

Colin and Georgina **Early signs and diagnosis**

Colin

First symptoms, not that I knew it, but that I've never had a flat chest, which seemed odd, but that's characteristic of Kennedy's. Not that I knew I had Kennedy's, but cramp, especially in my 20s. Awful, awful cramp, and we kept thinking it's lack of salt, whatever.

Then we found out that my mother was a carrier, but I was doing manual work. And in '98 I was starting to find harder to get off the ground, harder to lift up things. And then the ultimate was super fit dad came almost last in a running race for his children and old men were going past me.

So that's with mum being a carrier. You start to put things together. We studiously ignored it. We knew there was nothing you could do about it, so we just kept on living a normal life. It wasn't that bad initially, didn't affect my life.

Georgina

I think we knew about it in '94 when there was a team over from the States. This is the first time we actually heard about Kennedy's disease and Colin's mother was tested and found to be a carrier. And it made sense that Colin was probably going to get it because of the cramp.

And so we knew to look out for it. But of course we look back and we realise he had cousins and an uncle or an uncle that I remember meeting who had problems with speaking. But it wasn't much else. And so you didn't know the severity, you didn't know how bad it could be.

At the same time Colin's brother in Australia was thinking he was getting MS, or thought he'd got MS, because he suddenly couldn't get up with friends skiing. And, he fell over, he couldn't get up. So we knew to look out for it.

But as Colin said, we just carried on and I think it was many years before we actually finally went to the doctors armed with sheet printed out from the internet because, you know, you didn't expect a GP to have any understanding of what Kennedy's disease was. We knew there's nothing they could do.