

Submission to the Senate Inquiry into Aged Care

I have been living in a nursing home for six years. I am 46 now. I am very unhappy in the nursing home because of the care I get. I don't want to live in the nursing home.

I have to go to bed at 5:30. If I go out with my dad at the weekend, and get back late (after 5:30), I get into trouble. This is because the nurse has to put me into bed later.

Sometimes I stay in bed all day because the staff don't have time to get me up. Sometimes the staff don't get me ready in time in the mornings and I can't go (to my day respite program).

The staff are always in a hurry, and I feel very anxious. They give me my meal too quickly, and I can't eat. Sometimes I don't get enough to eat because they don't have time.

The staff lift me instead of using my hoist. When they lift me it hurts my hips, and I have a lot of pain. They are in a hurry.

When I go home to my dad's, he gives me a bath, washes my hair, and cuts my finger nails. The staff don't wash me properly or clean my teeth.

I did not get enough to drink when it was very hot last summer (2003/2004). I had to keep asking the staff for a drink, but I did not have enough. The staff do not have time to give me a drink.

I have to share a room. I asked the Matron (Director of Nursing) if I could have a room by myself in the nursing home. She got very angry with me because I wrote it in a letter to her. My dad has asked if I can have a room by myself, but they say no. The room I am in is very hot and does not have air conditioning. There is air conditioning in the single rooms.

As soon as I get home (from day respite) it's dinner time, and then bed, and I can't relax.

I get treated like an old person. There is nothing for me to do at the nursing home.

As soon as I get near the nursing home my body gets uptight. My body is nice and relaxed here (day respite). If dad takes me out for a day, I feel calm and peaceful. My body feels tense and in a hurry at the nursing home.

I don't want to live in the nursing home. I hate it. I feel worried and frightened of getting into trouble.

I want to live with people my own age. I want to be able to go food shopping, and get my own hair cut, and have my fingernails cut. I want to go to bed when I want to.

Submitted by:

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Nathan was supported in writing this submission by:

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Background information

Nathan has cerebral palsy in the form of spastic quadriplegia. This means that Nathan needs full assistance for all of his personal care needs: showering, dressing, eating, drinking, toilet.

Nathan also needs full assistance for all transfers eg getting out of bed and into his wheelchair, getting from his wheelchair into a shower chair.

Nathan needs a modified texture diet because of difficulties that Nathan has in chewing and swallowing. Nathan needs time to swallow one mouthful before being given another one. Nathan also needs to be given small spoonfuls at a time. Nathan needs sufficient time to eat safely: eating quickly increases the risk of Nathan aspirating food into his airway and potentially developing aspiration pneumonia.

Nathan has an electric wheelchair for mobility.