

Jim's Story

I tend not to talk about my disability first, because my disability is secondary in my life. I have Multiple Sclerosis (MS) which I was diagnosed with in 1986. One of the first symptoms I noticed was that I was losing feeling in my fingertips. I just started tripping over my feet a little bit at first, and it was that which got me thinking and made me go to a doctor. It sort of all went hand-in-hand. My condition has slowly deteriorated since then and I'm now confined to an electric chair all day. I can do very little with my hands anymore, which is a little bit disappointing because I used to be a qualified mechanic.

I live alone in a nice house in Strathalbyn. I have someone (a carer) come in the morning who gets me up and helps me through a morning routine, and someone in the afternoon to help me get some dinner ready. Then in the evening, I have a shower and go to bed. For most of the day I am on my own. I prefer that. I have a standard desktop computer, which is equipped with Dragon Naturally Speaking.

I have a positive approach to life in general and when I find something that's not working properly, I become involved and try and change it from the inside. I obviously have to accept the reality of my situation, and realise there will never be any sort of cure. I've never used any of the treatments available. I have found I've been able to live a reasonable life despite MS.

When I was first diagnosed and started having problems, there were very few services about. They were structured for the organisation's benefit, not the client's benefit. I didn't want to be somebody that fitted into somebody else's system, and that was my reasoning for getting involved in the original Options, Co-ordination and Consumer Advisory Group, so I could actually see what's going on for myself first-hand. I got involved in the administration side of things because I've never been an activist.

I don't believe in activism - it doesn't do anything other than highlight a point very briefly. I'm more of a systems person. I understand a department as big as Disability SA for instance, has to work through a number of systems, and those systems need to be oriented towards the needs of the person with a disability, not the organisation providing the services. I always found that was the case. So I actively went about changing that. We even produced our own service provider, Enhanced Lifestyles, which is a consumer managed organisation that puts us (people living with a disability) back in control. It's a very good arrangement, a very good organisation; we're very solvent, and we do a good job. But it is not perfect.

I believe that going through an organisation like Enhanced Lifestyles, gives me a form of self-management in relation to my funding. I have ultimate choice and control within the guidelines. With Enhanced Lifestyles I can choose and recruit my own staff which means I can choose people with a similar philosophy on life. I can find people with a similar mindset, so we get along. I can recruit people with specific talents. I can work out what time each shift will be, rather than have them occur at a predetermined time. I have a great deal of choice in what they do while they're here so it's not a prescribed routine. I tailor it to my needs.

It's not a large organisation; everybody within the administration is very familiar with all the clients. There's an instant rapport when you call the office. People get to know about Enhanced Lifestyles

mostly by word of mouth because we don't actually advertise. Our clientele is specifically adults who are able to direct their support staff, it's not about the support staff coming in and doing just what they think they should be doing. It's about people living in their own home, directing the staff to do whatever needs to be done at that time. So you need to be able to direct your own life to be a client.

I'm on the board of Community Living and Support Services (CLASS) here in Strathalbyn. We're a non-profit organisation that provides services to people with disabilities in Strathalbyn, Goolwa, Victor Harbor, parts of Christies Beach, Mount Gambier and Renmark. We're one of the largest organisations in South Australia because we have a very proactive board. We have businessmen, lawyers, and people with disabilities as board members. We have a parent of a young man with a disability as well.

I've had quite a bit of experience dealing with government departments and their systems, but also I've dealt very personally with a lot of people one-on-one. Communication is something I've been given the opportunity to learn over the years and I've felt I had something to contribute to people that were looking for a bit of a hand within themselves. I like to stick up for the underdog.

My own personality has enabled me to do the things I've done. It's just *me*. It's my unwillingness to give in. I've never changed. Mum was a big influence on me. She's a very strong, forthright individual who's very soft and accommodating on the outside, but never took anything that she didn't think she needed to. My Mum was a big influence on me, and my Dad was too, but my Dad wasn't as strong as my Mum, and I am more like my Mum than I am my Dad. Mum lives in Port Broughton, and I live in Strathalbyn, so we're quite a way apart. I have called her every Sunday night for 35 years.

People that know me know how accepting I am of other people and how easy I find it to speak to other people, and give them the opportunity to speak as well. When you're alive, you have to live, and to live you've got to do things and be with people. You mustn't cut yourself off ... you must remain part of your community.

I am proud of my children and grandchildren. I have three children – two sons and a daughter - and three grandchildren. One son lives here in Strathalbyn with his family, that's two of the grandkiddies. My oldest son lives in Adelaide with his partner, and my daughter lives in Perth with her husband and little boy.

To somebody in a similar situation I would look them right in the eye, and say "Get confidence alright?" Well, if confidence comes from within, it cannot be taken away. It's like dignity, you cannot lose dignity. You give dignity away. Confidence cannot be taken away, it can only be relinquished. But confidence and the ability to do things only come from an inner strength and if you haven't got an inner strength, you need to work to find one. I believe you've got to spend some time with people first, look at their lives, and try and develop their life skills. You can't just go in and say, "Right, this is what you've got to do, you've got to do this, this, this and that." You've got to look at what they're doing now, and develop from that. They've got to slowly add bits; it's not something you can do in a day. It takes *mentoring* and *coaching* all the way through; it's not something that you can just switch on.

Regarding my interests I like going out and leaving the home, mixing with people and staying involved in what's going on in my community. Strathabryn is a lovely place. We've got really good health services that occasionally call on me for advice. The hospital here is very proactive in looking after people with disabilities. They've asked me once or twice to come in and do an appraisal on different things. Then, of course, we have the Julia Farr Housing Association short-stay Miranth House here. I occasionally go up there and chat to people visiting Strathabryn. Of course, we have plenty of work to do with the board at CLASS and Enhanced Lifestyles.

Then I have my gardening. I set my garden up over the last 12 years or so, just so I can be a part of it and be in it, because I knew at some stage I'd be in an electric chair, and I wouldn't be able to do a whole lot. It's pretty low maintenance. My house is a three bedroom, full size house with a front yard and back yard. I grow orchids. I've got two in flower here at the moment - one is a cymbidium orchid. You know the ordinary ones you see with the long strappy leaves. It's an intermediate, which means it's not a really big flower, but there are 17 flowers on one stem and 16 on the other. The secret of growing orchids is location, location, location!

I've been deeply involved for so long with so many professional people that I really respect and admire what I've learned from them; I soak that sort of stuff up. I was President of the Physical Disability Council of South Australia, I was Chairman of the APN Consumer Advisory Group, and I was intensely aware that what we were all achieving at the time was a very formative thing for the future. I was completely absorbed by what I felt was absolutely necessary ... a better life. I don't think life should ever stand still.

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