

## Learning to live with Huntington's disease

### *Chapter 3. Lost & Found: The older son's story*



#### **Intro**

I am the older son, grandson and nephew in a family that has Huntington's. I am happily married, studying at university and live in West London. I love to play guitar, football (though I play less and watch more nowadays) and going to see live bands. I'm not from a "normal" family as my mother and father divorced when I was very young. Luckily mum remarried my second father (I have two. Greedy, I know). My biological father lives in Brunei, a small country on the island of Borneo.

Well, that's my CV, so I hope I have the job, and this is my story, so far...

#### **The Beginning**

I have no memory of suddenly finding out what HD was. I have a series of memories of picking up bits and pieces of information about it that seem to have led to the point I am at now. My first memories of the disease were going to see my granddad at his London flat. I was young, only about 7 or 8. I didn't know him very well. A history of violence and alcoholism had forced him and my grandma apart when I was a baby. This we later discovered was due to HD.

The only discernible memories I have of that day were the overpowering smell of tobacco smoke, the nicotine stained computer and Brian (my granddad) giving me all the change in a little wooden box he kept on the shelf. A sum total of probably six pounds; I was ecstatic. But not for long. It was obvious to me even then that he was unwell. He was using walking sticks at this time, as he was struggling to stay upright. I could only guess this was due to the disease. I hate seeing people struggling with the things that most take for granted, such as walking, so to see one of my family members in this state was horrific. I think that was the last time I saw him living on his own, as he was later moved to a nursing home.

#### **The Nursing Home**

When my mum used to say we were going to see Brian at the nursing home I would internally protest, but smile and agree. I hated the drive from London to the country. It took about two hours, and a stifling sadness always filled the car on the way. Once we arrived we would walk through a hospital-like area – through corridors connecting big rooms with people sitting around them - to Brian's room. That walk was always strange, passing people who had no idea where they were, or were just incapable of looking after themselves. I used to think to myself "My granddad's not like this, is he?" When we arrived at Brian's room, we would often take him outside into the garden. He was in a wheelchair by this time. The garden was beautiful, and

overlooked rolling green fields, with horses often roaming freely in the background. The smell of flowers and cut grass was a stark contrast from the odour of decay inside the building.

Eventually (I think I was 14 or 15) Brian died. I wasn't entirely sure how to react. I didn't know him very well, and found it hard to be around him. I actually knew my great-grandfather (Maggie's dad, or my mum's mum's dad, that is) better than I knew Brian. My mum was obviously devastated at her dad's death and I felt guilty for not feeling the same way. When mum told me he had died, I was in my bedroom with one of my friends, who asked me if I wanted him to go home. But I didn't feel any emotion, so I said no.

After the funeral, time passed and we all got on with our lives. Over the years I started noticing mum's physical control slipping very gradually – things dropping out of her hands and her walking being a bit unbalanced, for example. I tried to ignore it, but as I knew what HD was by this time, I got worried. I even tried to convince myself that she was practising her crappy punk dancing around the house and it wasn't involuntary movements. Sorry mum, I'm going to get a clip around the ear for that one.

This went on for a while, probably a couple of years, and I knew that if I had noticed, then my step-dad Phil would have too. He had. He pulled me aside one day and asked me if I thought mum was ok. I was shocked, but I knew that this conversation was inevitable, and had a whole speech planned in my head about how I knew, and how we could deal with it. I could only answer with "Yeah she seems fine to me". It was too much for me to admit.

After that discussion we came to the conclusion that there was a 90% chance that Mum had it. At this point Mum had said to Phil that she didn't want the test that would show if she had the Huntington's gene, because she didn't want to know. This posed a dilemma. If we knew and she didn't and didn't want to know, we would have to keep it to ourselves (confusing eh?). I really didn't like this dishonesty. Not only would we have to deal with HD in the family, but we would also have to keep it a secret.