

Chapter two. The lucky one? The sister's story



I am Sandy's sister Wendy. Sandy is seven years older than me. So, from her point of view, as she was growing up, I was her annoying little sister. Geoff, our brother, is between us age-wise, which helped reduce the clashes we had. When Sandy left home at 18, she and I became friends (we weren't when we were younger) and ended up having babies within seven weeks of each other: her second, and my first child. That was a great time in my life; we were so close. I was tested for HD in 1997 and I do not have the gene. So, I am the lucky one of the three of us. I will not get the illness, and neither will my kids. My husband and mum will not have to watch me become more and more ill and unable to do all the things I love to do. I am the lucky one, aren't I?

About Dad

I grew up in a strange household. On one hand we were very lucky. Dad had a good job, we lived in a big house and had (on the surface) all the material things you could want. But the flip side was dad. He was so unpredictable, one minute loving and fun, the next yelling and abusive. Sandy once told me I never really knew dad, because by the time I arrived, he had changed. She was always much closer to him, I was definitely a mummy's girl; but then she was safe and consistent. He wasn't.

My teens were the worst. Thankfully he worked in Kuwait so we did not have to see much of him. When mum and dad eventually split up, I felt massive relief; I wouldn't have to see him anymore. Then he wrote and told me that if I wanted him to continue paying parental maintenance, I had to meet him every time he was in the UK and write to him while he was in Kuwait. I had no choice. We could not live without his money.

I did as he asked, and it was pure hell. When we met, he would spend all the time we were together telling me that the awful things he used to do, things that I had personally witnessed, had never happened. Mum had made it all up to make him look bad. I was seventeen, and my brain was being tied into knots. If it hadn't been for mum, I would be a total wreck. She kept me sane; she told me we didn't need the money that badly and that nothing was worth being treated like this. As soon as I turned eighteen I cut him off completely and had nothing to do with him for many years.

Learning you are at risk

My older daughter was a year old when we found out Dad had Huntington's Disease. Sandy knew first, but delayed telling me so I could enjoy my daughter's first birthday. A week or so later she broke the news to me. It didn't seem too major a deal at the time. He had previously been diagnosed with Cerebella Ataxia, so a new diagnosis of yet another illness we had heard very little about was not too daunting. But, after a visit to my doctor to find out more, things began to slowly sink in.

I realized that I might not be around to watch my daughter grow up. I might not be at her wedding. I remember taking her to a fair and acting as if everything I did with her would be the last time. I wanted her to have such a great day that she would always remember me like this, her mum, full of life and happy.

Although I remember certain things about those years when I was at risk of inheriting Huntington's, my defence mechanism is to forget. Just as I had managed to forget all the awful things that happened in my childhood. You don't really forget of course. You just blank them out, as it is too painful to live with constantly recurring memories of the violence, the drinking and the fights. The one question that always stuck with me as I was growing up was 'Why is my dad not like other people's?' I just thought he was an awful person. Even with the diagnosis of HD I could not suddenly wipe those years away and say "It wasn't him, it was the disease". I am afraid it does not work like that for me.

So, I didn't really have a dad. Lots of people don't. But to me it didn't really matter that much, because I had a loving mum, a brother and as I grew older, a relationship with my sister. I know Sandy would agree that we did not get on in the early years. She was seven years older than me and I was the annoying baby sister. It was only after she left home at 18 that we became friends.