



PARKINSON'S
— WITH GEOFF —

EMBRACE YOUR JOURNEY WITH PARKINSON'S

How I manage my Parkinson's cognitive symptoms and cognitive health: A practical guide

Introduction:

Hello and thanks for taking a few moments of your time to listen to my own personal experience with the cognitive aspects of living with Parkinson's Disease (PD) and how I try to minimize their impacts and slow their progression. This guide is focused almost exclusively on the cognitive aspects of PD, not the motor skills impairment; why?: because I am fortunate so far to have PD motor skills impact that are a bit problematic, but not as near to the same level as the cognitive aspects yet – I won't share with you what I don't have experience with.

Who am I ?

My name is Geoff, I am a regular plain white tee shirt kind of guy, nothing special, in my middle ages (not FROM the Middle Ages, thank you !) and my professional background is in the aerospace industry, mainly in leadership roles in Customer Service. And guess what?, most of the time, people that don't know me would not have any idea that I have PD, unless I am having one of my "wobbly days", wherein my right leg and right arm are weak and want to do their own thing, and on those days I use a cane for support.

I am definitely not a medical professional, so, please do not use this guide as a primary or definitive treatment of care plan, please always seek the services of

a good Neurologist, preferably one that specializes, or at least has experience with, working with people with PD, and coordinate with your primary care Doctor and other professionals that will be part of your evolving care plan.

Why am I sharing my experiences ?

I want to help people, there's nothing more to it than that. I started experiencing some of the more classic and recognized symptoms of PD, such as a trembling right hand, less facial expression, apathy, memory impairment etc., but the most troubling and disruptive aspects of my PD journey so far have been cognitive. My formal diagnosis of having PD, after many months of different tests was in Fall 2022. I was not surprised at the diagnosis, although there is no history of PD in my Family, but my Aunty passed at an early age due to Multiple Sclerosis, which is not the same as PD at all, but has some common pathology and symptoms. Of course, I had many questions, and I am fortunate to have one of the most thorough, caring and funny and "tough love" Neurologists out there, she is wonderful.

But, there are no black and white answers for PD, and each individual will have different experiences, progression rates, etc. I found that, at least in the 2 geographic areas I have lived in since my diagnosis, there really is not much real-life non-medical support. There seemed to be quite a few support groups for people with Alzheimer's Disease, and for the relatives of people with that disease, but not much for people with PD, especially in the early stages of the disease. I wanted to share my experiences to help others so that they are not alone, they don't have to be alone in this journey, and I have been guided and found ways that really help me – I want you to have that knowledge so you can try them if you wish.

What is PD ?

I sincerely hope that you have been seeing a qualified Neurologist and that after multiple clinical tests, it is them that has advised you of your diagnosis, and that you have not come to that conclusion by yourself by doing internet searches for root causes of various symptoms you may have been experiencing. If you have not been formally evaluated by a medical professional, please do so. Let's be honest with each other, if we jump on the internet and look for medical symptoms, causes and definitions by ourselves, we are likely to come away depressed, confused, misinformed and inevitably we will all have only 12 hours to live; yes, I am being silly with that last statement, it is not true at all, but if you have ever done a Dr. Internet symptom/disease search, we know we can all find something we or our relatives will latch onto that could be completely wrong.

PD is a progressive degenerative neurological disease, that can occur to anyone at any age without any specific trigger. It is generally associated with older people, and yes, it is often associated with trembling limbs, shuffling walks, and more visible symptoms. PD is generally accepted by the medical community to be caused by a breakdown of the normal dopamine production and transmission pathways in the brain. PD in and of itself is **definitely not** a guaranteed shortened lifespan; PD is often accompanied by conditions such as depression. PD in and of itself is not a mental illness – you are NOT crazy (well, sometimes I am, but not because of PD !).

Beyond the standard medical treatments and medications, primarily those that can improve dopamine production, as well as separate medications if you do suffer from depression, difficulty sleeping, etc., there are MANY things you can do to help yourself. For the tools and exercises that I use, I have to make a conscious point of adopting them as a new lifestyle. Think of these methods the same way you would approach a diet – losing weight is usually a lifestyle

change if you want the results to stick – you can't run once around the running track, swap one steak meal for a steak salad and go the gym once and expect to lose 10 lbs and keep it off; if you have been able to do that, please tell me how, I am seriously interested.

Strategies and tools that have been helpful for me:

Some of these are simply good health and common sense, but if you have been delinquent in the past on the basics, NOW is the time to take it seriously, OK ?

1. Regular physical exercise

At this first heading, some of you are rolling your eyes and thinking to yourself “yes Geoff, I know that, I've been doing it all my life”. Good. Keep doing it. The PD, and the lower dopamine levels are likely going to have an impact on your motivation levels for many things, including your exercise routine. You will have to make more of a conscious effort sometimes to do your exercise routine. Remember, I am focusing in this mini guide on the cognitive aspects of PD, not the motor skills; you may need special physical therapy already, your medical professional should be guiding you in this regard if that is the case.

My preferred exercise regime has always been working out with weights at the gym. My motivation to get off my behind and get to the gym is slowly reducing, I have to make myself get out of the door and go to the gym, but it is essential that I do. Your body releases many good chemicals and hormones when you exercise it properly and regularly, these can help with the slowing of PD progression too, as long as you are consistent. I have noticed that I cannot move as much weight at the gym as I used to, I am not quite as strong, and it

used to annoy me and it would be easy to say “to heck with it then”, but don’t do this, keep going. If you need to lower your weights, do it, but try to keep the number of reps up. But be safe, most people in the gym are more than willing to spot/support you on an exercise, so don’t be afraid to ask for help, do not risk injuring yourself.

The other exercise I do is really simple – walk ! But, as long as you are physically able and stable, make that walk count. Get your heart rate up, try to walk those magical 10,000 steps per day if you can, and my strategy is to make at least 7,000 of those steps occur in one dedicated walking session. Again, the chemicals and hormones released benefit your body every time and can help your body slow the PD progression. Ideally, I try to do this at least 5 days per week. If you can’t do that, at least get a 30 minute dedicated walk into your day, 4 times per week is my suggestion. Again, only you if you are able, stable, and have no other health conditions that prevent this.

Any aerobic exercise such as walking, swimming, strength training is beneficial. Also, make sure you do exercise that helps with your flexibility, try some yoga for example. Put a physical exercise routine into your calendar and stick to it, move it only if you have to, but I said move it, not skip it.

2. Healthy Diet and Nutrition

“Oh Geoff, come on man, we know this already”. Good. But, lots of people know it and don’t do it, PD or no PD. I am not a nutritionist, but I know the basics, even if I still sometimes give into my cookie cravings.

If you don’t already have the good nutrition basics as a fundamental way of life, now is the time to sort it out. You need to have a good balance of fiber, protein, carbohydrates and healthy fats.

Your brain needs the glucose from carbohydrates to function properly, but there are many sources of carbohydrates. When I consume an entire packet of cookies in one go (sorry honey, yes, that does still happen, when you are not looking), you are putting a lot of carbs into your system, in fact you are creating a large but short lasting spike in glucose, this is not what you need. You need more complex carbohydrates that break down slowly and have a more stable effect on glucose and insulin production, so your brain has a steady, balanced supply.

I needed to keep those cookies out of the house, and the complex carbs are found in things like brown rice, whole grains, starchy vegetables such as sweet potatoes, corn, and, thank goodness, most fruits. Fruit is now at the top of my shopping list. The carb haters of the world will be horrified to hear this because, yes, fruit has its own version of sugar, but this is good energy, and a much better carb than processed foods, breads, cookies, etc. For me personally, fruit is a gift, because it has carbs, but also fiber, and it is sweet – I love sweet things. My body is able to consume a lot of fruit without putting on weight, but, not everyone is like that, but everyone should be eating at least some fruit if they are not already.

I usually start my day with a home-made smoothie, which includes kale (yup, you heard me, that stuff), spinach, some berries (blueberries, blackberries, raspberries), low fat plain yogurt, sometimes some good quality protein powder, especially if it is a gym day, of course ice cubes, and you can always include some milk and even a small tub of the ultra low calorie Jello to get the sweetness and consistency you prefer.

Do eat healthy fats and consider some supplements (with the concurrence of your medical professional) such as an anti-oxidant, some Vitamin D and omega-3 fatty acids.

The rest is common sense for diet – a good mix of fresh vegetables, proteins of your choice, fish and chicken are my standards, and the complex carbs I mentioned above. You can obtain all kinds of diet suggestions and plans on the internet, but make sure they are not extreme or fad diets. A Mediterranean style diet is a good platform, I would not recommend an ultra low-carb or keto diet for myself, my body just goes into shock and survival mode, and I get “hangry”, but maybe they have worked for you in the past. If you are trying to lose weight now and you have PD, a sensible diet and exercise routine as outlined above will work, no special diet is needed, just consistency and common sense.

Do I need to mention water? I hope not. Regardless of PD, unless you have a medical condition that prevents it, you should drink at least around 64 fluid ounces (or nearly 2 liters) per day. Yes, you may have to make more bathroom trips, but you need the exercise anyway. Coffee, soda/pop, etc. do not count towards your water intake, pure water (or you can add a decent flavor powder to it if you must) is essential. Your brain and heart are comprised of approximately 2/3rd water, enough said. And the 64 fl oz guide is just that, a guide. If you are living in a hot, humid environment, you may need more than this. Also, if you are more active, or a heavy person, you will almost certainly need more than this. Again, if you have other underlying medical conditions, especially if they are related to your kidneys or heart, check with your medical professional and seek their input a good daily water intake amount.

Talking of coffee, I love my coffee and still drink it, but I do make a point of not having more than 1 cup of regular fully caffeinated coffee per day, after that it is decaf or a blend of regular and decaf. Honestly, I don't know if PD cares either way, but too much caffeine is not a good thing usually. Remember, we are dealing with cognition here, and caffeine can affect cognition on a very short-term basis, regardless of PD, so I try not to complicate things with it.

3. What can YOU do for you brain today ?

OK, so perhaps I have bored you with some of the basics above, hopefully you are still reading though, because here are some things I do EVERYDAY to help slow the progression of PD, especially the cognitive side.

- A) Recall (ironic, memory is one of the largest impacts PD has had on me, and not in a good way), that I said this is a lifestyle, and your brain is like the rest of your body, it responds best to consistent and frequent exercise.
- B) As part of my regimen, I use the framework of the **“Live with Intent” program, that is published by the Parkinson Voice Project Organization.** You can obtain a free copy of their comprehensive training program and find out more about more about the excellent, scientifically developed program at <http://ParkinsonVoiceProject.Org>. Again, this is free for anyone who asks for it, and they also have a growing network of “Live with Intent” therapists that can ensure you work the program properly and help you live it. I was initially a bit skeptical about how useful the program would be, as some of the training seems very basic, but trust me, if you get into it with intent, and live it, with intent, there is way more going on in your brain thanks to this program than you realize. Later on, I will share with you how I use it, and delve into some of what is going behind the training (disclaimer: I am NOT a Parkinson Voice Project employee, volunteer or trained therapist, I am a recipient of the program). The underlying premise of this program is to shift your thinking and actions from your brain’s Extrapyramidal System (the “automatic” part of your brain) to your Pyramidal System, which is the intentional part of your brain. It has helped me.
- C) I use a cognitive training **App called Brain HQ by Posit Science**™. This has hundreds of different mind exercises and many levels of each exercise, but you don’t have to hunt and peck which exercises to do,

although you can do that if you wish. It is structured and will lead you through a whole range of exercises tailored for you, increase the difficulty levels as you improve, and you will be set weekly goals. I spend a minimum of 1.5 hours per week on this, usually more, because I like the challenges, and perhaps I am imagining things, but I do feel sharper when I have completed a session. You can download it from the App and Play stores. There are other apps too, such as Lumosity, you can try those and see which one you like best, for me personally, I found Brain HQ to be the best combination of structure, science and challenge – it is not a grouping of “games”, far from it.

- D) Another tool that I use, but it is not specifically intended for any neurological or medical condition, and I can't tell you I have validated the science behind it, is listen to a simple “Theta Wave” audio file(s). In fact, the human ear cannot detect the frequency of theta waves, so they are embedded with some relaxing tones/background music. You can find out a lot more about these on the internet and You Tube™, but the one I use personally is called “**The Genius Wave**” from the website: <http://geniuswaveoriginal.com>. You can read the website and research, and you will also find contrarian views on the internet (what a surprise!), all I can tell you is that I listen to it at night 3 or 4 times per week, and I feel something different, could it be the panacea effect? Maybe. But it seems to do positive things for my creative thinking, so I keep listening. You can be the judge for yourself.
- E) And of course you can **keep your brain active by doing games like Sudoku, crosswords**, etc, instead of binge watching something on the television.
- F) Also, it is important for me **not to isolate myself from society**, even if I am having a bad brain fog day. I make a point of getting out to do my walk as I mentioned and during that walk, even if I'm having a foggy day and can't remember my own name, I consciously make an effort to smile at

people and say hello, I keep myself out of my own head as much as possible and try to do things with intent even if I don't feel like it.

4. Medications

You must be under the care of a qualified medical professional, but, I can tell you that my primary medication is **Carbidopa-Levodopa**, 3 times per day orally and I take it at the same time each day. This medication is a typical PD medication, it helps increase the amount of dopamine in your brain, as PD patients are lacking dopamine. I have had no side effects from this medication, it does not make me feel “high” or sleepy, in fact, one of my symptoms from PD have been random and basically disabling fatigue attacks, meaning I have to lie down and sleep, sometimes for several hours. I did a clinical in-lab sleep study and sleep apnea was ruled out, you may need to do this too. Carbidopa-Levodopa has significantly helped me reduce the frequency and severity of these fatigue episodes. Your medical professional will assess your suitability for this medication, and any interactions it may have with other medications you might already be taking.

5. Sleep

This is as basic as physical exercise and good nutrition and is essential regardless of PD, but you need to ensure you have a good amount of sleep and if you don't already have a good sleep hygiene routine, start one now. Good quality sleep is essential for brain health. Here is what I do:

- a) I aim for 7.5 hours of sleep every night and try to keep the same bedtime and wake-up time, in my case, lights out by 10.30 pm and wake up at 6.00 AM. I don't always achieve this, but it is my schedule.
- b) No smart phones (not even the brain training app) or PC usage closer than 1 hour to scheduled lights out (so, 9.30 pm in this case).

- c) I do watch none-news related TV content in bed, but again, lights out by 10.30 PM.
- d) I try not to eat anything after 6.30 pm so energy is not going into digestion of food.
- e) I avoid caffeine generally as I mentioned before, but definitely none after 5 pm for me.
- f) The smart phone can be on my nightstand, but I have configured it so it is silent during my scheduled sleep hours except for the handful of people that would call me if they were having some type of emergency; everything else has to wait.
- g) I don't usually have a problem falling or staying asleep, but if you do, it is OK to take a prescribed medication to help you if your medical professional does so, knowing your full context and medical conditions.
- h) I wear a Fitbit tracker that captures all my basic bio metrics and the app does a decent job of measuring the different stages and amount of sleep, it's good information to have and see how you are trending.

6. Other resources

There are many sources of information about Parkinson's on the internet, and as with everything on the internet, you need to be careful as to the source of that information and make sure it is credible. There are some organizations out there too that are a wealth of information, such as:

- a) The Parkinson's Foundation.
- b) Michael J.Fox Foundation (Michael has done so much tremendous work to help educate the World on Parkinson's, he is truly an inspiration, and even with his symptoms he still appears on TV and also rocked out on stage with Coldplay at the Glastonbury Music Festival in June 2024. He is an example to us all, 63 years old, living with Parkinson's for many years and still going strong – thanks Michael!).

c) And of course, the previously mentioned Parkinson Voice Project organization.

7. What next ?

I have shared with you just the tip of the iceberg of my personal experiences, and given you some ideas that you can try, see what works for you, but remember this, PD is not the end of your life, it does not define you, you can adapt and keep on enjoying life.

Stay connected and informed. I invite you to listen to my weekly podcast where I will share more details and personal experiences of things that do and don't work for me, let you know how I use the Parkinson Voice Project "Living with Intent" program, and I will have the occasional guest to cover some specific topics. I like to incorporate some of my dry British humor, so hopefully you will also get a couple of smiles out of each episode and if we have enough of us listening each week, maybe we can form an on-line forum for supporting each other in the future – I'm certainly willing to do this if there is a common desire. Subscribe below, I will not be sending you anything to "buy now, special offer for new subscribers", nope, none of that, I just want to share my own journey in the hope that it will help you.

Take care, and I wish you the best in your journey.

Geoff

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