

Elizabeth's Story

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

Hi, I am Elizabeth. I was born in Bourke, New South Wales (NSW). I live in Tasmania at the moment (although not for much longer) but I don't fall into the Tasmanian demographic of having been more likely to develop MS (multiple sclerosis).

(Editor's Note: Tasmania has a higher incidence of multiple sclerosis than mainland Australia, although the reason is unknown.)

I was in Bourke, NSW where I just grew up in the sun. So I had plenty of Vitamin D, but obviously something was going wrong—if they're right about the Vitamin D thing. So that was from quite young because, as I said, I was born there.

I always loved the heat—which goes against MS, because the heat makes us worse. And even though I still love the heat, it *does* make me worse but then, so does the cold. It's kind of a Catch-22 I find myself in. I love being warm, but to a certain point, then I can't walk and start slurring and it's a bit messy.

I came to visit a friend in Tasmania 13 years ago, and it wasn't the cold that made me stay here (because it was cooler). It was the fact that life was simpler and slower. That's not to insult the Tasmanian way of life. It's just that life in general is simpler.

There are less people for services. Take for example going to the hospital. If you have to see a specialist, it doesn't take as long because there's not as many of us. So it's easier to get into. We live in Huonville. It's half an hour to the hospital. You get a park almost immediately. You can virtually park out the front and just walk in, and it's a small hospital, so it's all really user-friendly.

That was the thing about Tasmania that I like the most, its user-friendliness, which really assists someone with MS, because when I started having trouble walking it wasn't so bad because you could park near where you had to go. Even if you couldn't get a disability park, you're still within a short distance of wherever you were going, whether it was the hospital or just shopping. So everything's just easier here.

But I am not going to be staying here for very much longer, because my family, my partner and our two children, aren't here. There's another thing that maybe at this point I should mention; I'm also pregnant.

(Editor's note: Elizabeth and William welcomed their third child, a daughter, after this interview was recorded.)

It wasn't planned. It was a bit of a surprise, and now we're quite excited, I suppose. At my age I thought it was menopause (I'm 44), and I had thought, "Oh well, that's

handy,” because we’re about to embark on a two year trip around Australia in a bus—a converted bus—which we were inspired to do by William, my partner.

He goes to a carers’ meeting, for carers of people with MS, and one of the people at the said at meeting: “I really want to go around Australia in a bus. I’m going to do that one day.” And one of the carers said, “Do it now, do it now.” When William asked why, he said, “Because I did when my partner was diagnosed and if we’d waited we couldn’t have done it because she’s now in care. She’s in 24-hour care and she’s in a really bad way”.

William came home and said, “We’ve got to do it now. I know that’s not going to happen to you, but you never know, and it’s not just with MS, it’s with anything”. It kind of inspired me, I’m not sure if inspired is the right word—it urged us to do it now.

So last year in about September, almost immediately, we went out looking at buses and bought one. We put the house on the market and it sold in a day. It was all just happening—it is very exciting. William’s finished work, he’s taken leave without pay, without an intention to come back, because the other thing that we’re also doing on the mainland as we drive around is to find somewhere that everyone would like to live.

If it’s too hot we move on, and if it’s too cold we keep driving. Because our children are Tasmanian they not so much like the cold as are used to it, whereas I just never ever got used to it. I have just got worse over the years coping with the cold. William’s from Tasmania, born and bred—he loves the cold—but he’s always said everyone can acclimatise, so he thinks we’ll be fine.

So, basically we’re doing that, in a bit of a hurry before we are too old to enjoy it. But you never know with anyone, it’s not just MS that can stand in the way. We’ve known people, who were going to do something like that, but then died of a heart attack.

They were planning to move to Mexico, bought a house, sold their house, the whole thing, and three weeks before they were due to go he died of a heart attack. They wanted to do it for so many years. They finally got around to it but just didn’t get there. So now she’s still here, and thinking, “Oh gosh, I wish that hadn’t happened. I wish we’d done it sooner”.

Hence, we have planned to start our journey at the end of May this year (2011). What we have to do is go and visit my parents first because they live in NSW and they’re quite old, so we want to spend a couple of months there, and that’s blown out now to four months so that I can have the baby. So the plan now is that by November we should be in Darwin—or on the way—on the way up the coast to our adventure.

With regards to my MS, walking is difficult but I can still do it. I have a walking stick but I try not to use it because it makes me feel disabled. So, instead, I sway all over the place and fall over a lot, but I still would rather keep trying.

I also have to rely on toilet stops. You may be aware of bladder issues with MS, and I find that really disabling because whenever I go somewhere (if we just drive to Hobart from here it takes half-an-hour) I will often have to stop half-way and go to the loo. And then when I get there the first thing I have to do is go to the loo—it's always at the back of my mind. So the good thing about being on the bus is that we'll have a toilet with us, so that will be good.

I'm not on any medications so I don't have to worry about keeping anything cold, or finding a chemist, or anything like that. I was on Naltrexone, an oral medication, and I stopped that because of the baby.

And the pregnancy and the breast-feeding will protect me from MS because it's in the literature that when you're pregnant and breast-feeding MS kind of takes a back seat. So it's amazing not to be affected by MS.

So, I wish the researchers would hook into that because there's got to be something there that's relevant. Apparently the natural steroids are high during pregnancy—I'm not sure why, it could be a pain thing—but it remains high while you're breast-feeding. So that's handy.

I do have really bad morning sickness, which I had with the first two children but that was 10 years ago and I had it really badly but not for as long. I still have it as I'm nearly four months pregnant. So any exercise is really hard because I have to keep stopping and hoping that I don't throw up. There are some days that I think, "No I'm not going for a walk today, it's too dangerous".

I have had MS since about 1988, I've sort of lost count, 23 years? So, all things considered, I'm in really good shape. Here I need to mention that William, my partner, he's great. I've had other partners, I've been married before, and none of them ever coped with the fact that I had to go to the toilet so much.

We'd be out driving and I'd say I had to go to the toilet, and William will make sure that we get there. He always makes sure that everything's okay. And that's just great. He's really supportive, and just doesn't say, "Oh, are you sure? Oh, it's really inconvenient". And it never frightened him. From the beginning it was, "Oh yeah, no big deal, there's usually something wrong with everyone, in some way. Everyone has some issues".

If I was going to give someone a tip it is: "Shop around for a decent partner." If he or she makes a big deal about having to stop at the toilet all the time, just move on. Because over the years it has got worse, not better. So if they're not coping at the beginning, it can just escalate into something insurmountable, which has happened to me in the past.

Just little things like bladder trouble, or trouble walking, or having to get a park close to where we're going, and if we don't, having to walk it and having to stop along the way, with a partner getting really impatient and saying, "Oh come on, what's wrong with you?" And I reply, "Gee, I have MS". Yeah, so that supportive partner is really vital.

And also friends! You need friends like that as well. If you've got a friend who says, "Come on, don't be silly. You'll be alright." Then ditch them as well.

With regards to accessing support, I suppose I didn't need much support in NSW because it was so early and I really wasn't that much affected. Since I've been in Tasmania, with the Tasmanian support system being so good, I found that the [Tasmanian MS Society](#) here in Hobart, has been really approachable and just great.

If I've needed an urgent appointment with a neurologist I'd just ring the MS Society and they'd just organise it, and they have counselling services as well, which is really handy with things that have happened along the way. And they'd be able to just talk over the phone, or I can go in there within a couple of days.

Whereas on the mainland because there's so many people it wouldn't be the same, because I would just assume that if the hospital systems is in such a mess then surely it would be kind of similar, because it's the health system. I have a friend on the mainland who also has MS and she doesn't ever go there because she says there's no point, they're useless, whatever that means.

So in future after our trip I would like to live somewhere warm, but somewhere small. Although I like certain aspects of the city, I don't like the hospital system. And especially as MS has progressed the crowds, they bother me but they don't frighten me.

Especially if I'm walking and I don't have my walking stick it's just hard—physically hard. And if I try and go to the toilet and there'll be a line-up of 20 people and I'll think, "Oh my god, oh no." Whereas that just doesn't happen in Tasmania.

So it's been great and my family has been a great support, especially family, with the children, with the babies, but William's mother has been a godsend, an absolute godsend.

There were days when I was exhausted and she would just come and look after the children, and I would sleep. It was really handy having that family support because a lot of people that I know who have MS have said things like, "Oh, you shouldn't have children or you shouldn't have more children because it's all so hard".

It is hard, but if you've got the support it's doable. It's like most people we speak to, say, "Oh, I want to do that". And I just say, "Do it". Thus I'm trying to be motivational, and not put a downer on others.

For me my biggest inspiration is my children. If they weren't there I wouldn't get up in the morning. I'd get up around midday, so they help keep me going. They give me the incentive to keep going.

My ten year old seems to get it more than my eight year old. And Valentine's great. If I fall over he'll come running and help me up, and he never laughs, not until I start laughing. So it's like if we're not having fun something's gone wrong.

I always have faith in myself, like when some doctors insist you need to get a drug. Because I was on Betaferon for a number of years and the stuff is dreadful and when I went off it doctors kept saying, "Oh, you won't qualify for the cure when it comes, and it will be all dreadful and you'll be in a wheelchair".

I just had to ignore that and think, "No, I'm not listening to you. I've tried that but it didn't work. Go away!" So I had to stand my ground, with my beliefs in that, even though doctors kept saying, "Oh, you'll be sorry. You need to do this."

I thought, no, "I've read the research, I've tried the drug and it just didn't work." It didn't work for me and I'm much happier now not on anything because I had to inject every other day and it was awful, it was absolutely dreadful. I was hysterical towards the end because I hate needles.

I remember thinking, "This is ridiculous. I can't do this." And I thought, "No, this is what I believe, so just do it". And I'm glad I've done it. And I suppose with the diagnosis it was sort of a similar thing. It took years to diagnose, and doctors kept saying, "There's nothing wrong with you", and I kept insisting, and finally I was diagnosed.

If I hadn't insisted it might have taken I don't know how long, because I know people who have been told, "There's nothing wrong with you," and gone away for five or ten years, and then come back to find out, "Oh, actually that was MS".

So it's just it's good to be validated. And, because I started to think doctors were sort of saying, "Look, maybe you need to see a psychiatrist, because this could be all in your head". And I started to think, "Oh my god, I'm going mad".

But when I got the diagnosis I thought, "Oh, thank goodness". I'm glad I insisted and kept going back to doctors until finally one of them would listen and do the right tests and, yes, I was diagnosed with MS.

So that was an important part of my journey. Although it was a particularly distressing part of my journey it was important that I just kept up with my belief that there was something wrong.

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