

Appendix 2: A personal story of living well in an aged care home

In 2010, my parents, Joan and Roy Russell, moved into an aged care home together. They chose the aged care home primarily because they could sleep together in the same bed. After Dad's death in January 2012, I visited Mum most days until her death in September 2015.

Mum was happy living in the aged care home. Many staff treated her with kindness, respect and love. She had her favourites – Charlotte, Alex, Argus, Vicky, Kunal and Jenny...

Mum made lifelong friends with several residents – though many of her new friends did not live for long. Her good friend, Trudi, died in 2014. Soon after, so too did Sam, Greg, Heather, Val and Alma.

I visited Mum around lunchtime. I sat at Mum's dining table with Trudi, Lorraine, Marion and Etta. Mum did not have a large appetite – but she was always given a full portion at lunchtime so that I could eat her leftovers. The food was excellent. The kitchen staff were all very kind to Mum, especially Tony.

I wanted Mum's quality of life in the aged care home to be as good as it could be. Mum had already lost her husband and most of her independence, and I wanted her to feel valued in her 'twilight years'. Mum established 'her seat' in the communal lounge room from where she observed everything with a registered nurse's eye. She gently rebuked staff who did not treat her respectfully: *"Please don't talk to me as if I am a child"* or *"My name is Joan, not sweetie"*.

Every Tuesday afternoon, Mum, Etta, Marion and I played bridge. Etta was once a State Champion. Although her hearing and eyesight were impaired, Etta could remember every card that had been played. She was a formidable opponent. Unfortunately, Etta hung up her cards after having a fall. Mum and I then started playing bridge on an iPad, though more commonly we did The Age crossword with Lorraine and Kay.

Lorraine and Kay had done The Age crossword for more than 60 years. These women had an excellent knowledge of synonyms. They also easily adapted to the increasing inclusion of short phrases in the crossword. There was laughter when we finally came up with "trip of a lifetime" for the clue "most remembered tour". However, the obscure general knowledge questions often left them bewildered. Rather than complain, these older women would ask me to pull out the gadget in my pocket and "google" the answers.

Mum looked forward to her monthly trips to her beach house, away from the routines of the aged care home. She came alive sitting on the deck, or in front of the fire, surrounded by people and dogs, chatting and reminiscing. At her beach house, she peeled the potatoes, top and tailed the beans – activities considered 'too risky' at the aged care home.

In 2012, a relative approached my brother and me to express her concerns that standards of care had declined since Pam had retired as the manager. Jane was forming a relatives' group. My brother did not want to get involved, but I did. The grievances mostly related to management, staff morale and standards of care (Russell, 2012). To the owner's credit, he responded quickly. The manager was replaced and staff morale and standards of care were restored. This incident demonstrated the vital role a manager plays in any aged care home.

After a year or so of visiting the aged care home, I was concerned that the media only reported negative stories about aged care homes. Surely Mum was not living in the *only* good aged care home in Australia. My plan was to write a positive story about an aged care home. However, things changed dramatically during the last month of Mum's life.

When Mum was dying, I sat at her bedside in the aged care home to protect her from inflexible routines and policies. I ensured she slept as long as she needed, and ate when (and if) she wanted. I had once worked as a critical care nurse – so I knew how to care for a dying woman.

Only a few PCAs had the skills required to care for Mum when she was dying. Michelle and Cheryl provided excellent care. However, some PCAs provided thoughtless task-oriented care. On one occasion, a PCA tried to change Mum's night incontinence pad when Mum was asleep. I asked her to let Mum sleep. She replied: *"It is policy. She must have a day incontinence pad because it is day time."* I questioned this so-called policy, and the PCA replied: *"I just work here. I do what I am told."*

Soon after this incident, I received an email from the Manager. She demanded that I leave Mum's bedside. *"I need you to let my staff do their jobs... Interfering with Mum's care is not helping her."* I replied:

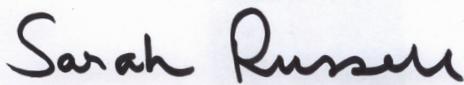
I hope you will re-consider your comments in your email and perhaps educate your less experienced staff

about working in partnership with family members. Some relatives want to be involved in 'hands-on' care, others don't. I believe this should be our decision, not yours.

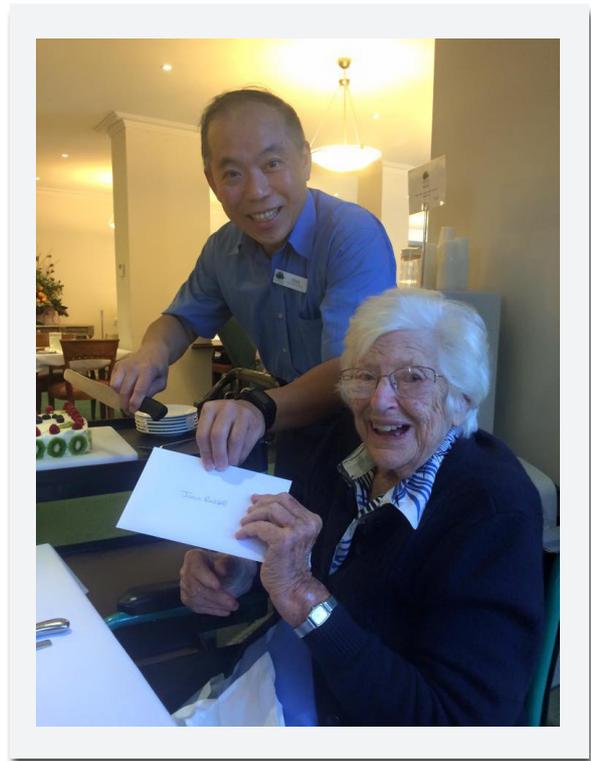
I did not have confidence that staff could do their jobs and refused to budge from Mum's bedside. Mum died peacefully, with a smile on her face. On the morning of her death, she said to me: "Darling, you really do need a hair cut".

The day after Mum's death, the aged care home's GP phoned me to confirm the time of death. Staff had told him she had died at 6.30pm. I told him it was in fact 5.35pm. He also asked me what he should write on her death certificate. After visiting Mum monthly for several years, I expected him to at least know her medical history. I suggested he wrote: "broken heart", but that is another story.

I doubt I would have become an aged care advocate if the manager had not emailed me a week or so before Mum died. As an aged care advocate, I have heard countless heart-breaking stories about aged care homes from both relatives and residents. I remind myself that these stories are only part of the story.



Dr Sarah Rusell



Joan Russell celebrated her 91st birthday with family and staff at Victoria By The Park



Sarah and Joan Russell