have appropriately trained staff and access to specialised clinicians and work to stabilise the individual so that they can be returned to mainstream services.

As reported in the Oakden report too, individuals who require psychogeriatric care are often unable to access care that addresses both their aged care and mental health needs because of structural barriers between the state-funded mental health system and the Commonwealth funded aged care system.⁵² These barriers and lack of adequate funding have led to a shortage of specialist facilities.

Some states provide specialised care through aged care facilities that are funded through the Aged Care Act and are topped up with funding from the State Government to provide

51 Psychogeriatric Care Expert Reference Group Submission to the Productivity Commission (2010).

52 Department of Health and Ageing (2008). *Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders*.

high levels of mental health support.⁵³ This system may work well in some states, but in others there is a clear lack of collaboration and a gap in services. As a result, there is a need to clearly identify who is responsible for the care of older individuals with mental health needs. Examples of this approach include the Psychogeriatric Nursing Homes in Victoria, and Psychogeriatric Care Units in Western Australia.⁵⁴ These facilities use ongoing behavioural assessment and rehabilitation, with the goal to discharge residents to mainstream facilities.

Psychogeriatric Nursing Homes in Victoria

The Psychogeriatric Nursing Homes in Victoria have been established in each health region and are designed to operate as longer term transitional care models, with clients being relocated to less intensive service options when appropriate.⁵⁵ These nursing homes have strict admission and discharge criteria and close relationships with acute and community-based service providers through the Aged Psychiatric Assessment and Treatment Teams. These teams provide assessment, case management, referral and access to support across the entire mental health services.⁵⁶

While the Government had allocated \$7.5 million in funding towards the establishment of these special dementia care units in the 2016-17 Budget, progress to date remains unclear, with none of the units established as at 30 June 2017.

Recommendation 13

Specialist Dementia Care Units which can provide one-on-one care for people with severe behavioural and psychological symptoms of dementia, which were announced in the 2016-17 Budget, should be established as soon as possible.

Expanded and enhanced palliative care

There is evidence to suggest that people with dementia may experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation (with the person with dementia or their family carers) over their choices regarding end of life care.⁵⁷ Furthermore, there is often a lack of appropriate emotional and informational support provided to family and family carers during end-stage dementia.

A survey of care professionals and family carers undertaken by Alzheimer's Australia found that consumers struggle to get access to appropriate end-of-life care for people with dementia. One in five family carers reported experiencing difficulties in securing care in line with the wishes of the person with dementia, and the majority lacked access to palliative care, hospice care, or care in the community.⁵⁸

Timely advance care planning and high quality palliative care are the preferred methods for ensuring quality end-of-life care for people with dementia. Individuals in the early stages of dementia should be supported and encouraged to participate in advance care planning to express their views about medical treatment and their preferences about end of life treatment. Each State and Territory has a different approach to documenting wishes in

53 Department of Health and Ageing (2008). *Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders*.

54 Brodaty, H, Draper, BM, Low, L (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-34.

55 Australian Government Department of Health and Ageing (2008). *Report to the minister for ageing on residential care and people with psychogeriatric disorders*.

56 Australian Government Department of Health and Ageing (2008). *Report to the minister for ageing on residential care and people with psychogeriatric disorders*.

57 Nuffield Council on Bioethics (2009). *Dementia: Ethical Issues*.

58 Alzheimer's Australia (2014). *End of life care for people with dementia: Survey report*.

relation to future health care. Families need to be provided with sufficient information after an individual receives a diagnosis of dementia in order to take appropriate steps in advanced care planning.

Consumer Views on End of Life Care

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

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

Many individuals with dementia and their families want palliative care which focuses on relieving the symptoms experienced by the individual rather than trying to cure a condition or delay the progression of terminal disease, and provides emotional, informational and practical support to family and family carers. Research suggests that often individuals with dementia are unable to access desired palliative care.⁵⁹

Regulatory processes in aged care should thus require aged care providers to encourage residents 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.⁶⁰

Recommendations 14

There should be improved access to information and support for advance care planning for people with dementia, their families and carers, as well as improved access to palliative care and pain management in aged care.

Workforce

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.

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.

The aged care sector workforce is a critical element in the provision of quality services, and this workforce must be available in the future in sufficient numbers, and at a high quality. To

59 Alzheimer's Australia (2006). *Palliative Care and Dementia*.

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

ensure quality, the workforce must have the appropriate education and training, skills, and attributes to provide the care that is needed. This includes the capacity to provide quality care to people with dementia, who are often frail and vulnerable, and often have complex care needs.

The prime consideration in developing strategies for the future aged care workforce must be the needs of the consumer. The overriding imperative is to ensure access by older people, including people with dementia, to high quality community and residential aged care services.

Ensuring adequate staff ratios and an appropriate skills mix

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 perceived 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.

Overwhelmingly, families consulted by Alzheimer's Australia have expressed a strong desire to see aged care facilities invest in staff as a priority – to retain and support existing staff, increase staff remuneration and recognition, and roster adequate staff numbers to facilitate better, more person-centred care. Inexperienced staff, frequent shift rotations and poor hand-over procedures were cited by families as some of the main causes for avoidable failures, as well as a substantial barrier to achieving person-centred 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.

Dementia is an ever changing and progressive condition, often with complex physical comorbidities and psychological and behavioural symptoms, which should be prevented where possible through better engagement and care, and which require careful assessment and management by appropriately trained staff. At present there are insufficient measures in place to ensure that the workforce is equipped to fulfil this role. Minimum standards of education and training should be required for staff working with people with dementia.

Over the past decade and more, there has been a significant shift in the aged care workforce. There is a trend towards employing less skilled (and lower cost) staff in residential settings in the delivery of direct care services. At the same time as the acuity of care required has been increasing, there has been a substantial decrease in the proportion of qualified nursing staff in the aged care workforce, and an increase in the proportion of unlicensed and unregulated personal carers. The number of qualified nursing positions in residential aged care has decreased by 8.4% since 2003, despite the number of residential aged care places increasing by 25.2%, and the proportion of aged care residents assessed

as having high care needs increasing from 64% to 83%.⁶¹ Registered Nurse positions decreased from 21.4% of the direct care workforce in residential care in 2003, to just 14.7% in 2012; while the proportion of Enrolled Nurses decreased from 14.4% to 11.6% over the same period. Personal Care Attendants now comprise 68 per cent of the residential direct care workforce, while Community Care Workers comprise 81 per cent of the community direct care workforce.⁶²

“More and more, older Australians are remaining in their own homes for longer, and are entering nursing homes only when their care needs are too complex to be managed in the community. That complexity of care means that more than ever, we need qualified nursing staff whose skills are valued, whose professionalism is acknowledged and who feel they can care for their residents properly.”⁶³

Research has shown that direct care workers are generally highly committed to care recipients, and are keen to have the time and the skills to improve the wellbeing of residents and provide quality care, which they see as core components of their work. However, aged care staff must also meet regulatory requirements, operate according to organisational schedules, and work within budgetary constraints. In the 2012 Aged Care Workforce Survey, 45 per cent of direct care workers said they did not spend enough time with care recipients. In particular, over 40% of nurses reported spending less than a third of their shift performing direct care. This reflects the increasing managerial role that nurses, particularly Registered Nurses, are performing while Personal Care Assistants in particular are taking more responsibility for direct care.⁶⁴

Although clinical care is only one component of quality, the reduction in direct nursing care to a residential care population with increasingly high needs may be problematic for achieving high quality care and avoiding unnecessary hospitalisations. Ensuring overall adequate staffing levels is also important to ensure that staff have sufficient time to interact with residents and assist them in meeting their physical and social needs.

Recommendation 15

To ensure quality and safety in residential aged care, funding arrangements should support appropriate staff ratios and skill mix.

Appropriate workforce education and training

To ensure quality dementia care, health care professionals and all care staff must be educated and trained in key aspects of dementia care including: person-centred care, the fundamentals of caring for people with dementia, psychosocial approaches to addressing unmet needs, pain assessment and management (particularly as people with dementia may be unable to verbalise their needs), and appropriate end-of-life care.

61 Australian Nursing and Midwifery Federation (2015). *Fact sheet 4: A snapshot of residential aged care*.

62 King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

63 Australian Nursing and Midwifery Federation (2015). *Fact sheet 4: A snapshot of residential aged care*.

64 King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

The 2012 Aged Care Workforce Survey found that direct care workers in the aged care sector identified “Dementia” and “Palliative Care” as the top two areas where they require further education and training.⁶⁵ This indicates an unmet need for education and training to improved knowledge, skills and confidence in caring for people with dementia.

The same survey found that working with “aggressive service users” (this is likely to include people with behavioural and psychological symptoms of dementia) was a normal expectation in 33 per cent of facilities, with another 47 per cent indicating that workers were required to do this in exceptional circumstances. The authors noted that this is likely to be a consequence of the growing number of older Australians with dementia and other mental health problems who are living in facilities.⁶⁶ As noted, behavioural and psychological symptoms often reflect unmet needs of the person with dementia.

A recent stocktake of Commonwealth-funded aged care workforce activities confirmed that the quality and quantity of aged and community care training varies significantly, with workplace placements for Certificate III students ranging from under 60 hours for some providers, up to two years for other providers. It was noted that industry involvement in the development of training packages is important to ensure that qualifications reflect contemporary industry requirements for existing roles, prepare workers for new and emerging roles, and support training pathways for career progression. The stocktake recommended, among other things, that greater targeting and evaluation of workforce training and education is needed to ensure responsiveness to identified workforce or skill gaps in the industry.⁶⁷

Similarly, a recent review of Commonwealth-funded dementia programs identified a need for better co-ordination and promotion of education and training programs, and improved consistency and quality across these services.⁶⁸

Alzheimer’s Australia offers a Certificate IV in Dementia Practice which is a consistent, high quality, practically based course and represents one means of addressing the current inconsistencies in education and training.

Learning pathways are needed for care staff to develop knowledge, skills and emotional intelligence, from basic level to advanced practice level. Government and aged care service providers have a shared responsibility to develop and fund education and career pathways for the aged care workforce. Government must maintain a commitment to supporting ongoing education and training to develop and sustain a workforce skilled in dementia care, and employers must also be committed and contribute to education and training.

Education and training programs must respond to the evolving characteristics of the workforce, including targeted education and training for the increasing proportion of the workforce which comes from culturally and linguistically diverse backgrounds.

65 King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

66 King D, Mavromaras K, Wei Z, He B, Healy J, Macaitis K, Moskos M, Smith L; National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

67 Health Outcomes International for Department of Social Services (2015). *Stocktake and analysis of Commonwealth funded aged care workforce activities: Final report*.

68 KPMG (2015). *Analysis of dementia programmes funded by the Department of Social Services*.

Further, there is a need to move dementia education and training from an outputs focus to an outcomes focus. Currently, education and training is essentially provided on the presumption that simply undertaking an activity or using a particular resource results in practice change; little import is given to whether this actually occurs. Practice change requires more than simply creating an awareness of knowledge; measures are needed to translate this to practice. Within workforce investment, priority needs to be placed on developing a cohesive, structured and integrated national dementia training and education program. Focus should be on practice changes, and on education and training activities that lead to better outcomes for people living with dementia and long-term sustainable change. Education and training on evidence-based care models, and on culture change processes, should be included.

Dementia training should be linked to clear levels of competency and/or practice standards, so that the learning outcomes of all dementia education and training activities may be aligned with the competencies/practice standards. Ideally, the outcomes of each education and training activity would be assessed using a framework to ensure that they achieve the intended outcomes and lead to practice change.

Alongside the development of individuals in the workforce, strategies are needed to develop leadership and cultural change at organisational level, and maximise opportunities to translate learning into improvements in practice.

Recommendation 16

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.

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.