

# A Caregiver's Guide to Parkinson's Disease





## TABLE OF CONTENTS

	Page
Overview .....	5
What Does the Term Caregiver Mean? .....	5
What Is PD? .....	5
Who Gets PD? .....	5
What Causes PD?.....	6
What Are the Signs or Symptoms of PD?.....	6
How Is PD Diagnosed? .....	7
How Is PD Treated? .....	8
Lifestyle.....	8
Medications to Treat the Motor Symptoms of PD.....	9
Surgery .....	10
Caregiving and PD .....	10
The Effects of PD, by Stage, on Caregiver Burden and Stress .....	12
Early Stages.....	12
Midstage .....	13
Late Stages.....	14
Conclusion .....	18
Appendix 1: Glossary .....	21
Appendix 2: Communicating with the Doctor.....	29
Appendix 3: Preparing for a Doctor’s Appointment.....	31
Appendix 4: A Care Notebook .....	33
Appendix 5: Motor Diary.....	35
Appendix 6: Resource Guide .....	39

### **Faculty Affiliations and Disclosures**

William J. Marks, Jr., MD, is an Associate Professor of Clinical Neurology at the University of California, San Francisco; Medical Director of the UCSF Center for the Surgical Treatment of Movement Disorders; Medical Director of the Center for Parkinson’s Disease & Movement Disorders, San Francisco VA; Medical Director of the Center of the Parkinson’s Disease Research, Education & Clinical Center at San Francisco VA Medical Center; Director of the San Francisco VA Comprehensive Epilepsy Center; Director of the Clinical Neurophysiology Laboratory at the San Francisco VA Medical Center. Dr. Marks reports that he received research funding from Celegene, Inc. and Boehringer-Ingelheim, Inc.; has a consulting agreement with Medtronic, Inc.; and is on a Speaker’s Bureau for Medtronic, Inc.

Susan Heath, RN, MSN, is a Movement Disorders Clinical Nurse Specialist and Associate Director of Clinical Care at the VA PADRECC in San Francisco, CA. Ms. Heath is on the Speaker’s Bureau for Medtronic Neurological.

Jeffrey Zlotnick, MD, CAQ, FAAFP, is Assistant Clinical Professor of Family Medicine & Primary Care Sports Medicine at the UMDNJ-Robert Wood Johnson Medical School and at UMDNJ-New Jersey Medical School. Dr. Zlotnick is also a Clinical Instructor at the Philadelphia College of Osteopathic Medicine, Department of Family Medicine, and is in clinical practice at the Easton Orthopedic Group in Bethlehem, PA. Dr. Zlotnick reports that he has received honorarium from the American Academy of Family Physicians.



## OVERVIEW

This guide to Parkinson's disease (PD) was developed with you, the caregiver, in mind. Certainly not every situation will pertain to every person, but we hope that we have provided information that will help you on your journey of PD. In this guide, we may use terms that are unfamiliar to you. To help you understand this document and to learn the "language of PD," we've created a glossary of terms in Appendix 1. We hope that you will find this helpful not only for reading this document, but also as you work with healthcare professionals and others who are involved in the care of people with PD. The following content is a frank discussion of the most difficult and advanced aspects of care for people with PD.

### What Does the Term *Caregiver* Mean?

Caregivers provide ongoing support and assistance to people who, because of a disability, disease, illness or age, are unable to care for themselves unassisted. Often, but not always, the caregiver is a family member who is not paid for providing the care. However, a caregiver may also be a friend, a neighbor or a paid caregiver.

The roles of the caregiver, which change over the course of the disease, are many, including physical, social and emotional support. In some situations, especially during the early stages of the disease, a caregiver may be a spouse; however, as the disease progresses and physical challenges limit the ability of the spouse to care for the person with PD, another family member, or a paid caregiver may take on the role of primary caregiver. Although caregivers may delegate some of the physical care to another person, most do not relinquish their caregiver responsibilities! Each situation is different. Although the term *caregiver* includes anyone who provides care, in this article, the term is defined as that person who has primary responsibility for caring for, or overseeing the care of, a person with PD.



### What Is PD?

PD is the second most common disease that affects the nervous system and is progressive, meaning that the disease becomes worse over time. The symptoms of PD are caused by a loss of nerve cells (neurons) in an area of the brain known as the substantia nigra. The purpose of these cells is to produce and store dopamine, a chemical that signals another part of the brain that controls movement (the motor cortex). Without enough dopamine present, the signaling is faulty, and the resulting movements lack their normal smooth appearance.

### Who Gets PD?

No one knows with certainty how many people have PD. Researchers use different methods to estimate this number, and their estimates vary depending on the method used. The best estimate of the total number of people in the United States who have

PD is about 1 million. Researchers predict that more people will have PD as our population ages. The average age at which people develop PD is about 60 years. Because people are living longer, the number of people who are aged 60 and older is increasing, resulting in more people who have PD. Young-onset PD is defined as disease that occurs in people aged 40 or younger. The economic impact of PD is estimated to be \$25 million per year in the United States.

The only truly well-established risk factor for PD is aging. Other risk factors may include exposure to heavy metals, pesticides, herbicides, and solvents, but these have not been clearly proven. Slightly more men than women have PD.

### **What Causes PD?**

The vast majority of cases of PD (90%) have no known cause. The remaining 10% of people have PD that is caused by a defect in one of the genes known to be associated with genetic forms of the disorder. The genetic forms of PD are more likely to be seen in people who develop young-onset PD.

### **What Are the Signs or Symptoms of PD?**

The four cardinal or main signs or symptoms of PD are resting tremor, slowness or lack of movement (bradykinesia or akinesia), stiffness (rigidity), and difficulty with balance (postural instability). In addition to these, other signs and symptoms of PD include those that affect movement (motor) and those that affect other body systems (nonmotor). Other signs and symptoms of PD can include:

- Anxiety
- Bladder problems
- Bland or masked facial expression
- Constipation
- Decreased sense of smell
- Depression
- Difficulty breathing
- Difficulty maintaining an erection
- Difficulty starting or keeping moving
- Drooling
- Heavy sweating
- Lack of arm swing when walking
- Lightheadedness or dizziness when standing
- Pain (e.g., shoulder pain)
- Skin problems, e.g., seborrhea
- Sleep problems
- Sleepiness during the day
- Small quick steps when walking
- Stooped or bent posture
- Small handwriting
- Soft or garbled voice
- Tiredness or fatigue
- Trouble swallowing
- Trouble thinking or remembering

Depression or anxiety may be present before the motor symptoms appear. Almost 90% of people with PD have at least one of the following problems at some point in the disease: depression, apathy, anxiety, or hallucinations. Doctors often don't recognize these neuropsychiatric problems in people with PD, so these symptoms are often not treated. Recognizing and properly treating depression and other neuropsychiatric problems can have a major impact on the quality of life for people with PD. Dementia may affect more than 50% of people with PD by the late stages of the disease. Many people with PD develop "executive dysfunction" or difficulty with multitasking, despite their previous abilities to manage complex tasks.

Up to 90% of people with PD have sleep problems, ranging from trouble falling asleep and staying asleep, to vivid dreams, groaning during sleep, stopping breathing during sleep, and REM sleep behavior disorder (RBD). During REM sleep (the stage during which people dream), people do not move as skeletal are usually inactive or at least very relaxed. However, in RBD, people act out their dreams, often striking out or punching and speaking during sleep. Sleep problems often have a very big impact on caregivers; in one study, 30% of caregivers reporting problems related to sleep. Because of this, many partners find it safer to sleep in a different room until this sleep disorder is successfully treated.



Approximately 40% of people with PD experience pain in the early stages of the disease. However, most people will experience pain as the disease progresses to the middle and late stages. Pain is a significant problem in the late stages of PD, for which most caregivers are unprepared. At first, caregivers can offer support to the person with PD who has pain; however, in the late stages of the disease, caregivers may need to more actively work with the medical team to help the person with PD to control or manage pain.

How quickly the symptoms of PD worsen varies greatly among individuals. In the early stages of the disease, motor symptoms seem to worsen more quickly than the nonmotor symptoms, with the reverse being true in the later stages of the disease. This doesn't mean that the motor symptoms stop getting worse, simply that the rate levels out over time. And the disability associated with motor and nonmotor symptoms increases throughout all stages of the disease, as does the rate of complications associated with the symptoms.

### **How Is PD Diagnosed?**

PD is a clinical diagnosis, meaning that doctors make the diagnosis of PD based on the symptoms that the patient tells them about and the signs that the doctor sees. These signs and symptoms include the cardinal symptoms mentioned previously. However, difficulties with balance are not usually seen in early PD. A patient has to have two of

the remaining cardinal symptoms for the doctor to diagnose PD. There are no specific tests that prove the diagnosis of PD.

The process of diagnosis can be difficult for people with PD and their caregivers. When people with PD receive the diagnosis, they and their partners may react in very different ways—experiencing everything from shock to withdrawal to sadness and even relief, sometimes experiencing the gamut of emotions in a matter of days and sometimes swinging back and forth among a variety of emotions. Some people with PD and their caregivers immediately seek as much information as possible, deluging themselves and their partners with data from Internet searches. Others enter into a state of denial, refusing to discuss the diagnosis and unwilling to share the diagnosis with friends, family members, employers and colleagues. This can be a highly charged, emotional time. Everyone handles this situation differently; stress can arise when there is a disconnect between how care receivers and caregivers who are family members or friends deal with this diagnosis and share information.

### **How Is PD Treated?**

Because PD does not yet have a cure, the main goals of treatment are to minimize symptoms, maintain the highest level of function in everyday life, and to provide the best possible health-related quality of life. Achieving these goals requires that treatment address both the motor and nonmotor symptoms of PD, as well as avoid unnecessary side effects. Caregivers are valuable members of the healthcare team and can provide support and assistance to ensure that the right medications are taken at the right time. (See the section on medications used to treat PD for a list of drugs.)

### *Lifestyle*

Eating a healthy and well-balanced diet is important for a person living with PD. A high-fiber diet or the use of fiber supplements may help to decrease the constipation that is a common symptom of PD. No evidence has been found that any food additives or vitamins improve the motor symptoms of PD. For people who take the drug levodopa, it may be best to time the doses of levodopa so that the medication is not taken within an hour or so after eating a high-protein meal.

Exercise is important and should be kept up for as long as possible. Exercises that don't require balance may be safest when balance problems become an issue. Exercising can help deal with the symptoms of PD not only physically, but psychologically as well. Many people find that exercise helps them to not merely cope with PD, but to challenge the disease on a daily basis. Community-based exercise groups are forming throughout the country to help people with PD maximize their stamina, posture, and balance.

Sleep problems in PD can be treated by improving sleep during the night (with medications or positive airway pressure for those people with sleep apnea) and decreasing sleepiness during the day. Getting outside and being exposed to sunshine (where possible) help many people keep their daily rhythms in sync.

Because of the impact PD has on voice quality and volume, some couples have the argument in which “one of them is accused of being deaf, whereas the other is accused of mumbling!” Voice training may be used to improve voice quality and volume in people with PD. Speech therapists can also assist in the later stages of PD for people who have difficulty swallowing

*Medications to Treat the Motor Symptoms of PD*

The main goal in the use of medications for PD is to supplement the level of dopamine in the brain, to balance the levels of dopamine and other neurotransmitters, and to decrease the motor symptoms associated with PD. Each person is unique, and which drug to start first is a matter of the physician and patient discussing and weighing the benefits and potential side effects of each treatment strategy and then making an informed decision.

**Drugs Used to Treat PD**

<b>Class of Drug</b>	<b>Generic Name</b>	<b>Trade Names</b>	<b>Adverse Effects</b>
Dopaminergic Precursor	Carbidopa-levodopa Carbidopa-levodopa with entacapone	Sinemet Stalevo	N/V, <sup>a</sup> OH, <sup>a</sup> hallucinations, paranoia, compulsive behavior, drowsiness, SOS, <sup>a</sup> dyskinesia, <sup>a</sup> motor fluctuations <sup>a</sup>
Agonists	Apomorphine Pramipexole Ropinirole	Apokyn Mirapex Requip	
COMT inhibitors	Entacapone Tolcapone	Comtan Tasmar	Diarrhea, nausea, dyskinesia, discoloration of urine
MAO-B inhibitors	Selegiline  Rasagiline	Eldepryl Zelapar  Azilect	Insomnia, nausea, OH, ↑ dyskinesia with levodopa, possible drug interactions
Anticholinergics	Benztropine Trihexyphenidyl	Cogentin Artane	Dry mouth, blurred vision, constipation, nausea, trouble urinating, decreased sweating, fast heart rate
Antivirals	Amantadine	Symmetrel	Insomnia, hallucinations, agitation, difficulty concentrating, dry mouth, edema, skin mottling

<sup>a</sup>Dopamine agonists are less likely than levodopa to cause dyskinesia and motor fluctuations and are more likely to cause impulse control disorders, drowsiness, and sudden onset of sleep (SOS). N/V refers to nausea and vomiting; OH, orthostatic hypotension.

The use of dopamine agonists has been shown to increase problems with compulsive behavior in some people, particularly in people who are predisposed to having impulse-control problems. These behaviors may lead to excessive gambling, sexual behavior, or shopping. Caregivers should be aware of the potential for this problem, especially when the dosage of a dopamine agonist is changed.

### *Surgery*

Surgery for the treatment of PD may be helpful for people whose symptoms cannot be adequately controlled by medication.

- Pallidotomy and thalamotomy, irreversible operations in which the surgeon precisely destroys a small part of a section of the brain, may be effective in treating the tremor, rigidity, and bradykinesia of PD, but are not effective in treating balance problems. These operations are performed less often today because of the permanence, or irreversibility, of the procedure.
- Deep brain stimulation (DBS) is a reversible and adjustable procedure that mimics the effects of pallidotomy or thalamotomy through stimulation of specific parts of the brain. DBS is now considered to be the surgical treatment of choice for people with PD whose symptoms can no longer be adequately controlled with medication. It improves the motor symptoms of PD and often decreases the amount of levodopa necessary for most people to control their symptoms, smoothing out their motor fluctuations.

## **CAREGIVING AND PD**

Caregiving itself can be stressful, rewarding, or, most commonly, both stressful and rewarding at the same time. People who find caregiving to be rewarding are more likely to find meaning and to feel intimacy and value in their caregiving. And those people who find their caregiving to be stressful are less likely to feel depression and strain. As one wife of a person with PD exclaimed, "*He* doesn't have Parkinson's, *We* have Parkinson's!"



The positive and negative aspects of caregiving are often dependent upon the mutuality of the relationship; that is, a give and take from both parties involved—the caregiver and the care receiver. Naturally, as PD progresses, the symptoms of the disease become worse, such that the caregiver must do more and more as the care receiver becomes less able to perform his or her daily activities.

It's not always the physical demands of caregiving that create the greatest burden. The caregivers of people with neuropsychiatric symptoms are shown to have higher levels of stress, as compared with caregivers of people without these symptoms. The more symptoms people with PD have, the higher their caregivers' stress levels. Simply

understanding the issues related to neuropsychiatric symptoms may help caregivers to better deal with these stresses. For example, caregivers may be less likely to overwhelm the person with PD who has difficulty multitasking if they simplify or limit to-do lists. Likewise, caregivers who realize that these difficulties are simply manifestations of the disease may feel less frustrated or be less likely to argue with the person when he or she can no longer manage the same errands or tasks that he or she once accomplished without difficulty.

Research has shown that social isolation and the caregiver's emotional well-being are the primary factors leading to caregiver stress. Social isolation arises not only because of the impact of the symptoms of PD on the ability to participate in activities outside the home, but can also arise between the caregiver and the care receiver when these individuals are married to each other or are in a long-term relationship. Over time, the caregiver loses his or her "partnership," with the care receiver. Depression is a factor that is associated with more stress for the caregiver.

For some people, taking care of their family members, such as preparing and serving meals, has always been tied to their sense of self-esteem. If they develop PD, the effects of the disease may make performing these tasks difficult and may lead to a decrease in feelings of self-worth and an increase in depression. One role of the caregiver in this situation is to allow the person with PD to retain as much autonomy and dignity as possible. This can be accomplished, for example, by providing assistance in those tasks that require the most mobility, such as grocery shopping, and having the person with PD plan and cook at least part of a meal.



As the person with PD begins to depend more and more on caregivers to function, anger, resentment, and depression are common. Both the caregiver and the care receiver often experience grief at their loss—loss of dreams, loss of companionship, and loss of the life that they had known. Almost universally, they move through their grief in the predictable stages outlined by Dr. Elizabeth Kübler-Ross in her ground-breaking work, *On Death and Dying*: denial, anger, bargaining, depression, and finally acceptance. However, caregivers and care receivers are often unaware of the almost universal nature of the process and may wonder why they are experiencing these emotions. They also often do not move through the stages in tandem, which may create conflict between them. Attending a support group for caregivers is very valuable in this stage of the disease or at this stage of care demands. Simply knowing that this is a normal process can be extremely helpful.

Children of people with PD, particularly those whose parents have young-onset PD, face a variety of challenges because of the disease. Social outings, recreational activities,

and vacations often become a thing of the past when a parent who has young-onset PD reaches the late stages of the disease. A sense of isolation, resentment, and burden are not uncommon among adolescent and young-adult children of a person with PD, as is fear for the future.

### The Effects of PD, by Stage, on Caregiver Burden and Stress

Stages of PD—Hoehn & Yahr Scale		
I	Early Stages	The symptoms of PD affect only one side of the body. They likely have little or no effect on usual activities.
II		The symptoms of PD affect both sides of the body. Balance is not affected.
III	Midstage	Balance is beginning to be affected. The symptoms of PD begin to have some effect on usual activities, but independent living is still possible. Disability may be mild to moderate.
IV	Late Stages	Symptoms have become severely disabling and help is required to complete most usual activities. Independent living is not possible.
V		Without quite a bit of help, standing or walking is not possible. Activities may be limited to lying in bed or sitting in a wheelchair. Skilled nursing care may be required.

Modified from Hoehn M, Yahr M. Parkinsonism: onset, progression, and mortality. *Neurology* 1967;17 (5):427–42.

#### *Early Stages*

Most people are able to continue to work and fully engage in society early in the course of PD. Throughout Stages I and II of PD, most caregivers of people with PD do not find that they have to help much with completing daily activities, perhaps only with the occasional pesky button. The caregiver’s primary role now may be support and understanding. The relationship between the caregiver and the care receiver will determine the best way to provide this support.

During the early stages of PD, the caregiver and family members may also begin to see subtle nonmotor aspects of PD. As mentioned before, neuropsychiatric problems such as depression and anxiety are not uncommon in early PD. Combined with the cognitive changes that may begin to become obvious, depression may cause the person with PD to begin disengaging from usual activities. Researchers have found that most of these aspects of the disease are caused by changes in the chemicals in the brain and are not simply a reaction to the diagnosis or the challenges of the physical symptoms. Awareness that the person with PD is not purposefully acting in a certain manner may help the caregiver deal with some of these issues. Treatment for the anxiety and depression are readily available, so these symptoms should definitely be brought up and discussed at a doctor’s visit. Medications may be beneficial, as may be working with a therapist who is knowledgeable about PD.

Although some people begin planning during the early stages of PD for future care that may be needed in the later stages of the disease, it is not uncommon for people to wait until later stages in the disease to discuss end-of-life decisions. Regardless of when this is addressed, it's important for care receivers to share their wishes with their caregivers so that their desires for care and life-prolonging procedures can be put into place at the appropriate time.

The two primary issues related to advanced-care planning include:

- (1) Developing a process whereby the person with PD makes known his or her wishes regarding end-of-life care.
- (2) Putting into place a plan to reach those goals in case the person with PD becomes unable to direct his or her care—a contingency plan.

The contingency plan will need to include an advance directive and a durable power of attorney for healthcare, including identification of a healthcare proxy—the person who has been designated to put into place the contingency plan. An advance directive is a list of instructions that the person with PD would like to have implemented if he or she becomes unable to make his or her own healthcare decisions. Examples of this are instructions regarding the use of a feeding tube, pain management, artificial breathing machines, intravenous fluids, and CPR.

These instructions provide an outline for the healthcare proxy, who is often a spouse, family member, friend, or even a physician. Preferably, the person with PD, family members, and the proxy have fully discussed the contingency plan in the advance directive so that all are in agreement or at least aware of the wishes of the person with PD. Typically, a copy of the advance directive is given to the person's primary care physician and to the proxy. The advance directive and durable power of attorney for healthcare are specific to each state in the United States, so these items should be completed for the state in which the person with PD lives.

### *Midstage*

In the middle stage of PD, the symptoms become progressively worse, new motor and nonmotor symptoms may appear, and the medications that are typically used to treat PD may become less effective. Subsequent stages are linked to significant jumps in caregiver responsibilities, which may lead to increased stress and strain. At approximately stage 2.5, halfway between Hoehn and Yahr Stages II and III, the number of additional caregiving tasks begins to increase because of increasing severity of symptoms.

It is also at stage 2.5 that caregivers report more negative changes in their own lifestyle. By the middle stage of the disease, most caregivers feel at least some strain and, by the late stages, most caregivers feel enough strain that it affects their lives and their ability to provide care for the person with PD. Depression, hallucinations,

confusion, and falling appear to be the symptoms of PD that are associated with the greatest strain for caregivers at the midstage of PD.

Freezing or balance problems increase caregiver burden. Having trouble walking affects not only the person with PD, but also the caregiver. Imagine, if you will, the impact of gait problems on a couple, one of whom has PD. The person with PD may have difficulty walking from the house to the car and then from the car to the place of worship, the grocery store, social events, etc. Using an assistive device, such as a cane, walker, or wheelchair, may allow the person to deal with gait difficulties, but, he or she may feel uncomfortable appearing in public using the device or these difficulties may become insurmountable. In that case, the person with PD may choose to remain in the home rather than rely on assistive devices.

Again, a sense of isolation may begin to set in, even during the early stages of PD, but more so during the later stages. Certainly, the caregiver can choose to continue to participate in activities, but he or she must often find someone to provide assistance to the person with PD at home and would then participate in activities without companionship. Gait problems and many other symptoms of PD may lead to social isolation, not only for the person with PD, but also for the caregiver. In addition, gait difficulties may lead to the caregiver taking on greater responsibility for shopping, housekeeping, and cooking activities, adding greater physical burdens to the isolation that the caregiver may be experiencing.

### *Late Stages*

Several key changes in the ability of levodopa to alleviate the symptoms of PD signal the later stages of PD. The person with PD may begin having dyskinesias, which are jerky dancelike movements of the head or arms, and motor fluctuations. Other symptoms that are the hallmark of more-advanced stages of PD include freezing, in which a person cannot begin a movement or can't step through a doorway, and more frequent falling.

As more and more dopamine neurons are lost throughout the course of PD, fewer neurons are available to store dopamine, and, instead of providing a steady state of dopamine, the neurons provide levels of dopamine that reflect the levels of levodopa in the blood. As the drug is broken down in the body, troughs or low levels of the drug in the blood occur, resulting in increasingly severe motor symptoms. Dyskinesias are thought to be the result of high blood levels of dopamine. About half of the people develop dyskinesias within five to 10 years after they begin taking levodopa, and most people inevitably develop them. Motor fluctuations can take three forms: dose failure, wearing off, or ON/OFF effect.

Dose failure means that the dose of levodopa simply doesn't work at all. Wearing off is a predictable shortening of the length of time that the medication works. For example, when people first start taking standard-release levodopa, its effects usually last for

three to five hours. However, with wearing off, the effects may now last only one to three hours. ON/OFF is an unpredictable lack of effect of the levodopa. A person with PD may take his regular dose of medication, be going about his usual activities, and suddenly the medication may stop working, leaving him rooted in place.

Without a doubt, the number of caregiver tasks increases during the late stages of PD, particularly for those caregivers of people with PD who choose to spend their final days at home in familiar settings with their family members and their pets surrounding them. Caregivers take on increasing numbers of physical caregiving tasks, often with little outside assistance.

In addition, many people feel ill prepared for carrying out the tasks with which they find themselves dealing, whether that is the stress of caring for someone who has neuropsychiatric problems such as hallucinations or dementia or sleep problems or the ability to handle emergency situations. One of the primary levels of strain during the later stages is the unpredictability of day-to-day living. This strain may be related to the lack of response or unpredictability of the response of PD symptoms to medications in the later stages of PD; not being able to sleep because of not being able to predict when the care receiver will be awake during the night or not being able to deal with the unpredictability of the care receiver's neuropsychiatric issues. The care receiver's inability to communicate toward the end of the disease may create even more stress for the caregiver. Some caregivers enlist the help of other family members or employ outside help to "staff" the night shift to allow the caregiver to have a break and a full night of uninterrupted sleep.

Although no medical training is necessary to care for a person with PD, there are some tasks that the caregiver eventually takes on that may prove to be challenging for caregivers of people with chronic diseases in general and PD specifically. Tasks such as making sure that either the care receiver is taking medications properly or that the caregiver is giving them properly and feeding, toileting, and pain control in the late stages of PD are issues for which many caregivers are not fully prepared and could often benefit from some assistance.

Often the caregiver can help the person with PD by learning how to recognize the signs and timing of when the medications have 'kicked in,' when the medications are working well, when the medications are wearing off, and when the person needs the next dose of medicine. The timing of the medication schedule and the response can be variable and challenging; but, if these responses are clearly reported, they can help the physician better adjust the medications.

A particular need that caregivers cited in one research study is the availability of professional assistance in establishing care



plans and in fully explaining the plans so that caregivers can more easily put the plan into action. Many people who were interviewed for this study did not realize that assistance is available for caregivers of people who choose to remain in their homes at the end of their illness. That assistance can often be provided by either palliative care services or by hospice, depending upon the life expectancy of the person with PD.

Palliative care simply means that treatment is provided for comfort rather than for cure—there is no limit on life expectancy. Most people have heard of hospice care. However, many people think that hospice care is only for people with cancer or perhaps end-stage heart or lung disease. This is not true, even though more than half of the people who avail themselves of hospice services do indeed have cancer. Hospice care is appropriate for anyone who meets the criteria for admission to a hospice program. Most hospice programs set their criteria by following the Medicare guidelines for admission, which are listed in the table. Insurance companies and state-provided Medicaid programs often, but not always, base their decisions for reimbursement of hospice services on Medicare guidelines. However, states and companies are not required to do so. Please talk with your insurance company or state Medicaid office for more information.

---

#### **Medicare Criteria for Hospice Admission**

---

- Certification by a physician that the person has an anticipated life expectancy of six months or less.
  - Acceptance by the person with PD and the family that care is palliative not curative.
  - Care is provided by a Medicare-approved agency or facility.\*
- 

\*If the person with PD is not on Medicare (or Medicaid), these guidelines are not required; however, these guidelines are generally followed.

Unfortunately, most people do not avail themselves of hospice services early enough, particularly those people who have long-term illnesses or diseases, such as PD. In one study of caregivers of people with PD who had died, half of the people with PD had been enrolled in hospice at the time of their deaths. However, the average length of time that they were enrolled was only 2.5 weeks. Perhaps one reason is the misunderstanding that hospice care is only for people with cancer; another may be the criterion that the person has an anticipated life expectancy of six months or less. Making this determination for someone with a long-term illness such as PD may be difficult. However, specific criteria may help to determine when people with neurodegenerative diseases, including PD, may benefit from referral to hospice.

---

## Indications that Hospice Care may be Warranted for a Person with PD

---

### Patient:

- Has severely impaired function, e.g., can't walk or feed self
- Is incontinent of bowel or bladder
- Has choking episodes or trouble breathing
- Has had significant weight loss (>10% in six months)

### Patient and family:

- Have comfort-focused rather than life-prolonging goals of care
- 

Hospice care is multidisciplinary, meaning that the services are provided by people with a variety of skills. All hospices have a physician who serves as the medical director. A registered nurse usually oversees hospice care, with nursing assistants or aides helping with bathing, comfort care, meal assistance, etc. In addition, speech therapists, dietitians, or both dietitians and speech therapists usually monitor food intake and assist with adapting foods or feeding regimens as necessary. For example, during the advanced stages of PD, a person will likely have great difficulty swallowing solid foods. The dietitian may suggest pureeing foods, and the speech therapist may recommend specific exercises or techniques to improve swallowing and decrease the chance of aspiration. At the time of death and for some time afterward (usually about a year), hospice care also provides bereavement counseling for families and loved ones of a person who has been enrolled in a hospice program.

---

## Hospice Team Members

---

- Counselors
  - Dietitians
  - Doctors
  - Homemakers
  - Hospice aides
  - Nurses
  - Social workers
  - Speech-language therapists
  - Volunteers
- 

Hospice care can be provided at home and in approved care facilities. Medicare rules regarding hospice require that, if requested, the services be provided in a person's home. It doesn't matter whether that home is the house where the gentleman with PD has lived with his wife for the last 58 years, an assisted living facility where the two of them relocated three years ago, or a skilled nursing facility where he moved three months ago when he fell and broke his hip—home is wherever the person deems it to be, and hospice care can be provided in any of those locations, as well as other locations.

In addition to the services listed in the table below, Medicare will also pay for other services, such as for controlling pain or other symptoms of PD, that are recommended by the hospice team. Respite care is an area that is particularly important for caregivers to understand. If you need a rest from day-to-day caregiving responsibilities, Medicare will pay for up to five days of care by either bringing people into your home to cover care or by admitting the person for whom you are providing care to an inpatient facility. There is no limit to the number of times that you can request respite care. If the person is enrolled in hospice through Medicare, there is typically a 5% copay for respite care, usually about \$5, and a maximum of a \$5 copay for medications. Again, please check with your insurance company or state Medicaid office for information specific to you if your care receiver is not covered by Medicare.

---

### Services Provided by Hospice

---

- Dietary counseling
  - Doctor services
  - Drugs for symptom control or pain relief (may need to pay a small copayment)
  - Grief and loss counseling
  - Hospice aide and homemaker services
  - Medical equipment (such as wheelchairs or walkers)
  - Medical supplies (such as bandages and catheters)
  - Nursing care
  - Occupational therapy
  - Pain control
  - Physical and occupational therapy
  - Inpatient care, short term (for pain and symptom management)
  - Respite care, short term (may need to pay a small copayment)
  - Social worker services
  - Speech-language therapy
- 

For more information on Medicare hospice benefits, please see the publication, *Medicare Hospice Benefits*, from the Centers for Medicare & Medicaid Services. <http://www.medicare.gov/publications/Pubs/pdf/02154.pdf>

### CONCLUSION

We hope that you have found this guide to caregiving helpful as you and your loved one make your way on your journey as a caregiver for a person with PD. Every situation is different, and every person faces the challenges and cherishes the rewards of living with PD differently. We have provided information that is pertinent to most people most of the time. Please use what you can and know that the remainder may be more applicable to someone else. Above all, keep in mind that communication among you, the caregiver; your care-receiving partner with PD; and your partner's physician, nurse specialist, or nurse practitioner are vitally important. This guide is not intended to

replace the care provided by a medical professional. Do not make any changes in or decisions about treatment without explicitly discussing the changes with your physician or other medical professional.

The information in the appendixes that follow can be very beneficial as you and your loved one interact with your healthcare team. We hope that the glossary that we've provided allows you to more fully "speak the language of PD." The glossary includes definitions of words that you'll encounter in this guide, as well as language that the members of your healthcare team may use on a regular basis.

The guide to communicating with your doctor (Appendixes 2 and 3) and the *Care Notebook* (Appendix 4) are intended to help you make the most of your visits with members of your healthcare team. We've provided questions that are pertinent to discussions surrounding new diagnoses, changes in symptoms, and new treatments. The *Care Notebook* is a resource that is worth spending the time to develop. Serving as a repository of information that is pertinent to the care of the person with PD, this Notebook serves as a two-way communication tool and will allow anyone you choose to share it with to have access to up-to-date and often critical information. The *Motor Diary* (Appendix 5) that we've developed and included in this guide can be added to the *Care Notebook* and will help your physician see how PD symptoms change throughout the course of the disease. You may also wish to keep copies of the durable power of attorney for healthcare and the advance directive in the *Care Notebook*.



## **Appendix 1: Glossary**

**Acetylcholine:** Acetylcholine is a type of neurotransmitter, a chemical that nerve cells use to communicate with other nerve cells and with parts of the body. It is also used by the part of the nervous system that is responsible for resting and digesting. It lowers blood pressure and slows down heart rate and breathing rate.

**Adverse effect:** An adverse effect is an unintended and negative effect of a medication, operation, or some other treatment. The reason that the term *side effect* is not used is because some side effects are positive. In fact, a specific medication may be used because of its positive side effects.

**Akinesia:** Akinesia is an absence of movement. It comes from two Greek words—*a* and *kinēsis*—*a* means without and *kinēsis* means movement.

**Alpha synuclein:** Alpha synuclein is a protein found in the brain. Nobody knows what the function of the protein is. In some diseases, it is found in large quantities clumped together. When looking at the brains of people after they have died, doctors often find these clumps of alpha synuclein in people with Parkinson's and other diseases, such as Lewy body dementia and multiple systems atrophy.

**Amino acid:** Amino acids are the chemical "building blocks" or basic structural units of proteins and are important in how all of the cells in the human body function. All proteins in the body are formed from a "pool" of 20 different amino acids. Some are essential amino acids and must be supplied by the diet. Others are classified as "nonessential." These can be made by the body and need not come from the diet.

**Apomorphine:** Apomorphine is a type of drug that is being studied to treat severe Parkinson's disease. It is made from morphine but does not actually contain morphine. It increases the levels of dopamine available in the brain.

**Autonomic nervous system:** The autonomic nervous system (ANS) is responsible for the processes in the body that a person doesn't think about—they are not consciously controlled. One example of something controlled by the ANS is the heart beating. No one has to think about telling the heart to beat, it just happens. But the heart can beat faster or slower. The two parts of the ANS responsible for this are the sympathetic and parasympathetic nervous systems. The sympathetic nervous system is responsible for the body's response under stress or in dangerous situations. It is called the fight or flight response and speeds up the heart rate. The parasympathetic nervous system is responsible for the body's response during rest, to bring the body back to normal. This slows the heart rate back down.

**Autosomal dominant:** Human traits, including eye color, hair color, and disorders, are passed down from one generation to the next through genes. A person has two genes for each trait—one from the father and one from the mother. In autosomal dominant disorders, it only takes one bad gene to have the disease. The bad gene dominates over the normal gene, which can cause the person to have the disease. If an individual has an autosomal dominant disease, each of his or her children has a 50% chance of having the disease.

**Basal ganglia:** The basal ganglia are structures located deep inside the brain. They are responsible for normal movement, such as walking. They are made up of three parts—the caudate nucleus, putamen, and globus pallidus.

**Blood-brain barrier:** The brain is a very important and delicate organ in the body. The blood-brain barrier protects the brain from being damaged by anything that can get into the blood system. The barrier keeps chemicals and toxins out. Many drugs that people take get into the blood system but cannot reach the brain unless they are specifically designed to do so.

**Bowel:** The bowel is the last part of the digestive tract. It is also called the intestines. There is both a large and small bowel. Nutrients and water are absorbed from the small bowel into the body. The leftover waste moves through to the large bowel. It is stored there until the waste is emptied from the body by a bowel movement in the form of stool or feces.

**Bradykinesia:** Bradykinesia simply means abnormally slow movement. It comes from two Greek words—*bradys* and *kinēsis*—*bradys* means slow or slowly and *kinēsis* means movement.

**Carbidopa:** Carbidopa is a drug that is given along with another drug, levodopa, for the treatment of Parkinson's disease. Levodopa provides dopamine; but, for the dopamine to work, it needs to reach the brain. However, levodopa naturally breaks down in the gut. Because of this, if levodopa is given by itself, not enough of it reaches the brain. Carbidopa slows down how quickly the body breaks down levodopa. By giving the two drugs together, more of the levodopa gets into the brain.

**Central nervous system:** The central nervous system (CNS) is made up of the brain and spinal cord. It coordinates and controls the entire body. It does this by sending signals to the body to move and receives signals from the body about the surrounding environment.

**Chromosome:** A chromosome is a thread-like structure made up of DNA and proteins. Each chromosome is like a string of beads, where each bead represents a different gene. There are 46 chromosomes, 23 pairs, in the nucleus of human cells.

**Clinical trial:** A clinical trial is a research study that tests how safe or how well a drug or treatment works in humans.

**Cogwheel rigidity:** Cogwheel rigidity is stiffness of muscles around a joint. If a person has cogwheel rigidity, and another person tries to bend and straighten his elbow, it will not move smoothly. It will be a jerky movement. Imagine the wheels of a clock moving against each other. They don't glide past each other. Instead they move one notch at a time, and then stop. This is what cogwheel rigidity looks like. It is a motor symptom of Parkinson's disease.

**Complementary and alternative medicine (CAM):** According to the National Center for Complementary and Alternative Medicine at the National Institutes of Health, CAM is a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine. Conventional medicine is medicine as practiced by holders of MD (medical doctor) or DO (doctor of osteopathy) degrees and by their allied health professionals, such as physical therapists, psychologists, and registered nurses. Some healthcare providers practice both CAM and conventional medicine. Although some scientific evidence exists regarding some CAM therapies, for most types of CAM, key questions are yet to be answered through well-designed scientific studies—questions such as whether these therapies are safe and whether they work for the diseases or medical conditions for which they are used. Complementary medicine is used with conventional medicine, and alternative medicine is used in place of conventional medicine.

**Constipation:** Constipation is a change in bowel movements from normal. Bowel movements are infrequent or the stool becomes hard and dry. It becomes difficult to pass the stool.

**Decarboxylase:** Decarboxylase is a type of enzyme that removes a part of chemicals. This stops the chemical from working. Decarboxylase breaks down levodopa in the body, keeping it from working in the brain. Carbidopa stops the decarboxylase from working. This allows levodopa to get to the brain without being broken down.

**Deep brain stimulation:** Deep brain stimulation (DBS) involves an operation in which a neurosurgeon (a medical doctor who specializes in surgery on the brain, spine, and other parts of the nervous system)

places very thin wires through tiny holes in the skull into the area of the brain that controls movements. These wires, called leads or electrodes, are connected to an insulated wire (extension) that is tunneled under the skin and connected to a battery-operated device called a neurostimulator. The surgeon sews the neurostimulator, which is about the size of a stopwatch, under the skin of the chest or abdomen. The device sends electrical pulses or signals through the wires to targeted areas in the brain, thereby blocking the abnormal nerve signals that cause the symptoms of PD. A physician or nurse uses a remote controller to transmit radio signals to adjust the electrical pulses generated by the neurostimulator.

**Delusion:** A delusion is a false belief that a person has either about himself or the world. The key to a delusion is that the person believes it no matter what. Even when someone shows evidence that the belief is not true, it doesn't change the person's belief.

**Dementia:** Dementia is not a disease, but a group of symptoms. It is a loss of mental processes such as memory, language, or the ability to think. The loss is significant enough to cause problems with daily or social function and becomes worse over time. Dementia is also characterized by personality changes.

**Depression:** Depression is a disease. People with depression cannot talk themselves out of the disease. Depression is characterized by many symptoms, including either a depressed mood or loss of interest in things that normally give pleasure. A person with depression also experiences weight loss or gain, fatigue, and feelings of worthlessness or guilt. Depression also causes a person to sleep and move around either too much or not at all.

**Dopamine:** Dopamine is a type of neurotransmitter—a chemical that nerve cells use to communicate with other nerve cells. Dopamine is especially important in nerve cells that send messages about movement.

**Dopamine agonist:** A dopamine agonist is a substance that acts like dopamine. It can be a medication that produces the same effects in the brain that dopamine does.

**Dopaminergic:** Dopaminergic is a word used to describe a chemical or a drug that either acts like or involves dopamine.

**Dysarthria:** Dysarthria means difficulty forming words or speaking them. It could be caused by a problem in the brain or with the muscles used for speech. As a result, speech can be slurred or slowed and difficult to understand.

**Dyskinesia:** Dyskinesia is difficulty with movement. It comes from two Greek words—*dys* and *kinēsis*—*dys* means difficulty and *kinēsis* means movement.

**Dysphagia:** Dysphagia is difficulty with swallowing. It comes from two Greek words—*dys* and *phagia*—*dys* means difficulty and *phagia* means to swallow.

**Dystonia:** Dystonia is a movement disorder where a group of muscles contracts uncontrollably. This causes twisting or twitching or unusual postures. When it occurs in a specific group of muscles, it is called focal dystonia. This happens in the neck (cervical dystonia or spasmodic torticollis), in the eye (blepharospasm), or vocal cords.

**Enzyme:** An enzyme is a protein made by the body's cells. There are chemical reactions that occur all the time in the body. Enzymes either speed up or slow down these reactions. Enzymes are not used up or permanently changed during the process.

**Festinating gait:** A person with a festinating gate will take very small steps. His or her feet never come all the way off the floor, so it looks like the person is shuffling along. The person cannot control the shuffling or take bigger steps.

**Freezing:** Freezing is when motion is halted. It looks like the person is nailed to the floor and can't move forward.

**Gait:** Gait is the style or manner of walking.

**Gastrointestinal tract:** The gastrointestinal tract is made up of the stomach and small and large intestines, as well as the mouth, esophagus, anus, and related organs.

**Gene:** Genes are the smallest units of heredity. The information from all the genes, taken together, makes up the blueprint or plan for the human body and its functions. A gene is a short segment of DNA, which is interpreted by the body as a plan or template for building a specific protein.

**Generic drug:** A generic drug is a drug that has the same active ingredients as the brand-name drug. It works the same way a brand-name drug works, but is usually less expensive. Generic drugs meet the same FDA standards as brand-name drugs.

**Hallucination:** A hallucination is something that a person sees, smells, touches, hears, or tastes but it is not really there. The hallucination is only present in the mind of the person. No one else experiences a hallucination because it is not a part of the environment.

**Hospice:** Hospice means, literally, place of shelter.

**Hypokinesia:** Hypokinesia is decreased movement. It comes from two Greek words—*hypo* and *kinēsis*—*hypo* means decreased and *kinēsis* means movement.

**Hypomimia:** Hypomimia means reduced facial expressions. This can be caused by weakness or paralysis of facial muscles.

**Hypotension:** Hypotension is low blood pressure. It comes from two Greek words—*hypo* and *tension*—*hypo* means low and *tension* means pressure.

**Incontinent:** Incontinent usually means that a person has lost control over his or her bladder. It can also, however, mean that he or she has lost control of his or her bowel, as well. A person will urinate or dribble urine when not using the toilet.

**Insomnia:** Insomnia is not being able to fall asleep or stay asleep for the night.

**Involuntary:** Involuntary means that a person does not have control over something. In the body, it means the things that a person does not have conscious control over.

**Levodopa:** Levodopa is a drug used to treat Parkinson's disease. It is also called L-dopa and, in the United States, is sold as Sinemet. Levodopa crosses the blood-brain barrier and is converted by the body to dopamine. A loss of dopamine-producing nerve cells in the part of the brain that controls movements leads to the symptoms of Parkinson's disease.

**Lewy body:** A Lewy body is a jumble of protein found in dying nerve cells in the brain.

**Medication:** Medication is a drug that has an effect on the body. It is usually used to treat a certain illness or condition.

**Memory:** Memory is how information is processed. It requires that a person is able to gather information. That information then has to be stored and held onto for a period of time. The final step is to recall the information when the person wants it.

**Micrographia:** Micrographia is small writing. It comes from two Greek words—*micro* and *graph*—*micro* means small and *graph* means to write.

**Motor symptoms:** The motor symptoms of Parkinson’s disease include tremor, stiffness (called rigidity), slowness or absence of movement (called bradykinesia or akinesia, respectively), and difficulty maintaining balance or unstable posture.

**Nausea:** Nausea in Greek means sea-sickness. Nausea is a feeling of discomfort in the stomach that precedes vomiting. A person does not have to vomit, though, in order to have nausea.

**Neurologic:** Neurologic refers to the nervous system. The nervous system is made up of the brain, spinal cord and nerves throughout the body. It can also refer to neurology. This is the medical specialty that deals with disorders of the nervous system.

**Neuron:** A neuron is a nerve cell. It is the smallest unit within the nervous system, which is made up of the brain, spinal cord, and all the nerves in the body. A neuron can send and receive information by using either electrical or chemical signals. This information is passed from one neuron to another neuron or to a body part using these signals.

**Neurotransmitter:** A neurotransmitter is a chemical made in the body that allows nerve cells to communicate. It is the messenger sent from one nerve cell to another.

**On-off phenomenon:** On-off phenomenon is a change that occurs because of Levodopa treatment. There is a sudden change in a person’s ability to move around. A person goes from being able to move with ease, “on,” to having difficulty with movement, “off.” It is very difficult to predict when this change will occur.

**Orthostatic hypotension:** Hypotension means low blood pressure. This sudden drop in blood pressure takes place when a person quickly sits up or stands up after having been lying down. It happens because some blood pools in the legs, instead of going to the brain, resulting in dizziness or even fainting. The cause may be a low volume of blood, a side effect of medication, dehydration, anemia, or another medical condition. Orthostatic hypotension may also be called postural hypotension.

**Pallidotomy:** A pallidotomy is a surgical procedure that destroys the globus pallidus, a structure in the brain. The thalamus is found deep inside the brain. Pallidotomy can be used to treat tremor and rigidity in Parkinson’s disease. It is rarely recommended anymore and has been replaced by deep brain stimulation.

**Parkinsonism:** Parkinsonism is a term that refers to a group of symptoms: tremor, rigidity, bradykinesia, and postural instability. These are usually seen in Parkinson’s disease, but there are other diseases that cause Parkinsonism. Certain drugs can also cause this and are usually reversible once the drug is stopped.

**Pill-rolling tremor:** To understand what a pill-rolling tremor looks like, imagine a person holding a pill between his or her first finger and thumb. You can get an idea by extending your first finger and your thumb and holding them together at the first joint of each. Slide the finger away from your hand and your thumb toward your hand—in opposition. Now reverse the movement, sliding your finger toward your hand and your thumb away from your hand. Slowly repeat these movements and you will have an idea of what the pill-rolling tremor looks like. People with Parkinson’s disease have this type of tremor

when their hands are at rest. At first, it may affect only one hand, but over time, it may affect both hands or may alternate, at times affecting one and then the other hand.

**Postural instability:** Postural instability is a difficulty with balance.

**Punding:** Punding is a behavior in which the person compulsively performs certain purposeless tasks over and over, such as buttoning and unbuttoning a shirt, picking at a scab, or collecting and sorting objects.

**Range of motion:** The range of motion is how far a joint, such as the wrist, hip, knee, or neck, can be moved. Active range of motion involves the person moving the joint himself. In passive range of motion, another person moves the joint through the full extent of its range.

**Receptor:** Receptors are the sites on one end of a nerve cell that receive messages from other nerve cells. These messages are usually sent in the form of chemicals, or neurotransmitters, by other nerve cells. However, certain drugs called receptor agonists act like neurotransmitters, but are not actually these chemicals.

**REM sleep:** Rapid Eye Movement (REM) sleep is one part of a sleep cycle. The eyes move around quickly, hence the name. This is the phase where dreaming occurs. During this phase, the body is paralyzed so that a person does not act out his dreams. Adults spend about 20% of their time in this phase.

**REM sleep behavior disorder (RBD):** During REM sleep, a person is normally paralyzed while dreaming. In RBD, a person is not paralyzed so he acts out his dreams. This can put the person or bed partner in danger of injury.

**Respite care:** Respite care is temporary or periodic care that is provided in a nursing home, assisted living facility, or other type of long-term care program so that the family member or friend who is the person with PD's caregiver can rest or take some time off.

**Rigidity:** Rigidity is stiffness or resistance to movement. It is one of several motor symptoms in Parkinson's disease.

**Seborrhea:** Seborrhea is an increased amount of the oily substance that is produced in the sweat glands of the skin. It causes the skin to glisten or appear shiny.

**Serotonin:** Serotonin is a neurotransmitter that is involved in regulating mood, appetite, sleep, and temperature, in addition to other body functions.

**Sexual dysfunction:** Sexual dysfunction is any problem with sexual activity. It could be a problem with desire, arousal, or orgasm. In men, it usually means having problems with erections.

**Sialorrhea:** Sialorrhea means having too much saliva. It causes a person to drool. It could be because a person makes too much saliva. It could also be because a person has problems swallowing, and the saliva stays in the mouth.

**Speech therapist:** A speech therapist is a professionally trained person. The speech therapist helps people with speech, language, communication, and swallowing problems.

**Thalamotomy:** A thalamotomy is a surgical procedure that destroys the thalamus, a structure in the brain. The thalamus is found deep inside the brain. Thalamotomy can be used to treat tremor and rigidity

in Parkinson's disease. It is rarely recommended anymore and has been replaced by deep brain stimulation.

**Tremor:** A tremor is a rhythmic motion involving a specific part of the body—the hands, arms, neck, head, vocal cords, trunk, or legs. The motion involves the muscles going back and forth, like a rocking chair. A person with a tremor cannot control the movement.

**Wearing-off phenomenon:** Wearing-off phenomenon is a decrease in how long Levodopa works. Over time, the ON state is shortened. The OFF state comes back quicker the more times a person takes the drug.



## ***Appendix 2: Communicating with the Doctor***

When the doctor tells you that your loved one has PD, you will likely want to ask a few key questions.

- What is the diagnosis and what does it mean as far as overall health?
- What can my partner and I do today about any health challenges involved with this diagnosis?
- What are the next steps?
- Is there an urgent need to make treatment decisions today?
- How do we decide on a course of action?

If you don't understand something the doctor is telling you about the diagnosis of PD or about medications or other treatments, keep asking questions until you do understand. Doctors often overestimate the health literacy levels of their patients—that is, their ability to obtain, process, and understand basic health information.

Every time the doctor gives a new prescription, make sure that you understand the what, why, and how of the medication. If you need additional information, your pharmacist can be very helpful in answering these questions as well.

- What is the name of this medicine?
- Why is the person taking it?
- What times of day should it be taken?
- For how long should it be taken?
- When should the medicine be stopped?
- Should it be taken with or without food?
- Are there any side effects?
- What should be done if the person develops side effects?

At various times in the course of PD, or when specific symptoms develop, certain questions will naturally arise for caregivers. A few of these are listed below.

I'm feeling overwhelmed.

- Is there someone I can talk with?
- Are there any resources so that I can get some help?
- Are there support groups in my area?

I've heard that there are experimental treatments.

- How do I find out about experimental treatment?
- What is a clinical trial?
- How can we participate in a clinical trial?

Don't wait until the doctor is headed out the door to bring up the fact that you have a list of questions. When making your appointment, you may want to indicate that you have questions for the doctor so that the appropriate amount of time can be scheduled for the appointment. Some of your questions may be answered during the visit, so they don't have to be the first item of discussion.

\*Permission for use granted by WE MOVE, Inc. ©WE MOVE, 2009.



### ***Appendix 3: Preparing for a Doctor's Appointment***

People with PD and their caregivers can find it very difficult to process information when they go to their doctors. This can happen for any number of reasons; it is often stress related or lack of familiarity with the medical language used by doctors. What can you, as a caregiver, do? Being prepared will help you and your care partner get the most out of your visit.

In an ideal world, all medical care is provided through a medical home that coordinates your care among a variety of providers and keeps all of your records—whether electronic or paper—in one place. However, if care is not provided this way, creating a *Care Notebook* (Appendix 4, next page) will help you and your partner to organize medical information.

Before you and your partner go to each appointment, write down any questions that you might have and prioritize the list. The doctor may have time to discuss only a few of these questions, and you want to make sure that you ask the most important ones first.

Caregivers can prepare themselves by reviewing certain questions. Be prepared to answer these questions at every visit:

- What is the main concern today?
- How is today's main concern affecting
  - Quality of life?
  - Ability to work?
  - Ability to perform regular activities around the house?
  - Ability to participate in recreational or leisure activities?

Bring a list of all of the medications that your care receiver takes, even if he or she takes these items only occasionally. Include any prescription drugs and over-the-counter medicines, herbal products, or vitamins that your partner is taking. Be sure to include the dose of each medication or product and how often it is taken.

Before the visit, help your partner to make a list of symptoms and, also, anything that makes the symptoms better or worse. In addition, let your doctor know if your partner has had any laboratory tests or imaging studies done since the last appointment and whether he or she is being treated by other doctors for other medical conditions.

Accompany your care receiver to appointments to serve as an extra set of ears. Having someone else there to listen and even write down the answers to questions may be very helpful.

Help your care receiver to be an active participant in care. Working in tandem with the healthcare professionals in a collaborative environment, having accurate up-to-date information from a reliable source, and assuming responsibility for managing the medical information in a *Care Notebook* will all help manage the health of someone with PD.

\*Permission for use granted by WE MOVE, Inc. ©WE MOVE, 2009.



#### ***Appendix 4: A Care Notebook***

A *Care Notebook* serves as a central place to organize all of a person's healthcare information. Using a *Care Notebook* will make it easier to find and share important information with people who are part of the healthcare team.

You can use the *Care Notebook* to:

- ▶ Prepare for appointments
- ▶ Keep track of changes in medications or treatments
- ▶ File lab or X-ray results or other test reports
- ▶ List contact information for key people on the healthcare team
- ▶ Compile information that you download from Internet searches, brochures, and other sources of information and support
- ▶ Record immunizations
- ▶ Note any allergies or adverse reactions to medications or foods
- ▶ Share information with family members and all members of the healthcare team

The following tips may make it easier to create and use the *Care Notebook*:

- ▶ Most people find it easiest to use a three-ring binder to create the *Care Notebook*. You may also want to buy a three-hole punch that slips into the rings of the binder. By keeping the punch handy, you can avoid the hassle of dealing with loose material. When you receive a report or other information, simply punch the holes on the spot and slip the new material into the notebook. Other people prefer to store their material in an accordion file, so use whatever method works best for you.
- ▶ Use dividers to separate the material in the *Care Notebook*. You can create the dividers in any way that is helpful to you. You may wish to include a few plastic sheets in which to insert information that can't be hole punched.
- ▶ When you first put together the *Care Notebook*, you will most likely want to spend some time creating a medical history. Make note of any operations or hospitalizations, as well as other helpful information on the person's current medical conditions.
- ▶ Include blank pages in a special section of the notebook for questions. In this section, you can jot down questions for upcoming appointments. Make sure to leave space so that you or your advocate can write down the doctor's responses to those questions.
- ▶ Keep the *Care Notebook* in an easily accessible spot. Make sure that a family member or other caregiver can locate the Notebook in an emergency and knows to bring it to the clinic or hospital.
- ▶ Bring the *Care Notebook* to all medical appointments.

You will want to create a *Care Notebook* that is specific to the person's medical conditions. The following are some suggestions of pages you may wish to include.

Contact information for:

- You and other family members
- Caregivers
- Emergency personnel
- Hospitals
- Physician/Healthcare providers
- Therapists
- Pharmacy
- Insurance company or even a copy of the insurance card
- Special transportation
- Equipment providers

Diary pages to track:

- Medication effects
- Sleep
- Activities
- Exercise

An appointment log that includes:

- Who the appointment is with
- The reason for the appointment
- The results of the appointment
- Any follow-up action that you need to take

A medication log that includes:

- Name of the medication, including any brand or generic names
- Date the medication was first prescribed
- Who prescribed the medication
- The dose
- How often or when the person takes it
- The way it should be taken
  - o With or without food
  - o By mouth, injected, or some other route
- Foods that should be avoided
- Date the medication was stopped and why

Treatment results

Hospitalizations

Questions for upcoming appointments

Test results

Calendar

Advance directive

Durable power of attorney for healthcare

\*Permission for use granted by WE MOVE, Inc. ©WE MOVE, 2009.

### ***Appendix 5: Motor Diary***

One way doctors developed to help decrease patients' OFF time and ON time with dyskinesias is to have them or their caregivers record symptoms in a motor diary. During an office visit, the doctor can then review the diary and see how the person's symptoms change throughout a usual day. Doctors have developed a standard way for patients to record their symptoms in a motor diary. This is so every patient records information the same way, making the results easier for the doctor to interpret.

A motor diary is used to keep track of ON time, OFF time, and ON time with dyskinesias during the time that a person is awake for an entire week. Upon awakening in the morning, the person records which of the three phases he is in. Every half hour after that, he will again record what phase he is in. During the night, he will also mark down any times that he is awake and make note of the phase at that time as well. It is very important to record every 30 minutes from the time a person wakes up until the time he goes to sleep. The person will also record when he takes his medication and any other thoughts that he has about how he is feeling at that time.

Once the diary has been kept for at least a week and shared with a doctor, the doctor and the patient can decide how often each day the person should keep recording. Some people cycle between the three phases of ON, OFF, and ON with dyskinesias quickly, so it will be important for them to keep recording in their diaries every 30 minutes. Other people cycle slower.

The sample diary on the following pages is divided into 30-minute periods. For each 30-minute period, please mark an X in the box that corresponds to your ability to move during that period. Remember to mark only one box in each period. If your ability to move varied throughout a 30-minute period, please mark the one box that is valid for MOST of that period.

Please keep in mind the following definitions when rating your ability to move. Please remember to record any times that you wake up during your sleep period and note your ability to move at that time. In the right-hand column, please record any medication and the amount of the medication that you take during the 30-minute periods.

<b>Term</b>	<b>Definition</b>
ON	You are able to move normally or almost normally.
ON with troubling dyskinesias (TD)	You are able to move, but are troubled by twisting or turning movements that you can't control. These movements are not the same as the tremor, or back and forth movement, that is part of PD.
OFF	You are very stiff and either have great difficulty moving or are unable to move at all.
ASLEEP	You are sleeping.

\*Permission for use granted by WE MOVE, Inc. ©WE MOVE, 2009



Date: \_\_\_ / \_\_\_ / \_\_\_

Day of the week:  Sunday  Monday  Tuesday  
 Wednesday  Thursday  Friday  Saturday

Time	ON	ON w/TD	OFF	Asleep	Medication or Comment
MIDNIGHT – 12:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12:30 AM – 1:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:00 AM – 1:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:30 AM – 2:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:00 AM – 2:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:30 AM – 3:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:00 AM – 3:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:30 AM – 4:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:00 AM – 4:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:30 AM – 5:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:00 AM – 5:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:30 AM – 6:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:00 AM – 6:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:30 AM – 7:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:00 AM – 7:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:30 AM – 8:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:00 AM – 8:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:30 AM – 9:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:00 AM – 9:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:30 AM – 10:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:00 AM – 10:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:30 AM – 11:00 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:00 AM – 11:30 AM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:30 AM – NOON	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Date: \_\_\_ / \_\_\_ / \_\_\_

Day of the week:  Sunday  Monday  Tuesday  
 Wednesday  Thursday  Friday  Saturday

Time	ON	ON w/TD	OFF	Asleep	Medication or Comment
NOON – 12:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12:30 PM – 1:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:00 PM – 1:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
1:30 PM – 2:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:00 PM – 2:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2:30 PM – 3:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:00 PM – 3:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3:30 PM – 4:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:00 PM – 4:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4:30 PM – 5:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:00 PM – 5:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5:30 PM – 6:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:00 PM – 6:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6:30 PM – 7:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:00 PM – 7:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7:30 PM – 8:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:00 PM – 8:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8:30 PM – 9:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:00 PM – 9:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9:30 PM – 10:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:00 PM – 10:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10:30 PM – 11:00 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:00 PM – 11:30 PM	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11:30 PM – MIDNIGHT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

## ***Appendix 6: Resource Guide***

### **Patient advocacy groups**

[American Parkinson Disease Foundation](#)

[Parkinson Disease Foundation](#)

[National Parkinson's Foundation](#)

[WE MOVE](#)

### **Research organizations**

[Michael J Fox Foundation for Parkinson's Research](#)

[Parkinson Research Foundation](#)

[PDTrials.org](#)

### **Caregiving organizations**

[Family Caregiver Alliance](#)

[National Family Caregivers Association](#)

[National Alliance for Caregiving](#)

### **US Government**

[Caregivers Resources](#)

Parkinson information

National Institutes of Health

Medline Plus Tutorial

[English](#)

[Spanish](#)

[NINDS](#)

[Social Security Administration](#)

[Administration on Aging](#)

