

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

Hello Senate

My first comment is “are you suggesting that there is a current plan in place?”

Tony, my husband, is a paraplegic. Paralysed in 1954 when he was 6 years old through contracting polio. We have been married since 26 November 1977. We have three adult children.

Tony is not able to stand up nor is he able to walk. He can not do many things, which most people take for granted. Tony can not carry a slab of beer yet others on a disability support pension can walk and carry a slab of beer and those that are legally blind, unlike Tony, receive a no means tested full disability support pension.

As we could not afford modifications to our ensuite and Tony did not have a wheelchair, for 20 years in our current house Tony crawled 20 metres from our bedroom to the bathroom every day to have a bath and then he crawled back again to put his callipers on and get dressed.

Until 12 months ago Tony was able to be upright via the use of callipers and crutches. This in many people’s mind meant that he was an able body with full walking capacity.

At one stage when I was on unpaid maternity leave from my full time employment Tony was initially refused Centrelink payment as he stated that he could work. Apparently that meant that he was as capable as anyone else of gaining full time employment.

Due to the additional physical stress of carrying himself around for so many years in a way the human body was not built for he is now permanently confined to his wheelchair. His right shoulder is wrecked and he has the option, within the next few months, of undergoing a shoulder operation. This means that his mobility will decrease to that of a quadriplegic for a few months during the six+ months anticipated recovery.

In technical terms I have been Tony’s “disability carer” for a bit over 32 years. I have for most of our married life been the main and mostly the only income generator. We are have been both self employed for the last 13 years and from our experience that is the only way Tony has been able to be employed.

When Tony has been involved in government sponsored employment programs they have asked if he minds him being removed from their books as by him staying on their books their figures look bad. They know as our experience has demonstrated that his ability to be placed in mainstream employment is realistically impossible.

Tony is a remarkable man with an extreme tolerance of pain and hardly ever complains.

People like us are forgotten about. Yeah we get \$106.40 per fortnight in carer's allowance however our Private health cover is \$124.30 per fortnight. We also receive \$80.60 per fortnight mobility allowance to assist with transportation costs but when you can not reliably get on to public transport unaided your choice of transport is very limited.

Things liking mowing the lawn, cleaning out the spouting, painting the house, general maintenance that you can not do in if you are a paraplegic are left up to me or we have to pay someone else to do. While it was relatively easy for me to do "all" twenty years ago I am twenty years older now.

We have just purchased a new wheelchair for Tony with no assistance from the government as there is a six month waiting list for him to be seen.

We have just purchased a new cushion for Tony at a cost of \$675- (discounted price) that he is eligible for government funding for however there is no money available for another 5 months. The scheme has run out of money. We could not wait five months as Tony currently has pressure sores that are not only painful but messy and can overnight be full of infection.

No body from the government has ever approached Tony or I and as far as we are concerned we are considered to be everyday Australians with no special needs required.

And try to book a holiday where wheelchair access is needed – you get the rooms at the back of the establishment with sub standard facilities (RACV Inverloch an exception although even there the rooms do not have good ocean views. Those rooms are reserved for the able body people). Compare the disabled rooms at Pepper Resort near Gold Coast to those of an able body – depressing is an understatement even though you can pay the same dollars.

And what about the taken for granted emotional support!!!!

Government has never really considered the reality of the life we live. We are a married couple so love is all we need.

Anyway if you wish to ask questions please feel free to do so. We will get on with our life regardless of the outcome of this committee enquiry.

Maria Rigoni