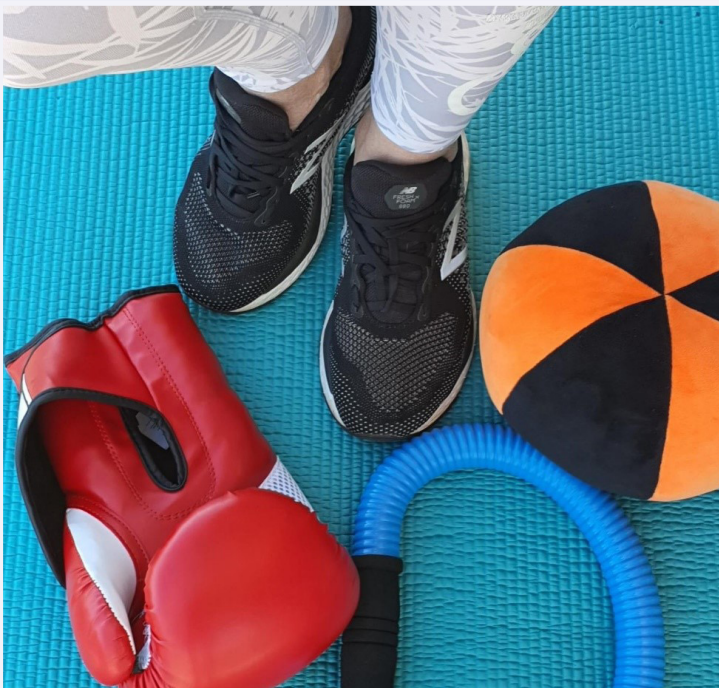


Walk in my shoes



ROBYN HIGGINS

aged 66, former primary school teacher/university tutor and now an energy bunny.



Parkinson's Disease: (PD) An incurable, progressive degenerative neurological condition affecting movement¹. PD is experienced by an estimated 10 million people globally with 38 new cases each day in Australia². In Australia, Parkinson's is not a high-profile disease, even though it is the second most common neurological disease in Australia² and there is little understanding of the disease or support for people living with Parkinson's, even though it touches many families and communities across the country. Robyn shares her personal and heartfelt story.

EARLY DAYS

"Damn, I was hoping it was carpal tunnel" was my response to my neurologist as he delivered my shock diagnosis of Parkinson's Disease. It was my 62nd birthday.

I had no idea even though, in hindsight and with more information, I had been experiencing symptoms for at least five years and more. Slowness of movement and gait change, minuscule handwriting, and constipation were now accounted for.

I had in my mind that presenting with a claw-like right-hand posture, caused by rigidity, would require day surgery to fix a nerve and I would be back at work the following day.

As it turned out, I continued to work full-time as a primary school teacher for the next three weeks, then with the support of family, friends, and colleagues chose to make fighting Parkinson's my full-time unpaid job with a life-changing, not life-threatening condition. The reward though not financial, is more profitable for me.

I have had and continue to have a fortunate life. Unlike the many negative experiences conveyed to me that others have endured in getting a diagnosis, my neurologist diagnosed the condition within 15 minutes. With observation, physical testing, and targeted questioning, he explained the loss of dopamine and how the medication works. He advised me to join the state Parkinson's body through which I could access physical therapies and a Parkinson's nurse. He also apologised for the poorly timed birthday news.



THE BREAKTHROUGH

Being diagnosed with any disease understandably brings on a grieving process, but this being an incurable, degenerative disease with no set treatment is unsettling, to say the least. My husband and I decided from day one to fight the beast that PD is. I've never done the why me? And I dwell minimally on the cause, of which there are several theories. I went through the grieving process remarkably quickly and moved on to advocacy within three months of diagnosis.

My focus is on dealing with the here and now to ensure a better future.

A general understanding is that Parkinson's is a tremor and Michael J Fox is what PD looks like. No two People With Parkinson's (PWP) experience the condition the same way, so treatment is unique to each person. Although I had a tremor, it is now managed with medication and only presents in periods of anxiety.

My balance is better than most other people my age. I can stand on one leg for two minutes.

We sought information, realised that targeted exercise is the only current method of slowing progression, and developed a proactive approach to dealing with the numerous symptoms which PD consists of. Now we know that non-motor symptoms of PD are a key determinant of health, and quality of life. They are often less appreciated than motor symptoms but are important source of disability. 90% of PWP experience speech and swallowing problems, potentially associated with loss of effective communication and serious aspiration from dysphagia.

My predominant symptoms are fractured sleep, constipation, loss of voice quality, night-time leg pain, disturbed sleep, dystonia in my right side, toe-curling making wearing shoes an issue, weight loss through loss of appetite, and urinary frequency and urgency.

We have researched newer treatment methods such as red-light therapy with the aim of staving off Parkinson's dementia and improving brain health. We have also accessed another device, the Mollie Suit an assistive device that aids in the therapy and treatment of improving movement and muscle control in people with movement disorders such as PD.

Never having set foot in a gym prior to diagnosis, my focus and direction changed to be proactive. The exercise program I follow consists of ten supervised therapy sessions a week and a home program. Some physical therapies are boxing, dance for PD, aqua therapy, physiotherapy, exercise physiology, speech therapy including daily speech exercises, cycling, beach walking, Smovey Rings, singing, painting, skipping, quoits, fine motor exercises, digital brain workouts, and PD Warrior, a targeted PD therapy program.

My long-term goal is to reduce symptom impact, slow progression, and continue to enjoy a quality of life. I am trying my best not to be stuck in a wheelchair unable to communicate or interact with my adorable grandchildren. It is to be a productive active wife, a good friend, and to be a contributing member of the Parkinson's and the broader community, advocating for, informing, and assisting others with PD.

We live in hope for a cure for the many yet undiagnosed coming behind us.

For now, PD awareness, support, and research are vital.

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