

Nerida's Story

Nerida told her story in a recorded interview. This is the transcript.

I am 41 years of age and I've had multiple sclerosis (MS) for 17 years. I live at Kangaroo Ground in Victoria, which is a north-eastern suburb of Melbourne. I live with my husband, Peter and two girls; Terissa who is 15, and Andrea who is 11 years of age.

We are in Melbourne because my husband is a network administrator at Wycliffe Bible Translators. I help out in a few administration areas and also meeting with people when that's needed. We moved to Melbourne from country South Australia 8 years ago.

We think Kangaroo Ground is a great place to be as it is a scenic environment, which is especially good for me now that I rely on my wheelchair for mobility and spend a lot of time sitting around. I can see the seasons changing and the local kangaroos grazing. Because we live and work in the same place it's very convenient as Peter is able to help me out when needed.

I have many friends and people who are happy to help us out. We live just down the road from the primary school where Andrea is in her final year. Terissa catches a bus to her high school from the primary school, so that's very convenient.

One of the biggest hurdles we have is that I'm unable to drive so Peter is the taxi for the girls with their social calendar and that can put a bit of a strain on family life. I'm concerned, particularly about Peter, that he is unable to be involved in other activities outside the family. Just because he's the taxi driver, it doesn't mean that he has to miss out.

With only one driver it puts limitations on what we can be involved with. We want the girls to be involved in as much as they'd like, but it's hard when things clash.

For example, on Wednesdays Andrea has hockey practice and Terissa is involved in a school group at Warrandyte where they're setting up a project with Bendigo Bank and we also have Bible-study at our house. Everything falls on the same day! We often have to negotiate whose turn it is to have transport or who's prepared to find a lift from someone else.

We're fortunate that we have family in Melbourne. I have a sister and a brother, who love to help out. We have many people in the church, here at the Wycliffe Centre, and the school Mums who are quite willing to help us out.

I guess the only limitation is that we get sick of asking for help, so there are times when it's available but we ourselves don't want to keep asking. This is probably because we feel others have a busy life themselves. It's a mental struggle I have—continually needing to ask for help—it's as if I am losing control of yet another thing.

I now have an individual support package and a case manager. Our application took three years working with the [MS Society](#) OT (occupational therapist) to receive

this support package. It gives me eleven and a half hours of personal care and domestic help.

I also receive massage therapy as part of this package. The local Council is subsidising a carer putting me to bed three nights a week. That's been awesome. It has certainly taken a load off Peter and the girls, so that they can breathe a bit. The package is also a great help to us financially as we would not be able to fund all this help ourselves.

I've got to the point where I prefer particular carers and I am confident enough to ask for these. I have had some very interesting carers come in. For example, I had two young men who came and did my housework. Fortunately it was holidays at the time as my daughters had to show them how to clean a toilet and hang up clothes.

They were hanging up towels long-ways so the washing wouldn't all fit! I also had to explain that vacuuming was like mowing a lawn, but I don't think they had mown a lawn either! It was a very interesting time but after having them come back, I had to ring up and say, "Look, I'm really sorry, but it's too exhausting". So, I haven't had them again.

We are impressed with how our girls help with the housework and meal preparation. It has often been that our eldest daughter took the leadership in housework, but recently our younger daughter has initiated the cooking and will often say to her big sister, "No, I've got control over this, we'll do it my way".

I would encourage others to go through the process of acquiring an Individual Support Package but not to expect it to happen in a week or month, or even within a year—be prepared to wait quite a while for it, but it's worth the wait.

Sometimes when you're applying for things, the wording of documents makes it almost sound like: "Why are you asking for this?" When we were going through applying for this package, at one stage we received some documentation worded, "This is support that you cannot get from family and friends, and should not simply replace that."

My daughter read it and said, "Oh Mum, we can help, I won't complain any more, don't worry, I can do it". To us it was implying that we should be relying on our family and our friends and extended family to fill in the gaps, like do the housework, do the showering etc., and you can't ask for support unless you cannot get support from family and friends.

We thought that is really rude of the government expecting family and friends to stop their lives to look after me. At the same time as they were saying that this package is to improve your lifestyle, they were turning around and saying, "But we're not giving it to you unless you've exhausted all other possibilities".

When making my application for an Individual Support Package I was fortunate that the MS Society OT (occupational therapist) helped me and gave good advice. The OT was very good and she advised me to put down the worst case scenario.

I found this difficult, as I am a fairly positive person, I don't tend to look at things from the worst perspective or in a negative way, but that didn't help when making my application!

The interesting thing is that when I look back now, as my MS condition has deteriorated since my initial application, it was great that I had her as an advocate to help me see the reality of my disability.

If you want to apply for a package like this I would suggest you seek help from a health professional who can then direct you to someone like an OT who knows what is available. It is difficult as a person in the public to know how you can receive help and what help is available.

I think it's really important to be involved in things you like doing when you are living with disability. For example, up at the local primary school for the last few years I've been doing a wheelchair challenge with the grade 5 and 6 students.

I challenge them to spend a day in a wheelchair to experience what it is like. This year I added to the challenge, asking students to get people to sponsor them to raise money for wheelchairs designed for Third World countries.

The children were so excited about spending the day in a wheelchair and ended up raising a lot of money doing it. As part of the experience I demonstrated how I travel in a vehicle with my chair locked in position, I then need a vest because my balance is not too good and then I need to put a headrest on my wheelchair.

One of the students commented, "All of this just to come down the road!" I replied, "Yes, you can't just decide to be somewhere in five minutes, it takes at least 10 minutes just to get in the car".

I enjoy giving the students this experience as they love to see what it's like to be in a wheelchair. The parents often thank me because I've given their children a chance to see what it's like to have to rely on a wheelchair for your mobility and other people to help you do things.

Students also participate in the MS Readathon. I used to go around to schools sharing what MS was and the symptoms I had. However, my youngest daughter found it very difficult to be in the school with Mum telling other students about her symptoms. When she finishes primary school I hope to be more involved with the MS Readathon.

I also teach religious education at the school once a week, again, it's being part of the community. I think it is good for the students because they get to talk and relate to a person in a wheelchair. Initially they're not sure how to relate to me, but before long they're just chatting and forget that I'm in a wheelchair.

It also gives the students an opportunity to help me because I need a lot of help as I have limited use of my arms and hands. Assisting me benefits them. They realise they are not going to hurt me, or 'get what she's got'—they enjoy helping.

Being involved takes a lot of effort and is exhausting; I need help. I would encourage people to take up offers when people ask, "Can I help you out with this?" For

example, I have a friend who helps me prepare for my religious instruction classes, because I couldn't actually do it without someone physically getting the materials out and helping me prepare for the lessons. My friend comes once a week for an hour and helps me, which means that I'm able to be involved with this.

Being involved in the community is very important to me. I must admit there are times when I'd rather just be a hermit and stay home and not have the hassle of getting out. However, when I make the effort I enjoy being with people.

It's worth giving it a go, and then when you do come across barriers, like you can't get into a building because there are stairs, people are more than happy to figure out a way that you can be involved. I do have a lot of pride and resist receiving help because I just want to be able to do things myself.

I do have to let go of a lot of control, to let people in. But at the same time I think that people, in turn, need to learn that they can't simply take over and just help you, they need to let you be involved in making decisions; it's a two-way thing.

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