

# One day the support was gone

The mental health impact of COVID-19  
on people living with dementia, their  
families and carers.

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THE UNIVERSITY OF  
**SYDNEY**



# Acknowledgement

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# About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

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 across Australia.

We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

## Executive Summary

The COVID-19 pandemic has affected people living with dementia, families and carers in a multitude of ways. Like all of us, the routines of day-to-day life have been significantly interrupted. A less obvious but no less significant impact has been the adverse effect that physical distancing, restrictions and lock-down measures implemented in response to the COVID-19 pandemic have had on the physical, social and mental wellbeing of people living with dementia, as well as those caring for them.

People impacted by dementia already experience lower levels of social engagement, inclusion and connectedness within their communities. This, coupled with the restrictions enforced through the COVID-19 pandemic, has meant that people living with dementia, their families and carers, are even more vulnerable to adverse mental health outcomes.

A nationally consistent response to COVID-19 (and any future pandemics) by the Australian Government, which includes a plan to support aged care providers to deliver quality care and minimise the mental health impact of pandemic responses, must continue to be made a priority. It is imperative that aged care, health, allied health and disability systems communicate effectively and work collaboratively to support the mental health and wellbeing of people living with dementia, their families and carers.

# Recommendations

Dementia Australia supports the additional funding and particular focus the Australian Government has given to mental health, aged care and COVID-19 health initiatives. This investment is pivotal to meeting the unique mental health needs of people living with dementia, their families and carers through the COVID-19 pandemic.

It is now critical that investment is directed more specifically to ensure that it has the most impact for people living with dementia, their families and carers.

Dementia Australia recommends that:

1. the development of future programs and supports acknowledge the unique needs of people with dementia through the development of key performance indicators or Aged Care Quality Standards based in a human rights framework;
2. critical priority is given to mitigating isolation and loneliness in people living with dementia and family carers by home and residential aged care providers and that the Australian government facilitates this through ongoing mental health and aged care support services;
3. people living with dementia have access to their designated carers by ensuring essential visits are safely integrated back into residential aged care settings following any lockdown period;
4. aged care providers be supported with resources and training to implement accessible, sensory-rich alternatives to face-to-face groups, services or family visits that promote inclusion, meaningful participation and social connectedness;
5. infection control measures and training are extended to carers so that essential visits may be maintained should crisis or emergency measures need to be reinstated;

6. to reduce the psychological impact on residents, their families and facility staff, independent checks are undertaken on residential aged care facility 'lockdowns' to ensure they are for as brief as reasonably possible to contain an immediate risk, according to government and health officer advice and maintain delivery of quality care;
7. a national aged care pandemic response be created to ensure that both further outbreaks are prevented and the mental, emotional, psychological and physical wellbeing of people living with dementia is protected;
8. a representative at each aged care site has access to appropriate support, resources and training to improve understanding and respect for the role of family carers as essential care partners for people living with dementia;
9. further targeted support and respite services be made available to family carers who have been impacted by the pandemic;
10. risk profiling for people living with dementia, their families and carers receiving aged care services be undertaken to identify particularly vulnerable groups requiring additional support;
11. Australians living with dementia, their families and carers are included and their unique care needs are catered for in all future pandemic response planning, communications and implementation through specific quality and management systems;
12. the additional Australian government mental health funding supports people living with dementia, their families, and carers through outreach programs, counselling services and training relevant workforce in recognition of the significant impact experienced;

13. aged care providers are supported with information and appropriate workforce training about the free COVID-19 support line for Senior Australians and are equipped with the skills to identify people living with dementia, their families and carers who are in need and/or could benefit from the service; and
14. adequate numbers of staff, with the right skills mix, are available to allow continued visits to people living with dementia in residential aged care by their families and friends.<sup>1</sup>

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<sup>1</sup> Commonwealth of Australia (2020) Royal Commission into Aged Care Quality and Safety, Aged care and COVID-19: A special report available at <https://agedcare.royalcommission.gov.au/sites/default/files/2020-10/aged-care-and-covid-19-a-special-report.pdf>

# Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 472,000 Australians living with dementia in 2021<sup>2</sup> and around 1.6 million people<sup>3</sup> involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.<sup>4</sup>

People living with dementia, their families and carers already felt isolated and lonely before the COVID-19 pandemic. In 2019, the Dementia and Discrimination survey of over 5,700 people, found that 63 per cent of people living with dementia believed that discrimination is common while 74 per cent said people have not kept in touch like they did prior to their dementia diagnosis. Additionally, 80 per cent had not been invited to social functions.

These results clearly demonstrate that people impacted by dementia already experience lower levels of social engagement, inclusion and connectedness within their communities. These sorts of experiences, coupled with the restrictions enforced through the COVID-19 pandemic, has meant that people living with dementia, their families and carers are even more vulnerable to adverse mental health outcomes.

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2 Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

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

4 Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra



# COVID-19 and Dementia

The COVID-19 pandemic has affected people living with dementia, families and carers in a number of ways.

One impact has been an increased risk of contracting a severe case of COVID-19 and the mortality associated with it.<sup>5</sup> As of 30 October 2020, in Australia, 685 of the total 907 deaths, or 75.5 per cent, were from residential aged care facilities.<sup>6</sup> While pre-existing chronic conditions were reported for 73 per cent (496) of all COVID-19 deaths, dementia was also noted on 41 per cent of death certificates.<sup>7</sup>

## Recommendation 1

The development of future programs and supports acknowledge the unique needs of people with dementia through the development of key performance indicators or Aged Care Quality Standards based in a human rights framework.

A less obvious but no less significant impact has been the adverse effect that physical distancing, restrictions and lock-down measures implemented in response to the COVID-19 pandemic has had on the physical and mental wellbeing of people living with dementia, as well as those caring for them.<sup>8</sup> In June 2020, Dementia Australia surveyed our network of Dementia Advocates (that is, people living with dementia, families and carers who work with Dementia Australia to elevate the voices of those impacted by dementia) about their experiences in order to better understand the impact of COVID-19.

5 Verity, R et al. (2020) Estimates of the severity of coronavirus disease 2019: a model-based analysis. *Lancet Infectious Disease*, 20(6):669-677

6 Australian Government Department of Health (2020) COVID-19 outbreaks in Australian residential aged care facilities, available at <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers#cases-in-aged-care-services>

7 ABS (2020) New Insights into COVID deaths in Australia, Provisional mortality statistics Jan-Jul 2020, media release 28 October 2020

8 Mok, V et al. (2020) Tackling challenges in care of Alzheimer's Disease and other dementias amid the Covid-19 pandemic, now and in the future, *The Journal of the Alzheimer's Association*.

Combined with analysis of qualitative and quantitative primary research conducted by the research team at the University of Sydney between July and October 2020, and data obtained from the National Dementia Helpline, it is clear that COVID-19 has had fundamental and lasting mental health impacts for people living with dementia, their families and carers.

People living with dementia, families and carers have come to Dementia Australia with stories of loneliness, frustration, stress and fatigue. Families have highlighted their concerns about the quality of care of their loved ones, the stress of not being able to see their family members living in residential aged care or in their own homes (where geography separates them), and the limited availability of services.<sup>9</sup> Life is already challenging for many people living with dementia, their families and carers. The global pandemic and associated restrictions, including social distancing and isolation measures, has compounded the stress and anxiety experienced by many.

In this discussion paper, Dementia Australia shares stories from those impacted by COVID-19 and dementia so that we may learn from their experiences and adapt or inform policies and programs to better support people living with dementia, their families and carers.

We also make some specific recommendations to address the mental health impacts that the COVID-19 pandemic has had (and continues to have) on people living with dementia, their families and carers.



**75.5%** of Australian COVID-19 deaths were from **residential aged care facilities**.

<sup>9</sup> Dementia Australia (2020) 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.

# Challenges of COVID-19 for people with dementia, their families and carers

The COVID-19 pandemic has seen Australia enter varying degrees of lock-down, with federal, state and territory governments enforcing restrictions to stop the spread of the virus and protect the health of Australians. However, as people have gone into isolation, they have largely been cut off from the often already tenuous or limited social interactions, support services and meaningful connections that promote mental health and wellbeing. This has had demonstrable flow-on effects on the mental health of many Australians, with people living with dementia, their families and carers especially vulnerable.

## **Recommendation 2**

Critical priority is given to mitigating isolation and loneliness in people living with dementia and family carers by home and residential aged care providers and that the Australian government facilitates this through ongoing mental health and aged care support services.

In a survey conducted by Dementia Australia in June 2020 with 86 people with a lived experience of dementia on the impact of COVID-19, people living with dementia, carers and families who rated their psychological health as poor or very poor rose from 7 per cent prior to the pandemic to 17 per cent.

The biggest challenge people reported was the loss of social interaction, face-to-face contact and physical contact.

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**“ Not getting that physical hug when I have really needed it the most. ”** – Person living with dementia

**“ Not having anyone to have a long conversation with. ”**  
– Person living with dementia

**“ Lack of social interaction, hugging the family especially hard as one became ill during lock-down. ”** – Carer

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Social isolation and loneliness are closely related concepts and have been found to predict premature mortality, depression, cardiovascular disease and cognitive decline.<sup>10</sup>

People living with dementia, their families and carers have also told us that:

- banning or limiting essential visits in residential aged care has caused or is causing carers and families significant distress, especially for older or vulnerable carers for whom these visits are their primary source of social connection;
- some residential aged care facilities have not been able to offer person-centred, appropriate alternatives to essential visits (video conferencing is not always suitable for people with moderate to advanced dementia);
- some carers and families have experienced considerable resistance from aged care staff or difficulties in arranging essential visits; and
- limiting essential visits has resulted in poor physical and psychological outcomes for residents with dementia, including weight loss, agitation and accelerated cognitive decline.

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<sup>10</sup> 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

### **Recommendation 3**

People living with dementia have access to their designated carers by ensuring essential visits are safely integrated back into residential aged care settings following any lock-down period.

### **Recommendation 4**

Aged care providers be supported with resources and training to implement accessible, sensory-rich alternatives to face-to-face groups, services or family visits that promote inclusion, meaningful participation and social connectedness.

The negative impact of changes wrought by COVID-19 is further evidenced in the recent and ongoing national research conducted by the University of Sydney research team, which aimed to investigate the impact of the COVID-19 pandemic on the life and wellbeing of people living with dementia and care partners, as well as their access to support and services.

The researchers found that a substantial proportion of survey respondents in residential aged care experienced a much less frequent visit by their families and friends than before the pandemic.

Allowing access to carers and families is about more than a social visit. Many carers - spouses, partners, children, grandchildren and friends - provide essential care to people with dementia. This includes, but is not limited to, helping with meals and dressing, providing communication and emotional support, and enhancing wellbeing. Carer visits are an integral aide to services delivered by many residential aged care teams. This is especially true in the current climate, when aged care workers typically report experiencing an unprecedented increase in their daily duties, inadequate levels of qualified staff with the right skills-mix and reduced availability of staff on the floor.<sup>11</sup>

<sup>11</sup> Australian Nursing and Midwifery Federation (2020) Aged care staff recommendations don't go far enough, media release 2 October 2020, available at [http://anmf.org.au/media-releases/entry/media\\_201002](http://anmf.org.au/media-releases/entry/media_201002)

### **Recommendation 5**

Infection control measures and training are extended to carers so that essential visits may be maintained should crisis or emergency measures need to be reinstated.

In the University of Sydney research team's qualitative study the issue overwhelmingly highlighted across all forms of care for both people with dementia and those involved in their care was the impact of diminished social connection. Furthermore, of those people living with dementia, families or carers in the community, the vast majority referenced having difficulty in accessing emotional or psychological support.

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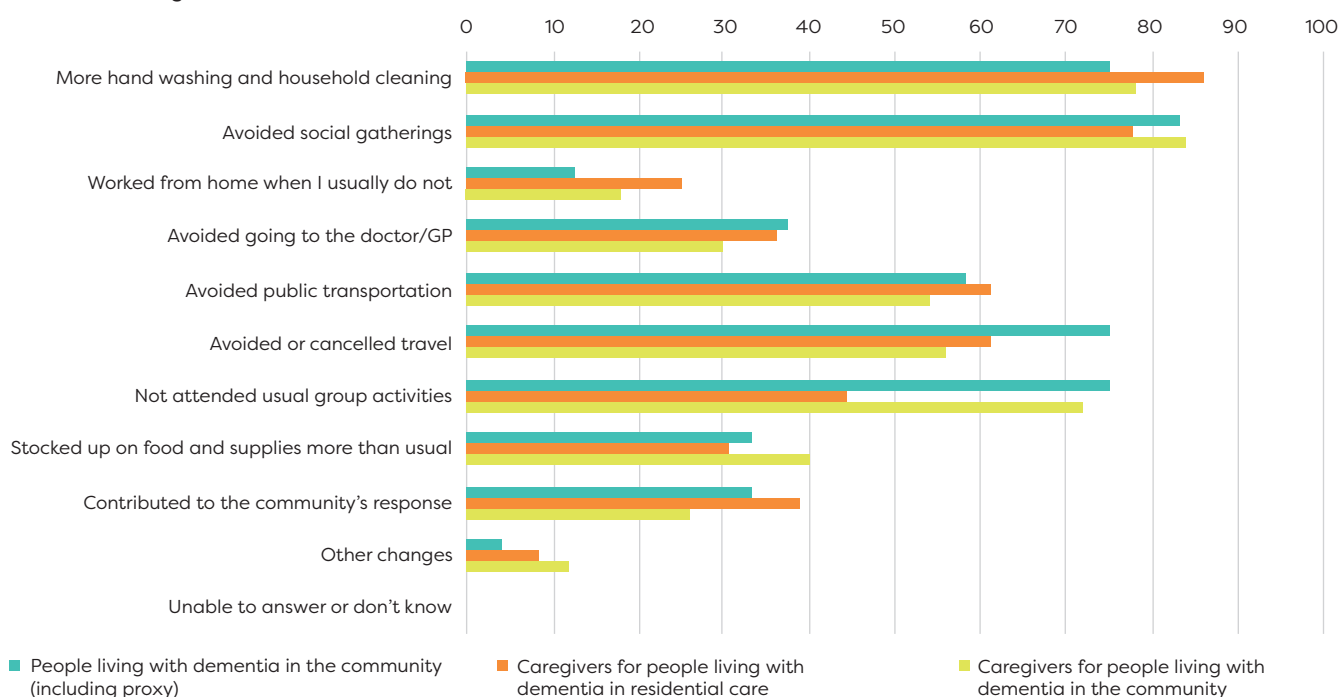
**“ The most challenging might be that she didn't get a visitor as regularly because it was impossible. ” – Carer**

**“ So, a lot of homecare people are being so well looked after by the family, and then there's a small proportion that doesn't, that people don't see the downside of stuff. I mean, there was a stage during the restrictions I felt really depressed, but then I have to look after him. He's in a worse situation. If I don't feel like cooking, he has nothing to eat. You get what I'm saying. I can't do that to him. ” – Carer**

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Not surprisingly, the COVID-19 impact survey also indicated that most people living with dementia in the community said they avoided or cancelled travel, usual group activities, or public transportation. 60 per cent of care partners of people living with dementia in residential care also avoided public transport or travel. More than 70 per cent of care partners of people living with dementia in the community did not attend usual group activities due to COVID-19.

#### Behavioural changes due to COVID-19



**Figure 1:** Proportion of survey respondents by behavioural changes due to COVID-19. Source: Jeon et al. (2020) Impact of the COVID-19 outbreak on the life and wellbeing of people living with dementia and care partners and their access to support and services in Australia: a national survey.

Given the known mental health benefits of social interaction, connectedness and meaningful participation, these findings raise the concern that the wellbeing of people living with dementia, their families and carers has been – and continues to be – adversely impacted by COVID-19.<sup>12</sup> It is important for governments and decision makers to weigh up the benefits of mandatory quarantine against the psychological costs to people's wellbeing.<sup>13</sup>

Where quarantine is seen as essential, it should last for no longer than required, give clear reasoning for quarantine and accurate information about protocols.<sup>14</sup> As much as possible, the negative effects associated with quarantine need to be minimised, particularly to those most vulnerable, including people living with dementia, their families and carers.

### **Recommendation 6**

To reduce the psychological impact on residents, their families and facility staff, independent checks are undertaken on residential aged care facility 'lock-downs' to ensure they are for as brief as reasonably possible to contain an immediate risk, according to government and health officer advice and maintain delivery of quality care.

### **Recommendation 7**

A national aged care pandemic response be created to ensure that both further outbreaks are prevented and the mental, emotional, psychological and physical wellbeing of people living with dementia is protected.

<sup>12</sup> Brookes, S.K et al (2020) The psychological impact of quarantine and how to reduce it: rapid review of the evidence, *The Lancet*, S0140-6736(20)30460-8

<sup>13</sup> Rubin, G J. and Wessley, S. (2020) The psychological effects of quarantining a city, *British Medical Journal*, 368:313

<sup>14</sup> Brookes, S.K et al (2020) The psychological impact of quarantine and how to reduce it: rapid review of the evidence, *The Lancet*, S0140-6736(20)30460-8



# Mental health impact of COVID-19 on people living with dementia

People living with dementia report experiencing a decline in their cognitive, emotional and physical wellbeing as a result of the impact of COVID-19. This, coupled with long periods of isolation, especially the removal of family visits in aged care, is likely to be causing significant and irreversible cognitive decline in people living with dementia.<sup>15</sup>

People living with dementia, their families and carers are having to respond to rapidly changing information and guidance while at the same time being isolated from their regular support systems and networks. There is a sense of overwhelming anxiety and confusion, not to mention a greater risk of behavioural changes and declining cognition as result of isolation.<sup>16</sup>


People living with dementia in residential care are disproportionately impacted and disrupted by COVID-19, with their dementia intensifying the impact. Access to health and care professionals has been limited, face-to-face support has been withdrawn, and the limited access to visitors is resulting in greater than average levels of loneliness and anxiety.



**Over 20% of people noticed a change to their overall cognition.**

<sup>15</sup> Dementia Australia (2020) 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, July 2020.

<sup>16</sup> Alzheimer's Disease International (2020) A position paper on COVID-19 and dementia, available at <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>



Some people living with dementia and family members have shared with Dementia Australia that they have noticed significant cognitive and, in some cases, physical, decline since the COVID-19 outbreak. According to The Dementia Australia's survey in June 2020, the rate of people who consider their cognitive health as poor or very poor has doubled during the pandemic – from 8 per cent to 16 per cent. There was also a downward trend across all cognitive ratings. Over 20 per cent of people noticed a change to their overall cognition.

#### **Recommendation 8**

A representative at each aged care site has access to appropriate support, resources and training to improve understanding and respect for the role of family carers as essential care partners for people living with dementia.

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**“ 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. ” – Carer**

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

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

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For many survey participants, cognitive deterioration has been matched by a corresponding increase in feelings of fearfulness, anxiety and loneliness.<sup>17</sup>

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<sup>17</sup> Alzheimer's Disease International (2020) A position paper on COVID-19 and dementia, available at <https://www.alz.co.uk/news/adi-releases-position-paper-on-covid-19-and-dementia>

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**“ My wellbeing deteriorated in the long isolation alone. ”**

– Person living with dementia

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

– Carer

**“ And quite a few of them – because I’ve got to know the other residents – quite a few of them became non-verbal in that time. ”**

– Carer

**“ Well cognitively he’s going downhill quite a lot. It’s very difficult to have conversations with him...And because I’m the only person he talks to, all he gets is what I think and what I say. ”**

– Carer

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Additionally, according to the COVID-19 Impact survey data, of the 17 respondents living with dementia in residential aged care 10 of the people felt much less socially connected since the pandemic, and 25 per cent of people living with dementia in the community felt much less socially connected. Almost 20 per cent of people living with dementia in residential aged care felt less socially connected and almost 40 per cent of people living with dementia in the community felt less socially connected. This, coupled with their findings from the EQ-5D (the most widely used multi-attribute utility instrument for measuring health-related quality of life) demonstrates the detrimental impact COVID-19 is having on people living with dementia. The EQ-5D found that, 75 per cent of people living with dementia in residential aged care experienced either slight or moderate problems with their mood; and 79 per cent of people living with dementia in the community experienced either slight or moderate problems with their mood, due to COVID-19. Notably, people living with dementia in residential care had far significantly

lower quality of life compared to those in the community or compared to care partners. The research team's qualitative study also highlighted the negative impact on their social wellbeing.

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**“ We used to socialise more. We used to go out more. ”**

– Person living with dementia

**“ I mean we sat and watched the news, but she had no recognition of it, had no idea what COVID-19 is. And for her response, a natural response with people, because she doesn't know who she knows, is she greets them like an old friend and gives them a kiss. And people were reacting, “Don't kiss me, don't kiss me.” And she was getting concerned about that. She was very off-put by that sort of reaction. And if you said, “Well, it's because of COVID-19,” she'd go, “oh,” but had no recognition of it. So that, for her, that was the major problem. She just did not understand why people were repelled by her friendliness. ”**

– Carer


**“ I asked him about two weeks ago, what his favourite activity was? And he told me sleeping. So all he wants to do is go to bed. ”**

– Carer

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**25%** of people living with dementia in the community felt much **less socially connected.**



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

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**“ 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). ”** – Carer

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## Mental health impact of COVID-19 on families and carers

It isn't just people living with dementia who are experiencing poorer mental health outcomes from COVID-19 and the associated restrictions. Families and carers are also reporting higher than usual levels of stress and fatigue in caring for someone at home and respite services are not meeting the increased demand.

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 that need to be acknowledged and addressed.

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**“ As a carer, I felt abandoned. ”** – Carer

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

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

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**“ Information offered no suggestions on what to do if you were a carer and you got sick. ” – Carer**

**“ 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. ” – Carer**

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The pandemic has also highlighted exacerbated issues in accessing respite services. Day centres and social support groups have been closed due to bans on public gatherings, excursions or day trips have been restricted, and support from extended family and friends has been more 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 burnout may result in an influx of premature residential aged care admissions, elder abuse or neglect.



### **Recommendation 9**

Further targeted support and respite services be made available to family carers who have been impacted by the pandemic.

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**“ 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. ”**  
– Carer

**“ [The most challenging part of COVID-19] Not having access to respite services so I can have a break from caring for my husband. ”** – Carer

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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.

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**“ 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. ” – Carer**

**“ 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. ” – Carer**

**“ Elderly parents feeling isolated (one in care and spouse at home alone) would really love a hug. Person home alone is really missing contact. Friendships they had, gradually lessened as they put their heart and soul into looking after the person with dementia. ” – Carer**

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Many of the social supports for carers of people living with dementia have also either decreased or disappeared entirely. Dementia Australia has heard from carers of people living with dementia that the combination of social isolation, increased caring responsibilities left by gaps in available supports, and an inability to have a break is leading to increased levels of stress and burnout.

Carers may miss respite services, home visits from relatives and friends, and other social activities. Many carers have felt isolated, with no close family members nearby, local shops being closed, or being unable to travel or scared of going out. The extended periods of confinement at home with a person living with dementia has, for many, resulted in increased levels of stress, and feelings of helplessness and depression. All of this, coupled with deterioration of psychological wellbeing in both people living with dementia and carers, can activate a vicious cycle that leads to worsening overall health and quality of life for all involved.<sup>18</sup>

#### **Recommendation 10**


Risk profiling for people living with dementia, their families and carers receiving aged care services be undertaken to identify particularly vulnerable groups requiring additional support.

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**“ I think that the carer needs that support from services to actually continue on the daily grind of being a carer and the fact that it’s all on your shoulders. That’s where I think it’s really difficult when you’re in isolation or when you’re in lock-down and you can’t get out, you know, that to me would just be awful and it must be making a difference to not only the mental health of the carer and the person with dementia. ” – Carer**

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<sup>18</sup> Mok, V et al (2020), Tackling challenges in care of Alzheimer’s Disease and other dementias amid the Covid-19 pandemic, now and in the future, The Journal of the Alzheimer’s Association.



Of 127 respondents to the COVID-19 impact survey, 67 per cent had been more worried or concerned about things since the COVID-19 pandemic. Compared to people living with dementia in residential care and people living with dementia in the community, care partners of people living with dementia in residential care were more worried than normal. More than a half of care partners of people living with dementia in the community also indicated that they had been more worried than normal.

This sense of worry then affects carers' quality of life, with results from the EQ-5D demonstrating that 55 per cent of care partners of a person living with dementia in residential care experienced slight or moderate problems with mood; and 65 per cent of care partners of a person living with dementia in the community experienced slight or moderate problems with mood due to COVID-19.

# A proactive response to COVID-19 for people impacted by dementia

While the COVID-19 pandemic has had an adverse effect on many people's mental health, there have also been opportunities and examples of people living with dementia, their families and carers experiencing positive outcomes.

In the in-depth interviews, some people reported that the 'slowing down' that COVID-19 created was actually a welcome relief that enabled them to rest and be more engaged in activities they enjoy or had not previously had the time and energy to be involved in.

People also told us that the uptake of technology, in some cases, increased communication and removed other barriers (such as public transport) in being able to connect and stay connected with others. However, it was obvious that video conferencing and technology is not always an appropriate alternative to face-to-face interactions for people living with dementia.

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**“ I think I managed well and was not negatively impacted. I missed seeing my grandchildren, but actually had more regular contact than normal whilst they were home from school - be it online. Staying home didn't bother me and I have been less exhausted than when I am having to travel around on public transport. ”** – Person with dementia

**“ 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 5 minutes or so. ”**  
– A former carer

People have also reported positive experiences in their communities. There were examples of kindness and understanding when out in the community. People also spoke about the appreciation for staff, such as aged care staff and supermarket staff, in the way they are doing their best in an unprecedented situation, which created a sense of comfort among people living with dementia and their carers/care partners.

Effective interventions for promoting mental health and wellbeing include those that facilitate engagement in meaningful activities, connection with others and psychological interventions to address loneliness. A positive of the COVID-19 restrictions has been the diverse and creative ways that people have sought to maintain social connection. This mobilisation of grassroots action has demonstrated community capacity that could address the enduring loneliness and social isolation experienced by many people including those living with dementia, their families and carers.<sup>19</sup>

People living with dementia, families and carers also shared what would have helped support them through the COVID-19 restrictions, what they felt was effective and what to focus on moving forward to improve their mental health and wellbeing.

### **Recommendation 11**

Australians living with dementia, their families and carers are included and their unique care needs are catered for in all future pandemic response planning, communications and implementation through specific quality and management systems.

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

Not surprisingly, through COVID-19 restrictions, people living with dementia, their families and carers wanted more social support. Some people found innovative ways to look after their wellbeing and connect with others during COVID-19. However, the lack of face-to-face social interaction, changes in services and reliance on technology remained a challenge.

There is an opportunity for the Australian Government, through the recently funded COVID-19 support line and varying outreach programs to help improve and maintain a sense of social connectedness moving forward. Through timely crisis support, access to respite, and social support, people impacted by dementia can experience improved mental health outcomes.

#### **Recommendation 12**

Aged care providers are supported with information and appropriate workforce training about the free COVID-19 support line for Senior Australians and are equipped with the skills to identify people living with dementia, their families and carers who are in need and/or could benefit from the service.

The COVID-19 impact survey showed that 67 per cent of people living with dementia in the community, 42 per cent of care partners of people living with dementia in residential care and 48 per cent of care partners of people living with dementia in the community wished to have a greater access to family, friends and/or neighbours. Additionally 20 per cent of carers of people living with dementia in the community stated they would have liked emotional and psychological support.

The Australian Government can build on the success of informal social engagement measures by investing in services that are proactive about connecting and engaging people with dementia, families and carers. The investment to support outbound calls from the National Dementia Helpline, as an extension to the Older Persons COVID-19 Support Line is a commendable start - to reach out to an estimated 10,000 people with regular, ongoing telephone and online support.

### **Recommendation 13**

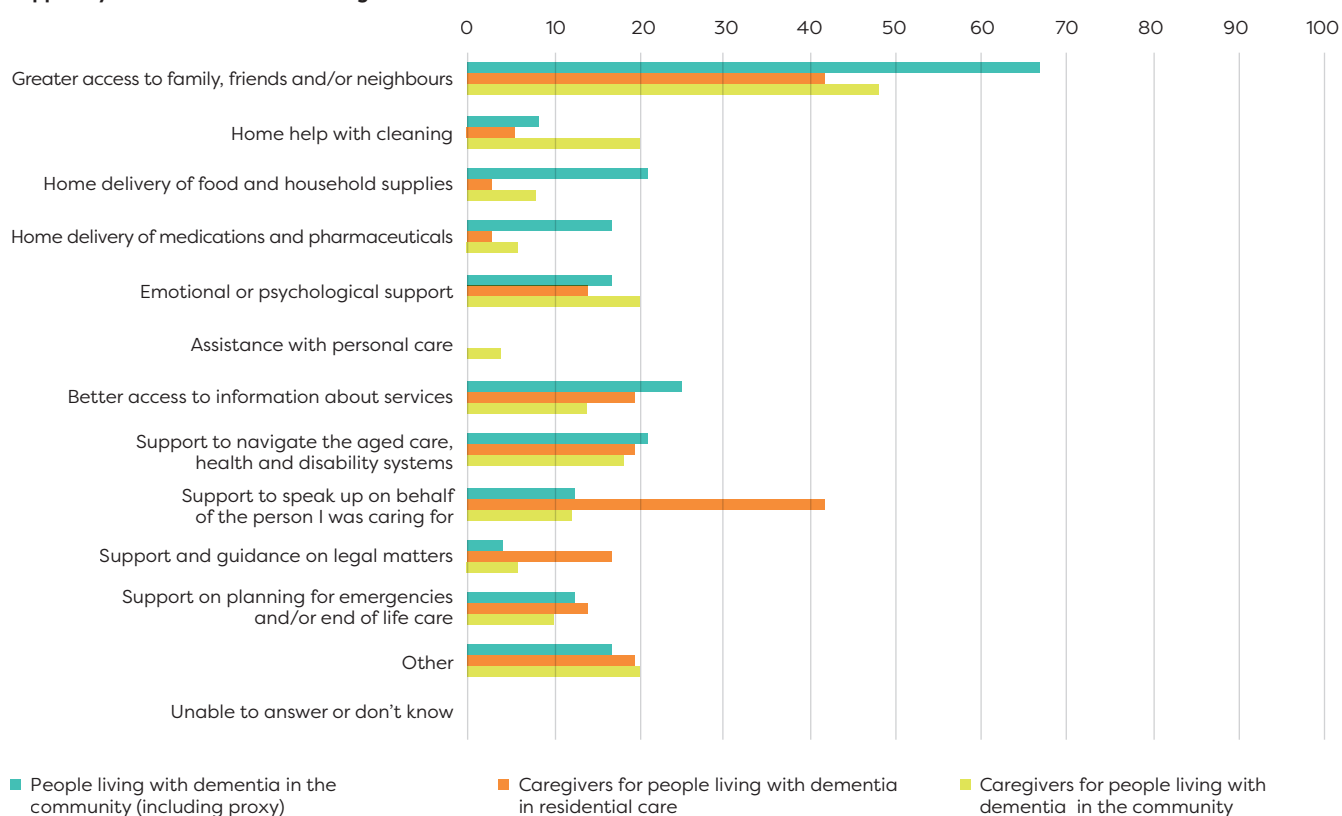
The additional Australian government mental health funding supports people living with dementia, their families, and carers through outreach programs, counselling services and training relevant workforce in recognition of the significant impact experienced.



**20%** of carers of people living with dementia in the community stated they would have liked **emotional and psychological support.**



### Supports you would like to have during the COVID-19 outbreak



**Figure 2.** Proportion of survey respondents by supports they would like to have during the COVID-19 pandemic. Source: Jeon et al. (2020) Impact of the COVID-19 outbreak on the life and wellbeing of people living with dementia and care partners and their access to support and services in Australia: a national survey.

These findings give justification to the timely investment in outreach programs and support through collaboration with governments, aged care providers, aged care peak bodies and relevant community organisations like Dementia Australia and Carers Australia to meet the mental health needs of people living with dementia, their families and carers.

Additionally, the Industry Code for Visiting Residential Aged Care Homes during COVID-19 has overall had a positive impact in ensuring people living with dementia, their families and carers remain connected, but the uptake of the code has been variable. As such, there is an opportunity for regulation of this code to be strengthened. This requires a systemic approach underpinned by regulation and governance. A system-wide shift in leadership, culture and workforce, broader than pandemic planning is needed to improve quality dementia care, workforce training and education, and ensure robust pandemic management strategies in the future.

#### **Recommendation 14**

Adequate staff with the right skills mix are available to allow continued visits to people living with dementia in residential aged care by their families and friends.<sup>20</sup>

<sup>20</sup> Commonwealth of Australia (2020) Royal Commission into Aged Care Quality and Safety, Aged care and COVID-19: A special report available at <https://agedcare.royalcommission.gov.au/sites/default/files/2020-10/aged-care-and-covid-19-a-special-report.pdf>

Ensuring there are adequate staff with the right skills mix in aged care to allow continued visits to people living in residential aged care by their families and friends is central to improving mental health outcomes and minimising risk of loneliness and isolation. This approach aligns with recommendation two from the Royal Commission Aged Care Quality and Safety special report into aged care and COVID-19.<sup>21</sup> Equally, through establishing dementia support pathways the mental health and wellbeing needs of people living with dementia, their families and carers can be further improved. This can be achieved through providing information and advice on dementia, support systems and the aged care system as well as facilitating peer support networks and providing appropriate education and counselling.<sup>22</sup>

## Conclusion

The impact of the COVID-19 pandemic has shown that psychological wellbeing is as important as physical health, particularly for people living with dementia, their families and carers.

Appropriate support, services and skilled professionals are needed to meet the mental, physical and emotional health needs of people living with dementia, their families and carers post COVID-19 and into the future to mitigate the negative impacts many have experienced.

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<sup>21</sup> As above

<sup>22</sup> Counsel Assisting's Proposed Recommendations at Final Hearing (2020) available at [https://agedcare.royalcommission.gov.au/sites/default/files/2020-10/RCD.9999.0540.0001\\_1.pdf](https://agedcare.royalcommission.gov.au/sites/default/files/2020-10/RCD.9999.0540.0001_1.pdf)

# National Dementia Helpline

## **1800 100 500**



For language assistance  
call **131 450**

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**dementia.org.au**

