



Speaking from Experience *Huntington's Disease*

Transcript for chapter 4 of 10: Diagnosis & testing

Sally and Malcolm (has Huntington's) - From the time he was 12, he knew he was at risk and I think he always felt he was going to get it. The same with lots of people who develop Huntington's. They live their life to the full, because they think it's only going to get to a certain stage and they'll get sick. I thought that it was going to be liberating for him when he would find out that he hasn't got it. I felt that right up until the time that he got the result.

Jan - It's scary. It took me a lot of nerve to have the test. I knew for years that I could have it done, but I didn't.

Paul and Marion (has Huntington's) - Marion was being persuaded to be diagnosed, but she refused to be diagnosed. She had tests, but she didn't want to know the results.

Graeme (has Huntington's) and Katherine - It was 1991 when I was diagnosed. They said that I'd had it for about 18 months before that.

Sally and Malcolm – It was dreadful. We had a very young family, 3 children under four, when Malcolm decided to go for the test.

Paul and Marion – I didn't want to see her go through what her brother went through. It's very traumatic and very heartbreaking. I had to think about the kids.

Jan - I was scared because I thought, how long can I drive? How long can I put my make-up on? Can I do my mascara? Who's going to put my high heels on my feet. Who's going to light my cigarettes for me? [laughs] You know, they were major issues to cope with.

Paul and Marion - A lot of things went through my mind and I was very, very upset myself – more than upset – to see Marion like that. Because along the line I always hoped that she will skip it. That's the luck of the draw.

Graham (has Huntington's) and Jan - I feel I was bitter towards Graham, to start off with. But then I realised that we wouldn't have had our four children. We wouldn't have had, well Graham's had 50 good years. We've been married 24 years, or 25, I can't remember now... 27 years before this happened. And so, really, I guess we've been blessed in that way.

Graeme (has Huntington's) and Katherine - I was a bit shocked. But I'm the sort of person who's sort of been taught to take things on the chin, and my parents have sort of been like that. I didn't sort of worry that much. So, I just sort of kept rolling along.

Sally and Malcolm (has Huntington's) - I was a really big shock for me. Malcolm seemed to be relieved. And in some ways, although I'm really glad I'm not the one who's got Huntington's, it kind of relieved him of a lot of the responsibility that he'd been feeling.

Jan – When I knew I had the gene, it wasn't such a major focus of my life anymore, where as it was before. Now, it just went into its place and you just got on with life. Instead of



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running, which I did for 20 odd years, I stopped and faced it. It just went into its place. It's really hard to believe but you can put it into its place.