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SUBMISSION TO THE AGED CARE
LEGISLATED REVIEW

DECEMBER 2016

EXECUTIVE SUMMARY

The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are now more than 340,000 Australians living with dementia¹ and over a million people involved in their care². By 2050 there will be nearly 900,000 people with dementia³. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050⁴.

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 annum⁵. Dementia also has a profound social impact. People with dementia experience stigma and social isolation⁶, and family carers often find it difficult to balance work, life and caring responsibilities⁷.

Many of us will be diagnosed with dementia over the years ahead, or will have loved ones faced with the diagnosis. We all need to know that our social, health, and aged care systems will be ready and able to respond, and that we as a society can achieve the best possible quality of life for people with dementia and their carers, at a cost that is affordable to us as a country.

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.

Alzheimer's Australia welcomes the scope of the review and strongly supports its intention to look at the impact of the changes to date and where we need to take the system in the future. It is important to note that while this review focusses on Aged Care, it is equally important to ensure the integration of services not just across the aged care experience, but between aged care 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. With these considerations as our primary aim, Alzheimer's Australia makes the following recommendations to the Review:

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

² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁴ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁷ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

Recommendation 1: That the Review consider the implementation of Consumer Directed Care and the mix of package levels and assess whether consumers are able to access appropriate care and services in a timely manner.

Recommendation 2: That the Review consider and include issues relating to the safety and quality of care for people with dementia, as well as the standards and processes relating to quality and safety in aged care.

Recommendation 3: That the Review consider support for carers, including the provision of respite care for carers of people with dementia living at home as a key component of quality in the aged care system.

Recommendation 4: The Review consider the specialist needs of vulnerable cohorts, such as people with BPSD, and assess the need of additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care.

Recommendation 5: That the Review consider the role that consumers and carers can play in the implementation of the CDC model. Alzheimer's Australia recommends that consumers and carers should be engaged as key partners in aged care quality and compliance processes.

Recommendation 6: That the Review ensure that informed decision making by all consumers, including those with dementia as well as their carers, should underpin the ongoing implementation of CDC, quality standards and processes and any future reforms for aged care services.

Recommendation 7: That the Review consider the accessibility and useability of key consumer information sources such as My Aged Care.

Recommendation 8: That the review consider the role a comprehensive aged care advocacy framework can play in supporting the implementation of CDC.

Recommendation 9: That the Review consider a licencing and financing framework that supports the implementation of a family/consumer facilitation role.

Recommendation 10: That the Review ensures a focus on equitable and affordable access to appropriate care for people with dementia in the aged care system.

Recommendation 11: That the Review consider the regulation of prices of Aged Care accommodation to address the variability in costs incurred by consumers. Alzheimer's Australia recommends urgent measures to improve affordability of care, as well as the inclusion of a strong consumer voice on the Aged Care Financing Authority.

Recommendation 12: That the Review consider the need for interpreters and appropriate cultural training for staff as an important consideration particularly for consumers

with dementia and to protect equity of access to aged care services across different population groups.

Recommendation 13: That the Review consider the need to mandate minimum ratios of staff to residents, and mandated minimum levels of qualified nursing staff to ensure to ensure quality and safety in residential aged care; Alzheimer's Australia also recommends a requirement for all stand-alone residential aged care facilities to have a Registered Nurse on site at all times. Funding arrangements for aged care should support appropriate staff ratios and skill mix.

Recommendation 14: That the Review consider the need for a cohesive, structured and integrated national approach to dementia education and training, including minimum standards for education and training for those working with people with dementia.

Recommendation 15: That the Review consider remuneration for all staff in the aged care sector. Alzheimer's Australia recommends that remuneration across Aged Care should be aligned with that for similar roles in other sectors including acute health care; and clear career paths should be developed and implemented for nurses and other workers in the aged care sector. Funding arrangements for aged care should support appropriate remuneration and career paths.

Recommendation 16: That the Review consider the relative increase of Residential Aged Care deposits when compared to sale prices of residential homes, and the impact this has as to act as an impediment to access for consumers.

Recommendation 17: That the Review consider and support a model of enhanced community-based aged care, which should be based around the provision of holistic care, in conjunction with other services, to enable people living with dementia to remain at home for as long as is feasible, if this is the person's preference.

Recommendation 18: That the Review consider a residential aged care model that involves ensuring the environment is as home-like as possible, and takes a flexible approach to providing the best possible care for the individual resident. Key elements include resident-centred care with measures in place to cater for people with dementia; culturally appropriate care; involvement of relatives and friends; effective pain management; minimal use of restraint; and use of specialist supports.

OVERARCHING ISSUES THAT IMPACT AGED CARE

Overall, while Alzheimer's Australia is supportive of the review and its intent, we believe there are other urgent issues, which while are beyond the scope of this review, have an overarching impact on the ongoing reforms.

1.1 People with Dementia in the Aged Care System

Dementia is a progressive disease and people with dementia require a range of supports and care. Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community⁸. Provision of comprehensive home based care, respite, and appropriate, high quality residential care, are therefore critical to meeting the needs of people living with dementia and their families.

For the 30% of people with dementia living in residential care, it is critical that all aged care services are well equipped and motivated to provide high quality care for people with dementia, as part of their core business. There are concerns about the quality of care provided to many people with dementia in mainstream residential aged care services. 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. People with severe behavioural and psychological symptoms of dementia have even more difficulty in getting access to appropriate support and care.

For the 70% of people living in the community, access to high quality, flexible home care services is essential and are key in delaying the admission to costly permanent care. Recent expansion of home care packages and the addition of the dementia supplement in all levels of packages has been a welcome support for people with dementia living in the community.

However the move to Consumer Directed Care (CDC) has also seen a rise in administrative costs associated with packages. Alzheimer's Australia has received reports from consumers of Commonwealth Home Care Package providers increasing their administration fees in response to the CDC changes, and charging up to 70% of packages on administration fees, in some cases leaving very little funding for actual care; and consumers have raised concerns that there is very little transparency with regard to these fees.

It is therefore essential that the Review monitor the implementation of Consumer Directed Care and the mix of package levels to assess whether consumers are able to access appropriate care and services in a timely manner.

Recommendation 1: That the Review consider the implementation of Consumer Directed Care and the mix of package levels and assess whether consumers are able to access appropriate care and services in a timely manner.

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

1.2 Ensuring Quality across Aged Care

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.”⁹

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

The number of older Australians with dementia is growing exponentially, and the core business of both residential and home-based aged care services increasingly includes providing care to people with dementia. The Australian Institute of Health and Welfare has calculated that more than half of the residents in aged care facilities have dementia¹⁰.

But the reality of life within an aged care service for a person with dementia is often very difficult. While the majority of people receive good care, unfortunately there are many instances where this is not the case. There are particular concerns regarding residential aged care, where Alzheimer’s Australia receives reports from consumers about physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end-of-life not having access to palliative care.¹¹

There is a spectrum of issues around quality in aged care facilities that range from poor quality to criminal negligence and abuse. The extreme examples of poor clinical care often hit the news, but the more subtle injustices of isolation, misunderstanding, and undiagnosed pain are often suffered in silence. Essential drivers of quality improvement include improved regulation, and publicly reported quality indicators. In 2015, fewer than 2% of aged care facilities failed to meet the Accreditation Standards. While it is encouraging that there has been improvement over the last decade, it suggests that the bar is set too low and there should be a focus on continued quality improvement.

Given the reports consumers share with us of their experiences in aged care as outlined above, we cannot be confident that 99% of facilities meet the expected basic standard of care and support. A voluntary quality-indicator program has commenced within the aged care sector however the program is in the very early stages with data not yet being publicly available. The initial indicators included as part of this program are clinically focused and feedback from consumers indicates that there is a need for publically available indicators that capture consumer experience and quality of life within aged care services.

⁹ Cited in Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 8.

¹⁰ Australian Institute of Health and Welfare (2012) *Dementia in Australia*, p.107.

¹¹ Alzheimer’s Australia (November 2013), Paper 37: *Quality of residential aged care: The consumer perspective* p 4.
https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf

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

Right now it is very difficult for consumers to ascertain quality of dementia care within residential care facilities. This makes the desired move to a more market-driven system challenging, as informed choice is not possible without good information. The ongoing development of quality-indicators in aged care is welcome but still limited. We need to move away from a narrow focus on standards and accreditation, to a broader focus on delivering real quality in aged care.

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

As the prevalence of dementia increases in our community, it is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business.

Recommendation 2: That the Review consider and include issues relating to the safety and quality of care for people with dementia, as well as the standards and processes relating to quality and safety in aged care.

1.3 Support for Carers

With the increasing reliance on home care, it is essential to ensure that there is adequate support for family carers. Respite plays a critical role in providing a break for carers as well as an important opportunity for social engagement for the person with dementia¹². Often respite is essential to ensuring that family members can continue caring for the person with dementia at home¹³.

¹² Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

¹³ Alzheimer's Australia (2009) *Respite Care for People Living with Dementia "It's more than just a short break"*

Unfortunately, few respite services have specifically designed services to support people with dementia. In fact, as care needs increase, respite providers often turn away people with dementia. Many respite services say that they are not staffed to provide care to people who have behavioural symptoms or who are incontinent.

There is a need for a dementia-supplement for respite providers, similar to the supplement provided within community care. This supplement should only be available to services who can show they have put in place strategies and training for caring for people with dementia. This supplement would acknowledge the additional costs associated with providing respite to this group and would create an incentive for providers to develop dementia-specific services which should include social engagement opportunities where possible. A respite supplement would be in line with the Government's focus on increasing choice through implementation of consumer directed care.

Recommendation 3: That the Review consider support for carers, including the provision of respite care for carers of people with dementia living at home as a key component of quality in the aged care system.

1.4 Specialised support for Behavioural and Psychological Symptoms of Dementia

People with severe Behavioural and Psychological Symptoms of Dementia (BPSD) often have difficulty accessing appropriate care and support. It is essential that Review consider and assess the care and support that people with BPSD are receiving.

Experts have suggested the need for specialised psycho-geriatric care for people with the most severe BPSD for a limited period of time. These facilities require secure grounds, higher staffing ratios, staff with specialised training and support from specialist mental health services. In Australia, the availability of these specialised care facilities is limited. Similarly, others have called for a specialised grant program to provide additional funding to aged care providers who put in place specialised services and supports for people with BPSD.

The Government has recently invested in the Severe Behaviour Response Teams (SBRT) as a complement to the Dementia Behaviour Management Advisory Service (DBMAS) to provide additional specialised support to people with severe behavioural and psychological symptoms of dementia. Alzheimer's Australia believes The Government must provide adequate funding to ensure access to quality aged care services and support for people with behavioural and psychological symptoms, through current programs such as the SBRT and DBMAS, as well as additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care. It is also important to take into account that it is not only people with BPSD who have particular care needs. Appropriate environments are also needed that support a person with dementia who is rated low needs and is relatively mobile and able.

Recommendation 4: The Review consider the specialist needs of vulnerable cohorts, such as people with BPSD, and assess the need of additional measures such as funding specialised psychogeriatric units or providing grant funding to providers who provide specialist care.

RESPONSE TO CRITERIA IN LEGISLATION

2.1 Unmet demand for residential and home care places

Alzheimer's Australia is not in a position to provide national data which would indicate whether or not unmet demand has been reduced. Anecdotal evidence from our consumer networks indicates that there is still significant unmet demand for appropriate, high quality services for older people with dementia, particularly those living in rural and remote areas, those with significant behavioural and psychological symptoms of dementia, and those with a need for culturally specific services, such as older people with dementia from Culturally and Linguistically Diverse (CALD) backgrounds or from Aboriginal and Torres Strait Islander communities.

Consumers have informed Alzheimer's Australia that it can be difficult to get residential and home care places dependent on the level of care required. The availability of residential beds may vary between areas, with pressure points in some areas and unused beds in other areas. Consumers also advise that low level home care is easily obtainable, but high level home care is not, in light of the fees required and the limited hours of care available (only eight hours care per week which then puts pressure on beds). Care is said to be more accessible for those with the means to pay high out of pocket costs.

<p>Recommendation 4: That the Review recommend the collection and assessment of national data that reflects consumer need and unmet demand across home care places.</p>
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2.2 Number and mix of places for residential care and need for further control

This issue is fraught with complexity. It is important to ensure that the care given is of the highest standard, in particular for residents living with dementia. The needs of the particular population and its cultural mix must be taken into consideration when planning approval is given for the development of new residential care or home care places. It is critical to protect access to service for people from special needs backgrounds or with specific care needs such as dementia. A genuinely open market may well increase the number of home care places, for example, but individuals and communities with special needs may not be best placed to advocate for service or place demands on the market.

Controlling the supply of care may limit the choices available to service users; increase waiting lists, resulting in people who need care missing out or waiting a long time; limit supply, giving residential aged care providers an incentive to choose wealthier potential residents or those with less complex care needs; and limit competition, which may affect quality.

On the other hand, reducing control may lead to reduction of services in less commercially viable areas. The current policies and controls in place that relate to ageing can have a significant impact on the psychological wellbeing and the level of care for people with dementia when combined with low staff ratios. Regardless of what controls are in place, robust measures are needed to ensure appropriate access to quality care, as discussed in the final section of this submission.

2.3 Steps that could be taken to change key aged care services from a supply driven model to a consumer demand driven model

Alzheimer's Australia supports the Government's commitment to aged care reform and the ongoing implementation of CDC across the aged care system. We support the broader intent of CDC and recognise its aim to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when.

However, we remain concerned about the current inability of mainstream services to deliver appropriate care and support for people with dementia. Specialist services such as dementia specific advocacy, information and support are critical. People with dementia and their families and carers will experience unique challenges when participating in CDC programs due to the complex symptoms and progressive decline in cognitive functioning that are the hallmarks of dementia. The issues raised by consumers as CDC has begun rolling out point to the complexities in balancing the needs of clients, service providers and governments, while ensuring timely access to essential services within a robust framework of consumer protections. This highlights the need for an increased and more robust focus on the quality of care provided to ensure standards of care are maintained and continually improved

To achieve a quality aged care system under a CDC model, it is vital that we have informed and engaged consumers, well supported in decision-making. For people with dementia, as for those people without dementia, having a say in their everyday lives is a basic desire and underpins a sense of purpose and well-being. Many people with dementia have expressed a desire to feel that they are participating in decision making regarding their care but also recognise that their ability to do so is, and will be, compromised by the very nature of dementia.

Recommendation 5: That the Review consider the role that consumers and carers can play in the implementation of the CDC model. Alzheimer's Australia recommends that consumers and carers should be engaged as key partners in aged care quality and compliance processes.

Consumers have identified the need for greater transparency across the implementation of CDC reforms. A central principle of CDC should be to ensure that the entire interactive communication process supports consumers to fully understand the proposed care plan and the choices available to them, and provides the information necessary to support informed decision-making.

Consumers have also reported being given only a few hours in which to make a decision to accept a place within a residential facility otherwise the bed will be offered to another family. Where there is no consumer choice, there is no market to drive quality improvement. Private aged care service providers, along with public providers, must be required to play their part

in a holistic aged care system that caters to both the market-empowered and the vulnerable. It is critical that policy settings are in place to ensure an appropriate balance between profit and community responsibility.

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

Recommendation 6: That informed decision making by all consumers, including those with dementia as well as their carers, should underpin the ongoing implementation of CDC, quality standards and processes and any future reforms for aged care services.

There is also a need to enhance the accessibility and useability of the My Aged Care website. Alzheimer's Australia has previously highlighted issues being experienced by people with dementia and their families and carers in using My Aged Care and similar feedback has also been highlighted in the recent evaluation report on My Aged Care by AMR Research. One issue of concern is the difficulty for consumers to access important information and support sources, such as those provided by Alzheimer's Australia, through the My Aged Care website.

For people living with dementia and their carers, especially and for those from other cultures, trying to access My Aged Care and juggling both what services are available as well as how to access aged care in their area is very, very difficult. Many of this age group struggle with computers and language and there is a need for trained advocates to be employed to assist people as needed over the phone or through shopfronts. Additionally, many remote areas do not have good internet access and this compounds the problem.

Another key factor appears to be the need for better support and training for contact centre staff to enable them to respond to the information needs of people with dementia, carers and families. This is concerning, not only because people with dementia are high users of aged care services, but also because carers of people with dementia often experience significant negative impacts, such as stress and depression. We are currently in a transitional phase to consumer directed care, and appropriate support for consumers and organisations should remain in place. The adjunct to consumer-directed care and consumer choice is consumer responsibility and accountability, and in this context it needs to be noted that the ability to easily negotiate the system is still very much in a developmental phase.

Recommendation 7: That the Review consider the accessibility and useability of key consumer information sources such as My Aged Care.

A comprehensive aged care advocacy framework is a critical element to support the implementation of CDC. The scale of reform across aged care is significant, and it is vital to ensure that consumers are supported, empowered and have their rights protected during this period of change and within an evolving aged care system. This is particularly true for consumers who are vulnerable and may have difficulty in expressing their needs and desires, such as people with dementia.

Recommendation 8: That the review consider the role a comprehensive aged care advocacy framework can play in supporting the implementation of CDC.

Alzheimer's Australia also recommends a licencing and financing framework that supports the implementation of a family/consumer facilitation role. This would address the current situation where the engagement of services with a resident's family post admission is fractured and incident related. Initiatives are needed that reward innovative models of care. Legislation to come into place early in 2017 will give residents more say in whom they wish to supply their care, who should administer this and how their care packages will operate. This a positive move and should be reviewed for its efficacy after an appropriate period of time.

Recommendation 9: That the Review consider a licencing and financing framework that supports the implementation of a family/consumer facilitation role

Alzheimer's Australia remains positive about achieving greater consumer choice and flexible services under CDC. For people with dementia and their families and carers, these objectives are particularly important given the progressive nature of the condition which requires responsive and individually tailored solutions from service providers that will evolve over time to remain aligned with the individual's situation. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported.

2.4 Means testing arrangements for aged care services, including an assessment of the alignment of charges across residential care and home care services

The cost of residential care has grown exponentially and the sale of the family home to cover the costs of entry plus the daily care fees has become a reality for many consumers. This is one of the major problems with the present level of services offered. It has not been easy for some families to find the necessary funds if the person requires high care, or to find suitable beds should the person have late dementia or multiple complex needs. Alzheimer's Australia is of the view that there are vastly insufficient concessional places available. Additional payments for "extra" services can be draining on families who cannot afford to support their loved one beyond paying for basic care. Access to allied health care services is often limited to those who can pay, if the resident does not score high on the respective ACFI assessment domains; and service provision is often reactive rather than proactive. Ensuring equitable and affordable access to appropriate care for people with dementia in the aged

care system is an urgent priority. In addition, people with a cognitive impairment such as dementia require appropriate supports and protections in relation to the financial arrangements that lie behind their care.

Alzheimer's Australia is concerned that with the introduction of higher fees and the addition of means tested fees for home care, many people are rejecting low level care packages, as they are generally not seen as good value. While there are many vacant low care places, there are often significant waiting lists for high level care packages. This pattern is problematic, as low level care previously helped people to start accepting help and introduced them to the system, enabling issues and needs to be addressed early and potentially assisting to delay the onset of complex care needs. Importantly, early signs of dementia could be picked up and acted upon in this phase of care. The situation today is that for many people, by the time they are willing to pay the fee for the higher care packages, their needs are complex and their care is much harder to set up. This also leads to more stress for families.

<p>Recommendation 10: That the Review ensure a focus on equitable and affordable access to appropriate care for people with dementia in the aged care system</p>

2.5 Regulating prices for aged care accommodation

All residential places now require a Refundable Accommodation Deposit (RAD) at entry, with the amount set by the provider. In addition, residents are charged the basic daily fee, the means tested care fee, and the accommodation daily payment rate; and some beds attract a special services fee.

These arrangements are complex, and the general public has little idea how the system works and how much care now costs, making informed financial planning for this stage of life very difficult. This information is not readily available through the My Aged Care website. Consumers have advised Alzheimer's Australia that when a person goes into care, financial considerations are now contributing to decisions about the type of bed, the type of provider and the level of care. These decisions are being made by the next of kin who may have a conflict of interest as they are also usually the beneficiaries of the will. This can cause problems, particularly when family members are not in agreement. There is a lack of safe guards in place to protect the older person when these decisions are being made.

Consumers also report that waiting times for care have always been affected by how heavy the person is (if a person requires a two person lift) and how challenging their behaviour is seen to be. It is seen that the wait for an individual could now also be impacted on by the ability or willingness of the family to pay the requisite fees. People who do not own their home may have no way of coming up with a RAD or partial RAD. Couples will also experience difficulties when one person needs care, especially if they do not have any spare cash and do not want to sell their home. This will affect their waiting time and their ability to access the facility of choice. There can also be dilemmas if two members of a family have to go into care one after the other, and even following the sale of the family home there is only enough money to pay for one family member.

Overall, the cost of residential aged care is becoming prohibitive for many as we live longer. Major concerns are being raised about this by consumers in the Alzheimer's Australia network. The variable daily fee rates in addition to the entrance fee (RAD) are causing major problems which need to be urgently addressed through increased regulation. In addition, adequate funding must be made available for people who have significant needs but are not defined as "complex", and for proactive, holistic service provision. Alzheimer's Australia recommends urgent measures to improve affordability of care, as well as the inclusion of a strong consumer voice on the Aged Care Financing Authority, as one means of helping to ensure that consumer interests are taken into account in future financing policy and arrangements.

Recommendation 11: That the Review consider the regulation of prices of Aged Care accommodation to address the variability in costs incurred by consumers. Alzheimer's Australia recommends urgent measures to improve affordability of care, as well as the inclusion of a strong consumer voice on the Aged Care Financing Authority.

2.6 Protecting equity of access to aged care services for different population groups

As noted above, anecdotal evidence from our consumer networks indicates that there is still significant unmet demand for appropriate, high quality services for older people with dementia, particularly those living in rural and remote areas, those with significant behavioural and psychological symptoms of dementia, and those with a need for culturally specific services, such as older people with dementia from Culturally and Linguistically Diverse (CALD) backgrounds or from Aboriginal and Torres Strait Islander communities.

To give a few examples, Alzheimer's Australia has been told by consumers that Aboriginal people do not have equity of access in remote parts of WA. Other cultural groups, such as the Greek community have established their own residential care facilities and for some time have provided culturally appropriate care, but it is reported that they are now being driven out by larger providers. Australia has a culturally mixed population and those with language and cultural needs and/or dementia need to have their access to their care protected. The need for interpreters and appropriate cultural training for staff is an important consideration particularly for consumers with dementia who may find it easier to communicate in their native language.

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

Recommendation 12: That the Review consider the need for interpreters and appropriate cultural training for staff is an important consideration particularly for consumers with dementia and to protect equity of access to aged care services across different population groups.

2.7 Workforce strategies in aged care services, including strategies for the education, recruitment, retention and funding of aged care workers

As the prevalence of dementia increases in our community, it is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business. 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.

There are currently significant threats to the availability and quality of the future aged care sector workforce in Australia. Although much greater numbers will be needed in the future, the current workforce is itself ageing, and services are already experiencing difficulty in filling vacancies.

At a time when the number of people needing access to aged care services is increasing, and the acuity of care required is also increasing, ratios of direct care staff to residents in aged care services are often decreasing, and the number and proportion of qualified nursing staff positions in aged care, particularly residential care, has fallen dramatically. Alzheimer's Australia is concerned that these trends are already impacting on the quality of care offered to some of the most frail and vulnerable people in our community, and that the situation has the potential to worsen in the future as demand pressures increase. These two issues – ratios of staff to residents, and levels of qualified nursing staff – are the two most important workforce issues that impact on quality of care, and they need to be addressed urgently.

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

To ensure quality care, management in aged care services must be committed to person-centred high quality care, and services must have adequate numbers of skilled, qualified staff. Mandated minimum ratios of staff to residents, and mandated minimum levels of

qualified nursing staff, are required; including a requirement for all stand-alone residential aged care facilities to have a Registered Nurse on site at all times.

Recommendation 13: That the Review consider the need to mandate minimum ratios of staff to residents, and mandated minimum levels of qualified nursing staff to ensure to ensure quality and safety in residential aged care; Alzheimer’s Australia also recommends a requirement for all stand-alone residential aged care facilities to have a Registered Nurse on site at all times. Funding arrangements for aged care should support appropriate staff ratios and skill mix.

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

Recommendation 14: That the Review consider the need for a cohesive, structured and integrated national approach to dementia education and training, including minimum standards for education and training for those working with people with dementia.

To attract and maintain the right workforce, improved pay and conditions and appropriate career paths will be needed. Staff working in aged care are relatively poorly paid for a very difficult and demanding job. This means that retention of staff is not easy to maintain, the choice of staff is limited and it is essential that recruitment and education of care workers is based on an empathetic approach, and qualifications that are meaningful and relevant to the population receiving care. Aged care funding arrangements must support adequate staff ratios and skills/qualification mix to support an acceptable level and quality of care.

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

Recommendation 15: That the Review consider remuneration for all staff in the aged care sector. Alzheimer’s Australia recommends that remuneration across Aged Care should be aligned with that for similar roles in other sectors including acute health care; and clear career paths should be developed and implemented for nurses and other workers in the aged care sector. Funding arrangements for aged care should support appropriate remuneration and career paths.

2.8 Protecting refundable deposits and accommodation bonds

For families, placing a family member in care is a costly as well as emotional experience. This capital investment from families need to be protected and it is essential that any contracts for ongoing care include measures to ensure that deposits or bonds are returned to the family as soon as possible and are safeguarded while being held.

The current arrangements are seen to be reasonably effective in terms of legislation and regulation. However, consumer understanding of the rights and responsibilities of providers and consumers, and appropriate adherence needs to be closely monitored and transparent. Another issue of concern is the rate of increase in the price of a bond or RAD in comparison with the sale price of the family home. Consumers have reported concerns at the large increase in RAD levels over the past decade, which is impeding access to care for many.

Recommendation 16: That the Review consider the relative increase of Residential Aged Care deposits when compared to sale prices of residential homes, and the impact this has as to act as an impediment to access for consumers.

2.9 Access to aged care services

Demand is growing at a faster rate than the supply of aged care services. There is also the perceived view that the move to CDC, and a market based system of supply and demand will fix inherent concerns with standards and quality of care that are widespread across aged care. Unfortunately, that’s unlikely to be the case for consumers of aged care services, and particularly for people with dementia.

Relying on a market in aged care to drive quality improvement is unrealistic for a number of reasons including:

- Consumers reluctance to leave a service once they enter due to the disruption of a move
- Lack of competition in rural and remote areas
- The need for urgent access- which limits choice based on availability
- Location preference having a large weight in decisions
- Consumers lack of information about clinical standards and best practice of care.

Vulnerable, resource-intensive consumers, including people with dementia and especially those with significant behavioural and psychological symptoms, will lose out if we rely solely on market forces to drive access. Measures are needed throughout the system to ensure

that that does not happen, and this needs to be considered across community and residential aged care services.

Across Community Based Services:

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

Thus the delivery of services at a consumer's home or through the community should be increased in order to reduce the rate of admission to permanent residential care. Alzheimer's Australia understands that carer burden is cited as the reason for most admissions into permanent care. If there are more supports available for carers within the community, there may be potential to delay admission to costly permanent care.

Recommendation 17: That the Review consider and support a model of enhanced community-based aged care, which should be based around the provision of holistic care, in conjunction with other services, to enable people living with dementia to remain at home for as long as is feasible, if this is the person's preference.

Across Residential Aged Care Services:

In many areas of Australia (and especially in rural and remote areas) there is little or no choice of service providers or residential aged care facilities. Most facilities are full, and there are waiting lists. This can make aged care consumers and their families afraid to complain about service quality, and unable to change to other services. Additionally, access to residential aged care services is often sought at a time of crisis where there is little time available for a thorough analysis of choices available and people with dementia and their carers are often forced into making decisions in a very short timeframe.

Thus in the case of residential care, the key to good care is ensuring consumers have access to an environment that is as home-like as possible, and that there is a flexible approach to providing the best possible care for the individual resident. Alzheimer's Australia advises consumers/carers who are considering residential aged care for a person with dementia to look for a residential aged care home with the following attributes:¹⁴

¹⁴ Alzheimer's Australia Help Sheet: *Residential Care and Dementia 4: Good Care in a Residential Facility*. https://fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare04-GoodCareInAResidentialFacility_english.pdf

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

Recommendation 18: That the Review consider a residential aged care model that involves ensuring the environment is as home-like as possible, and takes a flexible approach to providing the best possible care for the individual resident. Key elements include resident-centred care with measures in place to cater for people with dementia; culturally appropriate care; involvement of relatives and friends; effective pain management; minimal use of restraint; and use of specialist supports.

CONCLUSION

Alzheimer's Australia remains positive about achieving greater consumer choice and flexible services under the ongoing reforms, as well as through the outcome of this Review. For people with dementia and their families and carers, the objectives of this Review are particularly important given the progressive nature of the condition which requires responsive individually tailored solutions from service providers that will evolve over time and with the individual's condition. It is important to emphasise that these goals will only be achieved for people with dementia if their specialised needs are recognised and supported.

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 342,800 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 a sponsoring member of the National Aged Care Alliance and are involved in other key groups progressing aged care reforms including the Aged Care Sector Committee and the Aged Care Quality Advisory Council.

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