“The world breaks everyone and afterward many are strong at the broken places.” ***Ernest Hemingway***

Introduction: *‘The most cruel disease known to man’*

> “Huntington disease (HD) is an inherited brain disorder that causes progressive deterioration of the physical, cognitive and emotional self. It leads to severe incapacitation and eventual death 10-40 years after the onset of the disease. Although it usually affects adults between the ages of 30 and 45, symptoms can appear in young children and older adults.
>
> Common symptoms are uncontrollable movements, abnormal balance when walking, slurred speech, difficulty swallowing, thinking difficulties, and personality changes. Each child of an affected parent has a 50% chance of inheriting the HD gene, which is located on chromosome four. There is no cure and no effective treatment exists, but scientists are exploring possible treatments and caregivers are developing new approaches to care.”
>
> **- Jane S. Paulsen, PhD**

When people ask us what Huntington’s Disease is we say something like “Imagine the physical effects of Parkinson’s Disease, mixed up with the mental deterioration of Alzheimer’s and you’re in roughly the right territory. It’s terminal, but it takes its time, decades sometimes. Oh, and it’s hereditary: each of your kids has a fifty percent chance of inheriting it.”

We’ve heard Huntington’s Disease described as, variously, “the gradual and relentless dismantling of a human being” (ugh) and “the most cruel disease known to man” (double ugh).

It’s described as ‘cruel’ because it delivers not just a double whammy, or a triple whammy, but a relentless series of whammies that just keep on hitting a family over the course of years, of generations in fact.

It just keeps on coming

Steel yourself. There’s:

a gradual mental decline, with depression common and pronounced mental illness including psychosis and delusions not uncommon; thought processes decline as the illness gradually kills your brain cells and the connections between them

an emotional decline, leading to sudden mood swings, a blunting of emotions, loss of ability to relate to people you love, frustration, outbursts of anger and aggression;

physical decline as you lose control of your muscles, so walking, speaking and eventually swallowing become difficult, things keep dropping to the floor (including you), your arms and legs start moving independently;

the cumulative effect being that you usually lose your job, have your driving licence taken away, gradually lose the ability to walk, communicate, eat for yourself, look after other people let alone yourself, think things through properly…all the things you take for granted every day slowly slip away;

and then there's the ongoing whammy of worrying whether or not your children and their children will inherit it and start the cycle all over again. The symptoms usually don't appear till early middle-age, so there's an agonizing wait.

Had enough yet? Me, too. That's only a select list of symptoms, but I didn't want to hit you with all of them straight away. We're only on the opening pages after all.

Your inclination on reading all that is probably to recoil. It's a bit like being hit by a series of punches from a heavyweight boxer. "Take this, and that, and this, and that, and…" it just keeps on going. And, when it's done with you, there's the added pain of knowing that it may well start on your kids. It's enough to just make you want to lie flat on the canvas and think "What's the point of getting up? It'll just knock me down again?"

But, all over the world and throughout history, life triumphs because people have refused to stay down when circumstances have knocked them down. You can't stop Huntington's Disease constantly knocking you down – sometimes literally: I've got the bruises to prove it. And it doesn't just knock you down; it knocks whole families down.

Fragmenting families

The illness can seem like a juggernaut ploughing through the family, so massively, awesomely unstoppable that each family member ends up almost paralyzed by it; so cowed by its impact or its possible future impact on themselves and on the people they love that they feel powerless to do anything.

The sense of hopelessness HD brings can descend like a cloud on a family. It can freeze love and end up fragmenting that family as everyone runs for cover – either turning in on themselves because the pain of gradually losing yourself and/or the people you love to this relentless illness is too much to bear or, in many cases, physically leaving the family and breaking all contact for the same reasons.

No, you can't stop it knocking you down. After we found out we had Huntington's Disease in our family we got knocked about all over the place by it for a good few years. We were punch drunk, bashed about, reeling. We almost had one or two casualties along the way as one or other of us thought about giving up completely. Careers were derailed, rosy imagined futures disappeared in a puff of smoke. We didn't talk about it unless we absolutely had to. It was the monster in the room everyone tried to ignore, but couldn't.

If you can get through those early years of pain and panic and keep together as a family, you've done well. We are doing better now than in the first few years. And since communication is a great casualty of Huntington's – you can feel that there is nothing positive to say, so you say nothing to each other about it - it's time we talked to each other and to other families who are going through their own tough times, and to people who work with this illness. That is why we have put this book together. Huntington's is a family illness and deserves a family book, one that looks at it from every member of the family's point of view.

Stronger at the broken places

Huntington's changes everything. But, not always for the worse. Danny my younger son, who just turned fifteen, said the other day "I think having Huntington's in the family has made me a better person than I would have been." I think he's right. It's made us all have to be better people. We've had to rise to it. We've had to find strength we didn't think we had.

We've noticed that each of us has been broken in one way or another by this illness. We are not the same as we were before. It's changed us. Each of us has had to dig deep and go through a private rebuilding of ourselves after finding out Huntington's was in our midst. Not just once, either. It's ongoing. For a while we were fragmented and in disarray. But, we have grown back together as a family of individuals who are each stronger than we were before. We are indeed stronger at the broken places.

Sandy Sulaiman
Oxfordshire
England