

Now What? (Revised 7/2024)

I am often asked to talk with a friend or relative of a friend who has recently been diagnosed with Parkinson's Disease. This document is a part of the information I share with newly diagnosed PwPs (Persons with Parkinson's).

What to Do Next?

As I have learned firsthand and from discussions with many other PwPs, getting the diagnosis usually means, "I think you have PD, take this medication and come back in 90 days. If the symptoms are better, it's PD." (This may change soon with the discovery of at least 2 biomarkers for PD)

So, off you go with no information and a prescription. So, what to do next? In my case, I immediately started the quest for more information about the disease, the medications used to treat it, and ongoing research. You have probably done the same; perhaps that's how you found this post.

I have found the [Michael J Fox Foundation](#), the [Parkinson's Disease Foundation](#) and the [Davis Phinney Foundation](#) to be particularly informative and responsive to the needs of PwPs. Links to these organizations and others can be found by clicking on the Resources for PD tab on my blog. I have also included links to various organizations and publications from these organizations at the bottom of this document.

An excellent resource is the [Parkinson's 360 – Real Talk for Patients and Families](#) website. This initiative was recently launched by the Fox Foundation and on the website you will find a [digital book](#), [short films](#) featuring people with Parkinson's at various points in their journey, [seven tenets](#) for life with PD, a [whiteboard video](#) explaining the basics of the disease and [tools for living well](#) with Parkinson's. I highly recommend this site and the booklet they have available for download. The Parkinson's Foundation has a similar document "[What You and Your Family Should Know about PD](#)", also available for download.

The next thing I did was start my blog, [It Is What It Is](#), to chronicle my journey with PD and hopefully provide information for other PwPs. So, in addition to posts about living with PD, you will also find tabs that include links to resources for PD, a link to a PD Glossary, a list of other blogs I follow, and a [list of books](#) I have read. (I highly recommend the books by Dr. Okun and Dr. Ahlskog for newly diagnosed patients.)

A Few Other Recommendations

Here are some recommendations I've developed after 11+ years of being a PwP, researching PD, attending many conferences, expos, and other events, and talking with other PwPs.

The most important thing we have learned (as you will see on my blog) is you can't get too much exercise. Many studies now show that 2.5 hours of exercise a week can slow the progression of PD. And it can be any exercise: walking, running, weight lifting, cycling, yoga, tai chi, chair exercises, swimming, boxing, dancing, and more. If at all possible, get up and exercise!

The Davis Phinney site has some excellent free resources for exercising, including videos, workbooks, and more. (See the attached link page.) I am a big fan of the Parkinson's Cycling Class conducted at local YMCAs nationwide, along with playing tennis as much as possible. Other popular exercises are PD in Motion dance classes and Rock Steady Boxing classes held at various venues around the US.

EDITORIAL NOTE: I am not a medical practitioner. Before starting any exercise program, you should first discuss your plans with a qualified healthcare professional who is aware of your medical history.

If you are not seeing a Movement Disorder Specialist, you should try to find one. I know it's just what we all need, another doctor, but they are neurologists with a fellowship in Movement Disorders, and it has been shown that they provide the best care for PwPs. The Movement Disorder Society has a [physician finder application](#) on their site,

Non Motor Symptoms

While many of you are familiar with the cardinal motor symptoms of PD that are used to diagnose PD:

Stiffness (rigidity): muscle stiffness detected by a doctor on examination

Slowness (bradykinesia): decrease in spontaneous and voluntary movement; may include slower walking, less arm swinging while walking, or decreased blinking or facial expression

Resting tremor: a rhythmic, involuntary shaking that occurs in a finger, hand or limb when it's relaxed and disappears during voluntary movement.

I highly recommend that you take some time to learn about the 'non-motor symptoms' of PD, often called the invisible symptoms of PD. They can significantly impact your quality of life. They include facial masking, tiny handwriting, lack of smell, constipation, drooling, and many more. [Click here for a list](#) from MJ Fox Foundation.

Non motor symptoms will sometimes help explain a reaction to an event that is different than you expect. For example, facial masking (inability to smile or look interested) makes it difficult for others to see your reaction to something they have told you and may cause them to think you don't care or aren't interested, which may not be the case. Another common non-motor symptom is a soft voice, which causes people to ask you to repeat your comment or question. There are several PT classes such as [Big and Loud](#) or [Speak Out!](#) that can help with the soft voice problem.

Participate in a Clinical Trial

If you are interested in participating in a clinical trial, this is the time to see what is available. Dr. Hauser, a Movement Disorder Specialist at the University of South Florida, calls it the 'Golden Year' because often the patient is not on some of the medications which are normally a limiting factor in being accepted for a clinical trial.. You can read [his paper here](#).

Michael J. Fox promotes clinical trials with the [MJFF Clinical Trial Finder](#) application, where you input your location, symptoms, and how far you will travel for a clinical trial. The application then tries to match you to relevant

trials. They also include internet trials where you don't need to travel to participate.

Join the [Fox Insight Trial](#), which is a web-based longitudinal study to track the progression of PD among over 55,000 persons so far. The data from this trial is anonymized and provided to researchers to help define PD.

And finally, consider joining the MJFox Foundation [Progression Markers Initiative](#) (PPMI). This ongoing initiative follows PwP and controls over time and has resulted in a huge database of information for research. In fact the recent announcement of biomarkers for PD was the result of research done with this data. These biomarkers will improve diagnosis and research in the treatment of PD.

It is important to remember that there is a lot of PD research going on and a lot of good things happening in the world of PD. There have been 10+ new medications or treatments approved just in the 11 years since my diagnosis, and several more are in the pipeline.

SOME RECOMMENDED LINKS:

[Parkinson's Foundation](#)

[WhatYouAndYourFamilyShouldKnow.pdf](#)

[Medications.pdf](#)

[Fitness Counts.pdf](#)

[Caring_and_Coping.pdf](#) Excellent document for caregivers.

[Michael J Fox Foundation](#)

[Parkinson's360](#)

[Michael Fox Clinical Trial Finder](#)

[Michael J Fox Insight](#)

[Davis Phinney Foundation](#)

[Parkinson's 101 Understanding PD](#)

[Living Well with PD \(Every Victory Counts Manual\)](#)

[PD Exercise Essentials \(video\)](#)

Some recommended Blogs to follow (besides mine of course!)

[Science of Parkinson's](#) – a great resource about the latest research in PD presented in plain english.

[Twitchy Woman](#) – Sharon Krischer's blog provides excellent posts about living with PD. She is a strong advocate for meeting the needs of women with PD and has been encouraged by the Parkinson's Foundation and Michael J Fox Foundation to expand her concepts for women and PD groups.

[Parkinson's Humor](#) – by Yuma Bev – humorous views of living with PD

[Journey with Parkinson's](#) by Frank Church - former medical researcher/ teacher with PD

These are just a few of the many listed under the 'my blog list' tab on my blog [It Is What It Is!](#)

If you want to keep up with PD news, consider subscribing to one or more of the National Foundation blog sites or the news aggregator [Parkinson's News Today](#)