

Staying Safe in the Hospital With Parkinson's Disease



The experience of staying in the hospital, whether planned or unplanned, is stressful for anyone. For people who live with Parkinson's disease (PD), hospital stays can be especially challenging. Research shows that when people with PD are admitted to the hospital, they have longer stays and more often need rehabilitation afterwards, compared to people without PD.

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 the increased risk of falls present in a hospital setting and it is easy to understand how a hospital stay can pose challenges for a person with PD.

Additional challenges for people with PD in the hospital arise due to a lack of understanding about the disease 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 begun to regularly address non-motor or non-movement symptoms, such as sleep problems, gastrointestinal issues or reduced facial expression.

When hospitalized, your healthcare team may not recognize some of your PD symptoms, why they fluctuate so drastically and/or may not know that treating them requires careful medication management. They will naturally be focused on treating the condition that brought you to the hospital, which may be 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 healthcare team wants to give you the best care. While the Parkinson's Foundation works to ensure that health professionals have access to the latest PD research and care, you can take charge of your own care by educating hospital staff about the disease.

Like any other potential emergency, prepare now. If you haven't already, request your free Parkinson's Foundation Aware in Care kit to help you convey important information about your PD when hospitalized. Each Aware in Care kit contains useful tools and information to help a person with Parkinson's during the next hospital visit. Each kit includes tools to help educate everyone who provides care to you or your loved one in the hospital, including information about the importance of medication timing and medications that should be avoided for people with Parkinson's.

Keep your Aware in Care kit in an easily accessible place, 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 to ensure that the doctors are communicating with each other. Your

advocate should also talk to the emergency room staff or admitting office upon your arrival and to every new medical staff person after that, ensuring 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 — such as 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 others for communication, mobility and activities of daily living, it can be helpful to have your advocate stay overnight in the hospital.



Surgery and Anesthesia

Surgery brings up specific concerns for PD, mainly related to anesthesia. Discuss the following topics with the surgeon and anesthesiologist beforehand:

Anesthesia. Ask what type of anesthesia you will receive during surgery. Specifically request local/ regional anesthesia. General anesthesia can cause people with PD to become temporarily confused and possibly experience hallucinations. Sometimes this reaction can manifest several days after surgery. This can be upsetting and also affect your care. Hospital staff could misinterpret the confusion and treat you with unnecessary medications.

Medications. There are several common medications that may be given after surgery that will make PD symptoms worse. These include

many narcotics and anti-nausea medications, among others.

Always have your Aware in Care Kit with you when you are in the hospital so that you can share this information with your nurses and doctors. Keeping the Medical Alert Card in your wallet can help make sure you always have this information with you. Request your free kit at [Parkinson.org/AwareinCare](https://www.parkinson.org/AwareinCare).

Talk with your medical team about how to maintain your medication schedule before, during and after surgery. If your surgery is delayed, talk to your healthcare team about continuing your PD medications. If you are not supposed to eat or drink before surgery, ask about taking a carbidopa/levodopa orally disintegrating tablet (Parcopa®), which dissolves on the tongue. 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 others. Ask for an individualized plan.

Issues related to deep brain stimulation (DBS). If you have undergone DBS, bring your hand-held monitor to the hospital. Although 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. Check with your treating neurologist before undergoing an MRI; this is safe only under certain conditions.

Managing Medications — On Time Every Time

To avoid serious side effects, people with PD need their medication on time, every time — do not let the hospital staff skip or postpone doses. People with PD often have complex and precisely timed medication regimens, which can be difficult to maintain. Nurses are accustomed to dispensing medications on certain schedules and likely have an hour window to distribute medications within that schedule. They 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.

To help your nurses understand, make sure that the drug schedule, with specific times, is written into the doctor's orders.

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. Keeping a set of your medications in their original bottles in your Aware in Care kit will help make this possible.

Emphasize to the medical staff that delaying or stopping PD medications will not only affect your symptoms, but can also be dangerous. For example, missing the dose of a dopamine agonist may lead to withdrawal symptoms such as anxiety or pain.



Preventing Confusion in the Hospital

Confusion can be a major problem for hospitalized patients. This is unfortunately common and does not mean that your loved one had a major setback. Many things happen in the hospital that can contribute to confusion. Any infection in a person with PD can cause confusion. The introduction of new medications frequently results in disorientation and memory problems, especially with pain medications. Lack of sleep

can also contribute to a confused state. For some people, especially for those who have intermittent confusion at home, being in a different and unfamiliar environment may cause these problems. Finally, confusion is common following a surgical procedure due to the combined effects of anesthesia and pain medications.

Confusion will often disappear once the underlying cause is treated, whether by addressing the infection or withdrawing the offending medications. Diagnostic testing is rarely necessary. Frequent reassurance, support and comfort may be all that is needed to assist your loved one through this period. However, sometimes confusion can lead to behavioral problems, such as aggression, refusal to take pills and even hallucinations or delusions. In these cases, physical restraints are sometimes necessary to prevent self-injury. Some hospitals have bed or wheelchair alarms to alert nurses when patients attempt to wander, while other hospitals may recommend a private duty sitter to help promote safety.

When psychotic symptoms are present, such as visual hallucinations, antipsychotics may be used. Remember, in nearly all cases, pimavanserin (Nuplazid), clozapine (Clozaril), and quetiapine (Seroquel) are the only antipsychotics that should be used for someone with PD. **A person with Parkinson's should never be given Haloperidol (Haldol).** Occasionally, lorazepam (Ativan) or diazepam (Valium) can be helpful. These drugs, by themselves, may worsen confusion, but they also can calm the patient. These medications are only temporary and may be discontinued when the confusion resolves.

In severe cases of confusion with hallucinations and behavioral changes, it may be necessary to temporarily discontinue dopamine agonists, MAO inhibitors, amantadine, benzodiazepines, and pain medications if possible. Treatment in these cases with carbidopa/levodopa and pimavanserin, clozapine or quetiapine will usually result in improvement. Later, once patients are stable, they may be slowly adjusted back onto previous doses, if tolerated. This should always be done in



consultation with the neurologist who regularly treats the person with Parkinson's.

Bringing Your Own Medications From Home

While you are hospitalized, the nursing staff must control your medications. This is a safety issue and is standard hospital policy. In some cases, your medications may not be stocked in the hospital pharmacy. In such situations, your hospital physician might want to prescribe substitute medications. If at all possible, do not agree to any changes made without a consultation with your primary Parkinson's neurologist.

It is ideal that you continue to take your prescribed medications, but for the hospital to allow this they need to be in their original bottles and they cannot be expired. You can expect to give them to the nursing staff, who will then dispense your medications — without need for substitution while you are hospitalized. If you are enrolled in an experimental drug protocol, it is even more important that you follow this practice.

In some hospitals and outpatient surgical facilities, the doctor can write an order to allow patients to take their own medicines; however, the doses and times must be written in the chart and the pill ingestion must be supervised and documented.

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 begins again. To get the care you need be persistent in educating staff about your symptoms, medications and needs.

Educate and Communicate

Being in the hospital can be stressful. Remember, your team wants to give you the best care. Prepare ahead of time to take charge of your own care. Do not be embarrassed to ask hospital staff for help at any time and make sure they

understand your situation. If possible, bring an advocate along to help you with PD-related tasks while you focus on the most important thing: recovery.

We're here for you. If you are preparing for a hospital stay or need to request a FREE Aware in Care kit, call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) for answers to all your questions.



The FREE Aware in Care kit contains tools to help you get your medication on time, every time and avoid medications that could make Parkinson's symptoms worse.

Order your kit at 1-800-4PD-INFO (473-4636) or at [Parkinson.org/AwareinCare](https://www.parkinson.org/AwareinCare).