Pfizer Logo

Caregiver’s Guide for Parkinson’s Disease

Thursday, January 28, 2021

Parkinson’s disease (PD) is a complex neurodegenerative motor disorder, meaning there are many features of the disease that will change over time—slowly in most people. And, while no two people experience the disease the same way, there are a number of common symptoms caregivers can look out for that may help prepare them for the changes likely to occur during early-stage, mid-stage, and advanced-stage Parkinson’s disease.

As PD progresses, patients may have increased difficulty walking, talking, swallowing, or completing daily activities. They may also experience depression, anxiety, sleep disturbances, cognitive problems, mental health problems (caused by medicine) and/or impulse control problems. As a consequence, the role of the caregiver progresses and becomes more demanding, and will require the caregiver—whether a spouse or family member—to anticipate, recognize, and navigate new challenges. The more educated and prepared you are as a caregiver, the more successful you will be at overcoming the various challenges associated with your loved one’s disease.

Getting Started

PD patient management goes beyond the medications that provide symptom relief. In fact, a great way to prepare for what may lie ahead is to work with a healthcare “team” who can offer you advice about how to help your loved one live better with PD. Your team may include an *occupational therapist*, someone who teaches people

with PD alternative ways to perform daily tasks, a *physical therapist* who helps restore, maintain, and promote overall fitness and health, and a *speech therapist*, someone who fixes the difficulties with swallowing food and liquids and communicating.

You also want to consider home safety, this includes removing potential kitchen, bath and bedroom hazards, securing or removing loose rugs, making room for standing or spinning a wheelchair, and asking for a home safety evaluation. Again, as PD progresses, you should periodically make new assessments to keep up with the advancement of the disease.

Early Stage Disease

It may seem counterintuitive to prepare for late-stage disease when your loved one is in the early stages of PD, but this can actually be the best time to get organized and think about the future. There will come a time when he or she may be unable to tell you what kind of medical care, facility, or end-of life plan is preferred. So this is the time to make everything as clear as possible.

There is often a so-called “honeymoon” period when people with PD first start taking medication, when it can seem like the side effects of the disease are not so disabling. However, most medications are efficacious and then are less effective as the disease progresses. Still, you may be able to keep your loved one active by trading responsibilities when a change in the disease makes a usual task too difficult. For instance, if your loved one is unable to wash and dry the dishes due to grasping or range of motion difficulties, he or she can take over the bill paying. This kind of task-balancing can help to keep things feeling a bit normal.

Mid-Stage Disease

In mid-stage PD, medicine has an inconsistent effect, and due to fatigue, your loved one may become less active. Physical movement can become much more frustrating as it is unpredictable, and mood changes may affect the way a person feels and thinks. Early signs of dementia may also begin to show and tremors can become greater. Also, a side effect of PD medications called *dyskinesia* may cause your loved one to experience involuntary writhing movements. During Mid-stage PD, your loved one may have impaired balance, difficulty walking, and an increased risk of falling. Interestingly, the person’s handwriting may become very small; this is a condition called *micrographia*, which is common for people with PD.

Additionally, non-motor symptoms may become troublesome to the patient and the caregiver. Medication can help to address these symptoms as they advance; however, fatigue, mood changes, insomnia and depression are not always diagnosed in mid-stage PD. Also, other symptoms provoked by medication use tend to develop. At this stage, a good tip is to learn to be flexible when it comes to managing or working around the loved one’s fatigue. For example, it may be better to schedule fewer activities, break up tasks, errands, or other activities into shorter time periods.

Advanced Disease

Advanced-stage PD patients are often confined to a wheelchair; however, since the disease progresses differently in different people, many do not progress to the advanced stage. During this stage, patients are not able to live alone and caregiver assistance with all daily activities including dressing, eating, and walking becomes necessary. Medications that treat PD can cause hallucinations, delusions, agitation and mania. One study reported that dementia develops in many people after 9 years. So it is important to have made preparations early on, before reaching the late stages of PD. You may need to make decisions or plans with family members or other professionals on end of life medical care, living wills, or power of attorney.

Last But Never Least: Caring for Yourself

In my experience as a clinician, I have seen the PD caregiver become consumed in caring for the patient. It's true that there's a lot to do for your loved one, but many caregivers do not take enough time to focus on their own needs. Studies show that women caregivers who do not take care of themselves have more health problems (including depression and other mental health disorders) than women who do. If you are a caregiver who forgets to take care of yourself, here are some tips to keep in mind:

- **Get prepared.** Be realistic. Determine how much you can do yourself and what type of outside support is needed
- **Take care of yourself.** Get help. Don't try to do it alone. Include neighbors, friends, and others in the community
- **Foster your relationship.** Communicate. Make sure to maintain your relationship with the person with PD. Quality relationships can help reduce caregiver depression and improve physical health

Rachel Schindler, MD was previously a physician/scientist who lead the strategy for Neuroscience in the Clinical Sciences group at Pfizer's Global Innovative Pharmaceuticals Medicines Development Group. She is the founder and former Director of the Neurobehavior and Memory Disorders Center at University Hospital at Stony Brook.

[1] [2] [3] [4] [5] [6] [7] [8] [9] [10] [11] [12] [13] [14] [15] [16] [17] [18]

References

- **1.** U.S. Department of Veterans Affairs. I'm caring for a veteran with Parkinson's disease (PD): What do I need to know? Accessed February 3, 2016.
- **2.** National Parkinson Foundation. Mid-stage caregiving. Accessed February 3, 2016.
- **3.** Parkinsons.org. Parkinson's disease information. Accessed February 3, 2016.
- **4.** The Michael J. Fox Foundation For Parkinson's Research. Parkinson's disease information for caregivers. Accessed February 3, 2016.
- **5.** Family Caregiver Alliance. Parkinson's disease and caregiving. Accessed February 3, 2016.
- **6.** Parkinson's Disease Foundation. Complementary therapies. Accessed February 3, 2016.
- **7.** Suzman I. Safety at home. Parkinson's Disease Foundation Web site. Accessed February 3, 2016.
- **8.** Partners in Parkinson's. Advice for caregivers. Accessed February 3, 2016.
- **9.** National Parkinson's Foundation. General considerations. Accessed February 3, 2016.
- **10.** AgingCare.com. Farewell, Parkinson's honeymoon! Accessed February 3, 2016.
- **11.** Caring.com. Parkinson's disease: How medicines can ease symptoms. Accessed February 3, 2016.
- **12.** National Institute of Neurological Disorders and Stroke. Parkinson's disease: Hope through research. Accessed February 3, 2016.
- **13.** Parkinson's Disease Foundation. Mid-stage Parkinson's: Managing the movement symptoms. Accessed February 3, 2016.
- **14.** Roth E. Small handwriting and other early signs of Parkinson's. Healthline.com Web site. Accessed February 3, 2016.
- **15.** Parkinson's Disease Foundation. Nonmotor symptoms. Accessed February 3, 2016.
- **16.** National Parkinson Foundation. Tip sheet: Coping with your loved one's fatigue. Accessed February 3, 2016.
- **17.** Parkinson's Disease Foundation. Progression. Accessed February 3, 2016.

- **18.** Office on Women’s Health, U.S. Department of Health and Human Services. Caregiver stress. Accessed February 3, 2016.

Originally published, Thursday, January 28, 2021