



# COVID-19 case study

## #04 End of life



### **A resident's adult children want to visit for two hours every day in the final stage of her life but the aged care service only allows 45 minutes**

Jana moved into residential aged care after a serious stroke. In the three years since then, her health had deteriorated and she was worryingly frail. She had two daughters and a son all living in the same city as the aged care service.

Jana's son, Peter, complained to the Aged Care Quality and Safety Commission (the Commission) that the service was unreasonably limiting his and his sisters' visits

to 45 minutes each per day. He said his mother was dying and had a palliative nurse advising on her care. Given this, he and his sisters wanted to be able to visit her every day for two hours each – a total of six hours.

During the COVID-19 pandemic, visitor access when a resident is near the end of life has been a major concern for residents, family members and service providers. At the time of Peter's complaint, the public health directions were allowing one household (people living in the same house) to visit an aged care resident at the end of life for two hours a day.

The relevant public health direction defines 'end of life' as a situation where the resident's doctors expect death within 14 days or from a sudden acute crisis. The definition doesn't include someone with a progressive or incurable condition or general frailty and co-existing conditions expected to lead to death within 12 months.

After talking to Peter, the Commission complaints officer called the aged care service. The manager there explained that the service was just emerging from a COVID-19 outbreak and starting a period of close surveillance. It was taking direct instructions from the public health authorities, including on the length of visits it could allow.

The service manager said the service was following medical advice to care for Jana using a palliative approach but she had not reached

the end of life stage. The visiting palliative care team had confirmed this. Peter had been there at the time. The team had explained the difference between a palliative approach and end of life care and had told Peter that in their assessment his mother was many weeks away from end of life care. Jana's doctor had also advised Peter that his mother was comfortable and in a stable condition.

The manager confirmed that Peter and his sisters were limited to a visit of 45 minutes each per day. This was in line with the current aged care guidelines allowing daily visits from relatives for residents who needed emotional support. The manager mentioned that Peter's visits were difficult for the service staff because he wasn't complying with their infection control measures and his distress about his mother's frailty made him angry and abusive. However, the service was willing to extend his and his sisters' visits to one hour a day, which would mean three hours in total.

The complaints officer then talked to Peter again and told him the service would allow daily visits of one hour each but, because of the risk of a second COVID-19 outbreak, couldn't offer more than that. The officer emphasised how important it was for all visitors to follow the service's strict infection control precautions. At the end of the conversation Peter was still upset and dissatisfied and asked the Commission to review his complaint.

While the review was underway, Jana's condition suddenly got much worse. Her GP suspected that she'd suffered another stroke. Peter and his sisters had the option to move their mother to hospital but decided she should stay at the service and receive end of life care.

Acting on advice from her doctor and the palliative care team that Jana was now in the end of life stage, the service removed all visiting restrictions for her family. Her son and daughters could now visit for as long as they wanted to – on the condition that they fully complied with all the requirements for infection control.

Jana passed away peacefully some days later with all three children at her side.

This was a complex complaint to resolve in part because terms such as "end of life" can be understood differently by a clinician and a family member without a clinical background. In Jana's case, her family's uncertainty about the meaning of this term, when combined with their emotional distress at their mother's decline, and the essential COVID-19 restrictions, made finding a mutually acceptable resolution very challenging. Given the service's very recent experience of a COVID-19 outbreak, they were required by public health directives to take a cautious approach in relation to visitor access. Most importantly, the family were able to be together at the end.