



**dementia
australia™**

Royal Commission into Aged Care Quality and Safety

Response to Counsel Assisting's Submissions on Program Design

Dementia Australia

March 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.



Introduction

Dementia Australia welcomes the opportunity to respond to Counsel Assisting's submissions on program design. Although we broadly support the changes to program design that have been made since the publication of the original discussion paper and agree with the specific proposals outlined in the submissions, we remain concerned that the pressing issue of dementia is not sufficiently embedded in some of the finer details of the draft recommendations.

We acknowledge that the Royal Commission's final recommendations must incorporate system-wide transformation and avoid highlighting particular population cohorts, diseases or geographies over others, but, with the increasing prevalence of dementia, it is imperative that any future aged care system is equipped to respond appropriately to the needs of people living with dementia, their families and carers. A system designed for people impacted by dementia is a system that will work for everyone. Therefore, in our response, we have highlighted particular components of the recommendations or supporting information in which a specific reference to dementia in the Royal Commission's final report is, in our view, warranted.

As outlined in our original submission to the Royal Commission on program design, the current aged care system does not adequately support people living with dementia as part of core business. In order for dementia to become core business, a series of foundational shifts in leadership, culture and workforce capacity across all elements of the system is required – regardless of the nature or type of program design. If this transitional and capacity building work does not pre-empt or underpin the design of a new aged care system, the same barriers, challenges, and at worst, breach of human rights, will continue to impact people with dementia, their families and carers in any new system. Our submissions to the Royal Commission on workforce outline specifically how to build the capacity of the aged care workforce to deliver quality dementia care.

Response to proposals

Life planning

Dementia Australia supports the general approach of the life planning proposals, including cross-jurisdictional approaches to education and information, a more effective use of the Medicare Benefits Schedule and a focus on continuum of care for ageing. However, clearer and more consistent life-planning pathways for people with dementia (including diagnosis pathways) need to be a cornerstone of these proposals and may need to be articulated in the details that underpin your final recommendations – primarily because, for this condition above others, there are currently no clear diagnostic or service pathways on which to rely. The process to receive a diagnosis of dementia can be both lengthy and challenging. Even after a diagnosis of dementia, many people report feeling confused about where to go for support or they are unaware of supports that are available to them – which delays their opportunity to access early intervention services. In designing a new aged care system, therefore, it is important to develop diagnosis and referral pathways to support people with

dementia, their carers and families. A reference to dementia in the body of your final recommendations would go a long way to ensuring dementia is not overlooked in this broader design process.

The promotion of health literacy to improve people's life planning capacity could also include an understanding of the modifiable risk factors for dementia. In addition, the involvement of GPs in this life planning strategy, through health checks and information provision, is imperative. Of course, as mentioned, the development of dementia diagnosis and referral pathways is a key component of this type of approach. To ensure GPs are equipped to support their patients with dementia as well as their families and carers, mandatory GP dementia education¹ is both important and much needed.

Information and contact point

Dementia Australia supports Counsel Assisting's proposals relating to information and contact points. We echo the Counsel Assisting and the testimonies of many other individuals and organisations that a mix of face-to-face, online and phone contact is a more inclusive and flexible way of entering the aged care system.

Given the high number of aged care service users with a cognitive impairment, the detail of the model proposed would be strengthened by dementia-specific references. For example, if the final recommendations include reference to the importance of comparable criteria on services, an example that might illustrate this is publicly available dementia information on individual services (for instance, information on staff numbers, proportion of staff with dementia qualifications, or the dementia enabling/inclusive characteristics of the service), which will ensure that people seeking information are able to make informed decisions about services that are based on comparable criteria.

In addition, Dementia Australia recommends that all information/contact point staff receive mandatory dementia education to ensure that they are equipped to support people with dementia, their families and carers. If the initial contact point is not set up to respond to the needs of people living with dementia, their families and carers, a narrowed range of service options at best, or service inaccessibility at worst, will remain entrenched in a new aged care system.

Care finding and case management

Dementia Australia supports the care finding and case management proposals, noting that they span personalised approaches and a 'care finder' role. To ensure that the care finding and case management mechanisms work for people with dementia, and to avoid duplicating the barriers faced in the current system, we recommend that your final recommendations make particular reference to the need for:

- all care finders/case managers receiving baseline dementia education; and/or
- dementia specialist care finders/case managers being prioritised.

¹ Refer to Dementia Australia's response to Counsel Assisting's submissions on the future of the aged care workforce for details of the need for mandatory dementia education for GPs.

As a first step, there could be an interim specialist stream of care finders to support people with dementia, their families and carers until other regulatory, quality management and information mechanisms create a more transparent market for people with dementia to move through – that is, if there are more widely recognised and standardised pathways of service for people with dementia across the sector, then specialist knowledge to find the appropriate dementia-specific services may not be required in the longer term.

It is critical in any scenario that all/specialist care finders/case managers have the knowledge and skills to understand the service needs of people living with dementia. Without this specialist knowledge, Dementia Australia is concerned that a new aged care system will not be any more accessible and appropriate for people living with dementia than it is currently.

The experience of accessing the National Disability Insurance Scheme (NDIS) for people with younger onset dementia is an illustrative example of the unintended impact a lack of dementia-specific knowledge – and the reference to dementia-specific education in higher-level operational guidance – can have. Although younger onset dementia was recognised as part of the high level principles of the NDIS, the need for planners to have even basic dementia education was not referenced at a more granular level, and this has led to variable experiences of the NDIS for people with younger onset dementia. To an extent, the success of the NDIS for a person with younger onset dementia can be dependent on the dementia knowledge and skill of the local area coordinators and planners. Unfortunately, even recent reports from people with younger onset dementia and Dementia Australia staff still identify inconsistencies in the quality and accessibility of the NDIS planning process. Poorly tailored planning meetings and a lack of consideration of the progressive nature of dementia in identification of service needs can result from this lack of dementia awareness and education. Conversely, where planners have an understanding of younger onset dementia, people with younger onset dementia, their families and carers report positive engagements with the NDIS are directed to effective supports and have more proactive NDIS plans.

Dementia Australia therefore recommends that consideration must be given to the way in which dementia-specific needs will be addressed in the system of care finders and case managers in a new aged care system. More specifically, we recommend that the skills and training of care finders, particularly in relation to conditions like dementia, be outlined, at least at a high level, in the final recommendations.

Diverse Needs in Aged Care

Dementia Australia supports the proposal relating to diverse needs in aged care, noting the importance of inclusive services that are irrespective of setting and part of a whole of system approach. As we know, people living with dementia, their families and carers experience many challenges in the current aged care system; for people from diverse backgrounds, these challenges are further compounded and make access to services even more complex. A whole of system approach to addressing diverse needs is imperative.

Home support and care – additional points

Dementia Australia supports the home support and care proposals, including the principle of a single program based on a single eligibility assessment process and a differentiation between basic supports that can be provided at the discretion of a care finder and more complex supports. We note that holistic assessment requires consideration of care needs that span physical, clinical, cognitive and quality of life aspirations. As such, the final recommendations would be strengthened by including this level of specificity in the details to ensure new assessment arrangements for home support and care are inclusive of the full, identified spectrum of individual care needs.

Innovative accommodation models

Dementia Australia recommends that, in order to receive Government incentives, the final recommendation (or the details that flesh out the recommendation) specify that providers need to demonstrate how the proposed accommodation model meets the needs of people with dementia (given more than half of all people living in residential aged care have dementia). Features of quality dementia care in residential settings include:

- Engagement with people living with dementia, their families and carers to co-design service delivery models;
- Staff who have completed dementia-specific education and have access to ongoing training;
- Innovative approaches to engagement with people living with dementia including those with advanced dementia;
- Limited/no use of physical and chemical restraints
- A focus on enabling environments where residents are encouraged to do things independently to maintain both their physical and psychological function. Enabling environments also include structural changes to enhance mobility and accessibility for residents, allowing them to walk safely and freely inside and outside;
- Non-institutionalised and home-like environments where residents are able to meaningfully engage in 'everyday' domestic activities, gardening, and personal interests.

Dementia Australia also recommends that some incentives (either within aged care or in a broader residential or disability market) are earmarked specifically to develop innovative models to support people living with younger onset dementia (people with dementia who are under the age of 65). We note the recommendation made in the Commissioner's Interim Report to stop the flow of younger people with disability going into aged care and to expedite the process of getting those younger people who are already in aged care out. However, in the current disability system, there are little to no suitable accommodations for people with younger onset dementia and innovative models are particularly vital for this cohort. This specificity in the final recommendations will ensure that a new aged care system can, if required, support all people living with dementia, including younger onset dementia.

Informal carer support services and respite

Dementia Australia supports the proposals for informal carer support services and respite, particularly localised information and outreach, collaborative service planning and significant

overhaul to the scope and scale of respite. We also note, however, that respite is an area that requires significant upskilling of staff and an increased access to services to support people with dementia, their families and carers. As such, a reference to these capacity-building requirements may be appropriate in your final recommendations and mean that respite services in the future will be more readily available to people with dementia, families and carers, ensure that they can be more easily accessed as planned forms of respite, and be less likely to be used as emergency respite.

Assessment

Dementia Australia supports Counsel Assisting's assessment proposals, noting that they focus on a coordinated assessment network that has a full range of competencies and specialisations as well as access to revised guidance and tools. We suggest that the final recommendations include reference to the need for all assessment staff to have a minimum level of mandatory dementia education, at the very least appearing in the text as an example of specialisation. If assessment teams do not have a foundational understanding of dementia, the unique needs of people impacted by the disease may not be captured in their resulting services and supports, and lead to significant negative impacts for people living with dementia, their families and carers.

Wellness, reablement and rehabilitation in aged care

Dementia Australia is pleased to see a reference to wellness, reablement and rehabilitation services that are 'irrespective of cognitive status' in this proposal, as this specificity addresses a key challenge people with dementia currently experience in accessing such services. There is a widespread assumption in the present system that, because people with dementia are experiencing a progressive decline rather than having a disease trajectory with an obvious restorative path, they are not suitable candidates for wellness, reablement or rehabilitation services.

We note that, in a redesigned system, people with dementia may still need more targeted support to access these service types.

Dementia Australia also recommends building a more thorough evidence base for what an optimal package of wellness, reablement and rehabilitation services would look like for someone with dementia and how it might make the most difference to their independence, autonomy and quality of life. We would be willing to work with the Commission further on this if this would be helpful in informing their final recommendations.

Residential care – additional points

Dementia Australia supports the proposals for residential care as they relate to casemix, assessment and funding models, including thin markets. With regard to the point that states that "responsibility for care co-ordination and planning should be clearly placed on the residential care provider, subject to ongoing consultation with the older person...about their care...", we recommend that the final recommendations include specific reference to residential care providers needing to include people with dementia and other vulnerable

people in consultations about care plans and coordination Supported decision-making techniques could be referenced as one way of ensuring inclusive care planning processes to enable people with dementia to participate in consultations and decisions about their own care needs and goals.

Standardised data collection and analysis

Dementia Australia supports the proposals outlined to standardised data collection and analysis, noting that it must be designed to inform longitudinal evaluation at the user, provider, and system levels. We caution that a broad, far reaching redesign of ICT systems will be challenging, but we remain optimistic that the 'collect once, use many times' principle will reduce the administrative burden of the aged care system for people with dementia, their families and carers.

Conclusion

Dementia Australia would welcome the opportunity to discuss our submission with Counsel Assisting and the Commissioners. We reiterate that a redesign of the aged care system must be underpinned by a significant shift in the culture, leadership and operations of the sector, in order to ensure that it includes and supports people living with dementia instead of replicating the barriers and challenges they face in the existing system.

We strongly recommend that dementia is referenced in at least some of the final recommendations or in the supporting details – without this specificity there is a risk that a disease that impacts so many of the individuals for whom the system will ultimately support will not be at the heart of system redesign. A system that is consciously designed for people with dementia will be an inclusive system that supports everyone.

We look forward to the Commission's final recommendations and the way in which they will ensure that the aged care sector of the future has the ability and capacity to support people living with dementia, their families and carers.