



**dementia
australia™**

2020 ACAR – Identifying Residential Aged Care Needs

Submission

Dementia Australia

January 2020

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 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages 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 can 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 of all ages 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.



Overview

The Department of Health is seeking input from a broad range of stakeholders to get a better understanding of unmet needs in the provision of residential aged care, particularly in respect to specific geographic locations, special needs groups and other key issue groups.

Responses to the following short survey will help inform the distribution and targeting approach for new residential aged care places set to be made available for allocation in the 2020 Aged Care Approvals Round (ACAR) process.

The ACAR is a competitive application process that enables prospective and existing approved providers of aged care to apply for a range of new Australian Government funded aged care places, including residential aged care places, and financial assistance in the form of a capital grant.

The 2020 ACAR application period will commence in March 2020.

Introduction

1. What is the name of your organisation?

Dementia Australia

2. Which group best describes your organisation?

Peak Body/Consumer Group

Identifying Residential Aged Care Needs

3. Please select the State or Territory to which your responses relate (Required) Please select only one item

NSW

A Catchment Area is whatever geography is most meaningful to your organisation that allows you to convey where an unmet need for residential aged care exists.

4. Please ensure you select the appropriate Catchment Area Category before providing a response.

Catchment Area Category (Required) Please select only one item

Suburbs, Towns or Cities

5. Are there any particular Special Needs Groups or Key Issue Groups that you have identified as having an unmet need for residential aged care within your catchment area?

Dementia

Please provide a brief summary of the needs you have identified in your Catchment Area, including for any particular groups identified at Question 5.

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.

As Dementia Australia is a national organisation, our input on the unmet needs of people with dementia in residential aged care has a similarly national focus. Our 2020 prevalence data has identified numerous Commonwealth Electoral Districts (CEDs) that are particular hotspots for people living with dementia. The 10 CEDs with the highest prevalence of dementia in 2020 are below:

CED	2020
Gilmore (NSW)	4861
Lyne (NSW)	4857
Cowper (NSW)	4714
Richmond (NSW)	4531
Sturt (SA)	4,400
Page (NSW)	4286
Hinkler (QLD)	4098
Grey (SA)	4,086
Mallee (VIC)	4,076
Barker (SA)	4,071

However, in the absence of consistent, comprehensive and reliable data on levels of dementia in consumers of residential and community aged care make it difficult to approach this planning process in an informed way.

The needs of people living with dementia in these areas are remarkably similar, regardless of their geographic location. The key difference is that those in rural and regional areas have an even greater unmet need than metropolitan areas when it comes to accessing dementia-specific services and supports in residential care. Moreover, it is not just the dementia-specific needs that need to be taken into account when being provided with choice, but people who are looking for services that meet their cultural needs as well. This significantly reduces choice for many consumers.

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.

A common issue in reference to the Victorian CEDs (except Monash) (also see below), is that these regions have a high proportion of people from a CALD background and/or, who possess a basic level of English literacy.

Our collective experience at Dementia Australia points to the view that people in those regions, will generally avoid any paperwork. Many, rely on word of mouth and their local doctor to access services. Additionally, most will effectively wait until the last minute to place the person with dementia into care and often, the option of 'choosing the right place' becomes null and void by then.

As such it is recommended that in addition to investing in targeted awareness raising activities such as audio visual media and engaging highly regarded CALD community or rural community members as dementia ambassadors; that education is provided to aged care staff to help them better address such needs. This could be as simple as developing a one-page document with steps to consider when planning to access residential aged care.

Dementia Australia understands that 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).

Population projections particularly need to be considered as the prevalence of dementia is set to increase considerably in every catchment area as our population ages. Dementia Australia data suggests the prevalence of dementia will increase but there is no national dataset on dementia collected, either for incidence or prevalence. Regardless, Dementia Australia's data suggests these changing demographics demonstrate the importance of monitoring the prevalence of dementia to ensure aged care services can forward plan to meet the specific needs of people living with dementia, their families and carers. Specifically, the projected top 10 CEDs in 2058 with the highest prevalence of dementia include:

CED	2058
Berowra (NSW)	12611
Lalor (VIC)	10,865
Bradfield (NSW)	10685
Flinders (VIC)	10,134
Monash (VIC)	9,808
Gorton (VIC)	9,807
North Sydney (NSW)	9796
Scullin (VIC)	9,776
Holt (VIC)	9,328
Moncrieff (QLD)	9310

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 model seems 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 all 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 because there are no specific requirements around staff education or the built form.

The aged care system is complex and there is also currently a lack of transparent, comparable, publicly available data about aged care providers. This makes it incredibly difficult for consumers, especially people with a cognitive impairment, to make informed choices or compare services on a like-for-like basis. In order to implement true consumer choice, consumers need to be empowered to make choices.

Often though, consumers, especially those immersed in a period of crisis, do not 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 need to 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.

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

- Ongoing assessment, accreditation and quality reviews
- If a provider demonstrates in an application that they can meet the needs of people with dementia, there is follow up criteria that links to the demonstration of this
- 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.

Within your Catchment Area and to any particular groups identified (or more broadly), are there any innovations you would like to see that would improve the consumer experience for residential care recipients?

There are various innovations needed to improve the consumer experience for people living with dementia, their families and carers in the context of residential aged care. Specifically:

- Enhancing workforce capacity to understand diversity and maintain people's identity through developing relationships with them, their families and carers
- Involving people living with dementia, their families, carers and advocates as partners in care and care planning
- Improving quality dementia care through mandating minimum levels of dementia specific workforce training, immersive education and learning programs including virtual reality simulation
- Audits of the physical environment to ensure that they are dementia friendly given this can be a trigger to behaviours and other issues for people living with dementia
- A nationally funded program to reduce stigma and discrimination
- Better leadership amongst aged care providers to promote practice change
- Flexibility in provision of care and how and when it is received

- A consultancy model, that Dementia Australia has already developed, to build the leadership capability of organisations and enhance knowledge translation programs
- Enhanced focus on technology to reach into specific special needs groups: Rural and Remote; CALD and Indigenous.

Quality care should be included – and clearly articulated – in the design principles. Additionally, these principles need more of a focus on consumer driven markets, intend to improve access to residential aged care services and aim to facilitate an adaptable and viable residential aged care sector. Funding for residential aged care places 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. This funding should also be predicated on environments having been audited to ensure they are dementia friendly and that there is an audit of dementia education of staff to ensure that there are minimum levels of dementia education and ongoing professional development of staff.

The implementation of a National points rating system that ranks residential aged care facilities would allow consumers, who are often overwhelmed at the time of making the decision, to ‘at a glance’, know if a RACF is appropriate for their loved one. The value of an independent rating of aged care providers acts as a key driver to promote continuous improvement and aide consumer and staff choice.

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

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 indicators, policies with regards to restraints and medications, identifying clinical changes that will promote discussions for good palliative care 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. There also needs to be robust population data that feeds into local planning. This would aim to ensure that providers are demonstrating how they can meet the needs of the population in specific regions as well as being assessed on how they do this in practice.

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.