



# The impact of COVID-19 on people living with dementia, families and carers

A submission to the Royal Commission into Aged Care  
Quality and Safety

31 July 2020



## About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

## Statement about the Victorian ‘second wave’

The impact of a second wave of COVID-19 on Victorian residential aged care services has further highlighted weaknesses in the aged care system, not least regarding the capacity and availability of the workforce, clinical governance and the challenge of balancing individual care and wellbeing needs of residents with the safety of all living or working in the service.

In response to this situation in particular, Dementia Australia would like to suggest the following:

- That agency or casual staff may not have appropriate training in dementia care and will need additional support to understand how to care for someone living with dementia;
- That staff training in infection control and understanding dementia is prioritised on an ongoing basis;
- That any government-led surge workforce should have complete and thorough handovers with staff and/or family members who know the resident prior to going on the floor;
- That people living with dementia can become distressed or agitated if confronted by unfamiliar staff, contained in their rooms, or denied contact with family and friends;
- That residential aged care services
- always endeavour to work together with resident’s families to ensure the best outcome for each resident;
- That the additional and unique needs of people living with dementia should be factored into any pandemic response to ensure that they do not experience neglect, over-medication or deterioration;
- That many residents, their families and staff will experience grief, trauma, stress or anxiety and that their psychological wellbeing is as important as their physical health.

## Introduction

The COVID-19 pandemic has affected people living with dementia, families and carers in a broad range of ways. In order to better understand the impact of COVID-19, in June 2020, Dementia Australia surveyed our network of Dementia Advocates (that is, people living with dementia, families and carers who have opted to work with Dementia Australia to elevate the voices of those impacted) about their experiences. Combined with data obtained from the National Dementia Helpline, the responses from individuals make it clear that COVID-19 has generated both negative and positive impacts.

We have, for example, heard from former carers who have embraced the opportunity to exercise, rest and foster hobbies. Some people living with dementia have thrown themselves into social media and digital dementia advocacy, and report feeling more engaged in their communities as a result. Some family carers report positive experiences about how their loved one's residential aged care facility has managed pandemic protocols.

However, people living with dementia, families and carers have also come to Dementia Australia with stories of loneliness, frustration, stress and fatigue. Families have highlighted their concerns about the quality of their loved one's care, the pressures on staff and the inconsistency in the use of personal protective equipment.

The key issues Dementia Australia is focusing on in this submission are the following:

- That video conferencing and technology is not always an appropriate alternative to face-to-face interactions for people living with dementia;
- That people living with dementia are experiencing a decline in their cognitive, emotional and physical wellbeing as a result of the impact of COVID-19;
- That families and carers are experiencing higher than usual levels of stress and fatigue in caring for someone at home and that respite services are not meeting the increased demand;
- That long periods of isolation, especially the removal of family visits in aged care, is causing significant and irreversible cognitive decline in people living with dementia;
- That the *Industry Code for Visiting Residential Aged Care Homes during COVID-19* has had a positive impact; but
- That the impact of COVID-19 highlights existing weaknesses in the aged care sector, which requires a systemic approach to regulation and governance, quality dementia care, workforce training and education, and robust pandemic management strategies.

## Recommendations

Dementia Australia offers the following recommendations:

- That the 459,000 Australians living with dementia and the estimated 1.6 million people involved in their care are included in all future pandemic planning, communications and implementation;
- That, during this period, mitigating isolation and loneliness in people living with dementia and family carers is given critical priority by home and residential aged care providers;
- That further support and respite services be made available to family carers who have been impacted by the pandemic;
- That aged care providers be supported to implement accessible, sensory-rich alternatives to face-to-face groups, services or family visits;
- That facility 'lock downs' are for as brief as reasonably possible to contain an immediate risk, according to government and health officer advice, in order to reduce the psychological impact on residents, their families and facility staff; and
- That a national aged care pandemic response is required, to ensure that both further outbreaks are prevented (to the best of our ability) and the mental and physical wellbeing of people living with dementia is protected.

## The use of technology during the pandemic

The use of video conferencing and smartphone technology has become a defining feature of the COVID-19 pandemic: a way of connecting people without engaging face-to-face. However, some older Australians, particularly people living with dementia, have faced challenges using such technology.

Dementia Australia has heard from many people living with dementia who have embraced the technology both before and during the pandemic. For people whose condition has progressed, however, the platform can be difficult to audibly or visually navigate which, in turn, has deepened their sense of isolation.

“My real concern is that people with dementia who do not have internet or smart phones are no longer being considered as part of the population. They have rights under the United Nations’ Convention to be treated as human beings the same ways as those in a position to afford the technology currently considered as essential.”

“Hubby not being able to meet with his small group of blokes because he could not cognitively manage Zoom. People talk all at once and he could not just slip to the side or into one conversation. This made hubby anxious and agitated which created some stress for me to figure out how to manage the anxiety/agitation.”

For video conferencing technology to be successful in the home or in residential aged care, people living with dementia, families and carers need access to technical support and training where it is required. It is clear from what has been reported that families can be supported to connect with their loved one in residential aged care if they have some guidance on how to conduct a meaningful visit as well as positive encouragement and proactive aged care staff who can play a role in helping residents and families connect. People living with dementia may also benefit from training programs that are tailored to their unique needs. Dementia Australia is currently working with Dementia Advocates to develop a suite of resources to support people living with dementia to be more confident using these platforms.

“Not being able to visit my mother in the nursing home and she not understanding why. I was able to speak to her on the phone and after a month they were able to set up Skype calls though this was very challenging for her. She had never spoken to anyone on Skype and I could see she had a hard time understanding it. They would only last five minutes or so.”

“There were Skype calls set up which we had a few hiccups with as staff forgot or my mother would not cooperate. She now is more familiar with this process. It was a very hard time.”

It is also apparent that inaccurate assumptions regarding the readiness of access to smart phone technology, health literacy and accessibility can mean those communities who are most vulnerable to COVID-19 morbidity and mortality do not engage with public health messages. Partnering with peak bodies such as Dementia Australia is one way to ensure people with dementia and carers receive appropriate information and support. Still, only a fraction of the affected population is linked in with the aged care system.

“Keeping support group people up to date with changes in the aged care protocols for both home care and residential aged care facilities. Easier to achieve on the internet, but 25 percent of group do not have internet and some of those do not have smart phones. COVID-19 has shown how many people are not in the loop for support from the majority of organisations involved in aged care. I cannot visit them, as I do not have the transport and, until recently, I stayed indoors as I am in the vulnerable aged group for the virus. While I was still driving, and the virus was not around, I was able to visit people and take literature to them.”

## Loneliness and decreased wellbeing

According to a survey conducted by Dementia Australia in 2016<sup>1</sup>, people living with dementia were almost twice as likely to experience high levels of loneliness compared to the general public. Family carers were also significantly lonelier than other groups.

These experiences are equally relevant in the current environment. COVID-19 has significantly impacted the emotional wellbeing of people living with dementia, families and carers. Studies of previous infectious outbreaks show that quarantine can cause acute and post-traumatic stress disorders, as well as induce lasting anxiety, depression, exhaustion, sleep disorders, decreased motivation and detachment from others<sup>2</sup>. In Dementia Australia’s recent survey, the number of individuals who rated their psychological health as poor or very poor rose from 7 percent prior to COVID-19 to 17 percent during COVID-19.

“My wellbeing deteriorated in the long isolation alone.”

“Under psychological [health] I include some periods of loneliness due to distance from some sons and their families and lack of visitors due to the age of many local friends, making visiting difficult. The virus constraints have added to this a little.”

“Because of the support I received, my psychological health is good, without the support it would be poor.”

Whilst some individuals have found that social distancing restrictions encouraged them to adopt healthier lifestyles, according to our survey, 42 percent of people living with dementia and carers had reduced or stopped exercising; 21 percent reduced or stopped good eating practices and 17 percent increased their alcohol intake. 48 percent experienced changes to their sleep patterns.

“Overall health is poor because I haven’t been able to attend the exercise groups I normally attend.”

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<sup>1</sup> Dementia Australia, “Dementia and loneliness,” 2016. [Online]. Available: <https://www.dementia.org.au/media-releases/dementia-and-loneliness>. [Accessed 24 July 2020].

<sup>2</sup> Brooks, S., Webster, R., Smith, L., Woodland, L., Wessely, S., Greenberg, N., “The psychological impact of quarantine and how to reduce it: rapid review of the evidence,” *The Lancet*, vol.395, no.10227, pp. 912-920, 2020

The restrictions on physical contact between family members has been especially distressing. Absence of physical affection is magnifying feelings of isolation and loneliness in many people living with dementia as well as families and carers. Physical touch is a universal language that soothes, comforts and reassures. It is an essential element of compassionate care for people with advanced dementia, particularly for people who can no longer verbalise their needs. Even brief massage reduces stress and aggression in people with dementia<sup>3</sup>. It is therefore reasonable to assume that long periods without any physical affection will have a detrimental effect on people with dementia.

“No physicality, hugging, etc, is a severe issue. Mostly friends and family don’t come or contact.”

“Not getting that physical hug when I have really needed it the most.”

“Not being able to visit and hug is a really big deal. My mum is a huge hugger and she can't understand why that isn't possible. This has been a control put in place since very early in the pandemic so is not unique to the second wave but the second wave means this will be an issue for much longer than we had originally anticipated. The hugging station introduced at the home was a brilliant idea but I haven't been able to use it! When my brother visited he could see the hugging station but there was no instruction about how to use it, or if they could use it, which was quite disappointing.”

## Support for carers and access to respite services

Carers of people with dementia living at home have also been adversely affected by the pandemic. Public health messaging for carers predominately focuses on hand washing and changes to carer support payments, but there are a broad range of emotional and physical demands of a caring role. With an estimated 1.6 million Australians involved in the care of someone living with dementia, a tailored communication strategy that will reach family carers would ensure that informal carers are better equipped to respond to the changed environment.

“As a carer, I felt abandoned.”

“[The most challenging part of COVID-19 is] no assistance in caring.”

Family carers also report experiencing high anxiety about contracting COVID-19 and the possible ramifications for their loved one should they become unwell. They also worry about their loved one’s ability to stay safe when out in public. Maintaining good hygiene and social distancing whilst carrying out activities of daily living, such as grocery shopping, are significantly more challenging for family carers in the pandemic environment.

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<sup>3</sup> Suzuki, M., Tatsumi, A., Otsuka, T., Kikuchi, K., Mizuta, A., Makino, K., Saruhara, T. (2010). Physical and Psychological Effects of 6-Week Tactile Massage on Elderly Patients With Severe Dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 680–686.



"Information offered no suggestions on what to do if you were a carer and you got sick."

"Finding ways to take my spouse out of the house in a safe way. He gets agitated at times and needs to go for a drive, usually stopping for a coffee, which we could not do during the restrictions."

Disruptions to daily routines and reduced freedom of movement have also caused changed behaviour in some people living with dementia – examples shared with Dementia Australia include increased agitation, paranoia and low mood.

"Loss of support workers reduced our social connections."

"Hubby became a bit stuck on the masks issue and his paranoia increased. This affected his perception of whether or not it was safe for me to leave the home to shop, etc (even though he was fairly happy for me to take him out when needed)."

The pandemic has also exacerbated issues in accessing respite services. Day centres and social support groups have been suspended, excursions or day trips have been restricted, and support from extended family and friends is limited. Dementia Australia is aware of increasing levels of carer fatigue and stress the longer the COVID-19 pandemic lasts. Respite is reportedly unavailable to many families in need of assistance.

Without adequate respite and support, it is possible that months of pandemic-induced carer stress and 'burn out' will result in an influx of premature residential aged care admissions, elder abuse or neglect.

"It has been extremely difficult to access any form of support during the time. As we are waiting for our package to be approved by My Aged Care, we are limited to the resources we can access. There needs to be a more systematic approach to respite care, especially in the context of a global pandemic."

"[The most challenging part of COVID-19 is] not having access to respite services so I can have a break from caring for my husband."

"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)."

Family carers affected by aged care visit restrictions have felt acute loneliness, worry and helplessness. Whilst most family carers understand the rationale for strict protocols – and in many ways are reassured by them – being separated from their loved one has been deeply upsetting. Carers report feelings of grief and anxiety over the risk of neglect or harm, a loss of social connection, purpose and sense of self. For these individuals, having their loved one in isolation has been the greatest challenge posed by the pandemic.

"Sometimes it is the spouse now living alone that can suffer more isolation than the person in care. The person in care misses the group activities, but still has staff coming and going. The person at home has hardly anyone coming, perhaps Meals

on Wheels. I have watched my mum be hit harder in many ways than my dad in aged care.”

“My mother was kept safe during this time and the restrictions were very strict. I did not see her for over 9 weeks. It was emotionally very difficult for me and for her as she had no understanding of why I was not there.”

## Cognitive decline due to isolation

Loneliness and isolation can accelerate cognitive decline and increase an individuals’ risk of developing dementia in later life. Chronic stress can also impair cognitive function.

People living with dementia and family members have noticed significant cognitive and, in some cases, physical, decline since the COVID-19 outbreak. According to our survey, the rate of people who consider their cognitive health as poor or very poor has doubled during the pandemic – from 8 percent to 16 percent. There was also a downward trend across all cognitive ratings. Over 20 percent of people noticed a change to their overall cognition.

“My mother lives with me and has dementia. She was not able to attend the day centre and socialise. This affected her. I have noticed a decrease in her cognition. Working in aged care, I noticed the decrease in cognition in the residents. They have lost some skills that they had with contact with family and volunteers.”

“I am very social and enjoy the company of people. I believe that the dementia component of my disease progressed significantly.”

“It has been challenging for my elderly mother. We have been worried about her. She has deteriorated since COVID-19.”

Social support programs have been temporarily suspended, however, for people living with dementia and their family carers, these services provide vital connection, respite and stimulation. For many, replacing these services with telephone and teleconference sessions has not been appropriate. The lack of access to these kinds of services, and the lack of alternative non-contact options, has compounded their isolation.

Similarly, residential aged care facilities have taken different approaches to restricting access to external visitors, with some banning all visitors and providing inconsistent communication with residents’ families. Family carers have told Dementia Australia that this policy has been detrimental to the cognitive function of residents.

“The restricted visiting has been very difficult. The person in care has significantly deteriorated cognitively.”

“I can’t tell how her dementia is progressing as I can’t see her/spend enough time to get a sense of how loose her relational connections are becoming. I guess my main concern is that by the time we are able to visit again she may not remember us anymore and we will have lost that time forever.”

Dementia Australia is hearing that people living with dementia are experiencing an exacerbation of changed behaviour. In at least one aged care facility, residents are being sedated rather than using person-centred activities to address the disruption in routine.

“Very little consideration given to 'Isolation Effect'. Care facility was totally preoccupied with physical and compliance impacts of COVID-19 protocols. Then, when some residents became 'aggressive', they treated this in their normal context (progression of dementia) with sedative drugs and more isolation.”

“My father is a very social person, he acted out during the first few weeks, as he wasn't getting the interaction as before.”

In 2020, Dementia Australia's Centre for Dementia Learning established the Communities of Practice, a pilot program funded by the Priceline Sisterhood Foundation. The program trains and supports residential and community aged care workers to transform dementia practice in their organisation. In April, the Centre for Dementia Learning ran 30 Communities of Practice workshops on COVID-19 care. Participants were instructed to brainstorm and share ideas for meaningful activities with a low infection risk. Some of their suggestions and examples were:

- Sharing videos of fitness classes or taking virtual tours of famous sites, creating unique video content to display on the central TV channel
- Using the windows to run exercise classes or run performances
- Decorating the facility or resident's room
- Staff taking their meals with a person living with dementia
- Small group activities such as book readings, flower arranging, craft, bingo, happy hour, word games on a white board, walking tours of the facility garden
- Partnering residents with a buddy or linking with local schools and encouraging correspondence
- Using calming sensory stimulation
- Creating individual memory boxes
- Mobile coffee shop delivering coffee to the residents in place of café visits
- Matinee movie screenings for people in their rooms

“Residents who are capable - some would have been more than happy to be given a sense of purpose and hold activities with the staff for those residents that are more challenged - i.e. create a buddy system, read to visually impaired residents, play music. Just speaking to the capable residents if they wanted to partake in anything they felt they could contribute.”

## Impact of COVID-19 on the quality of daily care

It would appear that, despite the pressures created by the pandemic, a number of aged care facilities continued to provide the same level and quality of care as before. As always, there are examples of facilities doing exceptional and innovative work in providing appropriate and personalised dementia care.

“My friend commented that the quality of care did not change, but some of the residents were grumpy with staff about restrictions or extra hygiene practices.”

“Great care, only restriction was number visiting.”

“My 94-year-old mother is in aged care in NSW and she has been very well cared for. She had a heavy fall and was admitted to isolation and she has now transferred to a private rehab hospital to regain her strength and mobility. I contact her every day. COVID-19 has limited her outings and social interactions.”

When the aged care facility is clear about the reason behind the restrictions, what the protocols involve and provide regular updates on the wellbeing of the person with dementia, family carers are more likely to have confidence in the facility. This highlights the need for a standardised, best-practice approach to dementia care in all Australian aged care facilities.

“[Our facility] has been excellent in their communications throughout the pandemic, always keeping us informed about how they are managing the risks and keeping the residents safe and maintaining their quality of life despite not being able to have visitors or to get out and about. They have had very strict controls about visits to ensure they can manage the risk effectively whilst ensuring quality of care for the residents. Temperature checks, masks, etc were introduced at the very beginning of the pandemic even before any lockdowns.”

“Generally the controlled entry to the RACF has been thorough and reassuring. Questions raised have been explained and reassurance given. No COVID-19 infection in the facility at this stage.”

“All positive. All feedback positive. Any problems timely contact made.”

On the other hand, Dementia Australia has also been informed that some facilities have ceased site tours, essentially forcing families to make a ‘blind’ choice on their loved one’s new home. New residents are expected to remain in self-isolation in their room for 14 days. This situation is likely to be deeply upsetting for a person living with dementia who may already be confused and disempowered.

“This period coincided with my wife’s significant decline and admission first to hospital for a fractured hip following a fall, then into permanent care. The entire last two months have been hell. Particularly when aged care facilities were in lock down and not willing for potential clients to visit to inspect their facilities.”

Similarly, families and carers have reported a variance in the way in which services have approached staffing and the use of personal protective equipment.

“[Our facility] has decided to rotate staff - the PCAs - on a daily basis. This, of course, ensures that no one knows the residents, no one can take any real responsibility. There can be no person-centred care because staff members do not know the unique needs of individuals or which residents are at higher risk. For example, he has, three times, been given non-thickened coffee when I have been present to give him his morning tea! [The organisation] has reduced the hours of PCAs as well! The



PCAs have had 3.5 hours shaved off their time in the houses, each and every house! Can you believe that?! During a pandemic!”

These kinds of experiences speak to a systemic challenge for the sector to focus on workforce capacity, skills, education and availability.

## Restricted visits in residential aged care

The National Guidelines for the Prevention, Control and Public Health Management of COVID-19 Outbreaks in Residential Care Facilities in Australia, released by the Communicable Disease Network Australia (CDNA) advised that visitors should not be prevented from entering a facility unless they are unwell, there are active cases, or relevant government advice prohibits entry<sup>5</sup>. However, many facilities, historically risk-adverse, prohibited access to all external workers and visitors, including families.

Dementia Australia asked carers if they have experienced challenges visiting their loved one in residential care. 35 percent of respondents said they ‘often’ or ‘always’ experienced challenges and a further 21 percent said that they ‘sometimes’ experienced challenges. 17 percent said they never or rarely had challenges.

Despite advice from the CDNA that a blanket ban on family visits could have a detrimental effect on people living with dementia, some facilities ceased all visits for weeks and months. As a result, families and carers became increasingly distressed.

“Had to fight to get in and care for my parents. Contacted the Aged Care Commission on three occasions. The elderly must not be isolated even more than they are already. All care staff are doing a wonderful job, but management must understand that family must always be included - at the very least, one nominated family member.”

“I was unable to visit in person for about six weeks but was able to phone and drop off items he needed during that time. Face-to-face visits have resumed.”

Families and carers have told Dementia Australia that in some facilities the emotional and physical wellbeing of people living with dementia has been secondary to rigid adherence to self-imposed protocols. In one facility, staff refused to pass on laminated photos to a resident. Another carer could sense that her husband was nearing the end of his life but was still denied access for three weeks.

“Ability to visit my husband while he was in care and becoming increasingly unwell (he died in May) which I could sense, yet could not personally see him. So I was dependent on my persistent questioning and information provided by nursing and care staff. The facility was excellent in managing opportunities to visit except for three weeks when it could only be via phone or video. The remainder of the time it

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<sup>5</sup> Communicable Disease Network Australia, “Coronavirus Disease 2019 (COVID-19) Outbreaks in Residential Care Facilities,” Australian Government Department of Health, Canberra, 2020.



was scheduled for specific times which was okay; then moved into palliative care extended opportunities for final two weeks.”

“Due to COVID-19 my husband has lost close to 30 hours of my presence and care. Due to changes in roster my husband has lost 24.5 hours of PCA presence and support. He has lost continuity of care and close relationships. He has inherited stressed staff who do not know the residents and their needs.”

Even family carers who typically attended the service daily to supplement their loved one’s care – assisting with feeding, grooming, massage, or cleaning their room – were denied access. The removal of these supports makes people with advanced dementia who cannot communicate hunger, pain or their wishes particularly vulnerable to poorer health outcomes and, in the worst case scenarios, neglect or abuse. In one distressing example, a man lost 9 kilograms in four weeks because his daughter was not allowed to assist with meals.

“Because, all of a sudden, one day the care was gone, my father’s health declined rapidly. I communicated to the nursing home that COVID-19 will not kill my father, but the sudden change of care will. Within four weeks, my father lost 9 kg because he was not being fed like he used to. This was completely avoidable if the nursing home really, actually, understood what outside carers and families do. Finally, action was taken by being more attentive and providing frequent meals and check-ups. I was able to go in to feed him and his weight slowly increased.”

“My father is in a nursing home. It has been uncertain times for everyone. Though the nursing home said they were trying their best, they did not factor residents, like my father, who had carers and myself going in to feed him, clean his room, provide companionship.”

At the point of preparing this submission, visitor restrictions for families and carers had mostly eased (except some eastern states). Yet, there are reports that, in some instances, support workers are still unable to provide care. Similarly, families who offered to purchase additional care in residential aged care were turned down. This has concerning implications for people with dementia - particularly people with younger onset dementia, who use support workers more frequently, and people without family to attend to their additional needs. It would appear that there is a significant risk that some residents have not had contact with someone outside the facility since early March.

“I understand the strict guidelines to protect the resident but there was no outside the box thinking. I suggested if I could hire one of the staff members to help with the feeding, cleaning, companionship but, because of government regulations, this was not allowed. Humanity vs rules. In a time like this, there needs to be outside thinking - even to allow a three-week trial. I felt that extra staff needed to be provided to these nursing homes, or allow staff who are on 20-hour restricted visas to be able to work longer hours for a few months to support the resident's needs.”

Dementia Australia was one of 13 peak bodies who developed *the Industry Code for Visiting Residential Aged Care Homes during COVID-19*. Since the code’s launch in May, 50 percent of carers we surveyed had noticed changes to visiting protocols. 15 percent were not sure if the code had made an impact. 11 percent of carers noted no change. Some carers suggested the code should be mandatory.

“Before, I was only allowed one 30 minute visit a week in Mum’s room and two 15 minute visits in the front visitor lounge. As soon as the announcement was made, restrictions were lifted in regards to access provided, health rules were followed.”

“The nursing home kept families up to date all the time which was great. The nursing home is now allowing two visitors to one resident an hour a day, but there is a maximum number allowed in the home at all times.”

“Visitors are restricted. Only one family member a day. We have to wear masks, wash/sanitise our hands, avoid touching and maintain distance. No hugging or kissing.”

“The code should have been compulsory”

## Conclusion

It is clear that the COVID-19 pandemic has both highlighted existing weaknesses in the aged care system and added a level of complexity for regulators, providers, clients and residents, and families and carers in navigating and accessing aged care services.

It is also clear that a consistent focus on human rights, dignity and wellbeing of people living with dementia, families and carers needs to be embedded in any pandemic response to ensure policy and public health decisions do not contribute to greater morbidity, mortality or mental ill health.