Dementia Australia®

Progress Report on Implementation of Aged Care Royal Commission Recommendations

A Dementia Australia Submission

March 28, 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person’s functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer’s disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054, a projected percentage change of 93%. More than 1.6 million people in Australia are involved in the care of someone living with dementia.[i]

Dementia is the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.[ii]

Introduction

We welcome the opportunity to make a submission to this consultation in relation to the Inspector-General’s Progress Report on Implementation of the Aged Care Royal Commission Recommendations.

As the peak body for dementia advocacy in this country, we regularly survey the community we represent on the issues that are important to them. Our submission to this consultation is informed by feedback from people living with dementia and former and current carers who participate in our Dementia Advocates program.

We selected key questions from the Inspector-General’s consultation paper, including those that focussed specifically on dementia care services and supports, and surveyed over one hundred Dementia Advocates nationwide.

People living with dementia represented just over 20% of survey responses with former and current carers comprising just under 80% of responses. 13% of respondents identified as being from a CALD background and three per cent identified as Aboriginal and Torres Strait Islander.

We also surveyed Dementia Australia employees from the Consumer Engagement and Client Services Business Units. Their regular contact with Advocates and clients in the community provides valuable feedback about access to aged and dementia care services. The results from both survey groups, in addition to other sources of Advocate and staff feedback, form the basis of our submission. The quotes included in the submission are drawn from these sources.

Consultation Question 2 – Dementia support

a) What do you think of the new dementia support pathways?

The development of the dementia support pathways has been a lengthy and detailed process involving 31 Primary Health Networks (PHNs). Dementia Australia believes the pathways are an important initiative to improve diagnosis and referral pathways for people living with dementia, and their family members and carers. Dementia Australia acknowledges that the respective PHN pathways have captured local needs but notes that the uptake and use of the pathways is not known. Feedback we have received from people living with dementia, families and carers indicates that improvements in the diagnosis experience has not yet shifted in the right direction.

All PHNs have implemented their dementia support pathways and developed valuable consumer resources. However, at this stage of the initiative, it is unclear how information in the resources and pathways will be regularly updated to ensure the sustainability of each Network pathway.

It is also unclear how health professionals regard the pathways. Information about the value of the pathways in assisting with improving diagnostic, referral and other processes, will be critical in forthcoming evaluations of the efficacy of the dementia support pathways.

Our comments above are intended to provide a broader context in which to interpret the feedback from Advocates and Dementia staff members in relation to the opinions expressed about the dementia support pathways.

This question was answered by fewer than half the Advocates surveyed which may be indicative of a lack of knowledge about the pathways. There were a small number of positive responses; these included participants with personal experience of the pathways or those who noted that while they had no direct experience, the concept or idea of a dementia support pathway sounded constructive.

> ‘No personal experience but I commend the initiative. GPs are the first and constant point of contact for families in this situation and the more they are able to fulfill the role of case manager the better.’ Former carer
>
> ‘It is full of good information for the relevant person. Pathway is easy to follow. Easy to read, clear even though there is a lot of information it is well set out. Would have been great to have had when I was diagnosed. Person living with dementia
>
> ‘A very useful and positive step forward.’ Carer

Dementia Australia staff also noted that despite variable outcomes, the pathways were an important concept:

> ‘Great initiative, still a lot of gaps. Often receive feedback that people don't know about our services and were not referred to us by health professionals. Need more staff in community engagement in regional areas’.
>
> ‘Good in theory, however, there has not been a positive impact yet’.
>
> ‘The PHN pathways are a great blueprint and guide in encouraging health care workers to have a focus on mild cognitive concerns and dementia when engaging with clients, their care partners and families’.
>
> ‘I believe an early intervention approach is important, and for clinical specialists to be involved. It can reduce entry prematurely to acute care, and provide essential information to families as part of a holistic approach. Therefore, an important initiative’.
>
> ‘It provides for more targeted support specifically for those affected by Dementia. It has not had a major impact with increased calls from those referred by a PHN, but this may improve over time’.

The lack of awareness about dementia support pathways in our Advocate survey group was reflected in responses to the question. Nearly three quarters of respondents (73%) were either not aware of the dementia support pathways, had limited knowledge or did not think they were effective, as indicated in the comments below.

> ‘I am not familiar with Primary Health Network Pathways’. Carer
>
> ‘Not aware of them. How has it been rolled out? As a carer of someone living with Dementia, it has not been made known to me. I am now a consumer and from the outside looking in; it is a disaster. If the PHN provides dementia care/support I am surprised to learn this. FAIL.’ Carer

> ‘Cannot find enough specific information about these "new" pathways to make a meaningful comment.’ Carer
>
> ‘I have no idea what they are nor where to find them to review.’ Former carer
>
> ‘In spite of trying to be well-informed, I can see no real evidence of their existence.’ Carer

Advocates and Dementia Australia staff with direct experience of the pathways noted that outcomes were variable and that in many cases, the pathways had limited efficacy:

> ‘Given that the point of contact and services thereafter, are meant to be a collaborative and ongoing process involving, Patient's/ Family, GP, Specialist, such is occurs sporadically within the PHCN where I live. Is not effective, with regard to dementia per se.’ Person living with dementia
>
> ‘Reads well. No active changes in reality currently.’ Current carer
>
> ‘I'll never live long enough to work out how to navigate them’. Person living with dementia

Dementia Australia professionals made similar observations including:

> ‘There is a strong emphasis on carers, which is admirable, however does not acknowledge the journey of people who may not have a carer or family member. In many of these cases, the early signs of dementia are not picked up by anyone and so by the time a diagnosis is made, the person may be in later stages and have limited capacity to make decisions on their own care. While the pathways provide for referrals to appropriate services including DA, they do not reference the intensive navigation required to get aged care supports in place and manage them ongoing’.
>
> ‘Good concept, but do not overcome issues of staffing and service shortages’.
>
> ‘It's hard to say. In some parts of Australia, the PHNs are quite visible and actively connecting with groups involving and supporting PLWD to promote their programs and services while in other areas there is no visibility or engagement at all’.
>
> ‘I think newly diagnosed people living with dementia are falling through the cracks as they are often left to self-refer to Dementia Australia after the nurse has done the assessment. The referral process in regional Vic needs to change. Nurses are giving people they visit the National Dementia Helpline to call themselves and they don't call’.

The limited awareness of, and/or direct experience with, dementia support pathways points to the need for a more rigorous and concerted promotion of the pathways in primary health care and the broader community.

Efforts to promote dementia support pathways need to be directed at health professionals, including GPs and Nurses Practitioners, who are in a position to refer the person with dementia, and their family members and carers, to appropriate supports and services.

Improving knowledge about dementia support pathways in the broader community would also enhance understanding about the kinds of services and supports that are available for a person diagnosed with dementia and encourage healthcare seeking behaviour.

b) Have you noticed any ‘on the ground’ improvements to the available support and resources?

In the three years since the report from the Aged Care Royal Commission was released, there have been significant reforms in relation to the sector including the implementation of the Star Ratings system, the requirement for a Registered Nurse to be on-site 24 hours a day, seven days a week, strengthening of restrictive practices regulations, and the progressive rollout of Quality Indicators in residential aged care. Other reforms in relation to a Code of Conduct and regulatory measures have also made an important contribution to improving the provision of high-quality aged care in both the residential and community care sectors. Dementia Australia acknowledges that there have also been a number of significant challenges to the timely implementation of other reforms and recommendations. These include but are not limited to the wide-ranging impacts of the global Covid-19 pandemic, longstanding and ongoing aged care workforce staff shortages (exacerbated by the pandemic), and financial and other constraints on aged care service providers.

The impact of these factors and others is reflected in the responses from Advocates and Dementia Australia staff members in relation to the remaining questions about the observable improvement in access to and provision of aged care services and supports.

Sixty per cent of Advocates replied to the question about ‘on the ground’ improvements in aged care services and supports and of those, a modest number noted modest improvements, with most of these responses relating to the residential aged care context.

> ‘Yes, the Home is spending more money on entertainment, activities for residents and more incursions/excursions. Carer
>
> ‘I have noticed improved staffing ratios and willingness of aged care staff to keep families and loved ones informed’. Carer
>
> ‘Yes the support has improved with greater surveillance and governance.’ Former carer

Dementia Australia staff feedback supported the variable experiences of Advocates, with some noting that the Care Finders program had improved access for people living with dementia.

> ‘Improved access to supports through Aged Care Specialist Officers and Care Finders, though these services seem to be more readily accessible to clients living in regional areas rather than metro areas’.
>
> ‘Yes, the establishment of Care Finders has been an integral enhancement to dementia advisory services which Dementia Australia is involved in. But the word is still not getting to many people in rural and remote areas where services are limited’.

> ‘There appears to be increased awareness particularly among health professionals of the unique challenges of dementia. The contracting of Dementia Australia to provide a dementia specialist care finder service in Perth Metro has seen many vulnerable individuals access aged care services for the first time’.

While acknowledging the potential obstacles to achieving improved ‘on the ground’ outcomes in aged care service delivery outlined above, it was notable that nearly three quarters (74) of Advocates believed that there was no improvement, with many providing a strong and detailed rationale for their response.

> ‘Not in Regional areas. What would I be looking for? Post diagnostic support in our area? FAIL - memory Care Clinics? FAIL - Support & care for carers? Ad hoc with volunteer model via Carer Gateway. Waste of resources- well not really because it is the cheapest model available to Govt and that is the only people it serves is the people for respective Govts.’ Carer
>
> ‘No. Homecare support is still very low in terms of hours. Some aged care providers still accept residents living with dementia despite their staff & management having little or no training in, or the necessary experience with managing the needs of people living with dementia. This happens as the resident's cognition & behaviour changes. My experience is that sedation & chemical restraint is the "go to" for many not for profit & private providers.’ Carer
>
> ‘It is worse there is nothing.’ Person with dementia.
>
> ‘I have no memory of particular time-based markers of improvement in obtaining information and services on dementia, although I currently take advantage of counselling and carer groups.’ Carer
>
> ‘Not enough we need More support and Services specific to People Living with Dementias.’ Person living with dementia

As with Advocates, Dementia Australia staff also noted that clients reported that significant improvement had not been observed and there continued to be many difficulties accessing support and resources.

> ‘The aged care specialist officers and care finder offer some people support, however they are another layer of complexity for people to navigate that require them to be able to understand a complex, sometimes inconsistent, system before they can access it. In some areas especially respite and residential care the on-ground services have diminished due to the requirements of the royal commission combined with lack of services resulting in people living with dementia being avoided. Numbers allow some services to cherry pick their clientele to reduce their admin and service costs’.
>
> ‘No I haven't seen or heard about any on the ground changes to available support and resources for People Living with Dementia’.
>
> ‘Improved education but still a lack of practical support for people living with dementia (lack of staff)’

> ‘Access to respite remains an issue in rural and remote locations. We're still hearing from people that they can't get access to respite (in-home care and day-centre) to enable trips to the towns for shopping and personal care appointments. Many are leaving their loved ones at home locked in and worry the entire time they're away. Carers are not getting the break they need to recharge and as they age they are not seeking out support. Some told us the only time they get any real support is if their loved one goes to hospital.

c) Are you aware of improvements to specialist dementia care in rural and remote areas?

Just over half the Advocates surveyed responded to this question (55%). The small number of affirmative responses indicated modest improvements in specific aspects of service provision i.e. access to specialists or the provision of telehealth services to facilitate increased access to rural health care services.

> ‘I have not been directly involved with rural and remote communities but have been in contact with other dementia advocates in these communities and they report easier communication channels with Telehealth and teleconferences.’ Carer
>
> ‘Yes. I am aware of improved access to geriatrician services within our LHN. Not aware of anything else.’ Carer

One staff member pointed to the positive impact from the Care Finder program:

> ‘I cannot emphasis enough the impact Care Finders are having in the rural, regional and remote areas. I have formed fabulous working relationships with six Care Finders from Country and Outback Health. Working as a collaborative and trusting in our relationship has seen some extraordinary outcomes for people living with Dementia and their families, in finding appropriate support.’

However, as with the previous question, there was a strong and consistent response in the negative, with 82% of Advocates believing that specialist dementia care had not improved in rural and regional areas. Most participants did not provide substantive detail but those that did are included below.

> ‘No. And again, always told not enough specialists available in these areas. If lucky enough to make contact with one, it is then a VERY long wait to get the appointment for the person you are caring for.’ Carer
>
> ‘No - not to actual hands on dementia specific care. I am seeing a difference in the terminology in use and the management attempts to meet legal requirements - in sending out surveys and adding reference (and sometimes inclusion) to material into newsletters (such as feedback forms and standards). Carer
>
> ‘Unfortunate due to a lack of qualified Specialists, the improvements are currently unattainable.’ Person living with dementia

> ‘I wish I could say ‘yes’ but I feel it is not there or I am not aware. Real change comes from education and community interest in seeing people willing to shift culture change. There is a wave of people coming that will be living with dementia but we are currently underprepared and disinterested prob until it is upon us. A lot of the current workers and leaders in healthcare (private & nfp) and Govt will be the next consumers living with dementia. Statistically, it will be our largest cohort sadly. I don’t think they will accept the current status quo. A 1800 phone number is not an improvement; it is a pacifier. The Dementia Services Team is a small team trying to suggest ways of improving the lives of someone living with dementia caught up in antiquated system of adapted hospital environments and medical care models set up to house large numbers of people who all need similar levels of care by understaffed, undertrained and even uninterested staff. There is no incentive to do more or be more. What a HOT MESS!’ Carer

Dementia Australia staff also generally reported that there had not been much improvement in specialist dementia care in rural and remote areas.

> ‘No I haven't seen or heard of any changes to specialist Dementia care in the regional area I work, if anything there has been less available care and support in community, respite options and residential care’.
>
> ‘Feedback from clients indicates that specialist dementia care and service provision remains scarce or completely inaccessible (due to geography or lack of providers)’.
>
> ‘There has not been a change. I live in a rural area where health services in general are limited; there is still a stigma related to dementia. There is more awareness related to cancer support and mental health’.

d) Have you noticed any improvements in culturally appropriate dementia care?

Just over half of all Advocates responded to this question (54%), and there was a strong consensus (81%) that there was marginal or no improvement in the provision of culturally appropriate dementia care. The majority of responses lacked detail, but when it was provided, it related predominantly to dementia care services provided in the residential aged care context.

> ‘No, my mother is Sri Lankan, simple awareness like Dementia diagnosed residents revert back to mother young is not even trained in facilities. It must be all in the documents but practically no one is following or been properly trained to care for Dementia. All are students coming from overseas, do you think they know what Dementia is? And how to handle them? My mother can't even ask for water, its a problem for staff to do water rounds. There is a-lot to do when it comes to Dementia and Aged Care facilities.’ Carer
>
> ‘No - I'm not seeing things reach the staff providing the hands-on care. There seems a flurry of paperwork circulating within management and administration - very little of it about HOW to do anything - just what should be done.’ Former carer

Of the small number of positive responses, these again related to the residential aged setting and noted small changes in the provision of culturally sensitive dementia care.

> ‘Yes, the Home are celebrating many countries national days, cooking more multicultural dishes and on a special day doing activities specific to that country.’ Former carer

Dementia Australia staff had mixed experiences. Many reported that there not been any improvement in culturally appropriate dementia care. Some staff reported improvements, particularly in awareness and access to resources in community languages.

e) Is workforce training sufficient to provide the care that people with dementia need?

Fifty-eight per cent of Advocates responded to this question, and of all the questions in the survey, this elicited the most detailed, robust and consistently negative feedback. 80% of responses observed that aged care staff were not adequately educated about dementia and best practice dementia care in order to meet the needs of person living with dementia in the community or residential aged care setting.

> ‘No. Until dementia education for all workers in the sector is a mandatory requirement, there will be no tangible improvement as staff movements are fluid and inexperienced novice staff are employed.’ Carer
>
> ‘No. There is need for aged care staff to be trained specifically for the care of people living with dementia. Often young carers without any knowledge of the special needs of people living with dementia are asked to provide care. The result often is disaster for the person providing care, the family of the person living with dementia and the person themselves’. Former carer
>
> ‘Of course not!!! As a previous educationalist in the healthcare sector myself, I realise the difficulty in conducting training for workers - getting them off shift and motivated. We have been resorting more and more to online training, but it is not effective in checking on whether someone has actually ‘got it’! On-line ed does not contribute to culture change and that is what needs to change. I started to undertake a degree in Dementia Care and realised I would need to complete a cert 3 to gain work in the sector because I am not clinically trained. The medical model is myopic and entrenched but sadly better than nothing but only just. I am a carer who has had someone living with dementia living with us; I have become clinically trained informally but only to one person’s journey. Training is quite generalist because I think it is difficult to know and understand how each person will move along their dementia journey.’ Current carer
>
> ‘No, the quality of training has improved but it’s not retrospective to existing staff and it needs to be applied not just to the 'care' staff but to all the management and corporate structures.’ Person living with dementia
>
> ‘No - there is an appalling lack of understanding around how dementia impacts someone's cognition and skills. The term person-centric care is now used more consistently, and care plans take care to include background history. I see this as beneficial content for engaging with a person, but it doesn't encourage a mindset for

> engaging in a way that is focussed on how interactions are experienced by the person living with dementia. It isn't changing the skills - just the conversation - and sometimes the lack of awareness of effective communication means this is quite irrelevant to the resident.’ Carer

Some respondents noted that training was available, but staff were not necessarily supported to complete it. One respondent linked lack of training to the increasing numbers of serious incidents reports in residential aged care.

> ‘No. There are inadequate staff to meet fundamental needs of home care recipients, let alone time taken to educate staff regarding dementia care needs. For example, the carer who visits myself, educates herself re dementia, is outstanding. However, the Organisation does not have the “staff, time or resources to undertake special training in dementia”. Carer

> ‘No. Staff need ongoing training and support to assist in holistic and up to date recommendations for the residents we serve.’ Former carer

> ‘Well if the vast majority of violent and sexual assault in residential care are assessed as having no impact, that might give a hint to the quality of people “caring”.’ Person living with dementia

A few responses pointed to positive changes but even these were tempered by observations about limitations in some aspects of dementia care provision.

> ‘Again, I can only speak from my experience. Currently, as a carer for my husband with dementia, that includes staff at adult Day Centre, and those providing in home respite 2 x weekly. I have found them all to be extremely capable, and understanding of working with people with dementia. That said, my experience of care workers in a retirement village where I worked for many years, (until 2 years ago) such training for staff was considered unnecessary. If a resident was diagnosed with dementia (and given the average age now, of this cohort of people 'aging in place' in retirement villages, that likelihood increases) it was seen as 'the family's problem' !!’ Carer

> ‘It is not terrible but could still be improved. I think more awareness of preserving abilities and not rushing to remove all a person's independence would be helpful. Training around dental hygiene is also very lacking.’ Carer

Similarly, Dementia Australia staff consistently reported that dementia education is not meeting the needs of people living with dementia.

> ‘The current workforce training for aged care is not sufficient as it requires a cultural shift, a changed attitude to make a real difference. The change needs to start at the top’.

> ‘Based on the feedback from my clients who have a loved one in aged care there are still issues with staff turnover leading to lack of continuity in care and lack of dementia specific care. My clients tell me staff do not demonstrate any knowledge of dementia

> informed care and if they have a support plan/ communication plan this is rarely read or handed over to staff'.
>
> 'Appropriate dementia care is not the standard in most cases. Staff are not trained in providing support, which is also impacted by high staff turnover. Good dementia care works for everyone and should be the minimum standard. Organisations do not invest in dementia care training for staff, they just do the minimum they need to meet standards in most cases'.
>
> 'Making training available that is not mandated and funded to cover the time off the floor will not work. Our experience with brain hubs has shown that both community health and aged care providers are not prepared to send their staff to a course that takes them away from their jobs for three days. More needs to be done to ensure people entering the workforce have the required skills and knowledge BEFORE they start in aged care or work with people living with dementia in their homes. Upskilling the current workforce can only be achieved if the sector is supported to do so'.

Dementia Australia has also been made aware of systemic, ongoing problems in relation to the provision of support and care for people living with dementia who have complex care needs. We have received consistent feedback from the community via our Helpline, Client Services team and other sources in relation to the lack to timely and appropriate referrals to appropriate supports and services for people with changed behaviour and other complex needs, and in particular, the inability to access community and residential aged care, and respite services. These concerns are also reflected in the survey responses from Advocates and Dementia Staff members. There are a number of contributing factors including the absence or inadequate supply of tailored services and supports, and community and residential aged service providers declining to accept people with complex needs. Dementia Australia believes that underlying many of the challenges related to access to appropriate support and care for people requiring complex care is the lack of appropriately educated aged care staff. We believe that the urgent need to ensure uniform, high quality dementia education for the community and residential aged care workforce is critical to addressing gaps in access to dementia care services and supports. The specific issues relating to access to respite care are outlined in detail in Question 9.

> 'There are frequent calls to the Helpline from families/carers who cite challenges for their loved one in residential care or hospital as staff are not trained to provide dementia friendly care and often lack any knowledge on dementia'.
>
> 'Current workforce training is insufficient to provide the care that people living with dementia need. No staff working in my Mother's "Memory Support" Unit had any training in dementia care. I repeatedly witnessed aggressive and disruptive responses from residents living with dementia which could have been avoided with a respectful and informed approach. I saw very little learnings taken from these incidents by staff. Instead, the solution appeared to be to engage more staff to deal forcibly with showering etc.

> Early signs of over stimulation and agitation from a noisy, busy environment went unnoticed until the situation escalated and other residents and staff were negatively impacted and even put at risk by the disruptive behaviour.’ Former carer

> **‘**No. I think that all staff working with people with dementia in any setting should have at least a basic level of understanding of the disease. and for those in specialist services this should be in depth.’ Carer

Consultation question 5) Care finders to support navigation of aged care

a) How has the introduction of Care Finders impacted on peoples’ access to care?

As noted above in response to Consultation Question 2 b), Dementia Australia staff reported that in areas where there had been a successful introduction of the Care Finders program, this had resulted in improved access to services and the provision of clearer pathways for care and support.

> ‘People with dementia who previously may have ended up presenting to ED in crisis are being referred to care finders who work to register them with Memory and Assessment Clinics, go through assessment, and find and select appropriate supports and services. Previously, many of these people would have fallen through the cracks as they do not have anyone in their life to support them through the complex process of accessing, navigating and managing aged care services’.

> ‘I think the success of the Care finder initiative is hinged on whether people know about it. From my experience, people rely on, and trust their GPs to provide them with the information they need and this is simply not routinely happening’.

Others noted that better awareness of the program would increase the value and uptake of this initiative.

> ‘I think the success of the Care finder initiative is hinged on whether people know about it. From my experience, people rely on, and trust their GPs to provide them with the information they need and this is simply not routinely happening’.

> ‘Yes, but only for those who find their way to a care finder, they are not well promoted and the one's providing general support in Services Australia do not know enough about all services types to be able to support appropriately’.

Dementia Advocates were less positive with only half responding to the question, and of those, 69% answered in the negative. Many of the many responses demonstrated limited or no knowledge of the program and what it comprised. If Advocates had used Care Finders, it had not been a positive experience.

> ‘Given that this is my first I have read of Care Finders Programme, having researched what is available within my area, dementia is not mentioned.’ Person living with dementia

> ‘Found it unhelpful and people not educated or equipped to be in their positions.’ Carer
>
> ‘No its introduction is not Dementia Friendly.(Need Help to Navigate and How it apply to Each Individual.’ Person living with dementia
>
> ‘How do you find a care finder?’ Person living with dementia
>
> ‘Before this survey I'd never heard of Care Finders so I looked it up online. I wondered how someone would be aware of the service if they didn't know this term.’ Former carer

For Advocates who replied in the affirmative, there was endorsement of the concept but limited support for the efficacy of the program.

> ‘No personal experience but I support the initiative.’ Carer
>
> ‘They can be helpful but if the need for care is urgent, then services are extremely limited and there is limited or non-existent capacity within the system to meet the needs of the person living with dementia in these circumstances.’ Carer

b) Do you have any experiences with (or observations about) the Care Finders program that you wish to share?

Most Dementia Australia staff supported the value of the Care Finder initiative but emphasised that it required significant promotion in the community to increase awareness and uptake of the program.

> ‘Please keep funding this valuable resource. Their local knowledge of their community and the support they provide is priceless’.
>
> Most of my clients had not heard about Care Finders therefore broader public education is needed to raise awareness about the service.

Advocate responses to this question were mixed and the following are indicative of this:

> ‘Combined with the PHNS this is the way forward — navigation of the system is made easier if there is case manager support and that person is a constant rather than a new name on each inquiry.’ Former carer
>
> ‘How do they come into your life? Who refers?’ Carer
>
> ‘Too complicated for a PLWD. Need Assistance to Navigate it.’ Person living with dementia

c) What more could be done to directly assist people to access and navigate the aged care system, particularly people from diverse backgrounds?

Advocates and Dementia Australia staff provided detailed, varied and thoughtful responses on how to improve access to aged care services, particularly for diverse communities. Responses cohered around key themes including the need to enhance community awareness of how to access and navigate aged care services (including promoting My Aged Care and Care Finders), providing information about services and supports in accessible languages and formats, educating health professionals about supports, services and online resources so they can refer patients, and ensuring people employed to assist with services have an appropriate understanding of a person with dementia's potential care and support needs. The following comments are representative of Advocate suggestions:

> 'More information in languages familiar to people from diverse backgrounds. Workshops. Pamphlets at GP surgeries. Less red tape with Aged Care.' Carer
>
> 'Simplify paperwork and have more trained and understanding people that are easily contactable.' Person living with dementia
>
> 'My navigation of the system was severely hampered by the fact that I was the primary carer for my wife, now passed away. An informed and helpful GP would have made a difference, or a case manager who was aware of our circumstances and history and therefore able to point me in the right direction for the next step. Each step of the system becomes more difficult to navigate because of the increasing stress and time demands imposed on the carer, the very person who is charged with navigating the system.' Former carer
>
> 'Have multiple ways in which people can access help i.e. f2f, video call, multicultural staff etc' Person living with dementia
>
> 'Education, support and patience from Organisations responsible for assisting all persons and families where applicable.' Person living with dementia
>
> 'Simpler pathways to care, eliminate need for repeat assessments for minor changes in service access. Improve timeliness of assessments.' Carer
>
> 'Integrate awareness slots into social gatherings (probus, lions club, etc). Could direct them to regular social meetings that bring people together to talk about what is out there in an informal manner. Start informally communicating with people rather than requiring an intensive completion of forms or questions/answers before offering any assistance. 'Former carer
>
> 'Information needs to be more easily found online and at one destination with links to who can be asked for help. Centrelink is a nightmare to contact and set up a meeting with and unless you are lucky to find a helpful individual to work with on your personal needs - a soul destroying experience.' Former carer

> ‘Are we still asking this question? There is no magic bullet! People need to be in front of people - this about community not phone numbers and systems. One of the best programs I have seen recently was the community hub funding (unsure of its technical name) that was seed funding to help elder people come out of their homes and reconnect after COVID. I have watched numerous elder people go to the person employed in the role and get more help navigating the system than going to Centrelink. It will be de-funded in June which is derelict of the Govt of the day. It works because it puts the right person into the right person’s life. It’s not rocket science it’s about relationships. The new aged care specialist sitting with Centrelink is a great role but too few in number and spread over too much geography. We will burn them out because the system is too complex with too many people needing their help because the system is too complex. It’s a disappointing cycle. Sorry but I have seen a lot of change spoken about but it not evident on the ground as a consumer and their carer.’ Carer

Dementia Australia staff suggested increased case management and face-to-face contact in general, especially for those who struggled with online or phone-based services, dedicated CALD and First Nations Care Finders, and increasing the numbers of Care Finders who understand the needs of their local community in regional and rural areas. Other suggestions included:

> ‘People with sexual and gender diversity also need to be part of resource development that is specific to their needs. Generally, all diverse groups need to be better represented in the workforce and in decision-making roles. There's no point producing resources in language or that are culturally appropriate if the organisations providing the services are not culturally safe’.

Consultation question 8) Access to aged care in rural and remote areas

a) Since the Royal Commission, has access to aged care improved for people living in rural and remote Australia? If so, what has changed? If not, what should change?

As noted above, Dementia Australia staff observed that where Care Finders had been successfully implemented in rural and regional areas, this had made a significant contribution to improving access to aged care services. Several Advocates noted modest improvements to access to home care packages and increased residential aged care funding. However, there was consistent feedback from both Advocates (88% responded in the negative) and Dementia Australia staff that in general, access to services had not improved, and according to some, the situation had worsened since the Royal Commission report was released.

> ‘No. Where should we start? Needs a huge amount of accessibility for those areas to start with.’ Carer
>
> ‘No - not to actual hands on dementia specific care. I am seeing a difference in the terminology in use and the management attempts to meet legal requirements - in sending out surveys and adding reference (and sometimes inclusion) to material into newsletters (such as feedback forms and standards).’ Former carer

> ‘No, not for home care recipients. The need for educated staff is an ongoing problem and concern. There is form my experience, a greater important placed upon “house cleaning”, as opposed to the social and emotional wellbeing of clients.’ Person living with dementia
>
> ‘No not much better we have a day centre that’s advertised better, I think it already existed though, that is for a pop of 50k people.’ Carer
>
> ‘No. And again ,always told not enough specialists available in these areas. If lucky enough to make contact with one, it is then a VERY long wait to get the appointment for the person you are caring for.’ Carer
>
> ‘People are still having to leave their homes and move to the cities to receive services. Ageing in place should be made possible to ensure people can remain socially, emotionally and physically connected to the place they call home’. Staff member
>
> ‘Respite remains a crucial issue’. Staff member
>
> ‘Receive constant feedback that access is difficult for people living with dementia especially with behaviours due to their increased needs and staffing required to manage behaviours.’ Staff member
>
> ‘No, access to services, both in-home and residential, has become increasingly difficult. This seems to be for two reasons: no availability, and providers choosing not to accept people living with dementia into their services and especially for residential respite and permanent care’. Staff member
>
> ‘if anything, it has reduced. Limited capacity in workforce in all sectors. Clients are finding it harder to access care and support in all areas, community, respite and residential care’. Staff member

Only a few respondents provided details about how access could be improved but those that did nominated improved access to residential and home care services, including respite care, and the urgent need to improve the level of dementia education for home care and support workers.

> ‘Yes - increase in number of Home Care Packages has improved access, although finding staff to provide services is a challenge. Increased funding for residential care has definitely improved viability of services.’ Carer

Consultation question 9) Access to respite care

a) Since the Royal Commission, has access to respite care improved? If so, what has changed? If not, what should change?

Feedback from Advocates and Dementia Australia staff members point to the lack of discernible improvement in accessing respite care in the post Royal Commission context.

The consistent themes that emerged around access to respite care included availability (including emergency, overnight and short term respite care placement), residential aged care providers imposing a range of self-determined restrictions, concern around the quality of care provided by aged care staff with inadequate levels of dementia education (including those working in memory support units and those with specialised dementia care facilities) educated aged care staff and associated in relation to the safety and wellbeing of people admitted to respite care. These issues are outlined in more detail under sub-headings below.

Availability challenges

70% of our respondents reported difficulties in accessing both planned and emergency respite services. The scarcity of emergency respite options was a recurring theme, with many noting the absence of available emergency places and the impracticality and inappropriateness of using hospital emergency services as an alternative solution to care. The difficulty in finding overnight respite at short notice and the lack of available emergency care in urgent situations were consistent concerns. Respondents also faced challenges with the inflexibility of respite care options; in residential aged care, respite places were often only available for extended periods, which did not align with the immediate and short-term needs of the person living with dementia and their family members and carers.

Planning and booking respite

Many respondents expressed frustration over the inability to plan or book respite care in advance. Issues included having to place family members in distant facilities due to lack of availability of services locally, prolonged waits for vacancies, and the preference of some facilities to only offer respite as a precursor to permanent placement. There was consistent feedback from carers that the current system makes it challenging to secure respite care, especially when attempting to schedule regular breaks to manage the ongoing demands of caring. This lack of predictability and flexibility had a significant impact on a carers' ability to adequately plan for their own respite needs.

> 'Not easy to book in advance or get in an emergency.' Carer
>
> 'Unable to plan ahead and the fact that my husband does not want to go into respite preferring to stay at home with full time care which is very expensive even with a package.' Carer
>
> 'Due to a lack of service and support and harder to access these, more clients reaching crisis and the person living with dementia is entering acute care for long period of time as not enough services to support needs at home and respite and residential care facilities have limited spaces and are being more selective about clients they accept, many saying that they won't, or are reluctant to, accept people living with dementia'. Staff member

‘Try before you buy’

Respondents reported that some aged care providers imposed a number of self-determined limitations on the conditions under which respite care could be applied for. These varied within the sector but included rejection of applications if the person with dementia was perceived to required more complex care, only accepting bookings for a specified period of time and/or if the person was transitioning to permanent care. This had the effect of further restricting access to the already limited supply of respite options.

> ‘I had a 3 month plan to move my mum into respite for 3 weeks. I had to put mum in a facility that is one hour away from our home and where mum lived because no facility locally would take mum unless it was respite to permanent . I was told this by several providers. At that time, I did not know if my mum would stay in permanently or if she would return home to live with us. Carer
>
> ‘Not many facilities offer respite unless you are intending on using them eventually on a permanent basis.’ Carer

Complicated processes

The process of accessing respite services was described as “overly complicated”, “time-consuming”, and “exhausting”. Carers pointed out the inefficiency of having to navigate through multiple assessments, codes, and contact numbers to secure respite care. This highlighted the urgent need for a streamlined and flexible process that minimised the administrative burden on the person applying for care, was responsive to the changing needs of people living with dementia and their carers, making it easier to access essential services when and where they were needed.

Training and education deficiencies

As with the response to Consultation Question 2 e), the lack of dementia-specific knowledge and skills among staff providing respite care services was a consistent theme. Advocates noted that staff providing respite care often lack the understanding and skills to effectively support people living with dementia, including those with changed behaviour and other complex needs. Many respondents emphasised the need for the provision of high quality, person-centred dementia care education.

> ‘Staff available through aged care providers lack dementia specific knowledge and skills (their time is still beneficial but can create problems as well).’Carer

Concerns over safety and quality of respite care

The lack of dementia care education was explicitly linked with concerns about the safety and quality of care in respite services. Some carers expressed reluctance to utilise respite services after observing the quality of care provided. Concerns were expressed about the inability of some forms of respite care to meet the needs of people living with dementia in and the potentially adverse effects of respite care on the wellbeing and quality of life of the person with dementia.

The feedback from respondents consistently highlighted the need for respite services that are not only accessible when required, but that the care provided ensured a safe and supportive environment, tailored to meet the unique needs of those living with dementia.

> ‘Until respite truly accommodates the needs of someone living with dementia it might give a carer time out but the person living with dementia suffers during that period.’ Carer

Additional insights and experiences in accessing or navigating aged care services.

Advocates and Dementia Australia staff members were asked to provide any additional observations about experiences with accessing and navigating aged care services, particularly dementia care services and supports. Many participants took this opportunity to comment further and we have included a representative selection of their observations below.

> ‘To date it remains complex, frustrating and confusing. For those caring for a loved one with dementia, the various funding (state and federal) only add to the dilemma. A simple pathway, (to access services) with as much familiarity/continuity staff wise/ facility wise, as dementia progresses, is surely the ideal for all concerned. Carer

> ‘My experience was a nightmare. The first contact with My Age Care resulted in confusion and no help. Subsequent calls resulted in different staff giving different information. Being able to be assigned a package took several years. When we finally got one, the provider was unable to provide dementia specific Care Workers, was short of staff often and often provided young girls from overseas with poor English which resulted in a lot of misunderstandings and a couple of serious incidents’. Former carer

> ‘The use of Home Care Package to support external agencies for transport. Such agencies/Organisations are in receipt of government funding per se. Home care recipients are billed for services when and if required. Thus, the amount of time that would ordinarily have been provided for social care, home care, etc. is greatly diminished, as costs are exorbitant. This is only one area of concern I have highlighted.’ Person living with dementia

> ‘My navigation of the system was severely hampered by the fact that I was the primary carer for my wife, now passed away. An informed and helpful GP would have made a difference, or a case manager who was aware of our circumstances and history and therefore able to point me in the right direction for the next step. Each step of the system becomes more difficult to navigate because of the increasing stress and time demands imposed on the carer, the very person who is charged with navigating the system. ‘Former carer

> ‘I have worked in the system for many years, and now that I am in the position of navigating the system I worry for people without the resources and background that I have. I have experienced inconsistency in knowledge of providers, unnecessary requirement to repeat assessments, and general frustration in navigating the system. I look forward to the reforms that are coming up!!’ Carer

> ‘I used to say if you were 16 and started to navigate and understand the system, you would have enough knowledge to assess the system by the time you reached 70, Now I say if you begin at 16, then you may be able to assist you grandchildren to navigate the system next century’. Person living with dementia
>
> ‘I understand that it is a compromise & there are multiple demands on government budgets. I have been left demoralised & disempowered by the whole process & system. I do not hold any hope for real reform and do not look forward to my old age. Eventually, people living with dementia reach a stage where they are only existing and have no real quality of life. I would not wish this cruel disease onto anyone, particularly when I know that my mother did not want to end her life this way. A view she had expressed many times.’ Carer
>
> ‘Getting a Doctor to visit and provide onsite, individual care for a loved one with results provided directly to family is a huge issue. In all the time my mother suffered from dementia the home had issues with finding a Doctor that could care for everyone. It was more a care from a distance approach with the home sharing details that they thought relevant rather than any Doctor actually seeing my Mother themselves on a regular basis to ensure she had what she needed.’ Former carer
>
> ‘I have still to find a Aged Care Provider Who understands what a Person Living Dementia Needs and Best Practice is What Each individual needs ,As Medical Evidence shows.’ Person living with dementia

Dementia Australia staff reported that access and navigation of aged care services continued to be a challenge for people living with dementia and carers. There were reports of difficulties accessing advice from My Aged Care and the Carer Gateway. Access to support at home programs and respite care were also identified as critical issues:

> ‘There is a severe lack of respite care, residential respite is being used largely for people waiting for a bed. More respite options and better availability would make a huge difference to sustainability of care.’
>
> ‘Early admission to residential care occurs as carers cannot access the support they require, in a timely manner’.

Staff suggested that case management, support coordination or dementia hubs could help to improve access and navigation of care:

> ‘Dementia hubs in rural areas could include an office for counselling, service support, Dementia specialists and education. These need to be non-clinical, as there is too much focus on clinical access whereas these people/families need to talk and go to face to face groups for support. They have nowhere to go’.
>
> ‘There is a lot of grief and stress at this time which makes things more difficult. I think a support coordinator role would be very helpful for lots of consumers seeking and utilising aged care services’.

Conclusion

As with the survey data itself, Dementia Australia acknowledges that this submission makes for at times, dispiriting reading. The core messages and consistent themes that emerged from our Advocate and staff surveys and other sources of feedback highlight the persistent, ongoing difficulties people experienced in understanding what aged and dementia care services are available in Australia, and then in accessing those services. These challenges are clearly pronounced in, but not limited to, rural and regional areas. The issues identified in our submission in relation to access and navigation through aged and dementia care services are arguably compounded by an apparent lack of awareness about recent initiatives in the sector, including the dementia support pathways and the Care Finder program.

Dementia Australia recognises that some people living with dementia in community and residential aged care settings receive respectful and supportive care but equally, we would point to the inadequate level of dementia education that persists in the sector. The uniform and compelling contributions from people living with dementia, family members and carers in this submission attest to this. Given that two out of three people with dementia live in the community, and more than two thirds (68.1%) of people in residential aged care have moderate to severe cognitive impairment, it is clear that our community and residential aged care workforce is still not fit for purpose and lacks the mandatory skills and knowledge required to provide high quality dementia care.[iii] The many thoughtful, detailed and passionate observations from our survey participants and other sources highlight the reality that longstanding and well established workforce pressures, including difficulty recruiting, retaining and appropriately educating the aged care workforce, persist.

Dementia Australia is grateful for the opportunity to make a submission to this important consultation and would welcome further opportunities to discuss the issues raised.

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[i] Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023.

[ii] Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023.

[iii] Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023