Submission to Inquiry Aged Care Delays

I am a former carer for my parents, both now deceased.

My experience in dealing with their needs under the current system is one of frustration, delays and inadequate systems. In particular with regard to my mother, who had dementia, access and affordability to both services and equipment impacted all of us.

My mother, Virginia, was on a Level 2 waiting for a Level 3 package, when one day she simply ceased walking. It was instant and irreversible. There were not sufficient funds on a Level 2 to buy or hire the equipment needed nor were we in a position to wait. I fortunately was able to borrow a wheelchair on occasion and managed to purchase a second hand ‘hospital bed’ myself. New it would have cost $8,000, funds we simply didn’t have, nor was the cost ($1,800) reimbursable, as I had to purchase second hand. We couldn’t afford a hoist so were forced to physically lift her in and out of bed, onto the toilet and into the shower.

By the time she was raised to a Level 3 package, I was advised that she was in need of Level 4 funding. Not only was there an issue with having to save for the equipment needed, but the support we needed had also increased. In addition on a Level 3 we were unable to access Community Health Occupational Therapist (OT) services, which meant we had to wait up to 8 weeks and have sufficient money in her package to pay the fees for the OT, which varied between $600 and $800.

It now took 2 people to support her in all physical activity. Once we were able to purchase the equipment which included a shower chair, commode and wheelchair, we then had to wait for a Level 4 package before we could afford a hoist.

I did not have the funds to provide that equipment, nor was I in the position of being able to care for her without assistance. This process took years and was a continual struggle for all of us. My mother loved being outside, she had no desire to be kept in bed, however the struggle to move her in and out was undignified and wearing on her physically, and ultimately causing her great distress.

I had to get the OT assessment done twice more money to save for and once I was able to afford to hire a hoist my mother’s quality of life improved dramatically. It was a 2 year process.

Unfortunately we simply didn’t have the funds to purchase the hoist initially and therefore paid more for to rent it than to purchase it. We would have been able to afford to purchase if my mother had been on the package she needed when she needed it.

Subsequently she needed a different sling for the hoist and once again I was in a queue, this time a delay of up to 3 months to have an OT review her needs. There was no way around this despite the fact that she was no longer weight bearing and I was struggling to physically support her. One morning the sling failed and she slipped through, fortunately I was underneath her and managed to call my neighbours for help. After that I was unable to move her from the bed, she developed bed sores and I needed an air mattress for her however that was also dependent on the OT report. I scraped $1500 together to buy one for her.

Through this journey I was on a carer’s pension, at the end of it I am on a disability pension. I had a pre-existing condition which was exacerbated by my inability to get the right equipment in a timely manner. This situation adversely effected not only my mother’s health and quality of life but it has also irrevocably effected my health. I am now using a walker, an electric scooter and have physiotherapy regularly. I am currently being assessed for an electric wheelchair. I truly believe that if we had been able to access what she needed, when she needed it, I would be in better health physically and she would not have had to suffer so much pain and trauma. The system failed and quite frankly I do not see it improving. Waiting for someone to die to get the funding you need is not an adequate model under any circumstances.