

Introduction

My name is Katy Skene, I am 38 years old. When I was 19 I was diagnosed with MS. I had been living independently until I was 33, when I became acutely ill and was hospitalised. After three months, My health had improved, I didn't warrant a hospital bed. but I was not well enough to live independently. So I entered a nursing home at 34.

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

I believe that this term of reference is inherently flawed. The aged care system is never appropriate for young people.

I still vividly remember the first night I spent in the nursing home. I was put in a 'separate' room that divided my bed only by a thin curtain from the space of an elderly lady with dementia. I didn't know the code to open and shut the front door, and as my parents left, I remember bursting into tears and thinking that my life was on the other side of the door. It was like all the light and colours were on the outside, and there was no longer any colour inside. I think of my time there as being in black and white. I recently asked my parents about how they felt leaving me there, and my stepmother said, 'we felt like we had abandoned you'. My grandmother said it broke her heart. None of my grandparents were in aged care at the time.

I felt like I was a 'novelty' for the nurses, because of my age. The first morning I woke up there, I heard one of the nurses say, 'Oh look, we've got a young, pretty one here'. The person closest to my age was around 60 years old, her name was Judy, she also had MS and she was my closest friend there. We both hated it.

It hurt me that I was the same age as the grandchildren visiting their grandparents. My friends stopped coming to see me, because they were too uncomfortable. One of my friends said that it was too hard to visit her grandma in a nursing home, let alone one of her best friends.

I stopped looking after myself, because my spirit was crushed. My weight went down to 46kg. I thought that it would be so much better if I got back into hospital, than stay in the nursing home.

The only thing that stopped me doing something stupid to myself was the thought of my parents.

I absolutely don't believe it was the fault of the nursing home or the staff. The home was a good place, but only for people at the end of their life, not in the prime of it. The nursing home was not at all appropriate for me, it nearly killed me and at the time I hoped it would.



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

I am now living in shared support accommodation in Williamstown. There is no comparison between my situation now and the nursing home, it is a million times better. I am a social person and so I enjoy living with other people. It means so much that in the house, the residents' opinions account for something. The management asks for our input into how the house is being run. For instance, we get a choice about what we have for dinner.

In the nursing home, I felt like my flame was extinguished, but now there is a flicker again. I volunteer once a week as a kinder teacher, a profession in which I worked for 10 years. I am studying a BA in creative writing, I have coffee with friends regularly, I go to the football once a week, music concerts sometimes and I am on the disability advisory committee on the local council. In other words, I'm never home. In the nursing home, I felt like I was shut away from the community. Now, I'm actively engaged in it.



My ideal world

Nevertheless, in an ideal world I would be living more independently in the 'model' independent apartments such as those set up by the Summer Foundation. The fact that the Summer Foundation has a workable 'blue print' for this type of living arrangement means that it is not a hard problem to fix because we already have the answer. There just needs to be more of these apartments, which can only happen with increased funding. I joke with my housemate that people who have accessible apartments have won the 'golden ticket', they have 'won' their independence. But it shouldn't be a competition for those tickets, and we shouldn't have to fight for our independence.

I think that a 'big issue' exists in Australia around accessibility and housing for disabled people in general. I would like to see a certain percentage of all new residential developments being accessible to people of all abilities. We don't want sympathy, but equality. For example, we would like to be able to look for an apartment on domain.com and check a box that says 'disability accessible'.

Even though I am now out the nursing home, I also know that there are still young people in nursing homes and I want government to acknowledge that this problem exists. Just because I am out of the nursing home, the job is not done. There are still 360 young people in aged care facilities in Victoria. I would like to not feel guilty for having 'gotten out' of a nursing home, when there are still so many left behind.

I look forward to the Senate's response to this inquiry and subsequent action taken by the Federal Government.