



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

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About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

No matter how you are impacted by dementia or who you are, we are here for you.

Question 1: What have been the experiences of people with disability, their family, support workers and carers during the Omicron wave of the COVID-19 pandemic?

Throughout the pandemic, we have witnessed the disproportionate impact on certain sections of the community, in particular people living with dementia. Although some of the challenges faced by older people with dementia have garnered considerable public scrutiny - the residential aged care crisis, for example – it is important to recognise that people with younger onset dementia, which represent 8 per cent of dementias, have also been impacted in unique ways¹.

In the first half of 2022, Dementia Australia embarked on a project to gauge the impact of the Omicron variant for people living with dementia, their families and carers. As part of this activity, people with dementia and carers were invited to submit their experiences directly to Dementia Australia. Staff of the organisation were also invited to anonymously share anecdotes from their interactions with clients. The material cited in this submission comes largely from this project.

It should be acknowledged that most of the qualitative responses came from family carers, which reflects the significant impact Omicron has had on people with dementia in more advanced stages and their families.

Unsurprisingly, the most common concern involved residential aged care. Sweeping infection control measures or ‘lockdowns’ resulted in almost punitive living situations for people with dementia, with some residents banned from leaving their bedrooms for consecutive weeks. Not only was access to family and essential carers forbidden, but access to medical and allied health was compromised or delayed. Rules were inconsistent and ever-changing.

People living with dementia in the community - aware of their susceptibility to poor COVID outcomes - found themselves and their carers sheltering at home, even when no public health order was in place. Carers refrained from using services to protect the person with dementia from infection. Visits outside the home were solely for essential supplies or medical care.

¹ Cations, M., Day, S., Laver, K., Withall, A., & Draper, B. (2021). People with young-onset dementia and their families experience distinctive impacts of the COVID-19 pandemic and associated restrictions. *International Psychogeriatrics*, 33(8), 839-841. doi:10.1017/S1041610221000879

Public health orders reduced the independence of people living with dementia. Family carers were concerned that the person with dementia would either contract COVID-19 or incur a fine due to unintentional non-compliance. Changes to health advice were confusing and inaccessible to people with cognitive disability.

Similarly, accessible testing and vaccination services were limited. In regions where these services were available, people were often unaware of them. A shortage of in-reach and in-home services during the period impacted care access.

In-home care, day programs, and respite services were disrupted. COVID positive people with dementia and family carers or those deemed close contacts had home support services withdrawn. Infections in primary carers highlighted a lack of assistance for people with dementia who rely on friends and family members as their sole means of support.

Dementia Australia believes that the decision to 'live with COVID' did not take into consideration the multifaceted impacts this approach would have on people with disability. Australia must plan for future major health issues now, and those plans must prioritise reducing the burden on people with disabilities and family carers, and focus on inclusivity, safety, innovation and service continuity.

Question 2: What are the main concerns of people with disability about 'living with COVID' and the prospects of further waves and variants of COVID-19?

'Life with COVID' has been difficult for many people living with dementia, their families and carers. Services and programs they rely on for safety, wellbeing, and companionship have been disrupted. The ever-present risk of infection has meant that some feel they have no choice but to shelter in their homes. When cases climb, and the possibility of treatment rationing looms, anxiety about being denied intensive care and ventilation increases.

People impacted by dementia have told Dementia Australia that during this Omicron wave they have avoided leaving the house unless necessary and some families have avoided gatherings. Even after services were restored, people with dementia and family carers are hesitant to use them.

“We have again reduced the scope of outings to minimise the risk... such as it is now that we are fully vaxed.” Carer

“I don’t go out of the house for anything unless I have to, for example, medical appointments, necessary shopping, etc. I have become less active and have postponed my specific exercise classes, held in a gym, because of the risk of contact with someone who has COVID-19.” Carer

“A carer desperately needs a break from her Mum but is concerned about her contracting COVID-19 in respite.” Staff member

Isolation and loneliness are not limited to negative mental health impacts. They have been found to predict premature mortality, depression, cardiovascular disease and cognitive decline². Dementia Australia believes that priority should be given to strategies to mitigate the isolation and loneliness experienced by people living with dementia and family carers during the pandemic. This should be through open air alternatives to groups and services, an expansion of the telehealth model to include wellbeing programs, and targeted mental health services for carers.

People living with dementia are vulnerable to disruptions in supply chains and stock shortages. Dementia can impact on the ability to chew and swallow safely and means carers may require certain products to meet the nutritional needs of the person living with dementia. It is not uncommon for people with dementia to go through bouts of food refusal. When shopping for groceries is already a stressor, being unable to purchase the goods they need will magnify distress.

“It has been difficult to get the items at shops that my husband will only eat. I am finding it difficult to go shopping on my own due to my own health condition. Isolation is hard to cope with for long periods. We go days without seeing anyone. Gets very lonely as my husband has no conversation abilities now.” Carer

In the first year of the pandemic, in response to stock shortages due to panic buying, some supermarkets implemented discrete shopping hours for people with special needs. This initiative was well received by people living with dementia and family

² Smith, BJ and Lim, MH (2020) How the COVID-19 pandemic is focusing attention on loneliness and social isolation. Public Health Res Pract. 2020;30(2):e3022008

carers. Dementia Australia encourages all retailers of essential products to consider implementing dementia-friendly shopping into their operating hours.

Question 3: What actions have been, or should be, implemented to make it easier for people with disability to keep COVID-19 vaccinations and boosters up to date? What barriers have people with disability faced in trying to access vaccines or boosters?

Overall, people with dementia who live at home have encountered few difficulties accessing vaccinations and boosters. However, people with limited mobility are more likely to report problems due to insufficient mobile vaccination services (or a lack of awareness of such services) or primary health providers not providing home visits.

“A client...was not able to leave the house. He needed vaccination and, at the time, we couldn't find a home-visiting vaccination service. I know that GP in-home vaccinations have now been approved, but I'm not sure how easy this service is to access.” Staff member

“A carer has been told by her mother's GP that neither himself, nor the nurse, will come to the house to get her mother vaccinated. The GP previously came to the home for first shot. They were wondering if Dementia Australia could help.” Staff member

As COVID-19 moves to endemicity, and a vaccination booster schedule appears likely, it is important to offer accessible – preferably mobile – vaccination services to people with disability. In preparation for future waves, Dementia Australia recommends engagement with primary health providers to identify ways home-based consultations can be sustained.

During Omicron, people in residential aged care experienced significant challenges accessing vaccination services if they missed the facility's scheduled vaccination visit. This occurred when a person with dementia or family carer changed their mind, misjudged the person's risk, or was admitted after the visit. Family carers have had difficulties getting health professionals to attend the facility to administer a booster.

“The carer’s mother is in the later stages of the disease. Because she never leaves her facility bedroom, the family resisted having her vaccinated, as they were concerned about how this may impact her, as well as consent issues. Now the carers have tested positive for COVID. They are needing to have Mum vaccinated but cannot find a doctor that will come to the facility.” Staff member

“Getting my wife a booster is difficult as she cannot leave the facility. SA Health apparently serviced the staff and residents with doses 1-3, but as my wife wasn’t in care when it started, she is currently behind in vaccinations. She had doses 1-2 in-house, but I was told her booster would have to be done by her visiting GP but that has been difficult for them to arrange.” Carer

From 3 May 2022, it will be mandatory for residential aged care providers to report the number of residents yet to receive a COVID-19 vaccination who are willing and clinically suitable³. This is a welcome development that will help identify areas of concern going into the winter period. However, it is important that this improved reporting is complemented by better access to vaccination services. Ideally, a report of willing, unvaccinated residents would trigger an immediate health response.

“A person’s dad, who lives with dementia, was offered a booster but was confused about the changing guidelines and therefore declined. This ‘refusal’ wasn’t queried by staff, so he missed the booster shot. Now, because of lockdown, he can’t access providers either at the facility or outside the facility. So, even if the facility is listed as having completed the booster program, residents may be missed.” Staff member

Dementia Australia is aware of instances where substitute decision-maker or next-of-kin protocols were not followed during the vaccine roll out. This has led to people with dementia not receiving a vaccination against the preference of their nominated substitute decision-maker. This underlines the continuing issue of inadequate involvement of family carers in treatment decisions within residential aged care and

³ Australian Government (2022), *Residential aged care provider reporting requirements on resident and workforce COVID-19 vaccination*. Retrieved from Department of Health: <https://www.health.gov.au/sites/default/files/documents/2022/04/covid-19-vaccination-guidance-for-residential-aged-care-providers-on-reporting-resident-and-workforce-covid-19-vaccinations-fact-sheet.pdf>

the poor understanding of medical decision-making processes for people living with dementia.

“He’s living in aged care, where it goes through like wildfire. I don’t think it’s good enough. His decision-making ability is diminished, they know that. They should have called his Power of Attorney. They should ask us to speak with him. They just said he refused and moved on to the next person. They say there are a lot of people not getting [the booster shot]. Maybe you didn’t explain it to them enough and they don’t even know what they are refusing?”

Carer

Dementia Australia recommends that when a person with advanced dementia is identified as unwilling but eligible for vaccination, the facility must provide evidence that the person’s legal decision-maker and family have been consulted. A person with advanced dementia’s ability to participate in medical decisions fluctuates, so it is important that they are consulted at a time conducive for decision-making *for them* and if necessary, on more than one occasion.

Question 4: Have people with disability experienced barriers to accessing quality health care during the Omicron wave of the pandemic? This includes access to acute or emergency care; access to general practitioners and allied health services; access to mental health support; and access to critical tests or regular screening. What initiatives have supported the continuity of health services during the Omicron wave? Have telehealth services worked well? What have people with disability who have contracted COVID-19 experienced in accessing health care whether they are self-managing COVID-19 at home or have been hospitalised?

Dementia Australia is aware that people living with dementia in regional and rural areas of Australia – particularly NSW and Victoria where travel restrictions were in place until late 2021 – have not received been able to access their usual level of care.

“A family in regional NSW told me today that the geriatrician that usually visits regularly has not been to their area for about six months due to COVID-19.”

Staff member

Medical appointments via telehealth, particularly video conferencing when available, can be preferred by people living with dementia in early to mid-stages rather than face-to-face with face masks. People with dementia often use visual and facial cues to help them absorb information. Face masks may impede the person’s social cognition, creating further disadvantage⁴. Dementia Australia supports the continuation of subsidised telehealth for people in the community who benefit from this service.

[At a speech pathologist appointment with both people wearing masks] “I was really concentrating to understand what was being said, and I just couldn’t. It was worse than if it would have been on Zoom.” Person living with dementia

It should be acknowledged that for people with more advanced dementia, a face-to-face consultation might be more appropriate. Any future public health orders should therefore include reasonable exceptions that will allow face-to-face medical care to continue.

As previously touched on, people in residential aged care encountered barriers to accessing timely medical care. These barriers extended from primary care and allied health to other forms of service and support.

“No physio, no dietician, as they have been quarantined. I rely on the physio visit [to the facility] four times a week to ensure my dad’s aids are correct.” Carer

“A resident in independent living facility has reported several COVID-19 issues, despite the facility being well-managed in the way it supports residents. The residents continue to get no home care support (for at least three months now), because they cannot establish the vaccination status of in-home care staff, are fearful of the risks, and there are no workers available anyway. Elective surgery has been put off, meaning a deterioration in health. Other allied health appointments are also delayed, including podiatrists, care plans (appointments

⁴ Schroeter ML, Kynast J, Villringer A, Baron-Cohen S. Face Masks Protect From Infection but May Impair Social Cognition in Older Adults and People With Dementia. *Front Psychol.* 2021 Aug 13;12:640548. doi: 10.3389/fpsyg.2021.640548. PMID: 34489776; PMCID: PMC8418138.

cancelled more than once now) which delays people's proactive health care.”

Staff member

People with dementia who contracted Omicron were particularly vulnerable to not having their medical and personal care needs met. People in the later stages of dementia can require assistance performing activities of daily living, such as showering, eating, and walking. By removing personal support, a COVID positive person with dementia has a significant risk of falls, dehydration, weight loss or local infection.

“A person living with dementia contracted COVID-19 and fortunately recovered, but during his 10-day illness his only social contact was opening the door of his [residential aged care facility] room to retrieve a food tray. He has been assessed as having a high falls risk, so he cannot be left to shower alone. Meaning, he did not have the opportunity to shower for these 10 days. During this time, his medication was left at the door, rather than being administered with supervision to ensure his safety.” Staff member

“A contact currently has a terminally ill father who was treated in hospital for 10 days, where he was not washed once during this time. She has friends with similar stories, some who live with dementia. He eventually became an outpatient, but subsequent trips to and from hospital resulted in him catching COVID-19, so the aged care provider where he was booked for respite would no longer accept him. He eventually recovered from COVID-19 and is now in the aged care home, but this is after much anguish for the family because of the lack of communication between the hospital/health system and aged care, and his declining capacity. The father has no smart phone, so the daughter had to provide her mobile for text updates, which was the only form of communication with some health providers. She was eventually phoned and abused as if she was the father, for not updating her COVID-19 case status with the public health unit.” Carer

It is critical that health and aged care providers maintain essential personal care services for people with dementia who contract COVID-19. If COVID-19 positive residents are to be treated within the aged care facility, then those facilities should be adequately equipped to do so.

Most State and Territory hospital and acute care services permit essential carers under certain conditions, however, Dementia Australia has received multiple complaints from family carers unable to accompany a person with dementia during a hospital admission.

The Australian Government's *Partnerships in Care* initiative recognizes the "important contribution a visiting partner in care makes to the care, wellbeing, and quality of life of the individual receiving care."⁵

Dementia Australia believes *Partnerships in Care* should be adapted for the hospital and acute setting. This would recognise the specific needs of people with dementia in the potentially unsettling context of hospitalisation and highlight the importance of exemptions for essential carers.

Question 5: Have people with disability and the disability workforce been given clear, accessible and timely information during the Omicron wave of the pandemic? What barriers are experienced by people with disability, their family, support workers and carers when seeking access to personal protective equipment (PPE), rapid antigen tests (RATs) and Polymerase chain reactions (PCRs)?

As Australia approaches the winter season, it is important that we interrogate how we have implemented and communicated public health orders and make improvements going forward.

During the Omicron wave, Dementia Australia experienced an increase in calls from people confused by rapidly changing advice. Worrying about unintentional non-compliance by people with dementia added to the already considerable concerns of family carers.

"A carer contacted me as she was concerned about her husband, who is independently able to go to the shops. However, he is unable to use a smartphone and she doubted he would be able to explain if he was

⁵ Australian Government. (2022, April 12). *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>

approached about not signing in. I did contact the police and asked how they might approach this scenario. They said their emphasis was on educating the community not issuing fines. However, if one was issued, it could be appealed, which it likely would be based on medical advice.” Staff member

“My husband is very confused as to why we can’t go out as much. He does not fully understand the issues and due to his memory, forgets all the time. He must be reminded a few times a day. Shopping is an issue as it is hard for him to understand why he has to wear a mask all the time and usually wears it around his chin.” Carer

The public health orders in each state and territory currently assume a certain level of mobility, executive function, and technological competency. Family carers, coping without their usual services, and shielding from infection, do not have the resources required to visit various outlets to purchase RATs. PCR testing sites relied on being able to drive a car or stand for long periods of time. QR check ins required a smartphone. Support services and groups were cancelled rather than moved outdoors.

“A client waited almost three hours for PCR testing at one of the public clinics, in the rain, with his daughter. He wouldn’t leave his mask on and needed to go to the toilet when they got close to the front of the queue. He was quite agitated by the time they got to the testing station. There is a dedicated disability testing clinic in the ACT. Not sure if this service was available at the time, but I don’t think the information is widely known.” Staff member

A qualitative study of people with dementia and family carers in the UK mirrored the experience here in Australia⁶.

Dementia Australia believes that greater consideration should be given to how public health orders impact people with disabilities like dementia and their family carers.

Giebel et al propose public health orders can be improved by implementing them at three tiers.

⁶Giebel, C., Hanna, K., Rajagopal, M. et al. The potential dangers of not understanding COVID-19 public health restrictions in dementia: “It’s a groundhog day – every single day she does not understand why she can’t go out for a walk”. *BMC Public Health* 21, 762 (2021). <https://doi.org/10.1186/s12889-021-10815-8>

1. Individual – Better information (text, videos), frequent reminders, psychological and social support.
2. Service – Better remote support, face-to-face when feasible, prioritising services used by people with dementia.
3. Society – Increased awareness of hidden disability, shop workers better adapted, socially distanced outdoor areas.

Question 6: Has sufficient support been provided to effectively prevent and manage COVID-19 infections at home? What have been the impacts on people with disability who have had to isolate due to a positive case in their household or workplace?

Dementia Australia is concerned that insufficient support is available to people living with dementia and family carers who contract COVID-19. Advice which suggests ‘most people with COVID-19 experience only mild symptoms’ that can be managed at home⁷, assumes the person does not already require significant support to be safe at home. Dementia Australia was made aware that after notifying their provider of their COVID or close contact status, some people with dementia had their regular support and services withheld.

“Families had difficulties accessing their usual services and supports when they were isolating or if they had COVID-19. Many providers would not provide services in these situations, which made it very challenging for family members.” Staff member

“A primary carer and his wife, who was diagnosed six years ago, had COVID-19 and are now experiencing difficulties getting support into the house.” Staff member

We received reports that if a person’s primary carer needed to isolate, no agency staff person was available to step in and ensure the person with dementia, sometimes living alone, was cared for. An emergency respite shortage magnified this issue.

⁷ Australian Government (2022), If you have COVID-19 or are a close contact. Retrieved from Department of Health: https://www.health.gov.au/health-alerts/covid-19/testing-positive?gclid=Cj0KCQjw06OTBhC_ARIsAAU1yOV6tOGMBUoDDm0Kj0UgshTk8nd2polokYge9H1_IlcT6zRDutOvcTEaAlxiEALw_wcB&gclsrc=aw.ds

“She has COVID-19, so she can’t look after her sister with dementia and can’t find any respite options.” Staff member

As in-home care workers succumbed to infection and appointments were unable to be staffed, services for people with dementia were cancelled. Dementia Australia understands that in some instances the provider did not perform welfare checks to ensure clients were managing without assistance.

“I had a main support worker who had COVID-19. She was unable to work with me. The agency she works with, nobody called me to check I was okay, or I had enough tablets, enough food. They just couldn’t provide a worker. It was a struggle. I had to go into home quarantine. I ended up having to ask someone to stay with me because I couldn’t do it by myself. I think that a lot of people will be in this situation. Fortunately, I had family near me, but imagine if you didn’t?”

Person living with dementia

Dementia Australia recommends an urgent review into how in-home and emergency respite care can be maintained during future COVID-19 outbreaks. Local agencies should be equipped to provide welfare checks on vulnerable individuals impacted by, but not necessarily infected with, COVID-19.

Question 7: What have been the experiences of people with disability in accessing disability supports during the Omicron wave? Is there more that governments and relevant agencies should be doing to support disability service providers to keep providing services during future COVID-19 waves or other emergencies?

Day programs and centres for people living with dementia had been disrupted long before Omicron infections caused staff shortages. As a result of previous research suggesting that there is no clinical benefit, adult day programs were deemed non-essential services both in Australia and overseas⁸. This decision did not consider the importance and value of these services to people with dementia and family carers. Dementia Australia is aware of the negative impacts reduced social interaction has

⁸ Gaugler JE, Marx K, Dabelko-Schoeny H, Parker L, Anderson KA, Albers E, Gitlin LN. COVID-19 and the Need for Adult Day Services. *J Am Med Dir Assoc.* 2021 Jul;22(7):1333-1337. doi: 10.1016/j.jamda.2021.04.025. Epub 2021 May 7. PMID: 34044009; PMCID: PMC8103140.

had on people with dementia, with 40 per cent of people with dementia feeling less socially connected and 79 per cent experiencing slight to moderate problems with mood⁹ during 2020. Despite many other services 'reopening' adult day programs, day centres and respite services have been slow to return to their previous level of operation.

"There are no 'social groups' being held that I used to attend" Person living with dementia

"Clients experienced changes or rescheduling of services due to recommendations about what services/supports should be provided during different stages of the pandemic. Some supports, such as day programs or hydrotherapy, were not running during certain periods, impacting on the support for clients." Staff member

Staff shortages have significantly impacted the provision of planned and emergency respite. The National Dementia Helpline has received an influx of calls from carers unable to access respite due to service closures and shortages. Inadequate respite has multiple flow-on effects including increases in carer stress and burn out, impacts on carers' employment, and increases in loneliness and boredom for people with dementia.

"Carer (son) is 'unable to work as Mum cannot attend day respite which is currently closed due to COVID-19 staff shortages'." Staff member

"I have found that respite care services were, and still are, very limited. My family relies on respite as my mum (82) is the primary carer for my dad. He is still active and social but can only live at home with a full-time carer to assist. Prior to the pandemic, respite care was person-centred and appropriate. This type of respite has stopped, and my family are filling this gap. The only option we have now is residential day respite, where he stays inside all day playing Uno and doing craft. We have not had an explanation as to why services have not resumed. We have followed all the advice with booster shots, wearing

⁹ 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>

masks, etc. Carers like my Mum deserve support and appropriate, person-centred respite for their loved ones.” Carer

Now that we have a clear picture of the importance of adult day programs for quality of life for people with dementia and family carers’, Dementia Australia recommends that, going forward, these community services are classified as essential services and allowed to continue in COVID-safe ways. To alleviate respite shortages, further, even fixed-term, investment into increased service provision may be required until COVID-19 infections stabilise.

Question 8: How can people with disability, including those in closed environments and segregated settings be supported to maintain social and community connections during the pandemic? What formal and informal mechanisms have been implemented to support and protect people with disability living in closed and segregated settings during the COVID-19 pandemic to help prevent violence, abuse, neglect, and exploitation of people with disability? We are interested in hearing about closed residential settings, including group homes, forensic mental health facilities, prisons and youth detention, and day programs and ADEs.

Residential aged care does not fit the definition of a closed residential setting, however, Dementia Australia believes that due to the prevalence of dementia within residential aged care (up to 70 per cent according to some estimates¹⁰), and in recognition of people with younger onset dementia still living in these facilities, the impact of Omicron on residential aged care should be included in the Commissioners’ investigation.

Dementia Australia’s National Dementia Helpline has received an increase in calls seeking support and information regarding COVID-19 and residential aged care. A portion of these callers were in extreme distress.

“A carer’s mother has just gone into residential aged care as her father was no longer able to cope. The caller stated that her dad is really struggling. There have been COVID-19 cases, so the facility is in lockdown. The father

¹⁰ Australian Institute of Health and Welfare (2012) Dementia in Australia

has been teary and sobbing and wondering if he could have done more to keep mum at home.” Staff member

“A man with a recent history of stroke called. His wife has dementia and was visiting her twice a week, via transport, prior to lockdown. He was distressed and crying and ‘would not go on’ without his wife. He has looked after wife for two years, feels very alone and isolated.” Staff member

“I will not be able to have Christmas with my hubby. His nursing home is now closed to visitors to keep them safe as cases rise, here in NSW. I have to accept that they have to keep the residents safe, but I did have a good cry. A video call will have to do.” Carer

Anecdotal reports indicate that in 2021, COVID-19 management had improved in terms of balancing risk with resident rights and wellbeing since the first and second waves of 2020. The arrival of Omicron however saw facilities revert to stringent or facility-wide infection control measures (lockdowns). The impact of lockdowns was exacerbated by chronic staff shortages.

“He was placed into solitary confinement in his nursing home on New Year’s Eve. He is wheelchair bound and cannot propel himself, get out of bed, or even turn over in bed. He was left in his room apparently for 24 hours per day. He is unable to operate the TV remote, a telephone, or a radio. I was not allowed to go into the home, at all, for three weeks. I was offered a Skype call for 10 minutes once a week. He has to be spoon-fed by another person and also helped to drink from a glass. He is doubly incontinent and cannot toilet himself, nor can he clean his own teeth or bathe. I suspect he is left alone for long periods of time. He tells me that no one comes to help, and he has no one to talk to. It breaks my heart. I have been triple vaccinated and I have offered to come in to assist with feeding each day if necessary, including to other residents. The nursing home has had two residents and two staff infected with COVID-19.” Carer

“My husband has been in aged care for the last eight years. He is totally dependent. I normally visit five or more days a week and feed him, as well as providing other care for him. His facility has been in lockdown since Xmas Day. As they get to the end of one quarantine period, another staff member

tests positive, and the cycle starts again. He, along with most other residents, have been quarantined in their rooms for this whole period. He is mostly non-verbal, so I cannot communicate with him in any way.” Carer

Carers report that residents with dementia have increased frailty, distress, depression and cognitive decline when facility lockdowns are in place. When residents are frustrated or lonely, aged care workers are likely to be stressed and unhappy.

“The staff, I believe, are doing their best, but they do not have the time to spend with him at mealtimes that I do. There are some areas of care that have not been adequately met. I have also been concerned that he may not be getting adequate fluid intake. There was also concern because I was informed at one point that the residents could not have their air conditioners on.” Carer

“A client’s mother died before Christmas. His father, who has been diagnosed with dementia, has been placed in full time care on his doctor’s orders, because he was not managing at home and not accepting his wife had died. Since then, my client has not been able to see his father due to COVID-19 visiting restrictions and can only ring him. My client said that his father has become increasingly confused and distressed. He doesn’t understand why his son doesn’t come to see him. He feels everyone has left him.” Staff member

Visitor policies are inconsistent and can depend on each facility’s appetite for risk and interpretation of public health advice. In some instances, facilities made exceptions for family carers who engaged in self-advocacy. However, no softening of the rules was made for residents without an advocate, or for family carers too afraid of reprisal to complain.

“Last year the facility was in a state-imposed lockdown (but no COVID-19 locally). I had to produce government evidence that I was still entitled to visit. They were not making that information public, to other carers. When I produced the information, they reluctantly allowed me in. I got the impression I was not to tell anyone else.” Carer

The Industry Code for Visiting in Aged Care Homes (the Code), now in its sixth edition, in line with the rapidly evolving environment, can instruct facilities on managing COVID-19 whilst protecting resident and family carer wellbeing. However, the Code is not enforceable. Most aged care providers are working in what they believe is the best interests of residents, but there are no consequences for facilities that implement lockdowns in excess of the Code. It is important, too, that health departments and state and territory Governments make public health decisions that align with the Code and reinforce to aged care providers the importance of balancing risk with wellbeing.

Question 9: How has the COVID-19 pandemic affected people with disability experiencing violence and abuse in the home? Are you aware of any extra programs and support for people with disability who may be experiencing violence and abuse in the home during the pandemic?

Dementia Australia currently has no data to draw upon in relation to this issue, but has real concerns that people with dementia have experienced increased physical abuse, financial abuse, neglect and coercive control. In the United States, 1 in 10 older adults experience elder abuse, with only 1 in 24 cases detected¹¹. As social isolation increases the risk elder abuse, it is possible that the number of people living with dementia experiencing abuse and neglect has risen. Telehealth services many mask the signs of elder abuse, making it harder to professionals to identify cases. Shielding from infection may prevent a person with dementia from seeking support. Research into whether the pandemic has increased abuse and neglect of people with dementia in Australia is vital.

Unfortunately, Dementia Australia has heard of situations where the family carer is at risk from aggression caused by a person's dementia. Behavioural changes such as aggression, delusions, and agitation arise in more than 90 per cent of patients with dementia, with are mostly due to somatic or environmental stressors¹². Frustration

¹¹ Makaroun LK, Bachrach RL, Rosland AM. Elder Abuse in the Time of COVID-19-Increased Risks for Older Adults and Their Caregivers. *Am J Geriatr Psychiatry*. 2020 Aug;28(8):876-880. doi: 10.1016/j.jagp.2020.05.017. Epub 2020 May 19. PMID: 32534873; PMCID: PMC7234937.

¹² Kratz T. The Diagnosis and Treatment of Behavioral Disorders in Dementia. *Dtsch Arztebl Int*. 2017 Jun 30;114(26):447-454. doi: 10.3238/arztebl.2017.0447. PMID: 28705297; PMCID: PMC5523798.

and fear, common feelings for many during the pandemic, could lead to an increase in aggressive behaviour.

Concerningly, pressures on emergency services during Omicron meant that family carers were left in potentially unsafe home environments. This is a critical issue to be addressed with urgency.

“Due to COVID-19, a carer is unable to find any respite or aged care with availability. They phoned My Aged Care, who advised her to call the ACAT team. ACAT were unable to assist. Her family have been in denial about father-in-law’s dementia. However, he has become aggressive and has been pushing caller’s mother-in-law, who is frail and has health conditions.” Staff member

“Husband with dementia had been hallucinating at night and did not recognize caller in the morning. Caller called 000 in fear of her safety as her husband has been hallucinating multiple times the week prior to Christmas. The call took approximately 10 minutes to connect to an operator. The police were able to respond to the caller’s welfare check after one hour. The law enforcement officer shared that the ambulance service is inundated and at times may not be able to respond to calls.” Staff member

Question 10: Were people with disability, disability representative organisations and disability advocacy organisations adequately consulted in 2021 when governments were preparing to ease restrictions? How have people been consulted during the Omicron wave and to inform emergency preparedness, planning, and response for future phases of the pandemic and the winter season? What is required for more meaningful consultation?

Dementia Australia believes that they have had adequate opportunity to engage with government on issues related to aged and disability care provision. However, dementia, one of Australia’s most prevalent hidden disabilities, impacts all aspects of people’s lives. Dementia Australia recommends that peak bodies for both physical, psychosocial, and cognitive disabilities are consulted on all areas of pandemic

planning and decision making to ensure that people with disability do not continue to be disproportionately affected.

Dementia Australia believes that meaningful consultation cannot occur with the full participation of people with dementia, living both in care and at home, and representing the diversity of dementia types, ages, and backgrounds. Family carers must be recognised as individuals with needs in their own right and consulted accordingly.

Dementia Australia welcomes the opportunity to facilitate meaningful consultation with people with dementia and family carers on behalf of the Commission and other agencies.