

I am a parent of a young person who is currently living in a nursing home. My daughter is a 29 year old woman who, 12 months ago, was living in her home, paying off her mortgage in Belmont. She was working full-time as a special education teacher at Barwon Valley School. She was a really integral part of that school community and had been identified as a future leader.

She started experiencing headaches, weakness and double vision and it was initially thought that these symptoms were related to migraines. After months of suffering, she was finally diagnosed with a brain tumour. She was operated on the following day and subsequently suffered two strokes. The result for my daughter was complete lack of mobility and inability to swallow. She currently requires 24-hour care, largely because of her physical limitations and the fact that she has a tracheotomy and ventilator. The trigger for my daughter going into a nursing home was that it appeared to be the best way for her to have access to a full rehabilitation program.

**Term of Reference (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities**

A nursing home can be a dour, uninspiring and depressing place. The overall atmosphere is not very pleasant. Every other person is declining.

In the words of my daughter, "I feel like I'm in Big Brother- no privacy, unable to get out. I feel trapped because there is no freedom- I have to wait for someone to help me with everything".

In a nursing home, the whole place is not geared towards someone recovering. Therapeutic devices and tools may be seen as a nuisance rather than something positive. Where allied health therapists are coming into the aged care setting, the two systems have to work together and sometimes the aged care workers are inflexible. This has negatively impacted on my daughter's access to therapy. Personal technology (which all young people

use) is seen as clutter. Elderly people in the facility don't have as many items in their room and that is what the nursing home staff are accustomed to.

Aged care facilities are not designed for someone my daughter's age (29). My daughter gave a really good example of this and says "Things like getting my period annoy some nurses because old people don't give them that problem. Some nurses think that I shouldn't be in there."

### **Term of Reference (e) the alternatives to residential aged care for young people with disability**

My daughter was in the Austin Hospital in Melbourne. We were told that she couldn't return to Geelong Hospital unless she went into the ICU, which of course we said no to.

The first suggested discharge destination from the Austin Hospital was a residential care facility for people with ventilators with limited access to rehabilitation, which is in Fairfield, Melbourne. We live in Geelong and Geelong is my daughter's home and this facility would be an hour and a half drive from our home. We (including my daughter) refused this option. My daughter said "No, I need rehab".

Because my daughter was aware of all these discussions, she was getting frustrated and upset by the obstacles placed before her. We had to fight to return my daughter to Geelong and to be offered rehabilitation as part of her plan (which from the beginning had been spoken about). Then we were offered three options:

- a) inpatient at Geelong Hospital ICU
- b) inpatient at McKellar Rehabilitation centre (more limited length of stay)
- c) resident of Wallace Lodge (NH) with access to a full rehabilitation program

The healthcare professionals presented the third option as the most favourable. My daughter opted to choose the third option as we all believed it to be best choice for her recovery.

### **My Ideal World**

If my daughter needs to be accommodated in a care facility of some description (ie. Not in her own home), then she would like it to be a facility where all the residents are young like her. Her morale and demeanour would be boosted and this would help her recovery and rehabilitation. We all hope that the NDIS can fund the care and support needed to enable my daughter to leave Wallace Lodge once she's gained enough independence to do that.