

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 microwaved frozen Battenberg 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 this something else? When my Dad got there Nan was distraught, the doctor arrived shortly after and explained this was a hallucination due to the medication dosage being transcribed incorrectly. It should have been 0.5mg per dose. We were furious, upset, confused and concerned about any long term and lasting effects. We simply felt helpless – all we could do was wait for it to wear off. This experience frightened us – it was the first time we saw her vulnerability; here was something we had never seen before. Fear was something we would experience more of over the next few years.

The following two events in particular stand out for me.

Nan started to complain that her house smelt of smoke. At first we thought it was genuine and had someone check all heat sources; we even taped up gaps in the skirting board. After a few months of this had passed, Nan was still smelling smoke which we tried to link to her new central heating having been installed and its 'new' smell. We couldn't smell anything or find any dust and this is when alarm bells started to ring. We were concerned as she seemed so sure and was adamant it was happening and we still believed her somewhat as there was no

reason for her to fabricate this. At this point she was sleeping downstairs in a dust mask and had called the Fire Brigade out a couple of times during the night which we hadn't always known about. They kindly fitted some alarms to ease her anxiety. After a quick Google search we were sure she was experiencing 'Phantosmia' (phantom smell). This explained a lot. Unfortunately, Nan's next hospital appointment wasn't for a while and a Parkinson's Nurse was yet to be assigned, leaving us with few people to contact for advice. When we eventually spoke to her Consultant the reaction we received was "it's part and parcel of Parkinson's". Maybe there was more to Parkinson's disease than just tremors. She still smelt the smoke for another couple of 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 bears 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". We were getting very familiar with this phrase by now.

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



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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, something.

Years 8 – the present day (Advanced Parkinson's and Lewy Body Dementia diagnosis)

At the beginning of her 8th year with Parkinson's disease she had been in hospital and quickly discharged. This was via the social worker

who visited her twice as she was now deemed mobile due to having the ability to walk up two stairs. We had tried to argue against this point as we were frightened something was going to happen to her when she was at home, because we could not watch her 24 hours a day, 7 days a week. Nor would she have allowed this.

A month later, after many falls due to mobility issues, the last fall hospitalised her. My sister had found my Nan on the sofa with her hair matted with blood. She noticed a pool of blood on the floor at the side of her radiator at the bottom of stairs which were also blood-stained. It is clear what had happened – she had fallen down the stairs and hit her head. Nan had no idea she'd done this. It seemed now that the carer arranged by social services to come and visit her three times a day to make sure she was eating, drinking and taking her medication, wasn't enough. Heartbreaking.

This was the steepest decline we saw. Nan's face became more deadpan, she was either immobile or could run and became violent in hospital. Nan's aggression must have been horrifying as there have been accounts of her punching nurses, trying to escape from the hospital and refusing food. It was clear she would be going into a care home, which was the next difficult step.

Nan would have never wanted any of this; she always said she'd rather be dead than in a home. The decision my Dad and Uncle had to make that day was probably the hardest choice they'd had to make in their lives. We went through moments over the last few years where we thought she was possibly dying and preparing for that moment, and then she was diagnosed with Lewy Body Dementia on top of her Parkinson's.

The care home is perfectly fine, we have had a few funding applications rejected for her care but you hear about this across the board, as generally care homes are underfunded. We are

grateful for the care they provide as she is not an easy patient at all. The violence she shows, but the bruising from the falls is hard to see and surprisingly she's never broken anything – but with each fall you do think, 'is this it?'

The constant emotion you feel is that you want them to die, because you want them to go with dignity intact and still be that family member you know. This hasn't happened.

As I live in London I try to visit her when I can but it is emotional and just horrible every time, as you go in there and look at a shell of the woman you once looked up to. I have started to feel selfish about her visits, as I want every moment I can with her and have bought her presents so I'm doing the right thing, although she has no idea. Deep down this is all for me and not her, which is a very confusing feeling.

My Nan that I love dearly is now just her condition and no longer my Nan.

Thank you for reading this article

ACKNOWLEDGEMENTS

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/ServiceA-Z/Neuro/NEURI/Pages/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.

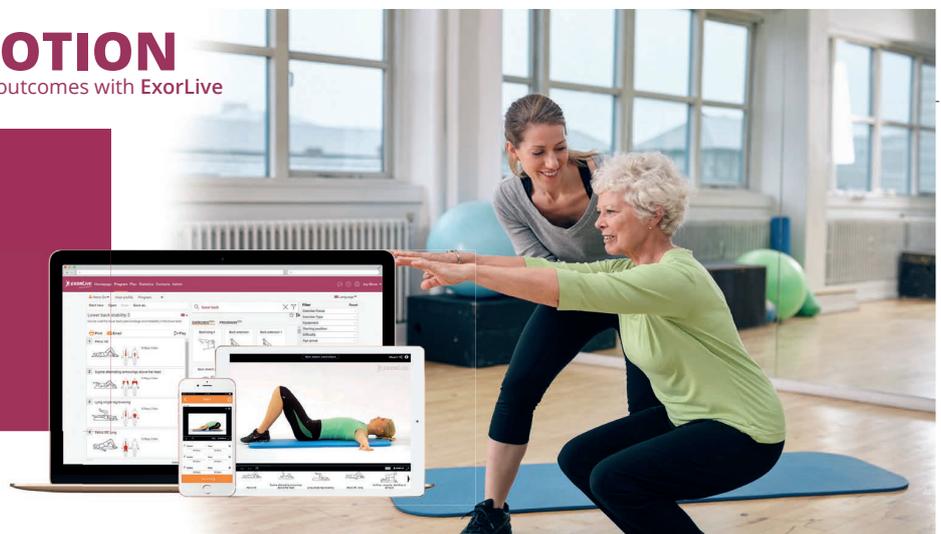
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