



**Dementia
Australia®**

The Commonwealth Government Covid-19 Response Inquiry

A Dementia Australia submission

December 12, 2023

Introduction

Dementia Australia is the peak dementia advocacy organisation in Australia and represents the more than 400,000 people living with all forms of dementia in Australia and the estimated 1.5million people involved in their support and care.ⁱ 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.

Dementia Australia welcomes the opportunity to make a submission to the Commonwealth Government Covid-19 Response Inquiry. Our submission draws on surveys of Dementia Australia Advocates (people living with dementia, families and carers who volunteer with Dementia Australia), de-identified data obtained from our National Dementia Helpline, and internal feedback from Dementia Australia teams engaging with our stakeholders. It is important to acknowledge that the COVID-19 pandemic affected people living with dementia, families and carers in different and diverse ways, and that future pandemics would have similarly diverse impacts. However, our surveys and consultations revealed there were a number of common themes and shared experiences that provide valuable feedback in shaping planning and responses to public health events in the future.

Our submission focuses on observations and recommendations in relation to three of the terms of reference:

- **Key health response measures (for example across COVID-19 vaccinations and treatments)**
- **Broader health supports for people impacted by COVID-19 and/or lockdowns**
- **Mechanisms to better target future responses to the needs of particular populations**

Improved provision of vaccination and reporting measures

Dementia was certified as a pre-existing condition in over 30% of deaths due to COVID-19 in Australia associated with a chronic condition.ⁱⁱ The Covid-19 pandemic highlighted the importance of access to vaccination, particularly for populations more vulnerable to the adverse effects of viruses, including those living with dementia in residential aged care.

Our stakeholders reported difficulties accessing Covid vaccination for people living with dementia in the community and residential aged care for a variety of reasons including poor communication, erroneous assumptions about decision-making for people living with dementia by those planning and providing vaccinations, failure to consult a support person if vaccination was declined, and inadequate record keeping and follow up when vaccination opportunities were missed.

Dementia Australia recommends proactive engagement with primary health providers to identify improved access to vaccinations in community and residential aged care settings, including mobile vaccination services. Equally, planning for the future must include accurate vaccination status record keeping ensuring that people living with disabilities, including dementia, have timely and equitable access to vaccination.

Improved services and supports for people living with dementia, their family members and carers

Continuity and quality of care is vital for a person living with dementia. The Covid pandemic highlighted the significant impacts on wellbeing for people living with dementia, and family members and carers, when care services and supports were reduced or withdrawn.

Existing issues related to inadequate access to respite services were exacerbated during Covid and resulted in increased carer fatigue, stress and ill-health, and associated risks of elder abuse incidents and premature admission to aged care. Future planning for pandemics must address the provision of adequate support and services, particularly in relation to respite services, to obviate these risks and support the wellbeing of people living with dementia and those who care for them.

Planning to reduce social isolation and support wellbeing

Dementia Australia surveys over the last decade have revealed that people living with dementia were almost twice as likely to experience high levels of loneliness compared to the general public, family carers were significantly lonelier than other carer groups and that feelings of loneliness, social isolation and illbeing in both these groups increased significantly during the pandemic.^{iii iv} A Dementia Australia survey noted that the number of people living with dementia, carers and families who rated their psychological health as poor or very poor increased from 7 percent prior to COVID-19 to 17 percent during COVID-19.^v Loneliness and isolation can accelerate cognitive decline and increase an individual's risk of developing dementia in later life. The effects of loneliness and isolation were compounded for some people living with dementia in rural, regional and remote areas, and from Aboriginal and Torres Strait Island, culturally and linguistically diverse, LGBTIQ+ and other diverse communities.

Dementia Australia recommends that mitigating isolation and loneliness for people living with dementia and family carers is identified as a critical priority in future pandemic planning and that State, Territory and Federal governments facilitate this through strengthening mental health and home and residential aged care provider services. As part of this prioritisation, Dementia Australia acknowledges the positive impact of the Australian Government's 'Partnerships in Care' residential aged care initiative and believes this should be adapted for a range of health care settings, including acute and hospice care, to support the wellbeing of people living with dementia.^{vi} We believe that allowing family members, carers and support people to accompany the person with dementia to hospital can play a critical role in supporting the wellbeing of the person and improving health outcomes and should be considered as an important component of pandemic planning for acute care settings.

Embracing innovative models of service and support

The use of video conferencing and smartphone technology was a defining feature of the COVID-19 pandemic. Feedback from our stakeholders indicate that many people living with dementia embraced the technology before and during the pandemic but for others, including people living with dementia with hearing and/or vision impairments, the various online platforms proved difficult to navigate and in some cases, had the effect of deepening feelings of isolation and illbeing.

Noting that many people living with dementia express a preference for face-to-face consultations for treatment, care and support services, and the diversity of experiences with technology enablers during the pandemic, in planning for future pandemics, Dementia Australia strongly supports a flexible model of service and support provision that is responsive to the diverse needs of people living with dementia. This could include an expansion of the telehealth approach in a range of contexts from clinical consultations to wellbeing programs, utilising other forms of assistive technology and offering open air alternatives for support groups, programs and services to ensure individuals remain connected to health care professionals and have access to appropriate assessment, treatment and care. Training for health care professionals, people living with dementia, their family members and carers will be a vital part of pandemic planning to ensure the accessibility and efficacy of these technological and other options.

Effective communication of public health information

Studies have shown that communication of health information during the Australian response to COVID-19 was variable, with critical information not reaching some communities and sectors of the population, causing unnecessary confusion and frustration and limiting the efficacy of public health measures including hand hygiene, mask wearing and timely vaccination.^{vii} Some of our stakeholders reported that information was not available or accessible, and that changes in health advice were at times confusing to people living with dementia, and their family members and carers.^{viii}

In planning for future pandemics, Dementia Australia supports an approach that tailors health information so that it is accessible and comprehensible for all sectors of the population. For people living with dementia, this could include but is not limited to information that accommodates the needs of people with linguistic and comprehension differences, and vision, hearing and cognitive impairments. Partnering with peak bodies such as Dementia Australia and people living with dementia should be considered in the developing information in appropriate formats.

Conclusion

For many people living with dementia, their family members and carers, 'life with Covid-19' was difficult. The social isolation and disruption to important services and programs had a significant impact on safety, wellbeing and quality of life and for some individuals, even with the resumption of services and supports, life has continued to be challenging.

The Covid-19 pandemic highlighted the vulnerabilities in our health and aged care systems, and the specific gaps in services and supports for people living with dementia, their family members and carers. Equally, it has offered an opportunity to reflect on how responses to a future pandemic might be improved. We hope that our emphasis on the rights, dignity and wellbeing of people living with dementia, their family members and carers and associated recommendations, makes a contribution in this context.

Thank you for considering our submission to this inquiry and we would welcome the opportunity to discuss any of the issues raised in our submission in more detail.

The Dementia Australia Policy team can be contacted on policyteam@dementia.org.au

ⁱ AIHW (2023) Dementia in Australia. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

ⁱⁱ Australian Bureau of Statistics, (2022), Deaths due to COVID-19: Associated causes, pre-existing chronic conditions, <https://www.abs.gov.au/articles/covid-19-mortality-australia-deaths-registered-until-30-november-2022#deaths-due-to-covid-19-associated-causes-pre-existing-chronic-conditions>

ⁱⁱⁱ Dementia Australia, Dementia and Loneliness, (2016) <https://www.dementia.org.au/media-releases/dementia-and-loneliness>.

^{iv} Dementia Australia (2020), One Day the Care was Gone. <https://www.dementia.org.au/sites/default/files/2020-11/PFOD-Discussion-Paper-Nov-2020-ver1.pdf>

^v Dementia Australia (2020), One Day the Care was Gone. Retrieved from Dementia Australia: <https://www.dementia.org.au/sites/default/files/2020-11/PFOD-Discussion-Paper-Nov-2020-ver1.pdf>

^{vi} Australian Government. (2022), Partnerships in Care Fact Sheet. Retrieved from Aged Care Quality and Safety Commission: <https://www.agedcarequality.gov.au/sites/default/files/media/partnerships-in-care-fact-sheet.pdf>

^{vii} National Centre for Epidemiology and Population Health, ANU College of Health and Medicine (2023). [Health messaging and migrant Australians: barriers and opportunities during COVID-19 and beyond](#)

^{viii} Dementia Australia (2022), The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. <https://www.dementia.org.au/sites/default/files/2022-07/The-impact-and-response-to-the-omicron-wave-of-the-COVID-pandemic-2022BRNDAPPVD.pdf>