

LIVED EXPERIENCE

Living with Parkinson's disease

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I am 40 years old and I am writing on the 4th anniversary of being diagnosed with Parkinson's disease (PD). As a consultant geriatrician, I thought that PD was a disease of older adults, so the shock of being diagnosed with Young Onset Parkinson's Disease (YOPD) should not be underestimated. The reader may be surprised that I did not realise I had PD given my occupation and symptoms that I will describe in this brief article. My story will be illustrative of the kind of challenges that people with YOPD live through. I hope that the reader will come away with a greater understanding of what it is like living with PD.

Good health is often assumed to be the normal experience of young people and I fell for this delusion. I ran the London Marathon in 2004 and have enjoyed running since then. My early symptoms were, therefore, put down to running injuries. My stiff hip and ankle were put down to back problems. My lack of sense of smell was put down to allergic rhinitis. Looking back, I had signs and symptoms of PD for many years prior to my diagnosis in November 2017. This is a common experience of people diagnosed with YOPD. Most people have to wait many years before they are diagnosed and start receiving effective treatments. I was fortunate that my GP referred me to the neurologist straight away and my diagnosis was made promptly – within 5 months. Being informed I had PD was a shock, even though my symptoms were there for all to see.

Symptoms I live with

Every PD patient is different. My right hand cramps up, so writing, typing and brushing my teeth are difficult. My right ankle is so stiff sometimes that it results in a limp when I walk. I suffered from severe cramping pain in my right foot. I do have a tremor but I am much slower than shaky. There are different types of PD and I suffer from the bradykinetic type. Exercise is good for me, but I fatigue easily when I am on my feet for hours. These are the more obvious symptoms, and these symptoms were present in 2017 and even earlier. There are hidden ones that have crept up on me over the years.

I have had no sense of smell since 2014 and so my taste is limited to sweet, sour, salty, bitter and umami. Constipation is a hidden symptom but believe me it is very

troublesome. My bladder control is variable, and it often feels like I have a bladder of an old man – urgency is really shocking. I've observed the correlation between urinary urgency and anxiety – both forming a vicious cycle. This is often my biggest struggle – often worse than my stiff right side. Apart from what a typical 40-year-old man normally deals with, PD rewrites the ageing process. Pain in PD can be severe and pain syndromes can be the first symptom of PD. My sleep problems are related to pains in my right foot and leg. I had cramping pains that made sleep nearly impossible. The medications help with this, but I now sometimes struggle to roll over in bed. Almost everybody with PD has sleep problems. It affects most functions that involve muscles, including speech. My voice is quiet and regularly I struggle to make myself heard. Speech exercises have helped but this is an ongoing problem. Masks don't help.

Despite the symptoms I had, I still didn't believe I had PD until I was told that the DaT scan was abnormal. Why? Well, this was probably a defensive mechanism – who wants to live with a progressive neurological disease at the age of 36?!

A progressive disease I live with

Having known you have a progressive neurological disease means that you know that you are only going to get worse. It's all downhill from here. The speed of progression is unknown, so prognosis is unknown. I was greatly encouraged when I first saw my neurologist who reassured me that people with YOPD (those under 50 years of age) tend to progress more slowly than standard PD. She said that I can expect a normal life expectancy. Research has shown that we can slow the progression of PD. Exercise can and does slow the progression. It is fascinating to think that a movement problem is best treated with movement! In many respects, PD made me get more fit. I regularly run, do exercise with weights, swim and row. I can lift weights in the gym that I could never do before PD. My running has slowed down a little, but I can still run 5 km in under 25 min. My daily routine always involves some forms of exercise, but they complement rather than replace medications. Diet is another area to focus on and I have tried to adopt some of the dietary advice into my lifestyle, but I do like ice cream!

I adjusted to taking medications relatively easily. I downloaded a medication app on my phone that alarms when I am due my next medication. I started taking one tablet a day. As time has gone by, my neurologist and PD nurse have increased my medications and I now take tablets four times per day at 6:45 am, 10:45 am, 2:45 pm and 6:45 pm. It is crucial to take my medications on time. It is helpful to take my medications at least 30 min before food so that the drug is absorbed better. I take further tablets to help with my sleep. I know that I have progressed because my drug doses have increased and the 'off' periods have increased. Off periods are debilitating. The medications wear off and I feel everything is slower, even my thinking. I can feel when the next medication is due and get frustrated with myself for being slower than normal.

I do remember when I was first diagnosed, looking into the mirror and thinking to myself, 'what now?' This is an important question to ask whether you have Parkinson's or not. What are you living for? What is the purpose of my life? My Christian faith has always given me direction in life but now it is even more important. I never asked, 'why me?' I asked the question 'why not me?' When I used to look in the mirror, I would take pride in my achievements up to that point and try to console my fears that I hadn't achieved more. I was a workaholic and PD has begun to chip away at this identity crutch. Now, I am less focused on work because I have come to appreciate that there is a lot more to life than work. I seek to honour God and impact people positively in whatever way I can.

A degenerative disease I work with

Before PD, I was a busy consultant where I was responsible for an inpatient acute elderly care ward, a rehabilitation unit, surgical liaison work and supervisor for many junior doctors. I was on-call regularly, including late evenings and weekends. In short, a demanding job – both mentally and physically. Now, I struggle staying on my feet for hours, so ward rounds have become increasingly difficult. I get anxious more easily and my speech often means that it is difficult for patients to hear me clearly – particularly troublesome as a geriatrician. The COVID pandemic made me feel disabled because tying a plastic apron behind my back is painfully slow. It was the final straw that made it clear that my job plan needed to change. My colleagues have been very supportive. I have moved towards a clinic-based job so that I am not shattered by being on my feet for too long. This has been humbling but has allowed me to take on different challenges, such as being a medical examiner and roles in medical education. As my disease progresses, I will need to adjust my job role accordingly. I am very fortunate that my job doesn't

require manual dexterity and I can continue to work with relatively minor adjustments.

I still see and treat many patients with PD. When I do, I draw on my professional and personal experience to improve the care of these people. I treat them as I would want to be treated: with respect and compassion. I do occasionally imagine myself in the future, looking like my patient in front of me. How will I manage? What would I want from the doctor looking after me? How will my loved ones manage? I try not to dwell on it too much but sometimes I can't help it. It is perfectly natural to try to work out what the future might hold but that is folly – no human knows what the future holds for any of us.

When I was first diagnosed, I knew that PD is a progressive neurodegenerative disease, so I thought that with every passing day, my condition would be slightly worse. Life, of course, is more complicated than that. I have good days and bad days; good periods of time and worse periods of time. Now, I cannot remember what life was like



without Parkinson's. Some of my greatest achievements and happiest moments have been since my PD diagnosis. I ran the Edinburgh marathon dressed as a Storm trooper in 2017. I completed the Yorkshire Three Peaks challenge in less than 12 h in 2019. I got married in January 2020 and I lead a normal life with PD.

That is the point I want to finish with. Some view PD as a death sentence but I view it differently now that I myself have PD. There are many challenges, but everybody has challenges – many have challenges far greater than mine. I have learnt to adjust to the new normal and have found joy in life in ways that had previously been unappreciated. Some friends talk about fighting against PD. I don't fight against PD but rather fight for joy with PD.

Biography

Andrew Deane received his MBBS in 2006 from King's College London. He has been a Fellow of the Royal College of Physicians (London) since 2019. He has worked as a Consultant Geriatrician at the University Hospital of North Durham, Durham since 2015, where he has developed an interest in surgical liaison work. He was diagnosed with PD in 2017. He is married and lives in Durham. His interests include running, hiking, spending time with friends and church.

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