

Submission to Senate Inquiry

“Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia”

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Statement about sharing:

I am happy for my submission to be published

Signature:

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Introduction

I am a young person who has been living in a nursing home for the last 10-months. I am 54-years of age. I have an ABI, cortical blindness (so low vision), unsteady gait, limited dexterity, speech impairment and short-term memory impairment. I need support for dressing/undressing, medication, meal preparation, showering, and advocacy. The trigger for my admission to the nursing home was oxygen deprivation that I experienced while in A & E at hospital before the doctors managed to insert a tracheotomy. The lack of oxygen resulted in my ABI and most of the other impairments. I went to hospital with a sore throat. I spent 5-weeks in hospital, then 7-months in rehabilitation. I went directly into the nursing home from rehabilitation.

Funding

I am solely dependent on the disability support pension. I have recently applied for a small funds package that will pay for my gym membership and, some taxis and public transport costs. With a larger funds package to cover some regular personal care support, I could actually move out of the nursing home but that option is not available to me.

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

People don't understand dementia – there are over 100 types. The lack of knowledge around that, and the lack of knowledge (and often spoken English) by the RAC staff means they can't possibly understand the problem. And I don't have dementia, I've got an acquired brain injury (ABI). This is something very different. The staff don't understand ABI either. I find myself losing my temper with them. I don't want to do that but living there is so frustrating. The lack of understanding makes living in RAC very difficult in both a practical and emotional sense.

I wanted to go to the gym for further rehabilitation.. Someone from the ABI Mobility Unit of Guide Dogs Victoria came to see me after I moved into the RACF. She made an assessment that I could go out by myself to the gym but they wouldn't let me until the doctor was brought up to date. When the Dr signed it off, the staff from the Leisure Team at Royal Talbot, the rehabilitation hospital, came with me to the gym a few times until I could safely get there and back.

Apart from now going to gym, I am effectively boxed in with the old people and the staff who cannot differentiate between dementia and ABI – which have very different presentations - and so cannot possibly make informed

decisions on that basis. This is a problem when they cannot make decisions that so affect my life even though I can really make my own decisions and really have the cognitive ability to do so. But because I can't remember names and takes a bit longer to speak and to learn new information, I get treated as if I'm dementing.

It is very hard to live with people who are dementing. I have made friends in the RAC, but more so with others with a physical disability rather than the dementing disability. But roughly 99% of people living in the RAC Facility have dementia.

I have very few visitors. It is very hard on anyone coming to see me because the other residents with dementia try to grab hold of them which makes them feel very uncomfortable. My sons and my ex-wife do come and see me. Luckily they do know what to do if someone grabs them. While most people understand, they are clearly uncomfortable when this happens.

Three weeks ago, the RAC doctor came to visit. When I was going to go out to the gym (I had been going for a week by myself at that stage), I

called out to the doctor to hold open the door for me. He said no, and slammed the door in my face. He thought I was a dementing resident just trying to get out.

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

Towards the end of my rehabilitation it came time to consider where I was going to live. Alternative accommodation choices consisted of nothing. The rehabilitation staff did not provide any choices or options at all. It was my ex-wife who found the facility in which I now live. Share accommodation could have been an option. I qualify for share accommodation, as I am semi-independent. I need assistance and support for showering, dressing, medication, and meals. I am independent with toileting, undressing, getting into bed by myself, getting up by myself, going to and from the gym. I could feed myself independently if the RAC used the correct utensils however since they don't, I require feeding assistance. This makes it particularly hard to keep up my skills that I was taught during my rehabilitation. The RAC promotes total dependence not adult independence. I am quite capable of independent living with supports but I haven't been given that option yet.

My Ideal World

In my ideal world, I would live

- In independent housing
- With room for my sons to visit
- A private lounge room
- I would be in my own place, not sharing with anyone but I am happy to share until something else comes up

In my ideal world, my support needs would be met by

- Independent cooking support
- Independent dressing support
- Retain my independent access to gym
- I would be going to the gym, yoga, swimming 5-days per week – I would need support/guidance for the yoga (1-day per week), and support for the dressing/undressing required for swimming (2-days per week). The staff at the gym already help me with the gym equipment.