



## Parkinson's Disease - Life Experiences

Parkinson's disease (PD) is a part of your life whether you have it or if someone you love has it. In either case, it has already changed certain parts of your life whether you know it or not and the changes will continue to happen in varying degrees over time. Two things are certain with PD, you will progress and it will be at your own pace. Everything else is up for grabs!

### So what is Parkinson's disease?

Parkinson's disease is considered a movement disorder, as the muscles and structure of the body do not receive clear instructions from the brain due to a deficiency of dopamine. Dopamine is a hormone that helps the brain control our movement. It's that simple, an impaired ability for a region of the brain called the substantia nigra to make dopamine. The question plaguing the medical community is why some individual's cells are making less dopamine. Many potential causes of Parkinson's disease have been identified but it remains unclear why people develop Parkinson's disease.

### What happened to your brain?

The cells in the substantia nigra region of your brain are not making enough dopamine to make your body work as it was designed to function. This inability likely did not just switch off one day with a command or some tragic, horrific incident that you can put your finger on and say, "Yes, that's what gave me PD." The onset is likely to be much more gradual and even insidious in how it effects life changes and the way you do things. It may have been an occasional bout of "the shakes" in your hand, easy to explain "I may have stressed it too much with that wrench" or "it's the hand I broke seven years ago", or in my case "the one a bull stepped on", yes a 1200 pound bull! But we don't think about the way your arm doesn't swing like it should or the times we have stumbled or the lack of strength we used to have. All of those symptoms can be explained by aging, being clumsy or some other excuse. Your brain is probably still making some dopamine but just not enough to overcome the effects. The good news is there are several types of medication designed to help the brain make more dopamine, without supplementing dopamine outright.

### So what really happened to my brain?

While, the research is incomplete at this point, there is building evidence that parts of the dopamine producing cells gets confusing signals and they do not take out the trash, and this "trash" or spent protein builds up in those cells and causes them to succumb or at least be too sick to work making dopamine and they stop or greatly reduce production of this essential hormone.

The pituitary gland tells the substantia nigra to step it up but then they do not tell the cells to clean up their room! They keep things to themselves, waste products and all. Next thing you know the person is severely impeded by PD and finally seeks medical advice and treatment.

### **What's the latest news?**

One area of ongoing research is being done in Iowa, North Carolina and California that examines the effects of pesticides on the frequency of PD in farm families and those working in and living adjacent to agricultural fields. Preliminary research is finding increased rates of PD related to exposure and use of rotenone, maneb and mancozeb, paraquat, and "agent orange." That is not to say these are smoking guns just that in studying the populations in the sample group of farmers and rural residents there is an increased rate of PD, among other things, associated with these materials being used. One worldwide study of the literature found 108 studies increased rates of PD ranging from 33-80% related to pesticide use. But somehow, either from pesticides or things we introduce into our bodies or something we have existing, the cells communication system gets impaired or then they do not communicate as well. Is this an exhaustive list? Not likely. Chances are that there will be more pesticides and other chemicals, such as solvents that will be implicated eventually, only time will tell.

There are also inherited forms of this condition and if you are in one of those families you may be aware of it. There are genetic tests that have identified the genes involved and they are making headway in this path of discovery. The search continues.

### **Symptoms**

Table 1 provides a list of purported symptoms. You may have some, a few or many. Everyone's PD is unique to some degree.

### **What can you do?**

Seek the advice and treatment of a neurologist you respect and visit them regularly. Medical professionals are the keys to the next generation of drugs to help minimize or alleviate the symptoms of PD. So far, there is no definitive test for PD, so it is a process of trying different drugs to test effectiveness and tolerance<sup>1</sup>. It is more of a process of elimination. Each week measure your comfort and start a journal of your symptoms and how you feel so that you can share the information with your neurologist.

You cannot give up! People live a long time with PD and in all likelihood so will you. Exercise is key to success in tolerating this condition. You may not defeat it, at least not right away, but thanks to several foundations and many research efforts, progress is being made in the quest for answers. You can reach the Michael J. Fox Foundation website at [foxtrialfinder.org](http://foxtrialfinder.org) and look for a research trial that suits your situation and lend a hand in finding answers by participating in the research! Lots of folks have your condition and much research can and needs to be done so please consider helping by being a part of research.

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<sup>1</sup> Research continues faster than this document may reflect, early results of a diagnostic tool are underway but verification and adaptation may be a while forthcoming.

There are support groups around the country for various illnesses, as well as access on the internet. Find a support group that works for you and add them to the list of folks to keep up with. These support groups can provide a great social atmosphere but they also feature speakers for programs, and a great source of wisdom from those who have had PD for a while. You can feel alone, but these support groups work well with the help and participation of folks with the condition and those who provide their care. Last but certainly not least, be your own advocate. Nobody knows your body better than you. Keep a journal and ask questions of anyone you think qualified who might be able to help.

### **How can I help someone with Parkinson's disease?**

Assuming you are a loved one, either a spouse, sibling or offspring of a person diagnosed with PD, the first thing you need to do is consider yourself as a person living with Parkinson's as well. If you are a care giver, then you have PD as a part of your life also, so you need to become a student, if not an expert of this condition as well as the patient. Know that there are many forms of this condition; get to know the specifics and how it might progress in the case of your loved one.

Get familiar with the medications, the dosages, schedules and their side effects. Some of the side effects and dosing errors can be deleterious to the patient as well as you! Some of the side effects may include obsessive behavior, hyper-sexuality, nightmares, depression and more. Keep notes on all observations and take them to the doctor with you when you go. But generally keeping in line with what the relationship has been and what you know the person with the condition wants. There are support groups in many areas of the state that are for people with Parkinson's and meetings for caregivers. Keeping yourself happy and healthy for the person with PD as well as yourself is essential. Nobody wants to drag a loved one down with them. So stay fit and able for both of you!

If you caring for a person with Parkinson's that has not been inclined to be fussed over, give them the room they want as long as you can. These tend to be the traditional independent types and robbing them of that dignity before it must be surrendered is not called. Get them the time and space they need. It may keep that person going much longer than if they were to be closely tended or confined. Contact the AgrAbility staff for help in keeping your farmer farming! But at some point you will need to help that person see that their independence is in peril and things like driving and other functions will have to be curtailed and eventually given up.

In either case, you will need to be available and know when to say "enough" and to seek help with the patients care. Statistics indicate that a Parkinson's patient will spend an average of 7 years needing some level of qualified care, perhaps assisted living but eventually skilled care. The temptation will be to keep the patient home as long as possible. Keep in mind that their care needs will increase so plan on some resident care. If possible, keep an eye out for long term care insurance with an open enrollment perhaps as an employment benefit! Have a very honest talk with a financial planner and attorney to plan for the financial future of your family unit. Signing over assets to protect them takes time or they will be reversed.

Above all else, keep things as normal as you can for as long as you can. A person with Parkinson's needs a normal life now more than ever. Keep a sense of humor; it will help make the darker days bearable and the bright ones memorable. And don't ever be afraid to seek help. It is out there, you just need to find it!

## **AgrAbility Program**

The AgrAbility program is a USDA funded program that helps people involved in agriculture, overcome physical limitations so that they can stay active in their operations, lives and communities.

Contact AgrAbility Virginia:

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<http://www.agrability.ext.vt.edu/>

Or contact the National AgrAbility, call 1-800-825-4264 or visit them online at [www.agrability.org](http://www.agrability.org).

American Parkinson's Disease Association ([www.apdaparkinson.org/](http://www.apdaparkinson.org/))

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

Michael J. Fox Foundation for PD Research ([www.michaeljfox.org/](http://www.michaeljfox.org/))

National Parkinson Foundation ([www.parkinson.org/](http://www.parkinson.org/))

Parkinson's Action Network ([www.parkinsonsaction.org/](http://www.parkinsonsaction.org/))

Parkinson's Disease Foundation ([www.pdf.org/](http://www.pdf.org/))

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Table 1. Early Indicators and Symptoms of Parkinson's disease.

Early indicators	Intermediate symptoms	Advanced symptoms
Loss of smell	Tremor becomes more significant	Impeded gait and balance
Loss of taste for certain things	Loss of balance	Tremors much more debilitating effecting basic life functions
Speech patterns and volume	Posture	Difficulty swallowing/choking
Resting tremor begins	Loss of dexterity	Difficulty speaking
Loss of color and facial expression	No sense of smell	Greatly reduced strength
Reduced arm swing	Facial expression greatly impaired	All the above but more severe
Irregularity	Slow movement	
Drooling/excessive saliva	Stiffness of joints and muscles/cramping	
Smaller writing	Ratcheting joints	
Foot dragging	Depression, Anxiety, Fatigue	
Sensitivity to temperatures	Confused/overwhelmed Memory problems Desire to isolate	

**Note:** Just as the effects and progression rates are personal, so will be the severity, onset and sequence of the above list. For example, some individuals have PD but never have tremor. Others have primarily tremor but few other symptoms. Therefore, formulas, lists and books all have limited utility.