

As an Australian significantly effected by Thalidomide, I have largely survived on my own. I have simply got on with my life!

Despite my significant thalidomide deformities, I moved away from home in my early 20s into my own home. Renting was never an option for me, as I required too many specific home modifications - beyond what a landlord would ever agree upon. Establishing a home catering to my specific needs was a very expensive exercise - costs of which bore myself. Kitchen, bathroom and bedroom renovations specifically - have had to be very carefully designed to cater for my needs.

Martin Johnson, former Director of the UK Thalidomide Trust, acknowledged of people with Thalidomide disabilities – *“They’re degrading fast... They’re getting the type of damage you would expect to see in people 30 years older”*. (Martin Fletcher, The Telegraph: 6 January, 2016).

For 57 years, I have asked my body to perform every day tasks with my teeth; toes; leg deformities and, shortened arms with three (3) digits. I fight every day to maintain my independence. Reality will - sooner than later - dictate I enter permanent aged care at a much earlier age than for those midlife Australians who do not live with Thalidomide deformities. I have, on numerous occasions already, seriously considered moving into permanent care. I am acutely aware of, and am already grieving for, the loss of my independence.

My future is grim ... as I age with my significant Thalidomide deformities.

Given the bleak outlook of my ageing years, I have to wonder - how well will aged care facilities be prepared for *my* specific physical needs?

Perceptions surrounding ‘accessible accommodation’ for aged and disability care mostly centre around, ramps into buildings and railings in bathrooms. With my shortened arms and legs: -

- I cannot even reach any Australian standardised rails - regardless of their purpose!
- I cannot reach toilet paper - even in an ‘accessible’ bathroom;
- I cannot reach into cupboards and drawers
- I cannot turn on taps without lengthened tap ware;
- I cannot open/close doors with rounded handles due to the limited digits (three (3)) on my one usable hand and,
- I cannot reach bed lighting switches *even* in ‘accessible’ accommodation.

The questions must be asked:

- Will private proprietors of an aged care facility be prepared to make these essential changes for *me* so I can have maintain some dignity and ability to at least clean my own teeth; reach to fill a glass of water or, reach the toilet paper?
- Can an aged care facility be ‘directed’ to modify a room on their premises, to accommodate me in such modifications including (but not limited to) taps, doors, toilet roll placement and, electrical fittings - and
- Who would be expected to pay for such modifications?

I have had a lifetime of developing resilience - but I am weary ... *very* weary! The physical, financial and emotional cost of developing and maintaining independence for myself, has most certainly, taken its toll.

As an Australian living with significant Thalidomide deformities, a ‘one size’ model [in all areas of my life] has never fitted me in the past – how can I expect aged care would be any different?