

## **Now What?**

Often I have been asked to talk with a friend or relative of a friend that has recently been diagnosed with Parkinson's Disease. I created this document as an email attachment to send to those newly diagnosed PwP's (Person's with Parkinson's). I decided that I should post this information here for the benefit of other newly diagnosed Parkinson's Disease patients.

## **What to Do Next?**

As I have learned first hand and from discussions with many other PwP's, getting the diagnoses usually means "I think you have PD, take this medication and come back in 90 days, if the symptoms are better, it's PD".

So off you go with no information and a prescription. So what to do next? We immediately started the quest for more information about the disease, the medications used to treat the disease, and what kind of research was happening. You have probably done the same, perhaps that's how you found this post.

If you have researched the web at all you have probably noticed there are many excellent organizations that provide up to date information about PD. Of those, I have found that the [Michael J Fox Foundation](#), the [Parkinson's Disease Foundation](#) and the [Davis Phinney Foundation](#) to be informative and responsive to the needs of PwP. Links to these organizations and others can be found by clicking on the Resources for PD tab above on my blog. In addition, I have included a page of links to various programs or publications from these organizations that I've found useful as part 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 this blog, [It Is What It Is](#), to chronicle our journey with PD and hopefully provide information for other PwP's. 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 for newly diagnosed patients) In addition, check out

the monthly summaries from the Science of Parkinson's site to see what is happening on the research front.

### **A Few Recommendations**

Here are some recommendations I've developed after almost 6 years of being a PwP, researching PD, attending many conferences, expos, and other events, and talking with other PwP's.

- 1) The most important thing we have learned (as you will see on my blog) is you can't get too much exercise. There are many studies out now showing that 2.5 hours of exercise a week can slow the progression of PD. And it can be any exercise from 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 I can and attending the PD in Motion dance class weekly. Another popular exercise for PD is Rock Steady Boxing classes held at various venues around the US.

***EDITORIAL NOTE: I am not a not 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.***

- 2) 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 is working on developing a physician finder application on their site but it is not yet operational. In the meantime, you can email them at [info@movementdisorders.org](mailto:info@movementdisorders.org) and include your location and they will provide you with a list of MDS physicians in your area.
- 3) Take some time to learn about the 'non motor symptoms' of PD which include facial masking, tiny handwriting, lack of smell, constipation, drooling and many more. It sometimes will 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 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 your comment or question. (There is a PT class called Big and Loud that can help with that problem.)

- 4) 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 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. 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 have 10 - 12 internet trials where you don't need to travel to participate.

- 5) Join the [Fox Insight Trial](#) which is a web based longitudinal study to track the progression of PD among over 31,000 persons so far. The data from this trial is anonymized and provided to researchers to help define PD.
- 6) It is important to remember that there is a lot of PD research going on and lot of good things happening in the world of PD. There have been 6 new medications approved just in the 6 years since my diagnoses and several more are in the pipeline.
- 7) You are not alone! There are support groups both in person and online, and there are hotlines at all of the major organizations staffed to answer your questions and concerns. We are all in this together and together we will defeat Parkinson's Disease!

Some recommended links:

**Parkinson's Foundation ([www.parkinson.org](http://www.parkinson.org))  
Publications**

[WhatYouAndYourFamilyShouldKnow.pdf](#)

[Medications.pdf](#)

[Fitness Counts.pdf](#)

[Caring and Coping.pdf](#) Excellent document for caregivers.

**Michael J Fox Foundation ([www.michaeljfox.org](http://www.michaeljfox.org))**

[Parkinson's360](#)

[Fox Clinical Trial Finder](#)

[Fox Insight](#)

**Davis Phinney Foundation ([www.davisphinneyfoundation.org](http://www.davisphinneyfoundation.org))**

[Parkinsons 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, his monthly summaries are under the Science of PD tab on my blog.

[Twitchy Woman](#) - excellent posts about PD, Sharon started a Women in PD movement that is now nationwide and sponsored by the Parkinson's Foundation

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

These are just a few of the many listed under the 'my blog list' tab.

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](#).