



Going to the Hospital With Parkinson's: How to Be Prepared



The experience of staying in the hospital, whether the admission is elective or unplanned, is stressful for anyone. For people who live with Parkinson's disease (PD), hospital stays can be especially challenging.

Parkinson's disease progresses slowly and can be managed effectively through regular visits to a [neurologist](#) who specializes in movement disorders. For these reasons, people with Parkinson's are unlikely to be admitted to the hospital because of the disease itself, but rather for a disease-related event such as a fall, pneumonia, or a urinary tract infection — or for the surgical intervention known as [deep brain stimulation](#) surgery.

But recent research shows that when people with Parkinson's disease are admitted to the hospital — typically for reasons unrelated to PD, such as an elective surgery — they have longer stays, and more often need rehabilitation afterwards, than do people without Parkinson's disease. We need to learn why this is so — and to take action now to ensure the best care for ourselves and our loved ones.

Managing PD in the Hospital

Why do people with PD fare differently in the hospital from others? At the most basic level, the hospital setting is challenging. The anxiety that comes with being in an unfamiliar place can worsen PD symptoms, as can disruption of sleep patterns and eating habits. Add to that the increased risk of falls that is present in a hospital setting — the result of being in an unfamiliar environment where there are many hard surfaces on which to land — and it is easy to understand how a hospital stay can pose challenges for a person with PD.

Additional challenges faced by people with Parkinson's in the hospital arise due to a lack of understanding about the disease — its symptoms and the regular medications it requires — amongst hospital staff.

It is important to remember that our understanding of PD as a complex disease is fairly recent. In fact, it is only in the past 15 years that PD experts have come to regularly talk about the nonmotor or "hidden" symptoms, such as sleep problems, gastrointestinal issues or reduced facial expression.

Your health care team may not recognize some of your PD symptoms, may not understand why they fluctuate so drastically, and/or may not know that treating them requires meticulous medication management. Plus, they will be — quite naturally — focused primarily on treating the condition that has brought you through their doors, which (as noted above) is likely unrelated to PD.

This lack of understanding can seriously affect your quality of life, both in the hospital and after you are discharged.

Be Prepared: Communication Is Key

Despite these challenges, your health care team wants to give you the best care. And while PDF and other groups work to ensure that health care professionals have access to the latest in PD research and care (see second box at right), you can take charge of your own care by educating hospital staff about PD.

Like any other potential emergency, prepare now. Put together an emergency hospital bag (see first box at right) to help you convey important information about your PD in the event that you need to stay at the hospital.

Include a list of your medications and the medications themselves in their original containers. Keep the bag in a place that is easy to access, such as a kitchen cabinet. Tell your family and friends where to find it. Find an advocate — a loved one or friend — who can take charge of communication with hospital staff during a stay. You or your advocate should immediately contact your neurologist to let him or her know about your hospital stay. If the stay is planned, call in advance.

Tell the admitting nurse how your doctor may be contacted. Follow up later to ensure that the doctors are communicating with each other. Your advocate should also talk to the staff of the emergency room or admitting office upon your arrival, and to every new medical staff person after that, to make sure that they understand your PD symptoms and how to manage them.

If you have difficulty walking, your advocate can help arrange for assistance, or ask that your bed be placed close to the bathroom. If you need help with your medications — whether it is getting a pill out of the package or lifting a glass of water — the advocate can make sure someone is there to assist you. If you are dependent on help from others for communication, mobility, and activities of daily living, it can be very helpful to have your advocate stay overnight in the hospital.

Surgery and Anesthesia

Surgery brings up very specific concerns for PD, mainly related to anesthesia. Discuss the following items with the surgeon and the anesthesiologist beforehand (even in the case of emergencies, you will be given a chance to do this).

Anesthesia: Ask what type of anesthesia you will receive during surgery, and then specifically request local/regional anesthesia. The other option, general anesthesia, can cause people with PD to become temporarily confused and, in some cases, to experience hallucinations. Sometimes this reaction is delayed until a few days after surgery. This can of course be very upsetting, but it can also affect your care. Hospital staff could misinterpret the confusion, not realizing it is due to the interaction of PD and anesthesia, and then may treat you with unnecessary medications.

Medications: Alert your doctor that some medications that are given during surgery, including meperidine (Demerol®), for pain, and metoclopramide (Reglan®), for nausea, can cause confusion or worsen symptoms in PD. Talk with your medical team about how to maintain your schedule of PD medications before, during and after surgery. If your surgery is delayed, for example, be sure to keep taking your PD medications. If you are not supposed to eat or drink before surgery, ask about taking [carbidopa](#)/levodopa orally disintegrating tablet (Parcopa®), which dissolves on the tongue. As we suggest below, always share your list of PD medications with the surgical team, and check with your nursing staff to make sure your medication schedule is on your chart.

Pain Management After Surgery: People with PD can sometimes be more sensitive to pain medications than other people. Ask for an individualized plan.

Issues Related to DBS: If you have undergone deep brain stimulation (DBS) for PD, bring your hand-held monitor to the hospital. Although the doctors may shut it off during surgery, you will need it later. Be aware that equipment in the operating room can cause the stimulator to shut off. Avoid a procedure known as [ultrasound](#) diathermy. Also, check with your treating neurologist before undergoing a magnetic resonance imaging (MRI) scan; this is safe only under certain conditions.

Managing Medications

People with PD often have complex and precisely timed medication regimens, which can be difficult to maintain in the hospital. Nurses are accustomed to dispensing medications at certain times. They also may not realize that even a 15-minute delay can make the difference between independent function and poor mobility. Additionally, hospital pharmacies may not keep your specific PD medications in stock.

For all these reasons, it is important for you or your advocate to double-check the drugs and schedules in your medical chart. If the hospital pharmacy does not stock your medications, ask to use your own. If you are told that you cannot take your own medications, ask your neurologist to write a letter or call the hospital to assure them your own medications are best (see top box at right).

Emphasize to the medical staff that delaying or stopping PD medications will not only affect your symptoms, but can also be dangerous — a situation much like that of a person with diabetes who cannot delay taking insulin. For example, missing the dose of a dopamine agonist may lead to withdrawal symptoms such as anxiety, pain and restlessness.

On occasion, a person with PD may mistakenly be prescribed medications that further deplete the brain of dopamine (the chemical messenger that is lacking in PD) or block its action. Avoid such drugs, including chlorpromazine (Thorazine®), haloperidol (Haldol®), and trifluoperazine (Stelazine®). Request others in the same class that do not usually interfere with dopamine — such as quetiapine (Seroquel®) and clozaril (Clozapine®).

After Discharge

After a hospital stay, you may need to spend a few days at a rehabilitation facility. With a new health care team, the education process starts all over again. It takes another round of persistence to educate staff about your symptoms, medications and needs.

Conclusion: Educate, Communicate

Being in the hospital can be a stressful experience. But remember, your team wants to give you the best care and understanding of Parkinson's is increasing each day. Take charge of your own care by preparing ahead of time. Do not be embarrassed to ask hospital staff for help at any time, and make sure they understand your situation. And if possible, do bring an advocate along to help you with PD-related tasks while you focus on the most important thing: your own healing.

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