

Supporting Parkinson's Diagnosis

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A diagnosis of Parkinson's disease is riddled with uncertainty. The disease is both chronic and progressive, which means that symptoms continue for a long period of time and generally worsen over this time period. The symptoms and progression of the disease are unique to each person and families are often frustrated by the lack of a medical road map for predicting what lies ahead.

There are currently between one million and 1.5 million people in the United States with Parkinson's disease and men are almost 1.5 times more likely to receive a diagnosis than women. Parkinson's disease is mostly diagnosed when patients are in their fifties or sixties. For some, the condition can be severely debilitating in the long term, while others continue to function highly after 25 years of living with the disease.

According to the Parkinson's Foundation of Western Pennsylvania, *primary motor symptoms* of Parkinson's include:

- Resting Tremor often described as "pill rolling" that can involve hands, arms, feet, legs, chin, jaw or tongue
- Limb rigidity
- Slowness of movement (Bradykinesia)
- Postural Instability

Secondary motor symptoms associated with Parkinson's disease include small cramped handwriting, stiff facial expression, shuffling walk, stooped posture, muffled speech, decreased eye blinking and arm swinging while walking. *Non-motor symptoms* include visual dysfunction, hallucinations, pain, behavioral dysfunction, depression, anxiety or dementia.

If you or a loved one is experiencing any of the above symptoms, it is critical to reach out for medical advice to get a realistic picture of what the future holds and to decrease anxiety about that future. Early diagnosis also improves one's chances of benefiting from treatment options and movement programs to delay the progression of the disease.

Many families benefit from joining a local support group. Support groups exist to assist those with a diagnosis, family members and/or caregivers. Locally, we are fortunate to have the Parkinson's Foundation of Western Pennsylvania that provides support, exercise and lifestyle services including a "Parkinson's Primer" class to familiarize newly diagnosed persons with information about the disease, treatment options and coping mechanisms. These services are provided at the Foundation's central office in the Pittsburgh neighborhood of Bellevue and throughout Western Pennsylvania in various community locations.

Consulting with an elder law attorney is also recommended after diagnosis. Making plans while your loved one with Parkinson's is able to assist and provide input is certainly preferable to waiting until you have to make all of the decisions on your own. Early planning can help to protect resources, ensure that you have the necessary information about assistance programs that are available and equip you with the right legal tools and documents to manage your financial and healthcare affairs as the disease progresses.

Many programs exist to help those with Parkinson's to age in place such as Home and Community Based Services. However, resource limits are strict and the application process is difficult. VA Benefits might also be available to assist with costs. For wartime Veterans (and their surviving spouses) Pension Benefits could be a financial resource to hire private duty caregivers. Veterans of the Vietnam Era who served in certain areas might be eligible for VA Compensation Benefits related to their Parkinson's diagnosis. Benefits also exist to cover the extreme costs of a skilled nursing facility should such care be necessary in the future. An elder law attorney can assist you with considering all your options and help to clear up some of the uncertainty that comes with a Parkinson's diagnosis.

April is Parkinson's Disease Awareness Month. If you or someone you know has been diagnosed with Parkinson's, or is exhibiting some of the above-described symptoms, it is important that you reach out for medical help. The Parkinson's Foundation of Western Pennsylvania is also just a click or phone call away. The Foundation provides support, education and exercise programs that are proven to aid with the symptoms of Parkinson's. The Foundation has programs for every taste including dance and movement classes, boxing, music therapy, yoga, pickleball, caregiver support, lunch & learns and support groups, all led by highly qualified professionals free of charge. If you would like more information, please call the Foundation at 412-837-2542 or go to www.pfwpa.org.

Jennifer Rose is a Certified Elder Law Attorney with Julian Gray Associates. For over a decade, she has helped clients with their long-term care and estate planning needs. Jennifer is the secretary of the Board of Directors for the Parkinson's Foundation of Western Pennsylvania and through that role she is dedicated to helping those diagnosed with Parkinson's to lead longer and better lives through the programs, tools and services provided by the Foundation.