

Learning to Live With Huntington's Disease Book

Sample extract from Chapter 6. Mopping the ceiling: The husband's story

Unexpected early casualties

Huntington's shapes your environment in surprising ways. In fact, the house began to bear scars inflicted by Huntington's Disease before we even knew we were living with HD. It's as if our home was acting out something for us, reflecting with surface wear and tear some of the emotional damage we were all (the family members, that is) going through on the inside. I know that's fanciful, but I don't get out much. The impact of HD on the house used to puzzle me, appearing like crop circles overnight, to be discovered in the morning when you are most bleary-eyed, in need of coffee, and your brain is particularly slow at processing the unexpected.

There is a clock on the wall in our kitchen, for example. It's a cheap, yellow, plastic-framed clock. I looked up at it as I was filling the kettle the other day and noticed that the left half of the plastic surround was riddled with holes. I stared at it, confused, as the kettle started to overflow into the sink. Plastic-eating mice? Plastic-eating mice that can scale walls? My brain gave up.



Once there were handles

I'll give you a further tour of the kitchen so you can get a sense of how HD chips away at its surroundings. We have a glass oven door. On several occasions the door spontaneously and mysteriously came away off its weakened hinges and crashed to the floor, once shattering into a thousand pieces. I found what was left of the door in the morning, just before I stepped on it. As an aside, but continuing the theme of how slightly off-beam life is with HD in the family, that evening I found Sandy trying to cook a chicken in the oven, with no oven door. The heat hit you as soon as you walked into the kitchen. We had fish fingers instead.

I'd like you to notice the cupboards now, if you will. We have twelve kitchen cupboards. Each used to have a little knob or handle attached. Currently only six have a knob or handle. And they are of varying shapes and sizes. There is an ongoing sourcing and replacement programme for the knobs carried out, obviously not very efficiently, by me. One cupboard lacks its door and just gapes, showing off its tins of baked beans and packets of instant noodles to anyone who cares to glance that way and wonder where the door has gone.

It's in the garage, waiting to be re-hung. It's been waiting a year so far. Don't hold your breath. Then, over in the corner is the sleek-looking fridge-freezer, with no visible handles on the doors. Look closer. The absence of handles isn't actually a design feature. They were there when we bought it. But they snapped off years ago. We open the fridge, the freezer and the handle-less cupboards by scrabbling to get a hold on the edge of the respective door and then tugging.

Life is maintenance

The mysteries – what happened to the clock, why the oven door kept disintegrating, why the knobs and handles all break off – are eventually solved if you wait around and observe long enough. Sandy keeps her cigarettes in an overhead cupboard in the kitchen. A few days after noticing the shattered clock surround, I spotted Sandy walk into the room and fling the cupboard door open so she could retrieve a pack of cigarettes. That particular cupboard is one of the few still to have a knob on the door, a knob that crashed hard into the plastic clock on the wall, knocking yet another shard of plastic off it before the door swung back closed with a clunk. Mystery solved. Likewise the oven. Sandy stopped cooking a year or two ago. The oft-replaced oven door stopped coming apart in my hands about the same time.

We don't realize how much finesse we apply to the control of our muscles, the fine motor skills involved in closing a toilet seat without a loud crash or shutting an oven door without slamming it. It's a problem of amplitude. Someone with HD will hurl a glass oven door shut with the same amount of force they would apply to a heavy car door. The dial that controls muscle movements seems permanently set on full.

Brom, our older son, says his mum has super strength. I discovered more evidence of that this morning. The towel rail was on the floor of the cloakroom. It had been virtually welded onto the wall with as many different industrial strength adhesives as we could find, after it had hit the ground several times before. There was a liberal mix of *No More Nails* adhesive, super glue and that epoxy resin stuff that you mix together and then can suspend yourself from the ceiling with if you feel so inclined, all mixed together to keep the towel rail where it was supposed to be. You could sit on it if you wanted to. Or park a small elephant on it. Yet there it was, on the floor, with a towel rail shaped chunk of plaster gone from the wall, too. I think Brom has a point. No wonder we often tiptoe around Sandy to avoid getting her mad.

You can track where a person with HD is in a house by listening for the noises of household objects straining under pressure and sometimes giving way with a crack – the refrigerator door colliding at speed with the wall as it is flung open, or the occasional spectacular sound effect, such as the splintering of wood as a cupboard

door is yanked off its hinges and crashes to the ground. You soon learn to ignore the day-to-day sounds and only get up to investigate when it's a particularly dramatic one. Or the sound of breaking glass. Or a smoke alarm. There is one in every room and a fire extinguisher on each floor. Danny even has an extinguisher in his room. Other kids have TVs. He has an extinguisher. Every few months I annoy him by reminding him how to use it.

The oddest sound that ever brought us running was an exploding glass ashtray. Apparently they can deal with the heat of one or two smouldering cigarettes. But, when there are ten or so burning merrily away in the bottom of the glass, as was the case on this occasion, they shatter. Brom and Chan were on the other side of the living room, watching a movie on TV. Brom's mum had gone to bed, leaving the little inferno building up to the heat of a thousand suns or whatever critical mass it takes to explode an ashtray. And then, at the climax of the film they were watching, it blew, leaving little flames licking away at the wooden table top. If they hadn't been there to put it out...well, I guess the smoke alarm would have told us and we would have got to use the extinguishers for real. As it was, Brom and Chan poured a glass of water on it.

"Life is maintenance," I read somewhere recently. As I wander around with a screw driver at the end of each day, tightening the hinges on the cupboard doors – the perpetual banging loosens them and sends them crashing to the ground without regular preventive action – I have to agree.

Huntington's Disease impacts on your life and your surroundings in many small and varied ways. Taken individually, they are trivial. But if you let them, they can accumulate to clog up your life in a similar way to the accumulation of the tiny clumps of plaque that clog up the brain and cause the symptoms of Huntington's Disease in the first place. Which brings us to cleaning.

Mopping the ceiling

There's a character in the Peanuts cartoon strip who generates mess. One strip I remember shows him sitting still, doing nothing. In each panel, more and more mess has accumulated around him: things fall over, stains appear on his clothes, he becomes increasingly dishevelled. All without moving or doing anything. He appears oblivious to the mess and disorder accumulating around him. Flies start circulating above his head.

"We can't pay for house cleaning," says the social worker, "because cleaning isn't part of personal care." We are sitting round our dining table, four of us. Carol, the HD Association's regional advisor, who has convened this meeting-at-home with our new social worker and is there to help fight our corner, glances at me, ready to jump in when needed. "Whoever made up that rule hasn't lived with HD," I say. "There's a kind of tornado effect. Everything hits the ground: glasses, cups, tea, dinner, lamps, chairs." In fact, the force exerted by a flung arm from someone with HD is so powerful, the ceiling often needs cleaning.

I used to think it was just the floor and the walls that were regularly pasted with food and drink, till I glanced up and saw strawberry milk shake all over the ceiling one day.

It had formed a spectacular spray effect, as if Jackson Pollock had been in. I still haven't caught Sandy in the act of slamming her glass down on the table with the gravity-defying force that pastes half a glass of milkshake to the ceiling. So, I'm not sure how it's done without breaking the laws of physics. But the results have appeared several times while I am out of the room.

Mopping the ceiling has a surreal feel to it, as if symbolic of the way Huntington's tends to turn your world upside down. The first time it happened, Danny and one of his friends walked in through the front door and into the front room. I was mopping the ceiling. The ceiling, not the floor. They looked at me and paused. I paused, mop-to-ceiling, staring back. "Er, you won't tell your parents that Danny's dad mops the ceiling, will you, or they might not let you back", I said. Like teenagers everywhere, faced with a parental attempt at humour, they ignored it and headed for the Playstation.

"Actually", said Carol to the social worker, back in the meeting, "you can use a health argument for paying for the cleaning. You'd be surprised at how unhygienic, unsanitary even, it can get if the rate food is dropped isn't matched by the rate it's cleared up." Hmmm, clever, I thought. The social worker raised an eyebrow and made a note.

Groundhog day

Anyone who cleans knows that slight dip of the spirit you feel when you walk back into a room and find that the kitchen work surface or floor that you had left gleaming and spotless a few hours previously is now littered with used teabags, spilt and now congealed sugar and a patina of something sticky that you can't quite identify.

The difference with HD is just how accelerated this whole cycle becomes. Walk out of spotless kitchen and check answer phone messages in the home-office for ten minutes. Walk back in and your feet are sticking to something vaguely unpleasant on the floor; there's half a tin of sugar scattered across the work surface and, strangely, a knob of butter sitting in the middle of it.

You can over analyze the cleaning. The reason it seems so important is that Huntington's drags you in the direction of chaos. Life is less ordered. Accidents, spillages, outbursts, upsets are just below the surface, waiting to happen. You can't do much about that. But you can create as much order and spick and span-ness as possible around the person with HD as a kind of symbolic buffer, a circle of calm. You can't do anything about the chaotic thinking and unpredictability. But you can try for a Zen garden effect on the kitchen and the living room. As long as you're prepared to do it all again every ten minutes.

The alternative is that the person with HD ends up surrounded by a mess that accumulates at a superhuman rate, oblivious to it themselves. Being dishevelled is a sign of not being cared for. Being surrounded by mess speaks of the same thing.

So, the never-ending mopping up of spilt coffee, scraping of lasagne off the carpet, emptying of ash trays, changing of food-spattered clothes, making sure there are enough clean clothes for Sandy to change into, and, yes, mopping of strawberry milk

shake from the ceiling, is a constant and recurring act of love, or at least compassion. The mess becomes a symptom or a manifestation of the illness. Fighting back the mess becomes one of the few tangible things you can do to combat it.

BH or Before Huntington's

What can I say about us before Huntington's Disease was in our midst? It seems such a long time ago, somebody else's life, dimly-remembered. When we met in London in our early twenties, Sandy and I seemed to complement each other - the old yin-yang cliché. She had been a journalist, had got married, had a young child and was going back to college to get a degree. I had gone from a state school to Cambridge, where I had developed a large chip on my shoulder in resentment at the privileged, often not very bright private school types I was surrounded with there. After my degree I'd fled to Paris for a year to put off having to get a job. Then I came back to England wanting to become a journalist.

I was broke, teaching English to foreign students and living back in my parents' house when I first met Sandy. My mum was a childminder and Sandy used to drop Bromley at our house in the morning on her way to college. Sand later turned this into a joke that she used when telling people how we met. Our local authority, Hammersmith Council, was amazing, she would tell people. Not only did they find you a childminder, they threw in a new husband for free.

Journalism was our initial common ground. The complementary parts to us, the edges where we seemed to fit together well, were that I was the worrier, the glass-half-empty type, whereas she seemed serene and unbothered, as if she had a calm pool at her centre. I found this intriguing. She helped cancel out my mildly pessimistic way of looking at everything. We also shared a sense of humour and had a similar set of values. We felt that a lot of what people aspired to, particularly materially, was absurd. We both had a sense of being outsiders or non-conformists. Sandy in particular likes to see herself as a rebel. We both wanted a life lived by choice, not by convention.

Sandy, having been a fashion journalist, looked particularly unconventional – blonde, spiked hair and a self-assembled collection of budget clothing that always fell together to form something extraordinary. People turned to look in the street. Her friends were always trying to copy her sense of style, but never quite got there.

I remember a few years later working together on a writing job with Sandy. We were at *The BBC Good Food Show*, writing a show newspaper for the organisers of the event. As we left our hotel that morning, we passed in the lobby Karen Franklin, the fashion journalist who used to front a BBC TV programme called *The Clothes Show*. She was checking in at reception, as the annual Clothes Show event was on at the same venue as the event we were working at, but the following week.

Out of the corner of her eye, Karen Franklin spotted Sandy and I approaching the desk. She stopped signing in and turned to stare at Sandy, pen still in hand. She prescribed a 360 degree circle, turning slowly on the spot as she followed our progress out through the lobby and to our car. You could see the "Wow!" in her eyes. She was mentally taking notes. I couldn't understand what Sandy did with a few

chains, bangles and dangly ear-rings that turned dressing into an art form, but it was obviously a talent that even the fashionistas recognized. *Is*, I should say, not was. I've included that anecdote as an example of Sandy's unconventional approach to how she presents herself in public. She tends to make an impression. In fact, she enjoys it.

So, I was impressed by her style as well as her substance. Things didn't run entirely smoothly, however. Sandy came with a child attached and a marriage. But, the marriage was collapsing, by all accounts, and Bromley was an easy-to-love child. She and I fell in love, started a life together, and committed to sharing everything – both of us going out to work, taking it in turns to drop Brom at school, cook, wash up, clean, pay the bills and so on. We did the usual things a young family does – moved into a flat, got a mortgage, worked on our careers, spent the weekends taking Brom out to kids' theatres, to Chinatown in central London for dim sum, and to play football on Hampstead Heath.

The second half of our twenties and the first half of our thirties were happy times, I seem to remember – though this does feel, oddly, like someone else's memories. (It's as if we are not the same people now which, in many ways, we are not. Huntington's does that to you.) We had a shared and close group of friends. We went to the pub, had people over for dinner and Sunday afternoon pop quizzes, took Brom to parties where our friends all wanted to talk to him and ignored us because he was the coolest six-year-old in the world. Sandy and I were even in a rock band together for a few years, playing gigs in clubs around London. We were happy. Not all the time. But, mostly. We felt normal, in a non-conformist, slightly rebellious way, of course.

A slow unravelling

I can chart our apparent decline as a couple almost from the moment Danny was born. Sorry, Dan, if you are reading this. I'm not trying to lay that at your door. It's just a coincidence that you came along at that time. Actually, if it inspires enough guilt in you to get you to do more chores around the house to help me out then yes, it is all your fault.



*Sandy with Danny, 1992.
It's all your fault, Dan. Love Dad.*

Like your brother, you were and are a very-loved child. That happiness at your arrival masked the fact that your mum seemed to take a long time to recover from your birth. We were still a happy family. But, the first signs of fraying started to appear around the edges. Tensions started gradually, almost imperceptibly, to emerge.

Sandy seemed exhausted and distracted in the months after Danny was born, finding it hard to get back into the groove of work again and apparently unwilling or unable – I'm now not sure which – to ease back into the role of partner. That's what we had always been, partners. We never regained that. Instead, I began to stretch to fill parental, work and domestic responsibilities that we used to share, but that Sandy seemed temporarily unable to deal with. As time dragged on, the 'temporarily' became more permanent.

I found myself making more family decisions on my own and taking on more tasks that used to be shared, because they simply weren't being done. I became increasingly resentful and a nag. The pattern of our conversations changed, from sharing thoughts, ideas and feelings to me complaining that something hadn't been done (maybe dinner cooked or the bathroom cleaned if it was her turn to do one or the other) and Sandy responding with a series of defensive one-liners that became predictable after a while. The one I remember most clearly is "If it's that important to you, do it yourself." She often seemed exhausted and distracted.

Something crept into the tone of our conversations that had never been there before. It felt at best like a loss of respect, at worst a kind of low-level contempt.

Ends sample extract Chapter 6

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With contributions from her family

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