



34th World **Neuroscience and Neurology Conference**;
13th International Conference on **Tissue Science and Regenerative Medicine &**
38th Global **Psychiatry and Mental Health Conference**

Living with a Neurological condition - what's it like to live with 'Young Onset' Parkinson's Disease?

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Most of us consider ourselves to be fairly fit and active; we know that the best evidence points to Exercise as being paramount in maintaining our desired level of fitness. Certainly, we would probably never expect that despite being reasonably active, we could end up with a chronic condition. And when that chronic condition is one such as Parkinson's Disease, we really do not expect that diagnosis at all – certainly not at age 44. How could such a catastrophic diagnosis arrive at my door? I have a wife...I have children...I have a career...I have a bloody mortgage...what on earth is going on? Why has the earth beneath my feet shifted so disastrously? Parkinson's Disease is a degenerative, neurological condition and I simply wasn't ready for this sudden change in direction in my life. Join with me for a trip through the darkest places in my Brain; the tears for a life less lived; the ice-cold reality experienced when empathy doesn't exist and the glass is half... well...empathy. And yet...and yet...there is HOPE! There is LIGHT! There are some Consultants who are able to deal with People in a HUMANE way! And there most definitely is so much that People Living With PD can do for themselves, if we could only PROMOTE it, drive much greater AWARENESS of what can be done (hint: EXERCISE!!), and finally – but most importantly – if everyone would SMILE more often ☺ This journey is not over!

- The impact of a 'chronic illness' diagnosis - physically, psychologically and socially in my daily life
- The impact of PD on my family
- How my social/economic background and culture has impacted, both positively and negatively, on my health
- My perspective on the Healthcare system and Primary Care services - What works? What doesn't?
- Developing a positive experience and a positive relationship with Healthcare Professionals
- The Future...?
- A cure on the way? Maybe?

When someone who is 21-50 years old receives a diagnosis of Parkinson's Disease (PD), it is referred to as 'Early Onset' or 'Young Onset' PD. While the symptoms of the disease are mostly the same at whatever age it develops, younger people will experience the disease differently due to their unique life circumstances. Managing PD can be particularly challenging for a younger person and their family, from a medical, psychological and social standpoint. Because the majority of people who get PD are over the age of 60, the disease is often overlooked in younger people, leading many to go undiagnosed or misdiagnosed for extended periods of time. However, once it has been diagnosed, the rate of neurological deterioration is usually much slower in younger people, due in part to the fact that younger people have fewer general health problems and are more capable during physical therapy treatment.

While common symptoms of Parkinson's may be similar no matter what age you are, the deterioration is often different: younger people often have more involuntary movement problems due to the most commonly prescribed PD medication, levodopa. For this reason, young onset patients are usually initially



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treated with alternatives to levodopa. Other problems associated with Parkinson's such as memory loss, confusion, and balance difficulties tend to be less frequent in younger people with the disease. About 10%-20% of those diagnosed with Parkinson's Disease are under age 50, and about half of those are diagnosed before age 40. Approximately 60,000 new cases of Parkinson's are diagnosed each year in the United States, meaning somewhere around 6,000 – 12,000 are young onset patients. The cause of Parkinson's Disease is not yet known. However, PD has appeared across several generations of some families, which could indicate that certain forms of the disease are hereditary or genetic. Many researchers think that Parkinson's may be caused by genetic factors combined with other external factors. The field of genetics is playing an ever greater role in PD research, and scientists are continually working towards determining the cause or causes of PD. To date, there is no known cure or way to prevent PD. However, research is ongoing and remarkable progress is being made. There is very real hope that the causes, whether genetic, environmental, or some combination of the two, will soon be identified and the precise effects of these causes on brain function will be understood. Although there is no cure for the disease at this time, by identifying symptoms and determining a proper course of treatment, most people with the disease are able to remain active and lead fulfilling lives. My own experience is that a properly resourced, inter-disciplinary approach to treating each person with PD is the most effective pathway to as 'normal' a life as possible. Doctors who are specially trained to diagnose and treat conditions of the brain and nervous system are called neurologists. Some neurologists have a subspecialty in movement disorders and work extensively with patients who have PD and other similar conditions. These doctors also may have experience dealing with early onset Parkinson's symptoms. You can ask your physician if they have specific experience with younger patients, or whether they can refer you to a doctor who does. Larger hospitals or university systems often have movement disorders centers. If you do not live in or near a large city, you may have to travel further for an appointment. While not as convenient, you may find it worthwhile to work with a physician who deals exclusively with movement disorders. Often, once stabilized, in-person appointments are not required very frequently, and that has certainly been the case for myself. Every day my routine consists of a lot of exercise, balanced diet, social interaction, medication and (hopefully) a good night's sleep. Incredibly, Parkinson's is still referred to as being a 'progressive' condition. Excuse me, but there is nothing 'progressive' about a deteriorating, neurological condition that is, as yet, incurable. I will say, however, that I am progressing since my diagnosis and 11 years after receiving this 'gift that keeps on taking' I'm happy to report that I'm not cured but I am better. I would call that progress.

PD occurs when the cells in the brain responsible for producing dopamine decide, for reasons best known to themselves, to die off. Dopamine is a neurotransmitter involved primarily in movement, and in the risk/reward cycle. The symptoms are many and varied, but include the classic bilateral tremor, a shuffling gait and stiffness, especially in the shoulders and neck. Parkinson's is, primarily, a disease of diminution. It shrinks the space you occupy both physically and emotionally. When I told people about my diagnosis, their responses were often awkward, uncertain: "But you don't look sick" or, "It's very mild, then". What they responded to was their cognitive dissonance: I was giving them a new interpretation of me that they couldn't see. But I could see it in their faces. Parkinson's scares people – it scares me - but it's certainly not a death sentence. It's more insidious than that, but we can fight back...I just wish we'd do more of that.