

'I think you have Parkinson's'

BGS MOVEMENT DISORDERS SECTION AWARD

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Breaking bad news is arguably one of the toughest challenges for medical professions. However many techniques we are taught in medical school to soften the blow and make it easier for the patient, informing someone of a life-changing diagnosis is an enormous responsibility and not something that any doctor looks forward to.

As the title of this essay is 'I think you have Parkinson's disease', I wanted to write from the viewpoint of the recipient of such devastating news, taking the opportunity to think carefully about the patient's perspective of being diagnosed with a neurodegenerative condition.

I have conducted my research by reading forums written by people with Parkinson's disease, reviewing their experience of diagnosis and also by speaking to several patients about both the short and long term impacts of their diagnosis on their life.

I have tackled a variety of issues in this essay including the challenges faced by the doctor when breaking bad news; the role of the GP following diagnosis; how best a doctor can explain a complex neurodegenerative condition to someone not from a medical background; what types of treatment are expected for Parkinson's disease; and what advice can be given to people with Parkinson's to improve the outcome of their treatment.

'I think you have Parkinson's disease'. I watched the words come out of his mouth rather than heard them. My whole body was numb. I felt as though I had been thrown into a bath of ice-cold water. I could feel my hands beginning to shake, as if my symptoms were responding to the diagnosis. I felt my wife's hand squeeze mine. I watched his mouth make more shapes. I heard him say something about starting treatment and speaking to the nurse if we had any questions. A few moments later we were bundled into the car and sent on our way. 10 minutes. In that tiny forgettable fraction of the doctor's routine day, I felt as though my life had ended. (Han and Kagan, 2012)

What was going to happen to me? Could I still go to work? Was I still going to be able to play with my grandkids? Was my body going to become more and more disobedient until I needed someone to feed me and put me to bed? I began to cry again, slowly adjusting to the reality of the day's news.

I thought about my first trip to the GP all those months ago. I had no idea what was going on. The GP had asked me lots of questions, about smell, about handwriting, about things that didn't really seem to be important at the time. Yes, I'd lost my sense of smell a few years back. I thought it was connected to banging my head on the ground when my granddaughter jumped on me at the park. (Jafari et al., 2013)

Why hadn't I thought to mention it then? It didn't seem important and I didn't want to make a big fuss over nothing.

Eventually I did get to see my GP when my wife kept complaining that I couldn't bring her a cup of tea without spilling it. My hands had become shaky and I had begun to find it harder to balance and walk. Again I thought it was just due to age and my stiff knees. I was quite a runner in my day but my knees are now a painful reminder. (Breen et al., 2013)

We finally made it home and I sat down at the computer to see if I could make some sense of this new label. I shakily typed 'Parkinson's disease' into Google and clicked load. My heart raced as I read through the screens of information. Thousands of people all experiencing the same thing, some struggling as I was with the despair of recent diagnosis, others demonstrating the resilience and experience of long term sufferers.

I wanted to know about treatment. Was there any way to stop this horrible disease from consuming me; from taking over my whole body before I had a chance to live the rest of my life?

I looked up 'Levodopa', which seemed to be the treatment most people were talking about on the internet. I vaguely remembered the doctor talking about 'dopamine' saying that I didn't have enough of it. Most people seemed to say that Levodopa really helped their symptoms. So maybe it would help me too? I felt a flicker of hope but went to bed with my mind buzzing with unanswered questions. (Rascol et al., 2000)

The next day I shuffled back into the surgery, for the first time truly realising how difficult it was for me to move. My limbs moving rigidly like unoiled cogs. I felt as though I had a sign on my forehead, everyone was watching me, making assumptions about my condition and feeling sorry for me. (Burgener and Berger, 2008) After what felt like a year the receptionist told me it was my turn to see the doctor. She smiled and asked me if I needed any assistance getting to clinic with her eyes full of pity. I was embarrassed and ashamed of my own body.

I sat down in the practice room with my GP. Today I could hear clearly. We spoke for what felt like hours. It felt like therapy to speak with someone I knew. To be able to admit how I was feeling without shame. She explained that my Parkinson's was due to part of my brain called the 'substantia nigra' not working as well as it used to. Unfortunately, this would impact my ability to control my movements. She said that there were many treatment options available. 'Levodopa', the drug I looked up the night before, was normally given first.

I stared down at the little white pills, watching them jiggle as my hand trembled. I put one after the other onto my tongue and took a sip of water, swallowing nervously. I waited anxiously for my sweaty palms to stop shaking. The doctor had explained to me that it might take several weeks to get the dosage right, and that there were many side effects that might occur including seeing things and moving my body without meaning to. (Banerjee, Falkai and Savidge, 1989) I shut my eyes and prayed that when I opened them this

would all have been just a scary nightmare. The next thing I felt was my head hitting the floor.

I woke up in a hospital bed. The nurse smiled and asked me what had happened. 'I don't remember', I answered and for the first time I noticed that my voice didn't sound like my voice any more. It was weak and monotonous, almost robotic. I felt drained and completely numbed by the events of the past few days.

The nurse took my trembling hand and asked me if I was ok. I started to cry. 'I have Parkinson's', I choked, and as I said it the enormity of what I had just admitted hit me like a train. The nurse sat down in the chair next to my bed. 'I feel depressed. I feel alone. I don't understand what is happening to my body. Suddenly, after 59 years, I can't handle simple tasks and manoeuvres that I used to take for granted.' (Gotham, Brown and Marsden, 1986)

The nurse listened to me until I had finished. She had a kind face and eyes. I tried to smile. 'I'm going to put you in touch with a really helpful charity' she said. 'And I'm going to get the doctor to see you. I think we need to arrange some counselling or cognitive behavioural therapy to help you deal with your emotions. You've had an enormous shock.'

Weeks later and my dosage is finally right, my hands move where I want them to and I have stopped spilling tea all over myself every time I make a brew. Deep inside me there is a fear that the only reason I am coping at the moment is because of the little white pills I take every morning. Sometimes when I forget to take them, or when I go to the loo in the early hours of the morning, I can feel my fingers beginning to tremble and my legs begin to freeze up. I can feel the Parkinson's creeping up on me, possessing my body. (Adler, 1998) But more and more I try to push it to the back of my mind and concentrate on getting on with life. I feel happier too. The doctor has given me some anti-depressants and I have been going to CBT sessions to try and change my perspective on things. It's tough but I am managing my illness.

Of course, I know that gradually I am becoming more dependent on others. That one day the pills won't be enough to mask what's happening inside my brain. That my condition will deteriorate and I will require round the clock care. (Bunting-Perry, 2006)

My aim is to be positive and enjoy life and my family as much as possible until that day comes.

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Inspiration taken from the real life stories on the Parkinson's UK website.