Parkinson’s Disease: My family’s perspective

The inspiration for this article is my Nan who is currently fighting Parkinson’s disease and Lewy Body Dementia. This article will discuss how my family have been affected throughout her disease progression.

Early Stages (Years 1-6 of Parkinson’s disease)

My Nan did aerobics until she was 75, retired at 78 and kept the house cleaner than a show home. She was independent, strong-willed, courageous, honest and kind, the type of woman you would aspire to be. The only concern in the family at this point was the miscarowed frozen Flattenberg she used to feed my Dad when we would visit her. This was until she was diagnosed with Parkinson’s disease. Nan had previously confided in a neighbour, who was a nurse, of her annoyance at a trapped nerve in her hand which was causing it to tremble. Her neighbour advised her to visit the GP, who then referred her to the hospital.

The diagnosis was a huge shock as Nan had always been fit and well. This was unknown, upsetting territory but we were confident Nan could self-manage the illness with our help, as our understanding of the disease at this time was limited to the tremors. Nan was 79, not a spring chicken but a very strong independent woman who would certainly put up a fight.

Everything seemed normal for the first couple of months. The first challenge was her medication. The prescribed dosage on the bottle was 5.0mg per dose. The following evening my Nan was frantically calling my parent’s house at 2:00 am, crying so hard she could barely explain what was happening. She said that there were bugs and creatures coming out of her walls everywhere she looked. I remember my Dad’s panic as we had no idea what was happening. Could there be an infestation in her house or was it something we would experience more over the next few years.

The second event was a few years later. At this point we were used to Nan hallucinating as it became clear that she was very sensitive to her medication changes and experienced these ‘events’ at a slight dosage increase. She was found in the middle of the street at 1:00am by a neighbour, next to a main road in the middle of winter, talking to cars with her teddy bear as they were going to a wedding. It was a threefold horror call for my Dad to receive: winter, main road and hallucinations. Every outcome that night rushed through our heads. Nan was back at home a few days later and we were told again, “it’s part and parcel of Parkinson’s”. She had no recollection of this, her main concern was her teddy bear and if it had been left in the house alone.

‘Teddy’ was a bear that Nan bought from a charity shop. She clothed it and told of his harrowing backstory of abuse and operations against his will. The stitches were down the bear’s back and curiously it didn’t have a sound box in its stomach. We treated this as a pacifier for her as it was doing no harm, although it made us feel uneasy. The attachment to the bear was also, “part and parcel of Parkinson’s”.

For Nan to show improvement her consultant had to keep adjusting her medication. The hallucinations she had varied from hilarious (a Mexican dancing rat party) to outright horror (people in her house trying to kill her). This in itself caused emotional conflict, as the person you’ve admired and looked up to was suddenly tainted by this condition, although she was coherent and everything she experienced was real to her. She wasn’t aware these experiences were hallucinations. This was a very tiring process. We started to see the person we knew disappear.

Years 6-8 (The stage of denial)

Nan progressively started to get worse: more tremors, more hallucinations, phone calls of terror in the middle of the night, preparing meals for family members that had passed. It felt like her condition was out of control and nothing that we did could ease it. We felt completely helpless, frustrated and angry. This is when we started to normalise her behaviour and appearance. Nan was getting frail and weaker which we were putting down to old age, and as it was winter...
her paleness ‘usual’. The odd memory lapse she may have had was also old age. In hindsight this is because we didn’t want to see what was happening or think about it getting worse. The odd stay in hospital became more normal, as did the quick discharge and “It’s still just Parkinson’s” phrase.

As her disease progressed she went for memory tests via the psychiatric route, but was never referred to a memory clinic. She passed the tests easily as she memorised the answers, which usually would be a positive thing, but her ‘non-rehearsed’ response was overlooked. She could not have told you the colour of her jumper or the date. This was not helpful for us as we could see something was going wrong and getting worse. But there was nothing we could do.

Although I am unsure what effect it would have had, I wish there had been more advice, more in-depth explanation available on the illness. I feel this may have offered us an insight of what to expect as the disease progressed. “It’s just Parkinson’s disease” isn’t very helpful although it may be true. There must be more information or warning signs that families can be made aware of, and future potential developments of Parkinson’s such as dementia.

Advisory information on legal aspects such as Power of Attorney would be valuable as this is something we struggled with, being unaware there are two different types. Information leaflets in hospitals or easier access to online support would have been useful. It is difficult as a family member to think rationally as you are emotional; you want an answer, a cure, support would have been useful. It is difficult.

ACCOMODATIONS

1. My beautiful Nan as without her strength I certainly would not be able to write an article like this, although she will never read or understand it.
2. My family – thank you for your support throughout writing this article in what is an incredibly challenging time. We will continue fighting the fight, as they say, and in time I do hope that other family members do not have to experience this or feel more prepared for it if it does happen.
3. My colleagues (Neuroimmunology & CSF Laboratory, UCLH London) – I presented this topic to my team and the support and gratitude I received from them was humbling. (https://www.uclh.nhs.uk/OurServices/Servic - Z/NEUROLOGYPages/Home.aspx)
Please note that due to my Nan’s mental capacity I have obtained consent from my Dad who has fully approved this article and hopes that it reaches out to others in a similar situation and assures them that they are not alone in their struggles with coping with such a condition.

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