

14 July 2020

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
via email DRCEnquiries@royalcommission.gov.au

RE: response to emergency planning and response issues paper

Dear Commissioners,

Dementia Australia welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), in response to the issues paper on emergency planning and response. The recent bushfire crisis and the current COVID-19 pandemic have exacerbated the challenges people living with dementia, their families and carers face. People living with dementia are one of the most vulnerable groups of people in our society and it is important that COVID-19 in particular and its longer-term impacts do not inadvertently add to the challenges people impacted by dementia experience.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 459,000 Australians living with dementia in 2020¹ and around 1.6 million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³ Dementia is a terminal condition and there is currently no cure. Dementia is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.⁴

¹ Dementia Australia, *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra, 2018

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al., *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health, 2017; Dementia Australia, *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra, 2018; Alzheimer's Disease International and Karolinska Institute, *Global estimates of informal care*, Alzheimer's Disease International, 2018; Access Economics, *Caring Places: planning for aged care and dementia 2010–2050*, 2010

³ Dementia Australia, *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra, 2018

⁴ Australian Institute of Health and Welfare, *Dementia in Australia*, 2012

Living with a progressive cognitive disability places people with dementia at a heightened risk of the impacts of natural disasters and other emergencies. Exposure to a natural disaster may exacerbate dementia symptoms and increase the risk of functional decline, hospitalisation and mortality. People with dementia are also at increased risk of abuse, mistreatment and neglect during, and after, emergencies and crisis situations.

The 2019-20 bushfire crisis was a traumatic experience for many Australians; for people living with dementia, their families and carers there were added complexities. The ongoing media coverage as well as the thick smoke that blanketed many parts of Australia for weeks contributed to feelings of anxiety and concern. People living in bushfire affected areas, which were evacuated (some on multiple occasions), had contingency plans in place, and carers with loved ones living in residential aged facilities reported concerns about facility evacuation plans in the event that a bushfire threat escalated.

“As we live very close to bushland/National Park, and there was an instance of two separate fires across the valley threatening homes, we were very anxious until those fires were subdued. Anxious enough to constantly monitor the situation and pack a bag just in case; I also worked out where we could head to if we had to evacuate, in order to be safe. In both the bushfire emergency and the COVID-19 threats, my husband who has dementia felt alarmed and more highly anxious than I did as his carer. Not good times. The heavy smoke all over Sydney was quite frightening and created an atmosphere of dread.” Carer

During emergency situations, like the bushfires, there is an additional anxiety for carers of people living with dementia as they need to make decisions about how to best safeguard the person they care for. In the current pandemic, some family members have expressed concern about how they could continue to care for the person living with dementia should they themselves contract COVID-19.

During both the bushfire crisis and the COVID-19 pandemic, the accessibility and timeliness of information has been an issue. The ‘digital divide’ has impacted on access to information and communication. Although the Internet and digital technologies have enabled people to connect with family and the community during the pandemic, older people may have limited access to the technologies required and lack the skills to use them (or due to cognitive impairment, lack the ability to learn how to use them). This may also impact on an individual’s access to health information as well as services such as telehealth and online shopping.

“(We need to) ensure timely and accurate information to people living with dementia and their families, carers etc. Try to understand the effect the actual emergency and the changes to normal routine and habits would have on people with dementia.”

The COVID-19 pandemic has exposed and exacerbated the challenges people living with dementia, their families and carers experience. For many people, the need to socially distance themselves, however necessary, has led to increased anxiety, stress, loneliness, and disconnection from family, friends and even essential services (including home care, domestic support, meals deliveries and social support programs). Yet for people living with dementia, their families and carers, this vulnerability to the adverse impacts of social distancing is much greater.

“It was more difficult for my hubby with dementia. Although he understood much of the problem, he could not cope with the restrictions and there was very little I could do to help this. There was nowhere to take him when he needed to go out (he also has mobility problems so just going for a walk was not an option).” Carer

For people living with dementia, their families and carers, the extent and impact of social distancing and other COVID-19 measures is likely to be significant and potentially far-reaching. Difficulties in accessing and comprehending information, as well significant changes and disruption to familiar daily routines, can lead to confusion, stress, anxiety and agitation – which has subsequent impacts on their carers and families. The mental health of people living with dementia is being impacted, along with a decline in cognitive functioning for many, as a result of changes to routine, lack of mental stimulation, and social isolation. This has subsequent flow-on mental health impacts for carers of people living with dementia.

*“Because I have dementia and normally have some isolation thought I would cope OK with the extra isolation. I was surprised at how the community isolation did affect me.”
Person living with dementia*

Many carers rely on a person living with dementia receiving external support so they can have a much-needed break from their caring role and/or continue to engage in regular activities of their own. The lack of respite and usual activities has been detrimental to the mental health of both people living with dementia and carers. We are likely to see an increase in carer stress and burnout, and potentially in mistreatment and neglect of people living with dementia as a consequence.

The lockdown approach of many residential aged care facilities has impacted significantly on people living with dementia, their families and carers. Most concerning was that some facilities completely restricted visitors, even denying access to partners and family members

who are integral to the care of people living with dementia – for example, people who visit daily to assist with daily care and meals. Concerns have been expressed about the lack of oversight or monitoring during the lockdown period and the potential for people living with dementia to have been neglected or mistreated.

“I have found the COVID restrictions very difficult. I live on my own and my husband is in a care facility. For a long while I could not visit him at all and it took a long while for them to be lifted. I have to make an appointment to visit him and only at certain times (not meal times and I usually feed him!) and for less than an hour.” Carer

A human rights approach, which values participation and inclusion of people living with dementia, is critical to ensuring that people living with dementia, their families and carers are not overlooked or left behind during emergencies. Support services have an integral role to play in safeguarding and responding to at risk clients. In addition, people living with dementia need to be identified and included in emergency planning. People impacted by dementia have also identified that there is an important role for local government in including people with dementia in local emergency planning and response.

“People living with dementia should be part of the process developing strategies to handle any disaster - bushfire, pandemic, droughts and floods. If a plan is developed to handle a disaster it can be implemented immediately and support provided to those in need.” Former carer

Dementia Australia believes that dementia-friendly communities are needed in order to improve emergency planning and response for people living with dementia and to prevent violence, abuse, neglect and exploitation. A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value. Dementia-friendly communities encourage organisations, businesses, community groups and individuals to make practical changes that will have a positive impact on the lives of people living with dementia and their carers.⁵

“There should be a national approach as to how local communities can support people with dementia in these emergencies. Councils should have a Dementia Friendly page on their website where information, suggestions, help information, contacts for accommodation can be provided.” Person living with dementia

⁵ More information about dementia-friendly communities is available at <https://www.dementiafriendly.org.au/>



Dementia Australia would welcome further discussions about the issues we have raised to enable the concerns of people living with dementia, their families and carers to be addressed by the Royal Commission.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Maree McCabe".

Maree McCabe
Chief Executive Officer
Dementia Australia