

Chapter seven. A Cruel Inheritance: Brian's story



Brian Gibson, 25.5.36 to 18.11.95. Brian was a bright working class boy, a Geordie from the North-East of England. He became a trainee journalist and quickly rose through the ranks, first as a newspaper reporter before moving into TV. He was a TV news journalist, then a producer and editor of news and current affairs programmes at the BBC. He seems to have developed the symptoms of HD, which he inherited from his father, in his thirties. But it wasn't diagnosed till twenty years later. Two of his three children, myself and my brother, inherited the HD gene from him and have gone on to develop the disease.

Brian, my dad, died of pneumonia in a care home aged 59. This is a common cause of death for people with Huntington's Disease. My own chapter in this book, and my sister Wendy's chapter, plus the absence of a chapter from my mum who had such a terrible time in the later years of my dad's life, give the correct impression that the older Brian acted like a monster. In fact, I've seen that word used a few times in descriptions of Huntington's Disease – that it turns people into monsters – and I wince each time I see it.

There is a big question here about what the core of a person is. It's a question that is largely beyond me, but I wanted to put this chapter in this book as a reminder, at least in the first half of this chapter, of what my dad was like in the first half of his life, before Huntington's Disease changed how he behaved.

He didn't quite make it to sixty. Since we know how Huntington's typically progresses, with the onset of symptoms arriving in your thirties or forties, we can divide his life pretty neatly into two halves. Up to thirty we can assume he was free of the symptoms of Huntington's Disease, and hence that the way he behaved then was the real man. The first half of this chapter reflects this. After thirty, an age I've chosen simply because a) it's the halfway point in his life and b) we can be fairly certain Huntington's didn't make a significant appearance before then, he began behaving in the way that you will have picked up as 'monstrous' if you have read the other chapters of this book. That version of my dad, the Huntington's version, makes his appearance in the second half of this chapter.

There is a caveat I have to add here. Wendy my sister remembers stories showing that Brian did in fact have quite a temper when he was young. On one occasion he flew into a rage in a youth club and apparently put his hands through a glass window pane. He still had the scars on his arms as an adult.

Brian as he was

The dad I remember from my childhood was kind, loving, funny, creative, enthusiastic, passionate, slightly madcap, endlessly interested in everything, curious, articulate, charming and very clever. This is my recollection, I should emphasize. . Perhaps I am the luckiest of the three of his children as I am the oldest. So I am more likely to remember him when he was more himself and less changed by the Huntington's Disease.

As my sister Wendy has pointed out in her chapter of this book, even though we know it was the HD that caused his violent behaviour later in life, it is hard for those who were there and experienced it to separate out the person from the illness. Forgiving a person for that kind of behaviour is hard enough. But, with HD you need to go even further and not just forgive the person but acknowledge that they don't actually need forgiving. They weren't responsible. It simply wasn't them.

Maybe it's easier to do that if you know at the time that the HD is the cause of the behaviour. If you only find out decades later often the emotional scars are so deep set they refuse to heal. Or they heal very slowly. The logic that says "It wasn't him, it was the illness" doesn't change your feelings towards that person instantly, if ever. You end up with conflicting emotions.

When my dad died, my brother and I put together a remembrance piece to be read out at his funeral. My sister was in the US at the time and so wasn't able to have any input to what was said. The remembrance piece leaves out any reference to his Huntington's-influenced behaviour in the second half of his life because we wanted to remember him as he was, himself. On reflection, I think this sanitized version of dad that was presented at his funeral, a version that stripped out the Huntington's Disease, was largely at my urging.

Both Wendy and Geoff, but particularly Wendy (my brother was often away training and then at sea as part of his career as a ship's engineer in the oil industry), had seen the worst of my dad's behaviour in the couple of years after I left home to go to college in London. In fact Wendy recently told me that it turned into a major problem for her that she hadn't had any input into his funeral. She was horrified at the end result of his remembrance piece and how "perfect" he was made out to be. It actually caused her some trauma, which she had to take to a councillor, because it was like he was trying to erase and mess with my memories even from the grave. When dad had forced Wendy to meet him as a condition of continuing to pay maintenance so she could go to college, he spent most of those meetings denying he had ever done anything bad to our mum. So you can see why Wendy would be freaked by what I wrote. Sorry Wend.