Stephen’s Story

Stephen's story was told during an interview**.** This is the transcript.

I had MS for seven years this year, and I’m now blind and in a wheelchair. It is optic neuritis. I’ve got everything in place at home to be able to function. I just need someone to cook and do a little bit of personal care. The carers are there three hours a day, seven days a week, so [I just have} to just keep the house tidy and do my washing. They [services] are all covered financially by Disability SA.

I was married, but got separated; my (estranged wife) kept telling me she wants a normal life. She doesn’t want to deal with my disabilities and she hates illness. And that led to no communications, and that led to meeting her needs but she wasn’t meeting my needs, and then that led to a separation. As long as I said “yes” to everything, everything was okay. I got to the point where I was sick of being bullied. I mean like she always said that I’m not replaceable without me being in a nursing home…

I know my health is deteriorating but I just deal with it. I know, I’m going to have falls, that’s part of life. Yes, there are going to be accidents, they are part of life. But while I’ve got my communication and I’ve got my mind then I need to deal with that, I’ve got to deal with it in whatever way I can to survive.

I do undergo bad days, I had a bad day yesterday because I woke up and the urine bag was broken and I got out of bed and the carer put salad on my plate [and] didn’t tell me and I micro-waved it, micro-waved the salad, and then she took my bed pole away and I couldn’t get into bed last night so I had to call for help. She left the windows open in the house and so there was cool breeze, and it was freezing. I had to get help in last night just to do the little things. But they’re things that [I cant do], I can’t reach a kitchen window, so I need someone who knows exactly what my needs are, and where anything’s moved it’s simply put back in its place.

I’ve been legally blind for about two-and-a-half years. But I wasn’t really that concerned. To be honest, I’ve lost my legs and it didn’t really bother me until a year down the track when everything started to [change. I was trying to explain to my (estranged wife) that I could see her body language before knowing how she was feeling, and I was trying to explain to her that everything that happens around me now I’ve got to hear or feel or smell or touch. And I used to say to her, “I’d undress you with my eyes when I had my sight, but now I haven’t got my sight I need to hear it and feel it”. And she couldn’t work that out. She’s not the most affectionate sort of girl. But before I could just sit here and look at her. The sight didn’t bother me too much because I was used to getting things taken away from me. When I first lost my legs anyone that asked me how are things – well I’m getting robbed all the time, someone coming into my house and taking away my money and my personal items or just going through my drawers I just felt like “I keep getting robbed” and when I lost my sight it felt like I was robbed again. But the worst thing was that I stopped driving, because then I couldn’t just jump in the car and drive anywhere and go and get the milk and –

the simple things – go and get the milk from the shop, or go and get some smokes, or go and pick up our Cassie. I used to just drive and go through the drive-through departments so I didn't have to get out of the car. When I lost my sight I stopped using the computer, watching TV and you've just got to adjust.

But I am still managing myself, I'm still showering myself. I don't know how the hell I do it. Every time I get over the spa and get in the shower I don't know how the hell I do it, but you just do it. But I still shower myself, I still dress myself, and the only thing I can't do is prepare food and make cuppas, but I don't like moving around with a hot cup of water in my wheelchair. I still transfer into my chair and I still get up. I was sitting on the lounge and that was getting up got harder and harder and I had to ask for help, so I went out and bought an electric chair. I'm still managing that okay.

But I think it is important not to give up. I mean, you've got to ask yourself "Do you want to die, or do you want to deal with it?", and I've chosen to deal with it. And that's my way, and it's my choice "die or deal with it" and I chose to deal with it so you've got to do whatever you have to do to deal with it. I've always had that attitude., When I was well and I was getting promoted at work, I got knocked back for my promotions about 10 times. So you just pick yourself up and you go again, you just go for it until you get what you want. And inside with the whole disability you go to the doctors – they haven't got all the answers – all my symptoms are under control now because I have come up with the answers. I said to the doctors years ago that "I've got a problem with my bowels, what medication have you got?" And they won't give you the ones that suit you the most. So I went to the chemist and said "Look, I've got a problem with my bowels, what medication have you got?" and I found it myself, and then later on I thought "it's on the PBS, why am I spending $20. So you've got to work it out for yourself.

I've got a GP – I've been through a couple of them, only because when I got diagnosed with diabetes I was seeing one and he said "Don't worry about the diabetes, you've got bigger and better problems". Then when I had a blood test and got my diabetes checked out. It was all over the place, and so I went to another GP and I've had him for about three years now. Now I'm managing my diabetes and that's okay, and I'm doing my own insulin injections at night time, I can do it. My (estranged wife) said you can't do your own needle, and I said "Yes I can". I was asking for her for about three years to do my needle work before I went to bed, and she'd forget or I would ask about five times, but now I just do it. Now I'm on my own I just do it, and I'm doing it quite successfully, my diabetes is under control. Well it's just another symptom that's under control. So, any symptoms I've got, I want them under control. I think the only thing I couldn't handle is if I lost my mind and lost my communication.

My determination can also be attributed to my mum. My Mum's as tough as hell. And mentally – I think that if mentally you've got a good strong mind, and you're able to deal with it, then you'll get through it. But if you haven't got the mental strength then you won't be able to deal with it. And I think Mum's got glaucoma and she's going blind and she's got osteoporosis, and she's been battered and beaten by my sister, but mentally if you're strong enough you can get through it. I mean we've had a lot of disappointments throughout our upbringing and throughout our whole lives, but you've just got to deal with it, you've got to be strong.

Don't worry, I've sat there and cried and cried because I've been robbed of my independence, and "how am I going to cope?", but then I go to bed and the next day I'd just pick myself up and get on with it. So you just lose everything. Yes, I want to be the man that my wife wants me to be, yes, I want to hold hands with her down on the beach, but now I know that's not going to happen. You know, it's just not going to happen. This has no cure, and it's not going to happen, and this is what the disability's about so we've just got to deal with it. And if there's an obstacle, let's work around it, not against it.

So for example people might wonder how I cope with being blind, being alone and not able to do many things for myself. People often ask me if it gets lonely. I have a companion dog called Kobi and she is by my side every minute of the day. I got her from Royal Society of the Blind and she is a very loyal friend to me. There are many times during the day when she makes me laugh or smile. Having another heartbeat in the house makes me feel better.

However I would like to mention that out of the whole illness, the hardest thing with the illness, is trying to meet my (estranged wife) and daughter's needs, and knowing my needs won't get met. I've tried to buy their love and just pamper them with flowers and chocolates and gave those holidays, but that doesn't work. I always said to my wife that I would have been better off getting cancer because at least then I'd be dead in six months and I'd get more sympathy. She has made the illness harder because I've been trying to deal with it and she's been putting up brick walls to stop me dealing with it. I can't handle the anger and the anxiety and the discomfort I have in my life. I'm still a bloke, and I've got needs and she's not meeting any of them lately.

I must say that nobody in friends or family helped me get to where I am today. It was the Disability SA that supported me, I can't thank them enough. If it wasn't for them I wouldn't be where I am today. You know, without them and knowing that the help is out there I wouldn't have felt free (because I was being blackmailed and felt entrapped), trapped by my illness, and what Disability SA have done is to free me. I always thought that I couldn't live without my wife, and I always thought that daily life wouldn't function without her, and that's where I've been trapped by my illness. But Disability SA has provided me with that outlet to say "No, I am not trapped by my illness, we will help you." And I've always said I don't want sympathy, I just want support. I don't need sympathy. You know, this is my problem, but if you can support me that's great. And the only help I've had – real help – has been from Disability SA.

About being blind I feel, "Well, you wake up each morning and you want to see the environment. You want to see the people that love you and you want to see your family. You miss seeing your daughter grow up. It's the simple things, seeing your daughter grow up and, just seeing how beautiful people are, and their body language. Like, when we travelled we saw all the water pools in the Northern Territory and I'd love to do that again. I'd love to sit out in the rain and watch lightning and all that sort of stuff, its the simple things you miss. It's not the big things.

In relation to my self-managed funding, it was offered to me through my coordinator with Disability SA, because they used to dictate to me what I could and couldn't have, and she said "Look, there's a new scheme coming up, they're doing a trial run, would you like to be on that?". I said, "Hey, anything to stimulate my mind. And then I went to all the meetings about it, and then I picked everyone's brain. Knowledge is power, and I learned everything about it. And you just go on and you Just think "Okay, that's going to stimulate my mind, so it will take my mind off my illness". And so then, you know, if you're got to have a big day going to a meeting on the other side of town then that's what you do, and use everybody's brain and you put your opinion up. You've just got to find everything about it and do everything. I mean it's like when I first got diagnosed. I needed a ramp at the back of my house. I didn't know how to get that and I didn't want to spend eleven thousand dollars putting it in and so then I get on the phone and I find out who can help me and where. There are a lot of services out there that people just don't know about. And unless you have got the willpower to investigate it yourself you're not going to find it. It's like if one person didn't help you it makes you go for more. If you got rejected by one person you say to yourself "Okay, who else am I going to ring?". So you sit there and you pick your brain "Where else am I going to get this help?"

From my experience of life I would like to encourage people living with disability by firstly asking them: what do they know, and what do they know is around that is available for them? And then I would give them the knowledge to be able to help them finding out what their needs are and doing it. Second advice would be: how do they stand financially? Were they working? I got a lot of benefits from work. A lot of people don't know you can cash-in your super and get your TPD. A lot of people don't know a TPD even exists. I would guide them and educate them while they had to go through that process. There are a lot of people that, if they haven't got the mental willpower, they would never get on the phone, they would never investigate, and they would never do anything to help themselves. You've got to help yourself!

Three years ago I bought a large modern caravan and travelled around Australia with my then wife and daughter. I saw this as a last adventure before multiple sclerosis got too bad. During our travels on the Gold Coast we saw an exercise machine in a shop. I tried the machine and found it possible for me to exercise. I predicted that it would be suitable for many other people. With the vision of starting a small business when I returned from our travels I purchased 10 machines, figuring that this would be a way of gaining financially independence as MS progressed. On returning from travelling I began building a small studio to house the small business which would focus on offering the machines to people for exercise, similar to a gym. The business was successful although it only operated for six months. The breakup of my marriage resulted in no one being available to run the exercise sessions since my ex-wife had attended to this. The marriage breakdown also meant that half of the machines were no longer available. It is my goal to have the gym operational again so that I can maintain my life independently. I am not proud that the gym had to close but I look forward to a time when it is operational again.

I see barriers as challenges that I have to problem solve and overcome. I believe that using one's own personal resources to connect with the right people in the right places is critical to accessing the type of support that is needed. For example in my recent property settlement I realised that I would require a loan in order to pay my ex-wife for her share of the house. I applied to Homestart for a home loan but was only eligible for a certain amount because of my limited income. This meant I was $8000 short of the amount I needed to buy her share of the house. I realised I could not raise the $8000 I needed and pondered about what I should do. Staying in the house was really important to me because it is set up for me and I am familiar with the home environment. Not knowing what the outcome would be I made a couple of calls to politicians e.g. the Minister for Disability and the leader of the Dignity for Disability party. When they heard my plight they liaised with Home start to ensure that I was provided with the outstanding amount as part of the home loan.

I am determined and never give up in the face of a challenge. It's just a matter of finding the right people to talk to.

And people who still need motivation in their life come and meet me. If you need a ramp, I'll help you get one. Like you know, if you're not motivated I'll be your motivation tool. But come and meet me.

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