

# Isolation in a time of COVID

Isolation during the COVID-19 pandemic has been a difficult reality over the past two years – something that **Pauline Marsh** and her family learned only too well after her father, who is living with dementia, was isolated from them for a month, first in his care home and then in hospital. In writing about their experience, Pauline highlights the unintended costs of this isolation and suggests interventions to mitigate distress for people with dementia and their families during lockdowns in hospitals and aged care homes

**W**hen first diagnosed with vascular dementia 12 months ago, my Dad, aged 83, was noticing some mild confusion and memory loss. COVID-related travel restrictions meant that it was some 12 months later when I discovered his symptoms had progressed at an alarming rate. At a family gathering that summer he couldn't bring to mind where his children and grandchildren lived or worked, and the value of money eluded him. Also, past and present time seemed to have collapsed and he believed almost everyone he came across was – without doubt – a former employee.

Fairly swiftly, things worsened. Frequent bouts of anxiety and paranoia accompanied extreme mood swings, taking him and those around him on rollercoaster rides of highs and lows. And as is often the case for carers in this situation, Mum bore the brunt of these and similarly tricky behaviours.

## Residential care

Eventually, an emergency hospital admission for congestive cardiac failure triggered Dad's move to a residential aged care home in December 2021. To our surprise, this turned out to be the perfect move, at the perfect time. Dad immediately responded to the love and care he felt from the staff. With his walker, which he had refused to use at home, he moved in and out of the common areas making conversation with staff and residents. He joined in the dining room meals, and in activities that he had never



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tried before. Mum settled into a pattern of visiting – and we all started to breathe more easily.

Six weeks later, a staff member tested positive for COVID-19, and the care home was closed to visitors. Residents were contained to their rooms: no shared meals together, no walking, no activities.

When Mum returned to see him after the 10-day lockdown, she was shocked at his deterioration. He was unable to walk without support, and at a loss as to how to feed himself. One of his legs was swollen and inflamed, and so an ambulance was called.

## COVID positive

After a week of hospital treatment, Dad was ready to return to the care home – but when a routine Rapid Antigen Test (RAT) showed positive Dad was transferred to the COVID ward instead. Again, no visitors allowed. Mum went home to deal with her own bout of COVID. This kickstarted what was to become an extremely stressful three weeks for all of us.

Isolation during COVID has been a difficult reality for many over the past two years, but there were certain things that made it particularly challenging for Dad, living with dementia, but also for Mum and our family.

## Personal experience

In my role as an academic, I study various aspects of how we might improve the quality of life for people living with dementia. In this article, however, I'm deliberately writing from personal experience, as a daughter. I hope that by describing the challenges we faced as a family I might be able to convey something of the unintended costs of isolating people who are living with dementia – including the emotional burden. I think that personal stories can help inform the changes that need to occur in hospitals and in care facilities as the pandemic continues.

## Industry Code for visiting care homes during COVID-19

The revised Industry Code For Visiting In Aged Care During COVID-19, including an Essential Visitor policy code, was released by Council on the Ageing (COTA) Australia on 22 December 2021.

It outlines three categories of visitor status, each with its own infection prevention and control measures, ranging from green (no COVID threat) to Red (when there is an outbreak). The Essential Visitor policy requires that residents are always permitted to have at least one visitor, regardless of the COVID outbreak status (with appropriate infection control measures in place).

The Code has been developed and endorsed by 13 consumer and carers peak organisations including Carers Australia, COTA, Dementia Australia and Aged and Community Services Australia. It's freely available to download at: [www.cota.org.au/policy/aged-care-reform/agedcarevisitors/](http://www.cota.org.au/policy/aged-care-reform/agedcarevisitors/)

During the three weeks that Dad was isolated in hospital, we faced three main challenges: poor communication, a lack of support and a sense of powerlessness. Each of these created an enormous and unnecessary burden, and I conclude this article with some suggestions for how they might be mitigated.

### Poor communication

The first barrier we faced was poor communication. Finding out how Dad was going was the emotional equivalent to climbing Mt Everest every day. More often than not, when I called the hospital, the operator put me through to the COVID ward where I would encounter a recorded message which told me to call back in half an hour. Click. No option to leave a message, or even to return to the switchboard. Weekends were particularly bad. On one Saturday I started calling regularly at 3.30pm and finally spoke to a nurse at 6.30pm.

Undeniably, nursing staff were stretched. They would often apologise for not knowing much about Dad and explain that the nurse looking after him was busy. Sometimes they would read to us from notes, and not always current ones – some were from several weeks earlier. I tried not to think about the possibility that they hadn't spent the few minutes of time with him it took to realise he had dementia.

As time passed, trying to find out when Dad might be discharged became a next-level challenge. Why was he still on the COVID ward 10, 14, 18 days after the positive test? We were initially told the care home would only take Dad back once he showed a negative PCR test. Later, we were told not a PCR, a RAT. Regardless, either test can show positive for a long time following the infective period, sometimes up to months. A stand-off developed. The care facility needed a negative RAT, but the hospital would not test daily, nor even every two or three days. They claimed it was an excessive use of resources. The irony, of course, was the cost of Dad's now lengthy hospitalisation far exceeded that of a few packets of RATs. It was evident that poor communication extended not only to us, but between the hospital and care facility staff also.

Eventually, I learnt to ask for the Team Leader, someone I was able to quiz about discharge with more success. They genuinely shared my frustrations, but also seemed to listen to my growing concerns ("is he crying all the time?" I remember asking). Once someone serendipitously put me through to the medical registrar, something I had not thought would be possible. With refreshing honesty, he explained that Dad was caught up in COVID discharge politics, and they had asked management to intervene, but

for now there was nothing they could do.

### Lack of support

The second challenge was a lack of support for the person with dementia. It was unfathomable to me how an 84-year-old man with significant dementia could be kept on a ward for three weeks without some form of dementia support. There was no one to advocate on his behalf – and he was well past the stage of self-advocacy.

There was also a lack of support for us outside of the system – no dedicated support for carers of people living with dementia. We wondered what it must be like for people living with dementia who do not have a loving family (and assertive children) to advocate for them in this situation.

### Powerlessness

The final and greatest challenge in this experience was an all-pervading sense of powerlessness.

For Dad, vascular dementia had triggered behaviour changes that were not all bad. Luckily for me, he had become a most delightful father. He was very interested in me and my siblings – in our work, our partners, homes, children and pets – far more so than he had ever appeared to be before his diagnosis.

As he lost track of us, we had made him a family photo display which he regularly poured over, quizzing Mum for more information as he

stared at each picture. This attentive, loving father made me want to do everything I could to make his life with dementia a calm and happy one. Had it been possible, I would have gone to the hospital and personally inserted a swab up his nose twice a day to get the result we needed to get him back to his home. But it was not possible. It was not possible to do anything, it seemed, but wait, trust and sit with our powerlessness.

### Concluding thoughts

Eventually, the RAT was negative and Dad returned to his home at the care facility. He was sleepy, but otherwise, in Mum's words, "content". He did not remember the trip home in the ambulance, and we will never know what went on for him during those three weeks.

I completely understand and respect public health, and the COVID restrictions that reflect the science that informs them. But, like COVID-19, isolation for people living with dementia is also life-threatening and we must find a way to balance our responses.

The Australian Government's Department of Health guidelines for aged care providers during the COVID-19 pandemic highlight the impacts on older people from social isolation, which include physical impacts such as reduced balance, strength, bone and muscle mass, as well as reduced independent function and participation in meaningful activities. They note the negative psychosocial effects also, including fear, anxiety, loneliness, boredom, depression, and cognitive decline. Isolation has also caused health problems from reduced appetite, lack of assistance with eating, weight loss, malnutrition, dehydration, reduced immunity, reduced energy and motivation, slow wound healing, and cognitive decline (Australian Government Department of Health 2022,

## Resources and further reading

### For acute care

**Impact of the COVID-19 Pandemic On Hospital Care For People With Dementia: Feedback From Carers/Families and Hospital Leads For Dementia:** This interim report from the UK's National Audit of Dementia program shares survey findings highlighting the negative impact of the pandemic on the quality of inpatient care for people with dementia, along with encouraging examples of emerging good practice. The surveys were conducted in 2020 in hospitals in England and Wales: <https://bit.ly/COVID-improving-care>

**COVID-19 and Dementia: Difficult Decisions About Hospital Admission and Triage:** Alzheimer's Disease International (ADI) has produced this 'thought paper' to help families consider key issues when planning care for a loved one with dementia during the COVID-19 pandemic. Among the key points are that people with dementia have an increased risk of developing delirium during a hospital stay and that a lack of visitation during COVID-19 lockdowns can make it harder for the hospital team to provide a patient-centred care plan. It suggests families seek medical advice on whether the benefit of a person with dementia and COVID-19 being admitted to hospital is "worth the distress of being separated from family and isolated" and equally, if the person was to be cared for at home, how this would impact carers. The paper is available at: <https://bit.ly/ADI-COVID-and-dementia>

**Considerations For Looking After A Patient With Dementia In An Acute Care Setting:** This two-page help sheet from Dementia Support Australia is designed to assist hospital staff create an early connection with the person with dementia to reduce stress and anxiety for both staff and the patient and the need for more distressing and labour-intensive interventions. The guide also suggests ways that patients who may be isolated due to COVID can still be connected with family members and feel reassured. Available at: <https://bit.ly/DA-acute-care-support>

**Top 5 model:** Top 5 is a simple and effective tool for health professionals to use with carers to gain valuable non-clinical information to help personalise care for people with dementia or cognitive impairment. The information is documented on a Top 5 form and made available to every member of the care team. Top 5 toolkit resources for hospitals, aged care homes and community services are freely available to download from the NSW Government's Clinical Excellence Commission website: <https://bit.ly/Top5-toolkit>

### For residential aged care

**Ensuring Safe Visitor Access To Residential Aged Care:** This two-page fact sheet, produced by the Aged Care Quality and Safety Commission (March 2022) explains how providers can balance their responsibility to reduce the risk of COVID-19 with their obligation to prepare for and support essential visitor access during a COVID-19 outbreak (within the terms of any public health order). Available at: <https://bit.ly/agedcarequality-visitor-access>

**LTC Responses to COVID-19:** This website is a hub for resources from around the world to support community and institutional long-term care (LTC) residential aged care responses to COVID-19. It's managed and funded by the International Long-Term Care Policy Network and Care Policy and Evaluation Centre at the London School of Economics and Political Sciences: <https://ltccovid.org/>

p1). All of these mirror exactly the impacts of Dad's isolation.

The guidelines also point out the flow-on impacts on immediate families and loved ones, who experience "frustration and powerlessness resulting from their separation and inability to provide usual care and social contact" (Australian Government Department of Health 2022, p1).

It is impossible to know whether Dad's initial deterioration that led to a

hospital stay would have occurred without the lockdown conditions. Vascular dementia can have a severe downward trajectory, and congestive cardiac failure likewise. I am acutely aware of the scrutiny that aged care and hospital staff are under at the moment – and this article does not intend to add fuel to that discourse.

### Suggested interventions

There are three crucial interventions that I believe

could mitigate the distress for people living with dementia and their families during isolation and lockdowns in hospitals and aged care facilities:

- Implementation of the Industry Code for Visiting in Aged Care during COVID-19, including an Essential Visitor policy, throughout care facilities and hospitals (see box p11 for details).
- Ensure exercise, socialisation, fresh air and visits from at least one loved

one continues during lockdowns and periods of isolation, to prevent a range of negative mental, physical, emotional and cognitive consequences.

- Provide additional staff in aged care homes and on hospital COVID wards to facilitate specialist care and communication with and for the person living with dementia during isolation. This is work that is additional to what can be expected of nurses and other care workers: for example, facilitating daily calls with a nominated family member or friend, creating memory aids and taking time to personalise care and share conversations.

### Postscript

At the time of writing, the aged care home where Dad lives is back in lockdown. After two falls that required another trip to hospital, Dad has returned to the care home and its management has agreed to allow Mum 'essential visitor' status – a much-welcome step for us all. ■



■ Dr Pauline Marsh is a lecturer in rural health at the University of Tasmania. Much of her research work in health-enabling environments concerns the intersections between age, dementia, mental ill health, disability, death and grief with the natural environment around us



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