Neil’s Story

Neil wrote his own story.

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Acquiring a disability

I’m 50 years old and live with partial (also known as incomplete) quadriplegia. I had a boating accident in 1976 at Goolwa and broke my neck. It means I can’t do all the things I dreamed of when I was a kid. I lost the use of both my legs and I have only partial use of my arms. I wasn’t able to fulfill my dream of being a farmer on my parent’s farm at Kapinnie, 100 kilometres from Port Lincoln.

I really don’t remember how I responded to the diagnosis. I was very lucky to have a good family and community in the country. I think that makes a big difference, the country versus metropolitan. My brother was basically my arms and legs for many a year from there on.

I was adopted into my family at birth, along with my brother and sister. We all went to a private school in Adelaide. I recently found my birth mother. She lives in Germany and doesn’t speak English so I hope to be heading to Germany sometime in the next 12 months to meet her, my half twin sisters, half-brother and their families.

My attitude to the disability

I dislike the disability now and I probably disliked it then, but I have the attitude that I’ve only got one life, and I’ll make the best of what’s left of it with the help of my family, my community and the people around me. I think that was my attitude all along.

I always say I was probably young enough not to have a bad attitude. I was only 14 turning 15 when I had my accident. I suppose everybody took me in, in our local community. After eight months in hospital I returned to the farm, and I just became one of them. That was probably the best thing that could have happened to me.

I had six months at home on the farm with my parents and my brother. My sister was still at college. I used to push down to the sheds and sweep up. I just tried to be a part of that family. I tried to do what everybody else was doing to be happy.

Lucky to be alive

I believe I’ve got a wonderful life. I’m lucky. Firstly I’m alive, which is a blessing in disguise. Unfortunately, my family’s had so much tragedy. I lost my sister nine years ago after a car accident, and my Mum died six months after that from a terminal illness. So I just think I’m lucky because I’m alive!

My attitude to so much loss is tattooed on my arm “Such is Life”. Unfortunately, these things happen. We have automobiles and do things that involve risk, and I just feel lucky that I’m alive. I’ve had a chance to do many things in my life.
I’m no different to most other people. I think the majority of people want the best for themselves and the people around them.

I'd describe myself as a reasonably self-motivated person and I receive a lot of motivation from people around me to keep going. I see myself as fairly fun-loving. I'm proud that I've done things in my life, like the Sailing World Championships and trips away. I'm proud that I've been able to work most of my life since the age of about 20.

Experiencing the freedom of sailing

I was lucky enough to be part of two South Australian athletic teams in the early days after my accident. We went to Mount Gambier and Broken Hill, (not that I was great), but it was a chance to do it. I've sailed on 50 foot yachts; I've sailed on 14 foot skiffs in the Port Lincoln harbour. The freedom of being on a 14 foot skiff! They are a very fast boat, and the freedom I felt was just amazing. I've sailed in world championships in Victoria in access dinghies in the Liberty class.

Travelling abilities

I did a bit of travelling in 2003 with a carer. I drove from Port Lincoln across the Nullabor. Once we got to Perth, we went up to Broome and turned around and came back down through the middle of Western Australia. It was great.

My Falcon station wagon is modified so that I can drive it. 2011 was the year of an amazing journey with my partner. I had a 27-30 foot fifth wheeler (like a sophisticated caravan or a semitrailer) built in 2009, and we spent five months and one week, travelling up through the Northern Territory, out to Borroloola and King Ash Bay, and up through to Darwin. Then we went back down to Katherine and across to Broome, down the West Coast and home again.

At times it was hard getting in and out of the truck that tows the fifth wheeler. I have to be put in a sling, and use a twelve volt electric hoist to get up onto the seat which swings out from the vehicle, all built by Roadmaster Caravans in Adelaide who did an amazing job. Every time the person building it came across a problem, he'd ring me, or if I came across a problem, we'd talk about it in order to build a purpose built caravan and truck for myself.

The caravan was built so that the floor plan was fairly open. All the tables fold up or down to the walls. My bed folds up into the wall and becomes a couch during the day. You take the cushions off at night and press a button, and it comes down into a bed. It has a full shower and toilet in the back of the van.

Surround yourself with the right people

I think it was beneficial for me to spend time at the farm and then go back to Adelaide where I lived at Regency Park, which at the time was the Crippled Children's Association. I came back to Lincoln in 1982, and I think if you surround yourself with good people, things happen for you.

]I have the best carers anyone could want and good people around me. I believe if you have the right people around you with the right attitude, then you will go out and live. There is no need to sit back and say “Poor me”.

From the nursing home to community

I lived in the Mathew Flinders Nursing Home in Port Lincoln for six years after I became too old to live at the Crippled Children's Association. Naturally I wanted to get out of the nursing home so I wrote a lot of letters to politicians and government people saying it wasn't right. For the amount of money it was costing to keep me in Matthew Flinders or in an institution, they could keep me in my own supported accommodation.

Living independently

Eventually, not only through myself but through a lot of people doing the same thing, the care attendance scheme evolved, which is now Disability Services. They used the money to enable people to live independently, but I was the first country South Australian to live independently, in a unit the Housing Trust built specifically for me in a block of units in Port Lincoln. In Christmas 1987 I moved in there, and I really haven't looked back.

A love of music

I love music. Music is a huge source of pleasure and whenever I can I get to things like WOMAD or a concert in Adelaide. At times I make a point to go backstage and try to meet some of the artists I love. Music means so much to me.

Friends

I've known my best mate Kym since we were kids. I see him probably four or five times a year and we talk a lot on the phone. I've known most of my friends since 1982/1983, and we do things together. I like to get outside, I love the sun. I like photography as well and I take photos.

The importance of work

I've worked in a car yard as a spare parts service and sales assistant. I've worked in the fishing industry as a clerk doing wages and I've done most of the bookwork in running my parents farm. I've also worked in my current job for a disability enterprise, that's part of the Bedford Group, for more than 17 years. Basically I've worked as a clerk answering phones, doing BAS, WorkCover, tax, invoicing and these days, a lot more OH&S stuff.

I think work is very important. I'm not sure I could live in Port Lincoln or anywhere these days without working. I'd just go stir crazy sitting at home. I do not understand why anybody would want to sit at home and do nothing. I would have to volunteer if I didn't have a job somewhere.I only work part-time because I don't have to work full-time.
Working part-time allows you to be part of the community. Work enables me to give to those less fortunate than myself, particularly in the industry that I am working. I also get a lot back from those people because most of the people I work with have a disability, and most have the attitude "It's a privilege to have a job, and not a right". That's why I love my job because I now know and understand that attitude. I am lucky to have a job that I love.

Self managed funding

I have individualised or self-managed funding. I am part of the pilot scheme for Disability SA. My reason for taking part is I hope to see wherever possible, that people living with disability can take more control of their life, their care, and how much care they get. Unfortunately, we pay a percentage of our package to an organisation. If we administer our own funds, and are able to employ carers, we will have in the vicinity of 25 per cent more care in most cases. It all has to be set up and done legally with tax and WorkCover and superannuation.

I don't want any shortcuts, but that's the reason I did it because I want to see that happen. I want to see that happen in my lifetime because, as it stands at the moment, the organisations that provide our carers put their fees up every year. Their fees go up by more than CPI; so therefore, we get less care every year, and sooner or later, we won't have any care unless the government tops up more than they are now. We should have the ability to employ our carers, to cut out paying people wages in the non-caring part of these organisations.

I don't want to be paying organisations money when I can't get enough care. If I wasn't working, well I'd lose some of my care for a start, because I get care to help me to get to and from work which also helps me in other areas, so you've really got to look at how you can maximize the dollars the government is giving out. Some organisations are charging huge dollars, and not paying their carers what they should be getting. Carers don't hang around if they're not getting paid fairly.

Suggestions to others

As I said, I don't *like* being in a wheelchair, but I *know* that I have no choice, and that in my lifetime, there will be no cure for quadriplegia. So I can't sit back and wait for that to happen because if I sat back and waited and moped around and carried on, then people wouldn't want to be around me, and I don't want that. I want people around me, and I want to be around people.

I always say, "We're alive!" There are lots of families who don't have a quadriplegic son, because their son was fatally injured. I'd like to think that we could stop quadriplegia being around, but for now, I'd just say, "Look, you've got a chance at life; there are lots of things you can do."

I would implore anybody with a disability just to take the bull by the horns and make the best of the situation, and just say, "Look, I don't like being where I am, but let's make the best of it and move on. Let's move on, not backwards; let's look for the light, not the darkness, and we can all work together and make each other's lives better, whether that be working with your community or working with other people living with disability. We've got one chance at it, so let's live that one chance!"

As a young kid I would say "Look, you've got one chance. You can have a go at this. Get into your community, and don't be shy; don't stay at home because your community is made up of the people who will help you. Always ask for help. Asking for help doesn't necessarily make you less of a person." Sometimes I do things, and it might take me 45 minutes when somebody else could do it in five or ten minutes. "Take that help to get that stuff done properly, and quickly, so that you can go and do the more meaningful things in life, rather than have to struggle because people think that's independence."

So get out there and do things, and get involved with people and take help wherever you can if you need it because those things that take an hour to do are all consuming. I say to people "You should be doing the things that come easy to you, and if people are there to help you do the things that are really hard for you, take that help."

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