

My journey with Parkinson's



Parkinson's people need others. If you know a person with Parkinson's remember to encourage, to extend them with your support, and to invite them out for coffee, writes Sister Eileen Brown.

BY Eileen Brown SGS

The day is etched in my memory. As I left the neurologist's rooms warm tears gushed down my face. For a couple of years I had been experiencing a lack of energy, extreme fatigue, a strange walking pattern where my legs crossed over one another, and I found it hard to stay balanced. I had always walked quickly, but now I was teased by family and stranger alike about being so slow. "There is something wrong with you!" had been the refrain.

Hardest of all were the non-motor symptoms. I had enjoyed travelling around the diocese and giving presentations on liturgy with a team of people. Now I was developing panic attacks when I stood up to speak. As the disease took hold I couldn't even read at Mass, something I had enjoyed doing for many decades.

Parkinson's disease is more than a movement disorder. It is a brain disease where a part of the brain is dying and it manifests in a hundred different ways covering movement and coordination, together with problems with inner functions and psychological problems, such as depression or panic attacks.

Parkinson's can affect every part of the body – speech, swallowing, digestion, balance, the ability to stand up or turn over in bed, as well as the coordination needed to shower and dress, and very commonly, the ability to walk. Most Parkies walk with a distinctive gait. Even one's handwriting is affected. Many have a resting tremor; many others don't have a tremor or shaking. Most have difficulties with sleep and almost all would say they lose their "mojo" or motivation to do things or take initiative.

Dopamine is the feel-good hormone in the brain that is depleted in Parkinson's. Fortunately modern medicine has produced medications that can go some way to replacing the dopamine. As the medication wears off the person begins to experience many of the symptoms again, especially the stiffness and weakness. And so throughout the day there are these 'on' and 'off' periods. As the disease progresses the effectiveness of the medication lessens.

However, a person in early stages of Parkinson's may have a few good hours each day when they can do things. For me that is between 10am and 2pm and I usually organise my life around these times. Outside these times I will be struggling with various levels of depleted dopamine which reaches its lowest point by nightfall.

There is a great spectrum of symptoms and degrees of severity of Parkinson's according to how far the brain cells have deteriorated. So what does a bad day with Parkinson's look like? On a bad day I will wake up and try to move my legs and arms and nothing will happen. The battery inside me is dead! It will take quite an amount of extra mental effort for me to find the resources to move a limb. When I am finally up I will feel weak. During this bad day I may feel shaking in my legs and sometimes in my jaw and tongue. Getting out of a chair can be especially difficult. My appetite will be affected and I will lack all motivation.

What brings on such an experience? Usually a change in routine at night leading to excess tiredness or physical or emotional stress, or too much mental concentration the day before. The good news is that I have learnt to manage such days.

One of the secrets to living with Parkinson's is to stay active – to exercise each day. Having lived with PD for eight years now, I am one of the more fortunate who have found the combination of medication and exercise/activity that keeps me functioning reasonably well for a few hours most days. Along the way I have been blessed by good friends and companions who have helped me to stay active and have enriched my life, hence helping the brain to remain healthy.

How does one live with such limitations? I often regret that I can no longer commit to being involved in my congregation or parish or community as much as I would like. I do maintain a monthly liturgy meeting in the diocese, but otherwise I am retired. However, I am convinced that I can live the mission by the quality of my presence to each of the various personal assistants I encounter.

During ten weeks in hospital when I feared I would never walk again, I kept reminding myself of the value of calling each nurse by name and keeping a positive frame of mind. Some of them ran "You can't ask that" sessions on faith and religious life! This is my mission – to be a listening presence to all who cross my path and to be a grateful recipient of their healing ministries. It is to allow myself to be the wounded traveller. This is not a comfortable position for those of us who are so used to doing for others and being the Good Samaritan.

Parkinson's people need others. Behind the mask there is someone who needs stimulation. If you know a person with Parkinson's remember to encourage, to extend them with your support, and to invite them out for coffee. Both conversation and the coffee beans are great brain stimulants. Coffee, dark chocolate, blueberries and the companionship of good friends – these are the natural cures, these are good for all our brains!

Eileen Brown

Good Samaritan Sister Eileen Brown has enjoyed many years educating youth in faith and science. In later years she has had a passion for educating adults in faith, especially in liturgy, and ministered in the Wollongong Diocese by coordinating RCIA and liturgy. She contributes currently as a member of the Wollongong Diocesan Liturgical Commission.



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