



Chrissie

It was scary when we were first told. We made the mistake of coming home and googling. Some of the things were horrible, but everyone's different.

John had always worked, so six months after his first operation he was back at work. Six months after that they'd pensioned him off. Two years later it got to the point where he was coughing and blacking out. There were a couple of scary moments, and he's had about sixteen operations since then.

People think it just affects John, but it affects the whole family. You learn to handle what you can. The kids seem to be all right. Chloe's 19 and she's studying nursing. Keith is 15 and at school. I think they're okay because they grew up with it. Keith struggles a bit more sometimes, but he reckons that dad isn't sick, that it's just dad.

I did wonder if being together all the time was going to make us or break us. It was a big adjustment, but we've adjusted together. I think we're a lot closer now.

We talk more, and we're more open with each other. I think that with John being sick, we don't get petty about things. There are bigger things in life to worry about.

I could not possibly comprehend what John goes through on a daily basis, let alone the pain. I don't even pretend to know what he's going through. Making sure he's comfortable is the most considerate thing I can do for him. The hardest thing is that he's put up with so much pain for so long that it has become normal to him. I really couldn't imagine it.

If I could swap, I would. It's hard to watch the person you love suffer every day. I would swap just to give him a day off from that. I know he doesn't suffer all the time but he suffers a lot, and I would take that from him in a heartbeat. I know he wouldn't want me to, but I would.

John

I was walking like I was drunk all the time. I couldn't walk on uneven ground, or in the dark. I was born with with Arnold-Chiari malformation, but there were no dramas until I was 27. Then I was told that I would die if I didn't have an operation, but that I might die if I had the operation. That was the scary part. I didn't know what to do. Catch 22.

I used to take life for granted; things that I used to do so easily and now I can't. It shocked the hell out of me. Simple things like getting out of bed and walking was so easy one day, then I was waking up and having to learn how to walk again. At first I thought, 'Why me?' but after being in rehab, I thought there's nothing wrong with me compared to others. That was a real eye opener.

Chrissie is there for me. I don't have to ask for anything. I think it would be hard to do everything all the time like Chrissie. She does all the driving, takes me to all my appointments, does all the mowing.

We were both working before the symptoms started, and we'd be apart all day. Now we're together all the time and I miss her when she's not here. I've learnt that family is really important.

It's brought us all closer I think. I can talk about anything with Chrissie and our kids. We don't take things for granted, because one day I might not be able to do it. I really want to last long enough to walk my daughter down the aisle.

I wouldn't want to change places with Chrissie, and I wouldn't want her to go through it. I wouldn't wish this on my worst enemy. It's cruel. It really takes away from you, especially being so young, and with young kids. It's hard with kids growing up, and not being able to play with them.