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Royal Commission into Aged Care Quality and Safety
GPO Box 1151
Adelaide SA 5001

Submission by Human Rights Watch to the Royal Commission into Aged Care Quality and Safety on the Impact of the Coronavirus (Covid-19) on the Aged Care Sector

Summary

This submission by Human Rights Watch to the Royal Commission into Aged Care Quality and Safety (the “Royal Commission”) focuses on the impact of Covid-19 on people living with dementia in aged care facilities in Australia. Of particular concern is the practice of “voluntary lockdowns” by some aged care providers, which banned visitors outright in March, April, and May 2020.

Human Rights Watch interviewed families of residents from eight facilities in New South Wales and Victoria in May and June. These family members described arbitrary limitations on their loved ones' access to services and visits, and the harm that those limitations caused to their health, including weight loss and accelerated cognitive impairment. More than half of the people living in aged care facilities in Australia have dementia.¹ Our submission shares our findings and makes recommendations for the government to improve its protection of the right to health of older people with dementia living in aged care facilities.

Background

Available evidence has shown that older people are more likely to experience serious and life-threatening complications from Covid-19 infection. Older people also face a heightened risk of infection if they live in institutions like aged care facilities.

In response to the pandemic, Australia’s Prime Minister Scott Morrison announced on March 17, 2020 a limit on the number of visits to residents in aged care facility to one per day, with a

maximum of two visitors per visit. He also announced restrictions on the locations of visits within facilities. Many aged care facilities went beyond this guidance, banning visitors altogether. These restrictions were given the euphemistic term “voluntary lockdowns,” with exceptions only for palliative care visits. The prime minister’s announcement, along with various other controls, was in line with Australian Department of Health’s public health guidance on Covid-19 in aged care facilities.

On April 21, Prime Minister Morrison issued a statement calling on facilities to revise their visitor bans to allow visitors, subject to infection control measures. He highlighted that facilities’ isolation of older people harms them and their health, saying “it is not acceptable, fair or compassionate for any residential aged care facilities to ban visits from carers and families.”

On May 12, the aged care industry, together with advocacy groups, created their own code with more exclusions than the government’s public health guidance, which allowed one visit per day to each resident for social supports, professional services or advocates. It suggested that residents could have visitors where there was “a clearly established and regular pattern of involvement from visitors contributing to their care and support.” On June 19, the Australian Health Protection Principal Committee (AHPCC), the key decision-making committee for health emergencies in Australia, released a statement on minimizing the impact of Covid-19 in aged care facilities. The industry code adopted the AHPCC’s recommendations for unlimited visiting for spouses and close relatives, with infection precautions in place.

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Impact of Covid-19 visitor bans on people with dementia

Visitor bans by aged care providers cut off older people from vitally important family and social connections and supports. Older people who find themselves unexpectedly alone without control over their circumstances are at particular risk for a variety of severe, even life-threatening, physical and mental health conditions, including cognitive decline.8

Family members provide important care to their loved ones in sometimes understaffed facilities, supporting them to eat, exercise and other daily activities. A 2016 study of family caregiving in aged care facilities concluded that “The inclusion of families in residential care facilities is essential to create optimum care for residents... inclusionary systems surrounding care, food and mealtimes are one valuable means.”9 Another study found that “for more minor lapses in care [such as untrimmed fingernails], family members revealed that they were the ones bridging the gaps.”10 These are important supports for the physical health of people with dementia, as well as their social and emotional wellbeing.

Visitor bans also increase the risk of poor treatment in aged care facilities, such as overmedication. In October 2019, Human Rights Watch published “‘Fading Away’: How Aged Care Facilities in Australia Chemically Restrain Older People with Dementia,” which found that instead of providing support to older people with dementia, facilities use drugs to control their behavior.11

Relatives described the steep decline of people with dementia in aged care facilities during these visitor bans. “Patricia,” whose 90-year-old father is in a facility in Victoria, told Human Rights Watch:

Prior to the lockdown he was walking and going to play pool. He can't get to the bathroom on his own now... the whole behavior of my father before the lockdown, and after are totally different. I understand he has dementia; I understand that we would expect him to deteriorate, but without the family contact... he has deteriorated at a far more rapid pace.12

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Many of the interviewees described sadness over “lost time” because the lockdown limited their ability to see family members living in the facilities. “Felicity” from New South Wales described her 64-year-old husband’s life in an aged care facility under the lockdown:

    All I can think about is this man... he went from being out five mornings a week... to nothing... we have missed out on three months of his life. It’s just cruel. It’s cruel for us and it’s cruel for[him].\(^{13}\)

Some families reported avoidable weight losses. Patricia described how the facility called to say her father was not eating meals and was losing weight. But once she was allowed to visit him again, she discovered staff had left unopened food and drinks in his room rather than facilitating his eating.\(^ {14}\) A family at another facility in Victoria had to apply for permission from the facility to stay beyond half an hour to support a relative with dementia to eat, even though the relative lost three kilograms in just three weeks.\(^ {15}\)

However, some families and residents did feel restrictions were correctly balanced. The husband of an 80-year-old woman with dementia told us: “Fairly early on I think they did a survey and something like 80 percent of their residents generally said they were happy for it to be as it was [with no visitors].”\(^ {16}\) Another said, “I really supported their decision to not let people in, which was easy for me because... I could talk to dad as often as I wanted [on Zoom] and see how he was going on.”\(^ {17}\)

**Inadequacy of alternative contact during lockdowns**

Some facilities that invoked lockdowns attempted to facilitate video and telephone calls, as well as through-the-glass or through-the-gates visits. In interviews with Human Rights Watch, families described the challenges people with dementia have had in connecting to their loved ones through these alternative forms of contact. In some cases, these difficulties stemmed from their cognitive impairment; in others, it was because of a lack of support from facility staff. “Every facility just seemed to make up their own policy,” one family member told Human Rights Watch.\(^ {18}\) Some facilities did not offer the option of digital visits.

\(^{13}\) Human Rights Watch telephone interview with Felicity, June 24, 2020.


\(^{15}\) Human Rights Watch video conference interview with Maree, June 3, 2020.


Not all people with dementia can engage with video or phone calls. A son described his failed attempts to FaceTime his mother, who is 83 and has dementia in Victoria: “For my mother to acknowledge someone, you have to be there. You have to be very close to her face and then she will acknowledge you.” 19 A wife described her 80-year-old husband’s experiences with dementia: “They need touch, facial connection and smiles... and worst of all [he] can’t understand why loved ones are not there.” 20

Other families described technical challenges as well as the ineffectiveness of calls for people with advanced dementia. One said:

[The facility was] organizing visual access through Skype and we got one, unfortunately they hadn’t put his hearing aids in so he couldn’t hear, and it wasn’t very successful. ... Then we had another one the following week... He had problems communicating, he again wasn’t wearing hearing aids, he wasn’t interested in relating to us. 21

Families discussed the challenges of window visits because of the distress they caused those with dementia. Said one: “It took a long time to organize window visits. He got quite distressed, I got quite distressed, so we decided as a family that we were probably best to limit those. He could see us, and he kept trying to open doors.” 22

Family members also described window and gate visits as haphazard, rather than an organized and fairway to for people with dementia to have visitors. “The rooms that had verandas, they were allowing people to sort of go up to the veranda and talk through windows and things, but [my husband] was on a courtyard room,” said one family member in New South Wales. 23 Another described booking a through-the-gate visit that was canceled because of inclement weather, with no opportunity to make up the date.

Many facilities increased in-person visits by June, but some families told us that they were unable to obtain visiting reservations for weeks. “Gillian” said: “So we got the online booking and I went to book and almost everything was booked out already.” 24 For the next booking opportunity, she said every single spot was booked out for weeks.

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Concerns over Staffing Levels

Many aged care facilities have staffing levels well below what experts consider the minimum needed to provide appropriate care.25 Yet, during the pandemic, some facilities not only banned visitors, but also private care staff employed by residents. Before the pandemic, Australian Nursing and Midwifery Federation’s National Aged Care Survey 2019 found that nearly 90 percent of aged care staff reported current staffing levels at their facility were not able to provide an adequate standard of nursing and personal care to residents.26

The pandemic has only increased the demands on staff time, families said. One reported that, “The nurses are having to... [staff] the door, check [visitors’] temperatures and ask them the relevant questions... When the private carers go in sometimes they have to wait [to be checked] 15-20 minutes because the nurse is taking care of somebody.”27

Even some private care staff hired by residents have been excluded from entering facilities, further limiting people with dementia’s access to services and supports. Felicity told us about her husband’s loss of daily social care support: “I asked [the facility] today, ‘When will his paid carers be able to start coming back again?’ ... the nurse care manager ... she was like ‘We have no idea; they keep us out of the loop.’”28

Recommendations to the Royal Commission for the Government of Australia

Human Rights Watch recommends the Royal Commission urge the following actions for the Government of Australia:

Accountability on Permitting Visitors:

The Department of Health should recognize the risk of social isolation by monitoring visitor bans and require aged care facilities to eliminate them. Going forward, the Department of Health should ensure residents have access to physical visits. Any restrictions on visits should balance the protection of older and at-risk residents and facility staff, with residents’ needs for family and connection, and the important health benefits their visits provide. The burden should not be on

residents and family members to challenge aged care facilities' exclusion of visitors. The Department should publish a list of facilities restricting visitors that is updated on a rolling basis.

Adequate Minimum Staffing in Aged Care Facilities:

- Require a 24/7 registered nurse presence in all aged care facilities and establish stronger minimum staffing levels and ratios or other enforceable minimum requirements to ensure continuous, person-centered support for older people in aged care, and to observe Covid-19 safety measures.
- Consider automatic penalties for facilities that do not meet minimum quantitative and qualitative staffing requirements.