parkinson's australia

yop

CASE STUDY

PAULA ARGYROPOULOS/ NÉE SPYROU, 52

DIAGNOSED IN HER 20S WITH YOUNG ONSET

I have had young onset Parkinson's for most of my life. I have the Parkin genetic variant. Three years ago I couldn't walk 200 steps. I was housebound, frozen in time, my on-offs were fluctuating severely. I was depressed and apathetic, had severe dystonia and dyskinesia. I didn't want to live like that anymore...

Back to life, back to reality!

During COVID, I commenced a Parkinson's trial with subcutaneous levodopa treatment and am so grateful that I'm BACK BABY!

It hasn't magically taken away the Parkinson's. I still have my good days, now 90% and a few bad 10%, but in those instances I can give myself an extra 'rescue dose'. The only happens when I have overdone it on the exercise, i.e. 30,000 steps in a day and I get stressed and upset. There have been a couple of times I have turned up for my exercise physiology class and my walking is starting to go 'wonkey donkey' and my PT says, "Hey, have you turned your pump on?" then I realise I hadn't turned it back on then I changed it after my shower in the morning. Even then, I still do not get as bad as I was three years ago. It would take a few days for all the dopamine to completely leave my system.

I have had to work incredibly hard over the last few years for my body and mind to catch up with the dopamine benefits I was experiencing from the trial. I wasn't in great shape. I have lost a huge amount of my excess body weight because I can exercise every day now!

I know you probably hear it all the time by exercise is essential even if you can't walk or get out, do weights or a stationary bike at home. I cannot express to you how life changing the trial has been for me and others I know who are on it! I am praying it gets approved by the Australian regulators.

It hasn't been all good

My life has ben impacted in such a negative way 33 years of having Parkinson's has also been life and soul destroying. My marriage broke up, I raised my 1 and 3 year old babies as a single mother.

I lost my house, bank foreclosure. I moved back in with my elderly parents. I lost my capacity to work, having to rely on government disability support.

I couldn't socialise, I hardly went to events. My last 20 years I was dedicated to my children. It's been such a long bloody, horrible struggle but this is my story, my truth, my journey.

Hopefully I will continue to receive benefits from being on this this trial and hopefully everyone else with Parkinson's can too.

To contact our spokesperson please email:
info@parkinsons.org.au

For more information, visit our website at:
www.youngonsetparkinsons.org.au

Parkinson's in the hospital: the fall

Recently, I came out of nearly 4 weeks in hospital and rehabilitation hospital after I fractured my sacrum and L3 vertebrae from a fall onto a concrete floor.

The nurses, although very dedicated, hardworking, and mostly lovely, the majority had no clue about how to 'manage' my PD besides a couple who have worked with people with Parkinson's (PwPs) before. I am a very complicated case being on a trial subcutaneous levodopa pump, which I self manage. I knew more about it than even the doctors.

I present very well, even seems like I don't have Parkinson's. I'm 52, which is considered if diagnosed even today to still young onset. I know that sounds crazy but I have walked the long PD walk of 33 years, (but who is counting). First symptomatic in my late teens, having Parkin Gene variant PD which is thought to be slower in progression.

Once the pump is turned off my Parkinson's symptoms are quite severe, and within the hour present as in the advanced stage. The nurses need to be aware it's all about the timing of medications, hence why I strongly advocate for Parkinson's Nurse Specialists in all major hospitals and rehabilitation hospitals as a matter priority and urgency.

Even though I am on a drug trial, a subcutaneous pump which I self managed, they took all medications off me including the vials of levodopa that I use for my pump.

Somedays they would forget to bring it. I would ask for them as I change the vials every 24 hrs when I shower. They would be understaffed, go on to something more important and I would go 'off' and become very symptomatic, and by then I couldn't even get off my chair to walk to get the buzzer to buzz my nurse.

It's the same with PwP who have oral medications. If you don't have your medication on time ~ preferably 30 min before meals you are likely to freeze, go off and it's these dips in levels of dopamine in your bloodstream that are so important to keep at the right timing so you don't get those horrible 'off' periods and thereafter lagging affects and more fluctuations.

Not to mention I was given a contraindicated medication for severe case of nausea which suddenly came over. This nausea medication which makes parkinsonism worsen in effect and caused the most painful neck and jaw dystonia I have ever had and the after effects lasted for 48 hrs.

The nurses or doctors on rounds had absolutely no idea what to do. I called the exercise physio to massage my neck and jaw as I was in agony. I couldn't speak, my mouth neck jaw were contorted similar to cerebral palsy.

Lucky I had good sense to contact via email my hospital drug trial care team explaining what I was experiencing. I was completely terrified and tearful.

Even though it was a Saturday night 10 pm my clinical trial nurse, Sarah, god love her, got back to me straight away to say that she hoped that hadn't given me Maxolon for the nausea which I confirmed they had. And that what had triggered the painful onset dystonic response.

This hospital is mainly a geriatric rehab hospital and I saw many older patients who had Parkinson's, so really this should not of happened to me and it's not good enough. I was under the care of a Geriatrician specialist who when first came across me in the ward was surprised I was so young.

I know there is the Hospital Grab Bag to take with incase of emergency, however I was in such agony when I went to the hospital I did not even think of that. Then I was immediately put on so many painkillers when I was admitted to emergency at that I didn't know if I was Arthur or Martha.

It is so difficult to manage your medical contraindications and what you should not be having when you're so out of it. I literally couldn't keep my eyes open that first couple of weeks.

I eventually had to request to come off the particular pain medication because of horrible fatigue and balance issues, cognitive dissonance.

Then when I stopped the endone, I came out an emotional weeping willow, hot sweats and headaches for three days (on top of those symptoms I usually get having PD) and I figured, (as I kept asking the nurses but no one would confirm), could this be a result off coming off endone!

This is all happening whilst trying to get to two rehabilitation exercise classes a day with a Zimmer frame just incase I had another fall in hospital which was highly likely being off like a newborn baby deer, or the wonkey donkey!

I had been to the same hospital 20 years prior for pneumonia and although it had been renovated and the staff nurses were extremely lovely and apologetic, the system hasn't changed.

Parkinson's in the hospital: the heart

In the last week, I have had three ER hospital 'admissions' following on from my fracture of the sacrum L3 in which definitely were not pleasant, substandard non-informative, resulting in confusion, frustrated and left feeling I was treated as sub standard patient, as they basically had no clue what to do with me, to in NO end conclusion leaving me highly stressed.

I had a panic attack on the third visit had to be taken by ambulance, and I still I have no clear directive, other than an incidental accidental finding of fluid around my heart inflammation pericardial effusion. I didn't see a cardiologist in my second ER visit even though I'd been in there from 8.00 am to 1.30 am waiting to get answers. Outcomes treatment options.

I can't see cardiologist for another month 8 May. My BP has been consistently high the past year but it has been overlooked given I'm fifty shades of complicated. I threw them a curve ball and they were baffled. I am happy to document my week in ER! As further case study to advocate for hospitalisation in Parkinson's, safety outcomes or in my case sitting in triage in pain for 10 hrs in a wheelchair where the treating ER doctor refused to call my specialist neurologist even though he gave me his personal mobile number.

Let me know if you would like this documented I can do it other the next few days, as I have been told to cease my hospital rehabilitation, exercises physiology sessions, walking and even volunteering duties for a few weeks.

I strongly believe during these three seperate admissions there was strong discourse, no directive for a complicated patient as myself Parkinson's 33 yrs but presenting non symptomatic pretty well as on drug trial which they had no clue about. Which ultimately draws attention to the risks PwP face by drawing attention to the very present gaps and no communication between medical teams doctors, triage, nurse on duty and specialist, given the economic and clinical outcomes which burden the already struggling hospital healthcare system and leaving PWP at major risk and improving gaps and much needed care more education and PD nurse specialist.

I walked into my GP after the week of tour of duty of hospital ER and she said wow you've had an incredibly tough week reading reports from the hospitals.

Other articles about Paula:
https://www.smh.com.au/national/wobbly-mummy-stands-tall-20090829-f3aj.html

Download the Young Onset Parkinson's eXchange app on the Apple App Store (iOS) or get it on Google Play for more young onset Parkinson's stories like this.

GET IT ON Google Play
Download on the App Store