



**Submission to the
Department of Health
Consultation Paper:
Redesign of Dementia Consumer
Supports**

15 November 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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INTRODUCTION

Carers Australia welcomes the opportunity to respond to the Department of Health's Consultation Paper on the "*Redesign of Dementia Consumer Supports*". This submission has been prepared by Carers Australia with input from our Australia-wide Network of state and territory Carer Associations.

Carers Australia supports the redesign of dementia supports for consumers with the objective of achieving a more integrated and streamlined system of care. However, we are disappointed that there is less of a focus on the information and specific supports required by carers of people of dementia than we would have expected. Carers of people with dementia are vital to the daily management and care of those with dementia. Without their support, the cost to the economy would be much higher. (In a report released in February 2017, the total current cost of dementia in Australia was estimated to be \$14.7 billion, and this is expected to rise to about \$37 billion by 2056¹). However, the task of caring for someone with dementia (particularly in the later stages) is incredibly taxing, both mentally and physically. Carers have as much need for information about their own role and the support services which specifically cater to their needs as they have for information directly relevant to consumers.

Against this background, we were particularly disturbed that the only reference to the need for carer specific supports in the Consultation Paper is the statement that: "In recognition of the need to support and sustain the vital work of unpaid carers, the Australian Government committed to the development of the Integrated Plan for Carer Support Services".² The assumption seems to be that there is no further requirement to address the needs of carers in the re-design of consumer supports. We are very frustrated that consultation papers in relation to aged care from the Department of Health continue to promulgate a government position which is misleading. **The Australian Government has not yet announced the establishment of the Integrated Plan for Carer Support Services and it is not known if or when it might do so.** If the re-design of dementia consumer supports does not take into account carers' needs at this time, there is every likelihood that carers will again be left out of a reform process which is vital to their interests.

In this context we also note that carers have not always benefitted from aged care reform to date. The challenges of caring for people with dementia creates a particularly strong need for specialised services, such as respite care, to give carers a much needed break from caring and to help sustain their caring role. During 2017, Carers Australia received reports from the state and territory Carer Associations and other services, including Commonwealth Respite and Carelink Centres (CRCCs) and Commonwealth Home Support Program (CHSP) operators of increasing difficulty in accessing aged residential respite care. In response, Carers Australia surveyed these and other similar services to identify the extent of any shortage. The survey results clearly identified that there was not enough aged residential respite to meet demand, that available services were often not flexible enough to meet the needs of carers (for example, when respite was available and for how long). There were also

¹ Dementia Australia, Economic Cost of Dementia 2016-2056, URL: https://reports.dementia.org.au/costofdementia?qclid=EAlalQobChMI3572rL2F1wIVTB9oCh23IAPKEAAYASAAEqLg6fD_BwE

²

particular difficulties in accommodating consumers with high care needs, with a shortage of residential aged care facilities offering secure accommodation and appropriately trained staff to support consumers with dementia. Carers Australia will soon release the survey report and recommendations for improving aged residential respite care.

Carers Australia is also aware of the issues identified by Alzheimer's Australia (now Dementia Australia) from their Pre-Budget Submission for the 2017-18 Budget. We strongly agree with the long-term "National Dementia Strategy" proposed in that submission aimed at reducing people's risk of dementia, to ensure that people with dementia have access to quality aged care services and improve access to quality respite care for the benefit of their carers.

Carers Australia also believes there needs to be a stronger focus on people with younger onset dementia, who, due to their age, are at risk of falling through the cracks of the disability and aged care sectors, as neither sector believe they are best placed to respond comprehensively to the needs of these individuals and their carers.

QUESTIONS AND ANSWERS

4.1 Information Questions

4.1.1 Question one

Given the existence of an information line for several years and the continued ongoing low dementia literacy rates, are there additional supports that the information line and website can better leverage to increase dementia literacy in the community?

Consumers and their carers often turn to the National Dementia Helpline and the Dementia Australia website for key information on dementia and supports and services available. A free information pack, known as the "Dementia Kit", is available from this source. However not everyone will access this website.

Carers Australia believes consumers would benefit from resources that were available to them from the very first point of contact following diagnosis at the health care setting including GP clinics, specialist clinics, and hospitals. Given lower levels of digital literacy and internet access among the aged, these resources should in the first instance be made available in hard copy. The pack should include information on: the progression of dementia; relevant support services with contact details (i.e. Dementia Behaviour Management Advisory Services (DBMAS); NDIS support for people under the age of 65; financial supports available (including through Medicare and Home Care Packages), information on managing financial and legal matters; advanced care directives; and respite, counselling, education and peer support for both carers in their own right and for the person they care for. Handy resources such as promotional magnets or cards with useful numbers that consumers can contact should also be included. The pack could be adapted from kits already available, perhaps with some enhancements. It should be routinely handed to people newly diagnosed with dementia and/or to their carers.

While Dementia Australia runs information sessions and education programs for dementia consumers to increase dementia literacy, Carers Australia suggests increasing community awareness of these sessions with greater publicity, through flyers or posters in community and health settings, aged care settings, hospitals and through social media channels

4.1.2 Question two

Noting the outreach services outlined at 3.4, are there further considerations needed to better support:

- **consumers with low IT literacy or lack of access to IT infrastructure?**
- **special needs groups, especially with people with low literacy levels, from Culturally and Linguistically Diverse backgrounds or from regional, rural and remote areas to have equity of access to these core information supports services?**

As noted above, Consumers with low IT literacy or lack of access to IT infrastructure would particularly benefit from hard copy resources.

For Carers Australia, low levels of IT literacy among large sections of the ageing population is a very real concern in an era where access to important information and the processes required to access support services is increasingly dependent on online access and proficiency. Consumers with low IT literacy and lack of access to IT infrastructure miss the many social and economic benefits of being digitally connected, whether it is to manage their health and wellbeing, access education and services, organise and manage finances or simply to connect with families and friends³. The research paper led by Roy Morgan Research, *Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2017* found that Australians from low income households, people aged 65+, people with a disability, people who did not complete secondary school, Indigenous Australians and people who are not in paid employment are most digitally excluded. The study also found that geography plays a critical role. The study also found that the capital-country gap has widened in Victoria, New South Wales and Tasmania⁴.

There is an obvious need to train older Australians who lack digital literacy skills, especially with respect to accessing healthcare, aged care, carer support services, income support and other community services. We note that the Minister for Social Services has recently announced a new program to help older Australians to be connected through digital technology and to improve their skills.⁵ The program consists of up to \$20 million in small grants over the next three years and will be available to community organisations that join the Be Connected network to deliver training and support. We would hope this program embraces people with dementia and their carers.

³ Thomas, J, Barraket, J, Wilson, C, Ewing, S, MacDonald, T, Tucker, J & Rennie, E, 2017, *Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2017*, RMIT University, Melbourne, for Telstra.

⁴ *Ibid.*

⁵ <https://christianporter.dss.gov.au/media-releases/new-program-to-help-older-australians-be-connected-through-digital-technology>

Where cost is a reason for not being able to access digital services, the Government may find it worth investing in a “National Digital Access Scheme” for consumers and carers who are from vulnerable groups and who meet eligibility requirements. In our submission to the Australian Digital Health Agency on the “*The future of Digital Health in Australia – Consultation to develop a National Digital Health Strategy*”⁶, Carers Australia noted that, in addition to the cost of IT equipment, the cost of data services through telecommunications providers may be prohibitively expensive. At the very least it becomes an added expense that low income or disadvantaged households cannot afford. We suggested that consideration should be given to investigating an innovative chargeback approach to using data in the digital health space, whether that be charged back to the provider, Digital Health Agency, Department of Health, or Department of Human Services. Similar considerations apply to the aged care and disability sectors.

In terms of special needs groups, a “National Dementia Outreach Task Force” of staff specifically trained to communicate effectively with consumers and their carers would help to reach out to those from culturally and linguistically diverse (CALD) and Indigenous backgrounds, as well as people from outer regional and remote areas. The mobile taskforce should also look into incorporating staff who share a similar background to the target community.

Carers Australia acknowledges that Dementia Australia has already taken steps to educate consumers from CALD and Aboriginal and Torres Strait Islander backgrounds by publishing resources on its website in the “Diversity” section, including translated resources in 43 different languages, in addition to offering an interpreter service through the National Dementia Helpline.

Recommendations:

- **Increase community awareness of dementia information sessions and education programs through community settings and social media channels.**
- **In addition to assisting older people to develop digital literacy skills (with an emphasis on providing access to information and services of benefit to them), an approach to helping the financially disadvantaged have access to IT equipment in the home and a contribution to the costs of data should also be explored.**
- **Establishment of a “National Dementia Outreach Task Force”, composed of mobile groups of skilled and specialised staff to engage with and educate consumers and their carers from special needs groups.**

⁶ Carers Australia submission to the Australian Digital Health Agency (, 2017, *The future of Digital Health in Australia – Consultation to develop a National Digital Health Strategy*.

4.2 Awareness Questions

4.2.1 Question three

The Australian Government has been providing support for dementia awareness and stigma reduction activities for over a decade. However, less than 30 per cent of those people living with dementia who access Australian Government funded dementia consumer supports programs, heard about the supports from a health professional.

Noting the proposed awareness activities outlined at 3.3, given the continuing low rates of dementia literacy among health professionals are there other specific supports that would encourage self-management, independence and reablement to ensure people recently diagnosed with dementia connect to the available support services early?

As discussed in the Consultation Paper, there needs to be a system in place that allows early diagnosis and timely referral to dementia support services so that people with dementia make early use of services. More awareness raising needs to be done on the ground, and one simple strategy could be in the form of posters, such as “Are you at risk of dementia? Or is your loved one at risk of dementia?” at GP clinics, hospitals and other health care providers.

It would also be useful if, shortly after diagnosis, GP clinics or specialists were to contact the client (via phone or email) to reinforce the benefits of the support services identified in the Information Pack they received on diagnosis and of the National Dementia Helpline.

4.2.2 Question four

Are there any other groups which should be included in the targeted awareness and stigma reduction campaign and how should they be prioritised?

Besides people with dementia, carers of people with dementia also experience significant social stigma, which results in social exclusion, discrimination and disempowerment, often referred to as “courtesy stigma”⁷. People’s attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and their family accept and learn to live with the condition⁸.

In a recent survey, Alzheimer’s Australia found that 94% of people living with dementia have encountered embarrassing situations due to their dementia, 60% of carers found themselves in embarrassing situations and almost 50% of the general public felt frustrated when they did not know how to help people with dementia⁹.

⁷ Alzheimer’s Australia NSW, 2010, Addressing the Stigma associated with Dementia, URL: <https://www.dementia.org.au/files/2010NSWAddressingStigmaDiscussionPaper2.pdf>

⁸ *Ibid.*

⁹ Alzheimer’s Australia Report 2017, Dementia and the impact of stigma, URL: <https://www.dementia.org.au/files/NATIONAL/documents/dementia-and-stigma-2017.pdf>

Carers Australia acknowledges and supports Dementia Australia's effort to achieve targeted awareness and stigma reduction at a national level through the webpage dedicated to "dementia-friendly communities". The webpage comprises a "resource hub" with information and resources on dementia-friendly communities, a learning centre, which provides free online training, and an "online community" that allows consumers to find dementia-friendly places in their locality. Not only is this important for awareness and the stigma reduction campaign, but also to help educate the community on how to help those with dementia. The learning centre also enables individuals and organisations to become a "dementia friend".

Carers Australia also recommends that the Government support dementia-specific education and training for all personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia-care workers, health professionals and service providers. A successful example which can be drawn upon is the dementia education program targeted to family carers called "*Creative Ways to Care*", which was developed by a group of dementia experts. It has been run by Carers South Australia with excellent results for carers and stigma reduction within local families and communities. Carers Australia believes that using a similar approach would be highly beneficial for staff in the dementia space, especially if it was to be accredited and offered as an elective unit for support workers and health professionals completing their Certificate III in Individual Support.

Moreover, the awareness and stigma reduction campaign can be achieved through use of mainstream media advertisements (including television and radio), social media, through Facebook pages and groups and educational forums. These forums could be held at hospitals, universities and workplaces, which raise dementia awareness and importantly information on how to help those with dementia. This is pivotal in terms of long-term aged care planning for a better quality of life for an ageing population.

Recommendations:

- **Increased awareness-raising and education in relation to supports for people with dementia and their carers be directed to GP clinics, hospitals and health care providers.**
- **Government to fund and support dementia-specific education and training for personnel working in dementia care services to reduce prejudice and stereotyping amongst dementia-care workers.**
- **Use of advertisements in mainstream media, social media, through Facebook pages and groups and educational forums to increase dementia awareness and reduce stigma.**

4.3 Outreach Questions

4.3.1 Question five

Are there other factors to consider in ensuring services are appropriate and accessible to the most vulnerable or marginalised people living with dementia?

As already discussed in the answers to Question 2, the “National Dementia Outreach Task Force” would help target dementia specific services to make them accessible to the most vulnerable and marginalised of people living with dementia and their carers. The mobile taskforce should comprise a group of highly trained and specialised staff that attend to thin markets, such as those living in rural and remote areas and communities of high social disadvantage, much like the “pop-up” clinic described in the Consultation Paper.

The mobile taskforce should as far as possible comprise staff from a range of backgrounds. Emphasis should be placed on those with a strong health and community welfare background, a good understanding of the issues facing vulnerable and marginalised communities, such as Aboriginal and Torres Strait Islander people and people from a Culturally and Linguistically Diverse (CALD) background¹⁰, who are culturally sensitive, and who can also communicate in a language other than English.

4.3.2 Question six

Will this model of redesign services embed improved access to services and outcomes for people living with dementia into the future?

If the redesign of dementia consumer supports appropriately targets people with dementia and their carers by improving access to affordable support services across the nation, particularly from marginalised communities who experience social barriers, then it is hoped that this will improve outcomes in terms of dementia literacy, early intervention, brain wellness and physical wellness strategies, and behavioural management. It is important to address the needs of people with younger onset dementia and their carers in the redesign, so that they do not miss out on support services from either the disability or aged care sector.

¹⁰ Issues facing vulnerable and marginalised communities include poverty, cycle of disadvantage, discrimination and social stigma.

Recommendations:

- **Establishment of a National Dementia Outreach Task Force comprised of a highly trained and specialised staff members who, wherever possible share a common background with target communities.**
- **People with younger onset dementia and their carers be included in and supported by the redesign of dementia consumer supports.**

4.4 Intervention Questions

4.4.1 Question seven

Current early intervention supports only reach around 1 per cent of people recently diagnosed with dementia. The combined emphasis of the Information (3.2) and Awareness (3.3) elements of the dementia consumer supports are expected to reach a substantially higher proportion of the diagnosed population. Are there other elements that should be considered in order to increase the proportion of the diagnosed population who will know about and want access to these services?

Please refer to answers to all previous Questions.