

PARENTHOOD

*What's it like to be a parent with ataxia? These are the **personal** views of some Friends.*

I'd have ten more babies. (Liz)

I love being a mum. It's so rewarding. Emily's at the age (two and a half) where you can have a conversation. It's as if she know's what I've got. She helps me if I have a fall. She'll sit down with me, rub my leg and say, "It's OK, Mummy, don't worry". And if I cry, she gets a tissue and wipes my face. If I drop something, she'll pick it up – I don't ask her. If the phone rings, she'll get it and pass it to me.

But I'm not saying it's easy. She's realised that to change her nappy she has to come to me, and I can sit waiting and calling her for 15 minutes! Sometimes it feels like the day is never going to end. Being a parent is 24/7, and being a disabled parent is tough work.

I am very lucky, though. I have a wonderful husband who's a real 'hands on' daddy! He does his share, from changing nappies to bathing, or just taking over when I'm really tired. And I have a wonderful family close by.

I love Emily so much, and if I could, I'd have ten more babies. I'm not saying it's easy but I am saying it's worth it!

It was as if I was the only disabled mother in Manchester demanding to look after her own child. (Nicola)

Through my pregnancy, I searched for information on being a mum with Friedreich's ataxia - there was nothing. I didn't go to parent craft classes because there was no practical advice from a wheelchair point of view.

Giving birth, I was to discover, was the easy part. Now the real nightmare began. I was ready to go home with my baby, Jack, like any other mother, but I had to stay in hospital until social services sorted out some help.

I was stuck in the maternity ward, feeling extremely frustrated and distressed. It was bad enough not being able to look after myself (all the toilets and bathrooms were pretty inaccessible to me). But it was not being able to do anything for my new baby that I found unbearable. I couldn't reach anything and little effort was made to try and involve me in Jack's daily care because staff weren't available.

On the day of my release, my worries were far from over. After my mum went home and my partner Andy went back to work, things began to go wrong. The woman sent by social services was useless - she was there to look after Jack, not to help me look after Jack. The only thing social services offered was a carer for me and a separate person to look after Jack. In the end Andy gave up work to stay at home to help me with Jack.

Life was easier once Jack got a bit older but he was still quite a handful and I think Andy had had enough of being at home! Social services were very unhelpful. Andy and I finally got private help. I am still angry with social services for their blinkered, negative attitudes towards my desire to look after my own baby.

Twelve years later, Jack is in year 8. Andy and I are very proud of him - he's developing into a lovely boy, with a flair for writing and art, something we share. My eyesight has been deteriorating so now I can see very little - this means I can feel left out. But I am totally involved in Jack's growing up because both boys tell me everything!

The fun has returned. (Simon)

Being a Dad (or even being a husband) was something that I'd never considered five or six years ago. When I was single I hated times like Christmas and birthdays. But now our son Ben's around, the fun has returned.

Family days out are more enjoyable since we've had a wheelchair accessible vehicle, allowing me to take my electric wheelchair. This means my wife can look after our son and not worry about me.

Of course, having Friedreich's ataxia prevents me enjoying some activities with my son, who's now two and a half, such as playing football and other games. But I think Ben is becoming more and more aware of my limits.

My wife mostly deals with the physical side of things to do with our son's needs. Like every parent, I worry about my son when he is out of sight and this is increasing the older he gets. Although there are a lot of things to worry about, especially having Friedreich's ataxia, being a Dad makes me extremely proud and our son brings us so much pleasure.

My child would have a 50% chance of developing SCA2 (Martin)

Yes, I believe that children can be wonderful. But parenthood can involve a lot more than who does this and who does that. Family planning is fundamental to parenthood, and for many people with ataxia this involves extra issues and considerations.

My sister and I were born long before my father developed and was diagnosed with spinocerebellar ataxia type 2 (SCA2). SCA2 is dominantly inherited. There is a fifty percent chance that children will develop the condition. I was diagnosed with SCA2 aged 35, which caused my parents huge distress. Even now, we worry that my sister may develop SCA symptoms, and that her children will be at risk.

My personal parenthood decision is not to bring a child into this world knowing there's a fifty percent chance they will develop SCA2. Prenatal testing is possible for SCA2 but would involve the decision to terminate any foetus with the condition.

We are here for the kids. (Fay)

My first girl, Jade, was born in 1989, followed by Fleur almost two years later. I had no trouble during the pregnancies until the last months when the extra weight was hard to carry with my balance problems. I was very lucky, my husband Steve has been willing to help all the way through. I breast fed both girls - so much more convenient!

I got help from REMAP, a charity that enlists voluntary, usually retired skilled people, to adapt or modify things for you. Social services did nothing when I just had one child. I went into a wheelchair soon after I had Jade, simply because I was so tired. Steve was working nights so I had to manage the night feeds on my own, not easy but again breast feeding helped. Then along came Fleur. A whole new ball game with a two year old and a new born! Jade soon learnt how to do buttons, tie laces and dress herself and showed Fleur.

Neither Steve nor I had parents able to help, so social services eventually rewarded us with a weekend a month respite care. I got around on a pavement scooter with an adapted bike seat on the back. The talk of the town, we were!

When they were older, the girls walked by my side. I took them to Mother and Toddler groups like any mum, and then to school. I was always welcomed.

Once they were both at school, I helped by listening to the children's reading. Their friends have never stared at me. In fact, they often say it's 'cool' to have a mum in a wheelchair.

Steve did stop work when Fleur was two. Finding holidays for kids and the wheelchair isn't easy. But in 2000 we had our first trip abroad in Gran Canaria.

The girls are now 14 and 16. There are the problems any other parent of teenagers has - they don't seem to be caused by ataxia. The one exception is that neither of us works. We are here for the kids, as I often remind them, but we're not as well off as some of their friends. Being a mum has been hard work but very rewarding.

For me, mum is just mum (Jade, 16)

I don't really notice the wheelchair. When I was little, having a mum in a wheelchair was excellent. We were the same height, we got to skip the queues at theme parks. At school, everyone thought my mum was 'well cool'. My friends ignored the wheelchair and saw her for her.

She shouts and nags like normal ... with a couple of extra wheels and a higher demand for cups of tea. Having mum and dad at home every day when I get home from school is another advantage which most of my friends miss out on. So I see myself as quite lucky really!

I personally think that the greatest gift, no matter what your age, nationality or ability, is the gift of children. (Steve)

I have three children, Aimee 14, Hannah 12 and Oliver 4. I've found over the years the most difficult thing for a father in my position is my inability to play with my children. But many of my interests and hobbies are also interests of theirs. Aimee loves music, (although her tastes are questionable,) sci-fi films and computer games. Hannah enjoys listening to and playing music, art and writing. Oliver is a typical boy who likes to climb and play rough. We watch cartoons and films together and play shoot em up games on the PC.

Although I would love to be able to play football and rugby with my son, or swim with them, it isn't going to happen. I can still be a part of it by watching, supporting and offering encouragement.

Parents with a disability need to find a balance between what they can do, and what they wish they were able to do. When you've done that, you can prosper as a parent.

I should mention that there may often be the worry of you passing this nasty gene [for Friedreich's ataxia] by mixing it with your partner's nasty gene. At my genetic counselling, it was decided that chances of my wife being a carrier were not worth worrying over. It will cross your mind, but I don't dwell on it.

Our thanks to the parents who contributed this information.

Genetic testing

If you have a recessively inherited ataxia, such as Friedreich's ataxia, your partner can be tested to see if they are a carrier. If this is not the case, your children will not inherit ataxia but they will be carriers. If you have a dominantly inherited ataxia, for example one of the SCAs, there is a statistical 50 percent chance that your child will inherit the ataxia. More detailed information is in our leaflet *Genetics and Ataxia*. Prenatal tests exist for ataxias where the gene has been identified. Complex issues are involved, including the decision to terminate a pregnancy. They should be explored before testing with a genetic counsellor.

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We have a number of other publications on the ataxias available free of charge. We publish a quarterly magazine called *The Ataxian* containing articles on research, living with ataxia and other relevant information. Our website also contains news of research projects.

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