**Jo’s Story**

**Background**

When I got sick with a severe type of Multiple Sclerosis I had to leave my hometown of Melbourne and move to Adelaide. I left behind family (including my ex-husband and step children), my friends, my career and my business. My dog moved with me to Adelaide but sadly he passed away.

I hardly contact my friends and family in Melbourne because I need someone to pick up and hold the phone for me, I don’t speak loud enough for people to hear me and my ears are hypersensitive. When I’m game I’ll set up Skype.

**The reality of support and living independently**

Once I moved to Adelaide it took three years to get disability funding for 30 hours of support a week. At first I only needed a little bit of help and my Mum put me to bed, but we soon learnt that if you want family to survive, your Mum doesn’t put you to bed. So Mum and Dad paid for a support worker to put me to bed. It can take five hours to put me to bed on a bad day and my condition is so severe it makes me hard to handle.

After a while my Mum found it difficult to cope with me living at home, my illness and having support workers in the house, so a family friend found a nice, single bedroom apartment for me to move into. Luckily, this happened just 10 days before I was going to be put in a nursing home. I really enjoy living on my own. I live with support workers around me and only have about three hours to myself each day.

**Self-managed funding and accessing support**

I’ve been self managing my funding for five years. My support agency pays the support workers, but I roster, manage, interview and/or train them. Now with the individualised funding scheme, I have two or three agencies of my choice, not just the one the government chooses for me.

I have to rely on myself to arrange my support. Because my condition is so severe no agency will deal with me. They would only do payroll but not take responsibility for finding me support workers. I can’t just pick up a phone and say “Can I have a support worker? Send me someone”. I used to be able to ring my Mum and Dad but they’ve become too sick to assist me.

The South Australian Government doesn’t allow us to use funding directly, as an employer. It is not like in other Australian states, or New Zealand, where you can use funding to directly pay support workers. If that was the case here I could have two and a half full-time staff and I’d be fine. I wouldn’t have these problems. I have enough funding from the government; but I’m not allowed to use it.

**Using diet to treat pain**

I was a very strong person prior to becoming sick. I believe I can get better. I’ve tried a lot of the tricks they talk about; I did raw food for a year and a half and my pain got a lot better. I do an almost raw food diet now, which helps with pain immensely. I live in a lot of pain, but most of that’s from injury. When I hear about people in pain, I think, “Well, they obviously don’t know about diet.” My diet’s very strict.

**I am proud of my past career achievements**

I had a 22 year occupational design career. I worked around Australia and the world, and the reason I worked around the world was because I had wanted to. I visited the Australian Consulate in Japan, and I went to Bali to buy design materials and furniture for clients. When I was in Melbourne, I managed design at the casino, rebuilt the National Bank and all its offices. It’s called facilities planning when you go through offices, restructure all the work-stations, work out how 2500 people have to be structured, how much ergonomics is needed in that much space, and how to save efficiency of time. I eventually started my own business, specialising in medical and dental, because that’s where there was a niche market. Then as I became sicker I began to do auditing. People would give me their plans and I would write the process of what to do and how to do it.

**Identity and “image shift”**

I have had a fairly enormous change in identity but it’s only as much is I have allowed. Even though I live in Adelaide now I still wear black like a true Melbournian. I have the same haircut I had 12 years ago. I always like to look great, so I cover up. It’s called “image shift”.

**Designing wheelchair fashion**

Being in a wheelchair makes it hard to get changed. No one can provide clothes that are easy to take on and off. I had to find my own design and make my own things up, for example, I split my wedding dress down the back, and took it off in the middle of a fashion parade to show people how simple it was. Don’t worry, I had another dress on underneath! I wanted to show people that you don’t need to a glamorous team of people getting you changed.

You can just simply wrap yourself up with fabric and look amazing. You don’t have to wear the grandma shirts with the zips up the back and the buttons up the back, and the Velcro here. You can use pieces of fabric that just drape around you. I was lucky to be a designer. I’ve taken many people, who are using wheelchairs, to shops and assisted them to buy fashion that suits them. I refuse to wear a tracksuit. Shop assistants have also made clothes for me that I have designed.

**Accessibility to fashion**

People haven’t had the chance to be glamorous and pampered, to have that fun. I took some women in wheelchairs to a shop in Rundle Mall. The shop had a problem with all the wheelchairs, and the women who could get changed had to go to the men’s store three doors down. So even though the shop had the right attitude (were prepared to be flexible to facilitate access), it still wasn’t equal inclusion, but how often do people using wheelchairs really get to have that fun with fashion?

**A “survivor” personality - suggestions for others**

Friends say to me “No matter what happens to you, Jo, you always land on your feet. Even though it’s got really, really bad at times, somehow you always land on your feet”. I think it’s just my feet are like concrete!

I deal with grief by meditating. I find I have to spend time alone. Things are probably worse now, because it’s getting difficult financially, and it wasn’t that bad for a while. We were coping and surviving. But then all good things come to an end.

You’ve got to have this little fire inside of you, it’s a dream to keep working at. If you don’t keep action happening; nothing will change. If you continue to change, even just a little bit each day, then something will change. If you change a lot in a day, everything will change, but if you do nothing, then you’ll get nothing. And that’s mainly what I do with my grief is turn it into an action.

I think it’s different for people who have lived with disability all of their life than with a person who has acquired disability. I think their lives are different. Someone who’s had a type of life, and then acquires a disability, my advice is: “Remember something else you’ve done before you got sick that was hard, and how did you break through it?” I find something in my life that I can relate to that’s tangible, that’s really got nothing to do with disability, and follow the same footsteps, as if I didn’t have those life challenges. I use previous life experience of tough times, to relate back, and remember how I did it, to know how it can be done, with or without disability. But when you tie it only to disability, there are no answers.

**Give yourself time to cope emotionally**

I believe we ought to allow ourselves to be depressed for a short time and then be done with it. Allow it, and then that’s it. “Okay, I’m going to go off and be depressed,” and then I go to the bedroom, and it’s like “Okay, I’m done now”. Normally it lasts about two minutes, because I get bored. I go back and work on the computer again. That’s allowing for me time.

**Reach out for support and be specific about what you want**

Being a person with substantial disability I think people should reach out for help with difficult things in their lives. I don’t mean for the little things. I have phoned my mother in Melbourne for help but she could not provide that. You’ve got to find someone that’s got the time and inclination for what you want them to do. Most people won’t help if they don’t know what to do. If you want help you have to know what help you need and ask specifically for that to be done. I now have learnt to be specific. I’m trying to get a volunteer hair washer to come in once a fortnight and that can be very hard. You’ve got to be very, very specific and you’ve got to know what you want.

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