

Submission

Why am I sharing my story?

I am sharing my disability story with you in the hope it helps make some positive changes for people with disabilities in Australia. I am a 31 year-old woman and I have a chronic illness called Interstitial Cystitis, which causes me to be in chronic severe pain 24 hours a day, every day. I mentally, physically and emotionally suffer on a daily basis.

I have a low quality of life, whereby my partner has to do everything for me at home because I am in too much pain. I have the same sort of quality of life as a person who has renal cancer but no one has assessed me to know that. I wear morphine patches so that I can go to work and try to earn a living. I probably should not be working but I cannot afford to live on the disability pension, especially with my medical costs. I have many sick days so my earnings are low.

What are the facts?

I was diagnosed to have IC five years and gradually my condition has gotten worse. I was diagnosed with Interstitial Cystitis when I started my University degree and had to stop studying immediately due to the pain I was experiencing. After getting some treatment I returned back to University although it was extremely difficult for me because I could only study and was unable to work part time because it was too difficult for me physically to study and work at the same time. I got no extra support from the government even though I could not work and I was studying.

Once I finished my degree I got a job with a hospital in Melbourne. This hospital forced me to resign because of my disability and this caused me so much physical stress that I could not go back to work. I went on the disability pension to support myself but this only covered my medical expenses. I was extremely depressed because I could not afford to live but only pay for my medical costs and I wanted to commit suicide. My parents had to pay for living costs. What if they didn't have any money?

I finally got a job a year later but it was through very hard work and a flexible organization willing to support me with my disability. I work four days a week because my health cannot permit me to work anymore. Even though I work four days and still have a severe and debilitating illness I get NO SUPPORT from the government.

I still have extremely high medical costs and my quality of life by deciding to go to work is extremely low because I am pushing myself to the extreme each day. I push myself to work four days because it wouldn't be worth working for only three days. Working is so hard for me physically that I would like to work 3 days per week but I can't because if I work, it doesn't matter how many days, the government won't help me at all. This is wrong as I am trying to help myself and this country by pushing myself to work but no-one helps me.

There is nothing that specialists in western medicine can do for my illness. There is no cure for my severe pain. Therefore I self manage and treat my illness with integrated medicine by doing the following:

- Acupuncture
- Massage
- Yoga
- Osteopathy
- Psychotherapy

Without this treatment I could not get out of bed every day. I am forced to self manage my illness because there are no western treatments for my illness. I am forced to improve my quality of life by doing acupuncture and massage. These treatments help me to get out of bed each day but I get NO help from the government.

I have support from my partner who cares for me but he is unable to claim anything from the government because he earns too much money. Why should he have to clean my clothes, cook my dinner, clean the house and get no support from the government? I am an Australian citizen who is disabled and the government can't even help my partner help me. If my partner gets ill from all the stress of looking after me he too will need to go on the disability pension. The government should be helping people who care for the disabled as well as helping the disabled. My partner should not have to do everything for me. We should have some funding so we can access assistance in whatever way we need it.

I would like the government to start seriously looking at these issues:

Provide additional financial support to people with disabilities who are employed at a part time level:

Why do I get no help from the government to improve my quality of life just because I choose to physically push myself to work four days a week? Why can't I work three days a week and the government supplement me for

two days so I can have a better quality of life, live longer and work longer? Isn't it in the best interest of the government to assist me in self managing my illness instead of me becoming so sick that I need to go on the disability pension again. If I continue to push myself to work four days my illness will get worse and I will need to go back on the disability pension. And once I am on the disability pension I have a small chance of working again, only 1% of people on the disability get back into work. The government should be providing incentives to those people who are working and have a disability. Even if they can work for 2 or 3 days a week isn't it better for Australia?

Provide access to traditional treatment such as acupuncture either at hospitals or provide funding so that people can access these services, if that is what helps people manage their disability?

We know a large proportion of people with chronic illnesses get complementary medicine treatment/traditional treatment. I spend at least \$100 a week on acupuncture and massage to help me manage my illness and to reduce my pain. The government doesn't support me in any way. Why can't the government think about putting these kinds of services available to people with severe disabilities? Why can't someone assess the level of treatments available to me as a person with Interstitial Cystitis? From that the government can see I need extra support from other alternative treatments. I must try and improve my quality of life, the only way I can do this is by accessing traditional treatment, but how can I access this with no money or support from the government? I suffer physically and emotionally each day and need to see a psychotherapist but I cannot afford it. I had to stop my treatment and I know I am mentally suffering because I had to stop my treatment because it was too expensive. Would you rather people commit suicide than help them to see a psychotherapist? And you should be able to choose who you see as well. It is very hard to find someone that you can work with, and then the government say's "no you can't see that therapist" it is ridiculous. The government needs to ask people what they want and need, and what works for them. Everyone should be treated as a unique individual.

Why can't there be decent tax breaks for people with long term disabilities? How will I ever be able to own a house if I can only work part time hours because of my disability?

I spend over \$800 a month on my health - that could pay a mortgage. And because I am choosing to work four days I get no additional financial support from the government. Why does the government help people who have investment properties but doesn't help people who suffer from a long-term disability? It's not fair. How will I ever afford to own a home if I have such high medical costs? Why can't people with disabilities get more than 20% of their medical costs refunded? I spend nearly \$10,000 a year self-managing my health to enable myself to go to work – the government doesn't help me financially one bit. It is absolutely disgraceful. I am only 31 years old, if I didn't push myself to work and was to be on the disability pension for life how much will it cost the government? Also why does the government keep increasing the safety net for prescriptions? We need more assistance, not less. I now have to spend over \$1600 a year on medication before it is free. That is not fair for someone who has a long term illness. I should be getting help for the cost of my ongoing medication need.

My partner and I feel very sad about my future in this country whilst I am sick and continue to have a severe disability.