

THE SENATE
COMMUNITY AFFAIRS LEGISLATION COMMITTEE
Aged Care Bill 2024

Lived experience

My submission addresses the process our family experienced in navigating the recent entry of my mother to an aged care facility.

My husband and I are retired maths teachers and consider ourselves to be reasonably intelligent, articulate and fairly computer literate but navigating the aged care system can only be described as being fraught, stressful and at times a nightmare.

Mum is in her late 80's and was living at home largely independently with a little support from family and friends for housework, gardening etc. A widow since 2012 she is a part pensioner/superannuant, owned her own home, did not have a computer, was not registered on MyGov and conducted all her financial affairs in person.

She first registered in the My Aged Care system in July of last year when she needed a referral code to obtain some social support in the form of bus trip outings, trips she was enjoying immensely.

Mum became unwell with severe arthritic pain on Anzac Day this year and so began the cycles of 6 hospital admissions in both the public and private systems before she entered full time care. She attended the local hospital Emergency Department that day and after some tests was sent home with some medication. Three days later I rang the ambulance as she was in intense pain and mobility was severely compromised and she was transported back to hospital. She was admitted to the Emergency Short Stay Unit (EMU) and transferred to a private hospital. Over the ensuing weeks she was only out of hospital for around 6 days until she went into fulltime care.

Whilst in hospital in May it became evident to Mum and to us that for her to remain in her home, she would need more support. I contacted My Aged Care and requested another assessment be made. I received a date but had to cancel as Mum was still in hospital. I requested another date but was told that would not occur until she was back at home. A classic case of the chicken and the egg. She could not come home until she could access more care but to be assessed for care she had to be at home. Thankfully common sense prevailed, and an assessment was done over the phone. Mum was approved for personal care three days a week, meals on wheels and a couple of hours a week for social support.

At this stage she was not assessed to receive any federal government package. I locked in a schedule for support to begin with providers, but Mum remained in hospital, and I was told by one provider that as she was still in hospital the supports

would be cancelled and we would have to commence the approval process all over again once she was home. We did not realise that this in fact was not the policy.

However, Mum soon realised that she was not well or confident enough to go home again and felt she needed to go into full time care. As each day passed, we could see her losing weight, muscle tone and was basically withering away before our very eyes and she just wanted to die.

This was following a particularly unsatisfactory stint in the public hospital which saw her being discharged while still in intense pain and unable to eat anything other than clear fluids without vomiting. There was no indication of her being discharged the night before and she rang me to come and collect her with no communication at all from the hospital. I had previously asked for a discharge plan, but none had been put in place. There was no referral to a dietician etc. When we arrived to pick her up Mum was crying in the discharge room. We asked about a transfer to the private hospital but that was highly discouraged. We brought her home, but it was no surprise that we only to take her back in the local emergency department less than 6 hours later. In hindsight I should have asked to talk to hospital administration staff about her welfare.

After another two hospitalizations including one where we had to barricade ourselves in her room due to a code black, she decided mid-June that she was not well enough to be home by herself again and needed to go into full time care. She spent the next 7 weeks in a private hospital before going into care. As each day went by, we could see her losing muscle mass, losing weight rapidly and was basically withering before our very eyes and she just wanted to die, she would tell us that every day.

Hospital Aged Liaison Teams

We are all aware that there are significant issues with patients in hospital needing to stay admitted until a place becomes available at a residential care facility. During this time as was evidenced in my mother's case, the patients become weaker and sicker. Hospital is the not the place for them to be. One of our hospitals has a Hospital Aged Liaison Team. HALT is a team of nursing, medical and allied health professionals who are dedicated to reducing admissions or the length of hospital stay for older persons (65 + years old). They help patients to safely return to their own home or to access residential aged care. HALT staff have comprehensive knowledge of community packages, services, and programs. So why aren't these teams in all our hospitals?

I don't think it is unreasonable to say that with our ageing population it is critical that we implement HALT teams in all our major hospitals as a matter of urgency. Surely any program put in place to alleviate patients languishing our hospitals and not have them pass away before they enter aged care can only improve our aged care system.

Timeliness of ACAT Assessments

I contacted My Aged Care and requested an ACAT assessment to be conducted in the hospital but was told it would be at least 10-12 weeks down the track. I knew Mum would not be with us by then. The doctor and hospital staff said they would care for her as long as needed but they also knew being in hospital was not helping her. They also tried to contact the ACAT team but to no avail.

We were powerless to help and sought assistance and advice from an elected member of parliament who set about making enquiries on our behalf. Thankfully the ACAT assessment was completed in hospital at the end of June and Mum was approved for full time care. We thought that finally we were on the home straight but that was not the case.

Services Australia Interface

We immediately made an appointment with Services Australia to seek advice regarding her financial status etc and for me to become her nominee. We assumed that by changing details in Centrelink that My Aged Care, Medicare etc would automatically flow through as they are all under the one umbrella but that was not the case, and each had to be done separately.

Although we have completed all of Mum's financial details online, changed her personal details at the Services Australia office back in July, uploaded documents etc through MyGov, we waited yet again for another 35 minutes at the end of the phone last Wednesday as details still hadn't registered in the system.

Navigating the My Aged Care is clumsy as you are directed to one place and then once there you are redirected to another or worse still, have to try and find where to update details etc yourself.

Providing documents from sale of residence

It would be very helpful if all lawyers, conveyancers etc knew exactly the information and documents required by My Gov, Services Australia etc so that when a home is sold and RAD is to be paid the process can be completed efficiently and in an expeditious manner.

Power of Attorney

Thankfully we had made and registered the Power of Attorney for Mum in 2019 but had not invoked it as she was still conducting her own affairs. The system is inconsistent to say the least with each agency, financial, utility institution etc having their own sets of rules and procedures and no two are alike.

We question why there isn't a consistent set of rules or better still a central registry for registered powers of attorney that all institutions etc can access. One less stress for people navigating the system and having to supply multiple copies of individually notarized pages.

Interactions with Residential Aged Care Facilities

Most importantly while we were wrangling Mum's financial and personal affairs, we were trying to secure a placement for her in an aged care facility. That experience was akin to dealing with a secret society or swimming in barrel of treacle and I feared she would die before we found her a place.

Some of my experiences included

- The inability to directly contact a particular facility if they are part of a larger group.
- People not returning calls when they promised too
- Receiving contradictory advice from different people at the same facility
- Not going any further with an application when they were told my mother did not have a GP in the area
- Not following through with email when they said they would
- Never being told if there was in fact any chance of a permanent or very rare respite placement, with never-ending rounds of phone calls etc and not getting a response.
- All in all, very unprofessional practice when you are in fact dealing with the lives of vulnerable people.

We also had the added stress of packing up and preparing her home for sale so that she had the finances to pay the RAD. We were also visiting her daily, an 80-minute round trip on top of the time we spent with her. It was a full-time job.

Each day we would look at each other and question how people who had no family negotiated the aged care system or, if those family members did not have the skills to do so.

At the end of July, we were offered a placement for Mum at a facility we approached late in the process and after viewing it accepted it on the spot.

I am a strong person and both my husband and I have had significant health issues over the last few years but this process very nearly broke both of us. I am sure I am not the only family member of a loved one who has had sleepless nights, panic attacks and feelings of having no control over the situation.

Mum was completely unaware any of the problems we were having as she was grieving the loss of her independence and the home she shared with my late father.

The concept of being able to choose an aged care facility that is the correct fit for your loved one is an absolute fallacy. The reality is you HAVE to take what you can get.

I am pleased to say that Mum is now flourishing and regaining her strength after we nearly lost her in the hospital but why did it have to be so hard?