

PARKINSON'S DISEASE: DANCE THROUGH LIFE!

Shirley Read-Jahn (1954-61)

When Penny Harrison asked me to write an article on Parkinson's Disease, I agreed, in that many people think PD only attacks older people and that all of them manifest tremors. Not true!

I have Parkinson's. I am one of the older ones but I don't have visible tremors in my hands. I was diagnosed on 1 February 2018. I didn't believe it. I had lived a healthy exercise-filled life. But, my left arm betrayed me. Two years before, I had been performing a solo belly-dance using tall golden "Isis wings", named for the goddess Isis. I found I couldn't shake the left wing with my left hand to make it tremble to the music. When I walked, my left arm didn't react; it still just hung down, not swinging, as it still does. Doctors thought I'd had a stroke, but I was tested negative. It took two more years to get the true diagnosis. I became terrified of my future incapacity.

Parkinson's Disease is a disorder in which neurological cells carrying dopamine to the brain die. Dopamine is what our body uses to control our motor movements and muscles. As the disease progresses, it becomes harder to wash or even dress yourself. Many PD patients indeed, do shake, with tremors both externally and internally, their legs suddenly freeze to the ground, their voice softens and they become hard to understand. Unpleasant side effects occur such as constipation. Everything slows down.

I know PD sufferers who have been thrown out of taxis, being called drunk. I think, if I were to display visible tremors, I'd wear a sign saying, "I'm not drunk, I have Parkinson's" rather like some people with poor eyesight wear a sign saying, "Vision Impaired". Maybe that would help.

A dementia called Lewy Body quite often goes hand-in-hand with Parkinson's. The side effects are frightening: depression, anxiety, panic attacks, building up to even worse—true dementia. PD is often called a "boutique" disease because it is different for every sufferer. You can display the whole gamut of effects within 2-5 years, or, you can stay on top of it for many more years. I have been assessed for Lewy Body but do not have it—but I still have anxiety and panic attacks.

For me, a problematic side effect is that my typing is badly affected. My left hand jerks and puts letters in that shouldn't be there. I used to type 98 w.p.m. with no mistakes. Now I must correct every line I type, which, as an author, becomes tiring and tiresome. I'm sure you undersstand (whoops, sssee what . happensss! I won't correct the line.)

Another side effect is crying. Suddenly, often for "no reason" I burst into tears. The tears fall without warning; it can be annoying or even embarrassing if guests are around! I might be cooking dinner, darning some socks, not thinking of anything sad, certainly not even thinking of my illness, but just doing my "chore" when, out of the blue, I begin to sob.

Another side effect for me is nausea. My doctors have tried me on all sorts of different medications. For some months I was feeling nauseous 24/7, the only relief coming when I could finally fall asleep. For me, it's a nausea that feels similar to the hormonal morning sickness I suffered when expecting my baby. Now I start feeling ill around 5 p.m. (but not every day now), which means I tend to avoid evening appointments. My hope is that my body will get accustomed to the medications sooner than later, as I think it surely must do. The medications you take, such as levodopa, are effective for shorter periods of time as the dopamine level in your brain declines. As that happens, you experience daily fluctuations in symptom control, needing stronger and stronger medications.

There are brain operations, such as Deep Brain Stimulation, which can help when you reach an advanced, intolerable, stage of PD. You can make the symptoms more tolerable in various ways, but, nevertheless, Parkinson's Disease is incurable.

Therefore, attitude is key. After some six months of dismay after I was diagnosed, I "girded my loins" and decided to "get on with it". You don't die from Parkinson's. You "live with Parkinson's". Some other illness or accident (often falling) gets you in the end. My son's boss in New York has PD and is a close friend of Michael J. Fox himself (who has PD) and the boss is one of the Parkinson's Foundation's principal financial supporters. Through my son I learned that the boss, and Michael, claim that intense exercise is the answer to help you keep on top of the inevitable

neurological deterioration—to slow it down. I have become a guineapig helping the Foundation's research and do online trials for them every so often.

My neurologist believes I didn't get PD genetically. The only person in my family who had it was my uncle, my mother's half-brother. The doctor said I would have got it many years ago if I'd inherited it.

Young people can also get Parkinson's. My New South Wales Parkinson's Neurological Nurse has far too many patients, but is brilliantly capable and manages to still help them all, as needed. She has a number of young patients as well as the older ones. I am her patient No. 589. As of last week, she advised us she now has 700 (acquiring, on average, ten more every single month!), and has no help in sight of getting an assistant nurse through our Parkinson's New South Wales organisation. That's the bad news: too many people are getting this disease in Australia (and probably all over the world). In 2015 Deloitte's Living estimated that 1 in every 350 Australians lives with Parkinson's disease.

My first husband in the States has PD and is now wheelchair-bound. He became one of the USA's class action suit's defendants. They have proven that many of the military returning from Vietnam, eventually manifesting PD, got it through exposure to Agent Orange. I was asked, having been married to him in the late '60s and '70s, whether I'd washed his clothes when married to him and could, therefore, somehow have picked it up. But I hadn't been married to him when he was in Vietnam, so apparently I couldn't benefit from all the money given out, or have my house redone to accept a wheelchair—if that were to be what I'd eventually require.

I think I probably got Parkinson's from the landscape & gardening business I ran for years when I lived in the San Francisco Bay Area. I wasn't always completely careful about protecting my mouth or hands from the chemicals we sometimes had to use in the business. On the other hand, there's some thinking that there could be a connection between bowel problems such as Irritable Bowel Syndrome, and the onset of PD. I have had IBS virtually all my life. The only good thing about PD is that because everything slows down, I no longer have the type of IBS that demands immediate dashes to the toilet, but quite the opposite—regrettably!

To stay on top of the dopamine brain cell deterioration, attitude comes in. I do as much as I can of a lot of weekly exercise, as intensely as I can:

Monday afternoon: tai chi and yoga;

Tuesday morning: aerobics, bands, weights;

Tuesday afternoon: table tennis;

Wednesday afternoon: I teach belly dance;

Thursday afternoon: table tennis;

Friday: rest—sometimes more table tennis;

Saturday afternoon: table tennis;

Sunday: rest—sometimes more table tennis.



My legs feel like lead. This is a typical side effect some people have. I used to walk at least two miles per morning. Now occasionally I try to go on rather long walks, but find walking quite hard. Yet I can dance, as well as the other sports I do! Even one of my fellow-PD sufferers, Bernie, whose legs freeze in place suddenly, and who shuffles when he walks, can still jive and rock n' roll with the best of 'em! It's believed the brain creates a new pathway, with dopamine, when one hears music and gets up to dance.

Diet, too, as in life generally, is of importance when you have PD, especially when you experience problems in your throat, such as tremors. The medications you take affect your appetite. You can't tolerate alcohol when you're taking strong medications, either; they just don't mix.

Something else that is good for PD patients, to help their hand-eye coordination and focus (aside from table tennis), is art.

I am an author and an "outsider artist" of children's books. An outsider artist means I've had no formal training in art. Children and mental patients can be considered "outsider artists". My illustrations are, actually, rather childlike, but charming, I'm told! I hadn't drawn or painted since art classes at St. Mary's Hall (1954-1961), which I'd much enjoyed. I have the paintings that received honours still rolled up in my home office. They've travelled from country to country in my moves around the world! A selection is illustrated at the end of this article.

Drawing and painting takes a lot of focus, which is, so far, helping to hold Lewy Body Dementia at bay. It serves to keep my distressing panic attacks from being so frequent. I work in water-colour and gouache, and am considering maybe moving into acrylics and even oils.



Not only have I written, illustrated, and published my *Prince Oliver Penguin* trilogy, but also *Hidden in Plain Sight, a British Military Agent's Story*.

That last is, of course, not a children's book. It is about my father who was a spy in WWII working for MI-19, based in England and Moscow.

Illustrated (right) is the jacket design for the book.

Another book I am well into writing currently is my autobiography. My family and friends tell me I've led such a fascinating life that I should get it written down, particularly for my son to read, before I fall off my perch.



I am in the middle of doing the illustrations for another children's book called *Wally and the Mouse*. This centres on my observation of a water dragon we have living under our house here in New South Wales, and a fieldmouse (and his buddies) who took up residence in the water-well of a huge garden pot we grow *Strelitzia* in, and which I'd allowed to go dry for a while.

My husband accompanies me to markets where we sell my books together. I have also been invited to various places, including a primary school, to speak about my books, and to autograph and sell them. Our local library has given me a book launch. I was invited to prepare a collage of my children's books' art for the 2019 Shoalhaven Mental Health Fellowship Open Community Art Competition. On the collage was a note explaining that art has become a vital connection to my focus, avoidance of panic attacks and Lewy Body Dementia, and to conserve my mental health in general.

Hopefully, I can continue to live a good, productive, life, even with PD, holding it at bay for many years. After all, I've got even more books swirling about in my head which need to be released into the light of day!

For Shirley's books, please go to: [amazon.com/author/shirleyread-jahn](https://www.amazon.com/author/shirleyread-jahn)

Some of Shirley's paintings from her years at St Mary's Hall



SHIRLEY READ-JAHN
ST. MARY'S HALL
BRIGHTON 7
AT THE EXHIBITION
This is a painting by Shirley Read-Jahn.



The Royal Drawing Society's Exhibition-Competition, 1957
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This is a painting by Shirley Read-Jahn.

This picture was inspected by Her Royal Highness The Princess Royal, the Princess Mary, only daughter of King George VI and Queen Mary, at the exhibition of her visit to St. Mary's Hall on Wednesday, May 26, 1958. The picture was then presented to the artist.