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The new voice of Alzheimer's Australia

Residential Aged Care: Proposed alternative models for allocating places

A response from Dementia Australia

12 September 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

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



Response to the consultation on residential aged care allocation models

Please see below, Dementia Australia's response to the online survey

Current model

1. *What works well under the current residential aged care allocation and places management model for consumers and/or providers?*
2. *Are there other issue/s with the current model for the allocation and management of places for residential aged care that have not been covered in this paper? If so:*

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We work with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community. Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers. Dementia Australia also provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia welcomes the opportunity to participate in the consultation process for *Residential Aged Care: Proposed alternative models for allocating places*. In 2019, there is an estimated 447,115 Australians living with dementia. Without a significant medical breakthrough, the number of people with dementia is expected to increase to 589,807 by 2028 and 1,076,129 by 2058. Currently, around half of all people in permanent residential aged care have a diagnosis of dementia. With an ageing population, we can expect the number of people living with dementia in residential aged care to increase considerably.

Greater consumer choice and access to quality residential aged care is important to people with dementia, their families and carers, so it is imperative that people impacted by dementia are able to access care and support that exists within a transparent, flexible and responsive aged care system.

Our response to this consultation is based on feedback from people with a lived experience of dementia and focuses on the principles underpinning residential aged care allocations as well as the practical implications of any systemic change. There are benefits and issues associated with both of the proposed models and we explore the key components of each.

Dementia Australia acknowledges that the current allocation and place management model is underpinned by The Aged Care Approvals Round (ACAR), which is a competitive application process enabling prospective and existing approved providers to apply for new residential aged care places. The new aged care places are made available for allocation in each state and territory having regard to the aged care provision ratio, population

projections, and the level of current service provision. In theory, this process ensures that population trends (including the needs of people with dementia) are reflected in the place allocation; however, in practice, there remains a gap between what providers may say they can deliver within their ACAR application and what they might practicably deliver when the places are operational (e.g. meeting concessional ratios or the requirements of people with diverse needs or a cognitive impairment).

In addition, although the current ACAR model requires residential aged care services to be operated by approved providers (which are subject to the necessary accreditation, regulatory and monitoring processes), the current model does seem to enable poorer quality providers to operate and remain financially viable/operational – and market mechanisms are not strong enough to drive quality or genuine competition – especially as it relates to people with dementia. As demonstrated in the current Royal Commission into Aged Care Quality and Safety, as well as numerous Government inquiries into the aged care sector over recent years, poor quality dementia care can be delivered by approved providers who are able to operate, in part, as a result of their success in the ACAR funding rounds.

Of particular concern to Dementia Australia is the quality of care provided to people living with dementia in residential aged care. Dementia is not yet core business for aged care providers, which means that people with dementia often receive inappropriate and/or substandard care from staff who do not understand the complexity of dementia, how to engage residents with dementia or respond appropriately to the expression of unmet needs of residents. Even facilities which claim to be dementia-specific do not necessarily provide quality dementia care on a consistent basis.

Design principles

3. Are the proposed design principles appropriate?

Dementia Australia supports the proposed design principles, given that they focus on a more consumer driven market, intend to improve access to residential aged care services and aim to facilitate an adaptable and viable residential aged care sector.

4. Are there any other principles that you consider should be included?

The provision of quality care should be included – and clearly articulated – in the design principles. Funding for residential aged care places (however this is arranged) should be contingent on providing care that is of high quality, person-centred and responsive to the clinical, social and emotional needs of all residents.

Model 1: Improve the ACAR and places management

5. What are your views on the suggested improvements proposed under this model?

Dementia Australia supports the suggested improvements proposed under Model 1. The requirement to reduce non-operational places to maximise the availability of places to consumers is particularly welcomed.

The proposed improvements will go some way to stimulating the market and potentially give rise to greater consumer choice; however, the potential disruption to services – especially in regional or remote areas is of concern to Dementia Australia. It is also worth emphasising

that a more flexible allocation process will not necessarily translate into increased choice for people impacted by dementia.

Key design considerations

6. *How can this model ensure/encourage adequate supply of and equitable access to residential aged care and residential respite care (aside from increasing funding or revising the funding model), including:*
 - *in rural, regional and remote areas and other thin markets?*
 - *for consumers from vulnerable cohorts (such as Special Needs Groups, consumers with dementia)?*

Dementia Australia is acutely aware of instances of poor quality residential aged care for people living with dementia. These range from poor practice to neglect and physical or psychological abuse. High quality dementia care must become the norm, not the exception, in the aged care sector. The changes to ACAR proposed in Model 1 might encourage an adequate supply of, and equitable access to, residential aged care places for people with dementia, but it cannot automatically ensure the provision of quality dementia care.

As noted earlier, Dementia Australia recommends that the provision of quality care be included in the design principles of any reforms to ACAR. Approved providers must be able to demonstrate how funding will be used to deliver quality care for all aged care residents.

As context, Dementia Australia is currently working on a Quality Dementia Care initiative, which seeks to develop baseline and 'gold' standards of care and link them with the new Aged Care Quality Standards which came into effect 1 July 2019. This initiative adopts a human rights based approach with dementia-specific recommendations applied to each Standard reflecting the needs of a person living with dementia, their families and carers.¹ This includes dementia-specific training shared and supported decision making that centres on the person with dementia; flexibility and continuity of care; meaningful activities to maintain a sense of community connectedness; providing a sense of community and transparent accountability for quality dementia care, with key performance indicators that are specific, clear and measurable embedded into practice.

With regard to residential respite, Dementia Australia acknowledges the proposal to simplify the administrative process for providers to use residential aged care places to deliver residential respite. However, anecdotal evidence suggests that many providers are currently not offering respite places, especially for people with dementia with high care needs. Further, it is clear that residential respite places are frequently being used by people awaiting a permanent residential aged care place. As the Aged Care Financing Authority noted in its 2018 Respite Care Consultation Paper,² the number of residents entering permanent care within a week of a respite care stay has been increasing since 2010. This may indicate that care recipients who intend to enter permanent care are first accessing

¹ Dementia Australia (2019) *Our Solution: Quality Care for People Living with Dementia*
<https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf>

² Aged Care Financing Authority (2018) Respite Care Consultation,
<https://agedcare.health.gov.au/reform/aged-care-financing-authority/aged-care-financing-authority-respite-care-consultation-invitation-to-provide-feedback>

respite care while they arrange their financial affairs or await the completion of aged care means testing.³

Evidence from people impacted by dementia indicates that there is significant unmet demand for appropriate, high quality respite services for 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. However, robust data on the accessibility of respite services for people impacted by dementia – or the appropriateness of these services in delivering quality dementia care – is lacking and requires further investigation.

People impacted by dementia tell Dementia Australia that the process of applying for and securing respite care is typically a challenging one. A number of elements play a role in this:

- Navigating My Aged Care can be complex and time consuming;
- Conversations about respite typically occur at time when carers are very stressed or under pressure;
- The pathways to services are unclear, even when accessed via My Aged Care;
- Eligibility for respite does not necessarily translate into access to respite, let alone access to quality dementia-specific respite.

In order to address some of these challenges, Dementia Australia has previously recommended⁴ more comprehensive support to navigate the respite system and the identification and implementation of quality indicators to facilitate more informed decision making about respite, as well a distinct funding envelope for residential respite care places, with a dementia supplement available to providers who demonstrate they have strategies in place and a workforce able to care for people with dementia.

7. What other key changes could be made to the existing ACAR and/or places management arrangements to encourage a more consumer driven and competitive residential aged care sector?

Greater transparency is needed to facilitate a more consumer driven and competitive residential aged care sector. Without knowledge and information to make an informed choice, consumer choice could be more rhetoric than practice. The receipt of ACAR funding should be tied to the provision of quality care that is publicly reported on so that consumers are able to easily compare approved providers to enable them to be more informed.

That being said, residential aged care admission is often not a long-planned process for consumers and people with dementia are more likely to enter residential aged care during a period of crisis, for example following admission to hospital or as a result of carer burnout. Given these difficult circumstances, it is imperative that people living with dementia, their families and carers have simple, straightforward and streamlined access to the aged care system. Further, clearly articulated information on providers, including performance

³ Dementia Australia (2018) *Submission to the Aged Care Financing Authority (ACFA) Respite Care Consultation* <https://www.dementia.org.au/files/submissions/DA-submission-ACFA-Respite-Care-Consultation.pdf>

⁴ Dementia Australia (2018) *Submission to the Aged Care Financing Authority (ACFA) Respite Care Consultation* <https://www.dementia.org.au/files/submissions/DA-submission-ACFA-Respite-Care-Consultation.pdf>

indicators, policies with regards to restraints and medications, staff training and skills mix should be made available to consumers. Without this information there is no meaningful way to distinguish between providers and ultimately make an informed choice about residential aged care. Increasing the transparency of providers not only helps individuals to find the support they need, in a more simplified and logical way, it also provides an incentive for providers to improve the quality of care they deliver.

The sustainability of the aged care system for people living with dementia, their families and carers must be underpinned by a corresponding focus on financial sustainability along with clearly defined fiscal roles and responsibilities. It is imperative that government, the aged care sector and consumers work together to build a cohesive, sustainable aged care system that consumers want and which is viable for providers; can address workforce and quality challenges; provides the choice that consumers are seeking; and takes into account affordability for taxpayers and consumers.

Exploring the potential impacts

8. *In overview, what would be the potential impact of this model (consider benefits, costs and risks) on you or the stakeholder group or organisation you represent?*
9. *What do you think might be the impact on the residential aged care sector overall?*
10. *If this model were to be implemented, what are the potential impacts on, linkages or interdependencies with, other programs or reforms in aged care that might impact you or the stakeholder group or organisation you represent?*

For people living with dementia and their carers, there may be minimal impact of this model as the changes are largely administrative in nature. However, it is hoped that improved management of places would have a flow on effective for consumers. The ongoing certainty that Model 1 would provide for approved providers would also likely benefit consumers in the provision of a financially viable and sustainable residential aged care sector.

Implementation and transition considerations

11. *How could implementation of this model maximise the benefits and minimise risks/disruptions?*
 - *What steps/sequencing and timeframes would be appropriate to facilitate a smooth transition?*
 - *What specific supports or enablers would be required to ensure the changes are understood by all stakeholders and successfully implemented?*

If this model were to be implemented it would not impact too greatly on consumers, as the administrative changes proposed would happen 'behind the scenes'. However, the transition and implementation process would need to ensure that any changes to provider practice do not impact negatively on consumers' ability to access residential aged care services. Although the changes are largely administrative, it is imperative that there is clear and transparent information about how the system operates in order to facilitate consumer choice.

Model 2: Assign residential aged care places to consumers

12. Overall, what are your views on this proposed model?

Although in principle Dementia Australia is supportive of consumer-directed approaches, there are number of issues inherent in Model 2, which raise concerns for people with dementia, their families and carers.

Aged care reforms are increasingly based on the assumption that supporting people impacted by dementia should be part of core business for service providers. Combined with this concept has been an underpinning ideal of a consumer-focused and market-driven approach to service quality and innovation within aged care. Both elements are predicated on the idea that consumers who have the tools and comparable information to make informed choices will 'vote with their feet' on the services that are most able to support their needs and preferences as well as contribute to the cost of their care where they are able to do so, while those providers not able to meet consumer demand will either adapt or exit the aged care market. In the case of dementia care, these mechanisms are flawed and/or underdeveloped.

In particular, there are considerable lessons to be learnt from the process of reforms to home care over recent years including the introduction of consumer directed care and the subsequent opening up of the aged care market. Although this is has enabled the expansion of the home care market in terms of the number of providers entering the sector, it is has not necessarily improved consumer choice nor directly impacted the quality of care provided to people living with dementia at home. It has also arguably increased the level of confusion and stress associated with accessing care services for consumers.

The uncapping of residential aged care places inherent in Model 2 may not ultimately better meet the needs of people with dementia. First and foremost, older people, including people living with dementia, typically wish to remain living in their own homes for as long as possible. The extensive waiting list for home care packages is indicative of this. What people impacted by dementia tell us is that they want greater access to home care services, not necessarily residential aged care. In opening up the market for residential aged care provision, we could see an oversupply of services for which there is limited demand.

Further, processes with regard to the regulation and monitoring of approved providers would need to be overhauled. Despite its limitations, the ACAR process ensures that only approved providers receive funding to deliver subsidised residential aged care and this system of regulation subsequently holds them accountable. The implementation of Model 2 would require a redesign of the way in which providers of residential aged care are approved and regulated.

The aged care system is complex and there is currently a lack of transparent, comparable, publicly available data about aged care providers. This makes it incredible difficult for consumers, especially people with a cognitive impairment, to make informed choices. In order to implement true consumer choice, consumers need to be empowered to make choices. A significant change management process for providers, government and consumers would be imperative in order for Model 2 to be successful. And even in those circumstances, clarity of information and process would not necessarily lead to genuine

consumer choice – especially in more constrained markets, such as regional and remote areas of the country.

Key design considerations (consumers)

13. Creation and design of a prioritisation queue

14. What are your views on the establishment of a queue to access subsidised residential aged care, if the demand from eligible persons exceeds the available places?

As outlined in our earlier responses, people with dementia often enter residential aged care during a time of crisis. Although they may have an ACAT approval for residential aged care it is not regularly viewed as a first care option; consumer preference is to remain living in their own home for as long as possible. It is therefore unlikely that large numbers of consumers (or their carers) would place themselves in a queue to enter residential aged care.

15. What are your views on using date of approval and urgency of need as factors in determining a person's priority (noting these are the factors used in home care)?

Although we do not think a prioritisation queue would necessarily be the most responsive way of addressing unmet need for people living with dementia, Dementia Australia supports the idea that date of approval and urgency of need as operate as key factors in determining a person's priority for residential aged care to ensure equity of access. Urgency of need, however, should take into account the cognitive state of the individual as well as the level of carer stress. This requires that a holistic assessment is made to determine urgency.

16. What other factors should also be included in the criteria for prioritising a person in the residential aged care queue?

The informal care and family support available should also be included in the criteria for prioritising a person in the residential aged care queue if it were implemented.

Validity period of the assigned place

17. Where a place is withdrawn, how can we balance the need to allow consumers to re-join the queue while also avoiding creation of perverse incentives for people to join the queue without intention of taking up a place at that time?

We acknowledge the need to establish a validity period and a process for withdrawing places to maximise the availability of residential aged care places to the consumers on a potential prioritisation queue; however, we caution that the timeframe needs to be sufficient so as not to create greater stress for individuals, carers and families in what is already an incredible stressful and emotionally fraught time. As previously noted, people living with dementia often enter residential aged care as a result of a crisis which triggers the need for residential care. This needs to be considered in the design of any queue processes.

Request for entry into preferred aged care home

18. What additional information or supports would consumers need to assist them in selecting a preferred aged care home?

Consumers, especially those immersed in a period of crisis, often don't know what support they need or are entitled to access, nor do they necessarily know what support and services are available. When they do seek out information, the lack of sector transparency means that it is very difficult to find information about specific providers with regard to staffing levels, staff qualifications, the quality of dementia care and so on.

Essential drivers of quality improvement will include improved regulation and publicly reported quality indicators. People with dementia, their families and carers want to have clear information about the quality of services being offered and the impact of those services on quality of life. Without publicly reported measures of quality at the facility level, consumer choice will continue to be limited.

19. What would need to be in place to ensure equitable access to appropriate services i.e. in particular for consumers with limited capacity to pay, consumers from Special Needs Groups and those with dementia?

Other considerations to ensure equitable access to appropriate residential aged care services for people with dementia include:

- Equity and consistency in the approach to resident contributions
- Transparency around fees and charges payable by consumers
- The models of funding that underpin residential aged care and their appropriateness for ensuring the care needs of people with dementia are adequately addressed
- The modelling, viability and application of dementia-specific supplements in residential aged care, which would acknowledge the additional costs associated with providing quality dementia care (or serve as a transitional element while the aged care market re-balances or transforms to be truly consumer-directed).

Exploring the potential impacts

20. What would be the overall potential impact of this model (consider benefits, costs, and risks) on you or the organisation or stakeholder group you represent?

For people living with dementia, their families and carers the overall potential impact of this model could include:

- Potential benefits
 - Increased service innovation which could result in better care provided to people living with dementia
 - Funding provided directly to consumers could provide a financial incentive for providers to deliver quality dementia care and enable flexibility in service provision in response to consumer demand
- Potential costs
 - Increased stress and confusion in navigating an additionally complex system
 - Assessment of care needs may not deliver funding that equates to the cost of care delivery/provision
- Potential risks
 - Uncertainty and instability in the residential aged care sector as a result of changes could limit the availability of residential aged care places

21. What do you think might be the impact on the residential aged care sector overall?

Model 2 has the potential to deliver increased innovation and improved service quality in the residential aged sector as providers would have to respond to consumer demand in order to be a provider of choice and therefore gain access to funding from consumers. However, as indicated earlier in our response, this has not played out in the home care sector so there the model has been met with some trepidation from people living with dementia, families and carers with whom Dementia Australia has consulted.

22. If this model were to be implemented, what are the potential impacts on, linkages or interdependencies with, other programs or reforms in aged care that might impact you or the stakeholder group or organisation you represent?

As noted in the consultation discussion paper and forums, there are number of reforms and inquiries occurring concurrently to this consultation which need to be considered. As the peak body for people living with dementia and their carers, Dementia Australia is particularly interested in the interplay between any potential reform to ACAR and the outcomes of the following:

- The Royal Commission into Aged Care Quality and Safety
- The Resource Utilisation and Classification Study (RUCS)
- The Aged Care Workforce Strategy
- The Aged Care Financing Authority (ACFA) report on respite care

The Dementia Australia Quality Dementia Care Initiative outlined previously in our response also needs to be considered if this model were to be implemented.

Residential respite care

23. How could residential respite care places be distributed, and to whom, if residential aged care places no longer exist?

It is apparent from feedback from people impacted by dementia that there is a national shortage of dementia-specific respite care that meets the needs of carers and people living with dementia. Over half of primary carers of people with dementia have indicated they need more support, and the greatest single unmet area of demand is for respite care.⁵ Carers repeatedly identify good respite care as an important support for a sustainable caring relationship.

Yet as their care needs increase, people with dementia are often turned away from respite services, including residential aged care respite. Families and carers of people with dementia report that providers tell them that they are not staffed to provide care to people who have complex behavioural symptoms of dementia or have other high care needs. Current residential respite options are very limited, and not assisted by the fact that people seeking and waiting for permanent care are often using respite places, in a 'try before you buy' system.

A Dementia Australia review of respite care undertaken for the Australian Government made a number of recommendations for respite care policy, including the need for a dementia supplement for all forms of respite care, in recognition of the higher costs of caring for a

⁵ Alzheimer's Australia (2013) Respite Review Policy Paper, Available online at <https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-33.pdf>

person with dementia. A dementia supplement for respite providers, similar to the supplement which is provided within home care, is required - though the effectiveness and quantum of such a supplement must be modelled. A dementia supplement would acknowledge the additional costs associated with providing dementia-specific respite and create an incentive for providers to develop these services. It should only be available to services that can demonstrate they have the capacity to care for people with dementia.

Dementia Australia has also previously recommended⁶ more comprehensive support to navigate the respite system and the identification and implementation of quality indicators to facilitate more informed decision making about respite, as well a distinct funding envelope for residential respite care places, with a dementia supplement available to providers who demonstrate they have strategies in place and a workforce able to care for people with dementia.

Implementation and transition considerations

24. How could implementation of this model maximise the benefits and minimise risks/disruptions?

- *What steps/sequencing and timeframes would be appropriate to facilitate a smooth transition?*
- *What specific supports or enablers would be required to ensure the changes are understood by all stakeholders and successfully implemented?*

A clear and effective communications and marketing strategy would need to be put in place to ensure that consumers are well informed and understand the considerable changes if this model were implemented. The aged care system, particularly the funding mechanisms and processes, are complex and confusing for consumers. The Department would have to work collaboratively with consumer peaks, including Dementia Australia, to ensure that all stakeholders understand the system and how they would be required to access residential aged care under this model. A lengthy transition period with clearly identified timeframes would be required to facilitate a smooth transition.

⁶ Dementia Australia (2018) *Submission to the Aged Care Financing Authority (ACFA) Respite Care Consultation* <https://www.dementia.org.au/files/submissions/DA-submission-ACFA-Respite-Care-Consultation.pdf>