

## **Five frequently asked questions about hospitalization for patients with Parkinson's disease**

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Some people, if they are lucky, will never have to spend a day of their life in the hospital. Most patients, however, will need to be hospitalized for one reason or another. This is true of patients with Parkinson's disease (PD). Common reasons for hospital admissions from the emergency room can include infections of the urinary tract or lung (such as pneumonia), chest pain, heart failure, falls, and psychiatric issues. Common reasons for non-emergent hospitalizations include elective surgeries such as knee and hip replacements.

Hospitalization can be stressful for PD patients and their caregivers for a number of important reasons. For example, the neurologist who takes care of you and manages your PD medications may not have privileges at the hospital where you are admitted, and the physicians who are responsible for your care in the hospital may not know a lot about PD. Furthermore, the nursing staff may not have much experience with PD patients, and-- for various reasons including nursing shortages and/or cuts in staffing--will likely have little time to invest in learning. Finally, if you need to undergo surgery or other invasive medical procedures, you may not be able to take any medications—including your PD meds-- until the surgery or procedure is complete.

It is important for the patient and the caregiver to plan and to anticipate what is likely to happen. The combination of education and planning can alleviate many of the problems encountered in the hospital. This article will answer five of the most frequently asked questions that PD patients have about hospitalization.

### **1) When I am in the hospital, why don't I always get my medications on time?**

Many of the problems that PD patients encounter in the hospital involve medications. A common problem is timing. It is important to realize that hospitals and hospital pharmacies have their own dosing schedules. For example, if a medication is written for "QID (four times a day)," the standard hospital schedule may be 8 AM – 1 PM – 6 PM – 11 PM or some similar variation. A medication written for "TID (three times a day)" may be given at 7 AM – 3 PM – 11 PM or some other standard 8-hour interval schedule. Furthermore, many hospitals may have a policy where the nurses have a window for administering medications (generally, one hour before the scheduled time to one hour after the scheduled time). This window is provided as a practical compromise because nursing staffs are busy, and each nurse is involved in the care of multiple patients. Such a policy provides the nurse time to complete his/her scheduled duties, and provides flexibility in case of emergency on the ward. As a result, PD patients will in most cases receive their medications at seemingly random times.

How can such a situation be remedied? First, make sure that the drug schedule, with specific times, is written into the doctor's orders. For example, if carbidopa/levodopa (Sinemet) is given four times a day, but at 6 AM – 10 AM – 2 PM – 6 PM, make sure that the physician taking care of you knows that it should be given at those specific times. Also make sure that you bring with you the complete list of your medications and that the dose of each medication is correct. Carbidopa/levodopa can come as a 10/100, 25/100 or 25/250 tablet for the standard form, while the long-acting form (Sinemet CR®) comes in two strengths, 25/100 and 50/200. Other common medications, such as pramipexole (Mirapex) and ropinirole (Requip), also come in multiple strengths. Finally, when you first arrive in your room, talk with your nurse about the importance of receiving your medications on time. Explain that without the medications you can be immobile or uncomfortable, and that the medications allow you to move around independently. You may know more than the doctor and the staff about PD, and it will therefore become your job to help them understand your situation. While you will still need to be somewhat flexible (there are many other important duties that may occupy a nurse's time), sharing your knowledge with the staff can alleviate many problems. All hospital staffs want their patients to be well cared for during their stay.

**Pearl:** Not everyone in the hospital is familiar with PD patients, so you should be ready to share your knowledge about PD and help them understand why you need to take your medications at specific times.

## **2) Why can't I take my own medications in the hospital? Why do they substitute some medications for me?**

While you are hospitalized, the nursing staff must have control of your medications. This is a safety issue, and is standard hospital policy. It is not a reflection of what the staff thinks of you, so don't take it personally. If you let the staff know what medication is supposed to be given and how it is to be administered, there should not be any significant problems.

In some cases, patients may be taking medications that are not stocked in the hospital pharmacy. In such situations, the physician taking care of you in the hospital may have to prescribe substitute medications. If you want to take your own medications while in the hospital, you need to bring them from home in their original bottles and give them to the nursing staff, who will then dispense your own 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.

**Pearl:** Find out what the hospital rule is for taking your own medication. Always bring your medications in the original bottles when hospitalized, and bring a list of the medications, doses, and times of administration.

**3) My mother has PD and was recently hospitalized. However, she seems to be moving much worse in the hospital than she was at home. Why is that?**

Several explanations are possible. When PD patients have an infection of some kind, whether it is the common cold, pneumonia, or a urinary tract infection, they often feel like their symptoms worsen. Increased tremor or more difficulty walking may be noted. When the infection is treated and resolves, the Parkinson's symptoms generally return to baseline. Another symptom that may worsen when PD patients have an infection is swallowing. When swallowing is impaired and patients are weak, the food may go down into the lungs, causing an "aspiration pneumonia," which in turn, may further impair swallowing ability. In these situations, a speech pathology consultation can be useful to formally assess swallowing and to make dietary recommendations. In addition, a respiratory therapist consultation for "chest PT" may be helpful. Chest PT consists of several minutes of chest clapping to help mobilize the sputum and make it easier to cough.

Another possibility is that a new medication was started in the hospital and that medication resulted in worsening of the PD symptoms. Common offenders include antipsychotic drugs or anti-nausea drugs. Haloperidol (Haldol) is a common antipsychotic drug that is used in hospital settings and is a favorite of many doctors because it comes in an injectable form. This drug blocks dopamine receptors and worsens PD. Other commonly used antipsychotics include risperidone (Risperdal), olanzapine (Zyprexa), and aripiprazole (Abilify). The only antipsychotics that can be used safely in PD patients are clozapine (Clozaril) and quetiapine (Seroquel). Common anti-nausea medications that can worsen PD include prochlorperazine (Compazine), promethazine (Phenergan), and metoclopramide (Reglan). These medications have similar structures to the antipsychotics and should not be used. The anti-nausea drugs Trimethobenzamide (Tigan) and ondansetron (Zofran) are suitable alternatives that can be used without fear of worsening PD.

Regardless of the cause, all PD patients should be as active as possible while in the hospital. Moving around not only tones muscle, it allows faster recovery and prevents decomposition of the skin, which can happen when staying in one position for too long. Depending upon your condition, however, you may not have a choice, as your doctor may order bedrest. In that case, physical therapy should be ordered as soon as possible. Some patients may also need rehabilitation at a rehabilitation hospital or a nursing facility before being discharged to home.

**Pearl:** There are multiple explanations for worsening of PD while in the hospital. Infections should be sought and treated. Drugs that block dopamine, like haloperidol and certain anti-nausea drugs, should be avoided. Chest PT, speech pathology, and physical therapy may all be useful in the recovery process.

**4) My husband has PD and became confused in the hospital last time he was there. How can I prevent this?**

Confusion can be a major problem for hospitalized patients, particularly in the elderly. This occurrence is unfortunately common and does not mean that your loved one had a stroke or another major setback. Many things happen in the hospital that can contribute to confusion. Any infection in a PD patient can be enough to tip a patient “over the edge” mentally. Similarly, infections can adversely affect motor function, as we discussed above. The introduction of new medications frequently results in disorientation and memory problems, especially with the introduction of pain medications. Lack of sleep while in the hospital can also contribute to a confusional state. Continuous alarms from IV machines and hallway lights can result in frequent awakening. Nurses also may regularly enter the room overnight to take vital signs, to give medications, or to check on a patient. In some patients, especially in elderly people who have intermittent confusion at home, just the fact that they are placed in a different and unfamiliar environment may tip them into a delirious state. Finally, confusion is commonly seen following a surgical procedure. This is due to the combined effects of anesthesia and medications to treat the pain of surgical incision.

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 the patient 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 patients’ safety. If a patient has psychotic symptoms, such as visual hallucinations, antipsychotics may be used. Remember, in nearly all cases, clozapine (Clozaril) and quetiapine (Seroquel) are the only antipsychotics that should be used for someone with PD. 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 very 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 either clozapine or quetiapine will usually result in improvement. Later, once patients are stable, they may be slowly titrated back onto previous doses, if tolerated.

**Pearl:** Infection and medications are common causes of confusion during hospitalization, When the underlying cause is addressed, the confusion usually improves dramatically.

**5) I had deep brain stimulators (DBS) placed for PD two years ago. I now need to have knee replacement surgery. Will the doctors know how to take care of me?**

While thousands of patients worldwide have had deep brain stimulation treatment for PD and other movement disorders, many medical professionals and hospitals may still not be familiar with this treatment. Many patients with DBS undergo knee replacement surgery, and other procedures, without difficulty. However, there are a few points you and your doctors should be aware of. First of all, if you have had DBS surgery, you can only get a brain MRI, and it must be done with something called a head-receive coil. You cannot get a MRI of any other part of the body. This situation exists because, during MRI, the DBS device can become heated and can damage the brain tissue. There are also certain precautions that the radiologists must be aware of while performing a brain MRI. These are available from the FDA. Furthermore, the voltage on your stimulator should be turned down to 0 prior to having an MRI performed. Only an experienced programmer should supervise the procedure. If there is not an experienced member of the DBS team available in the hospital where you are being treated, and/or if the institution is not familiar with performing MRIs in DBS patients, it is probably best not to have the MRI, or to wait and have it at an experienced center.

The stimulators can sometimes interfere with the ability to obtain an electrocardiogram (EKG). This test may be important if you happen to have cardiac problems before, during, or after surgery. Therefore, you should bring your portable Medtronic Access Device or Access Review Device (or a magnet that comes with the device) to turn off your stimulator in the hospital. Make sure you know how to turn your stimulators on and off before going to the hospital, and before having any type of surgery. (Again, do not assume that the medical staff will be able to turn them off for you.) Similarly, if you need a brain wave test called an electroencephalogram (EEG), or will simply be monitored during an inpatient or outpatient procedure, you will need to know how to turn your device off.

If you are undergoing surgery and you have DBS, most anesthetics are safe. However, some precautions need to be taken when using electrocautery. Electrocautery stops bleeding during surgery and could potentially reset your stimulator to its factory settings. As a precaution, only bipolar electrocautery is recommended (with grounding placed below the level of the device). If your neurologist is on staff at the hospital where you are having surgery, he/she should confirm that your stimulator is on and that the correct settings are reset following surgery. If your neurologist is not at the hospital where you are being operated, you should schedule a follow-up appointment to recheck your settings soon after you are discharged from the hospital.

**Pearl:** Be aware of what procedures can be done safely with DBS, and be ready to assume primary responsibility for turning it on and off for procedures.

## CONCLUSION

The above tips and scenarios will hopefully aid in minimizing problems for PD patients who are hospitalized. Be aware that for unclear reasons some PD patients worsen following general or local anaesthesia, and some even feel as if they never return to their baseline. In general, local anaesthesia is thought to be safer than general anaesthesia. If

you have problems with thinking and memory, these issues should be evaluated prior to surgery as they may also worsen following surgery.

Finally, it is important for you to have discussions with close family members about what you would like to have done in case of a life-threatening emergency. They and the medical staff should be aware of your medical wishes. You should choose an advocate who can ask questions and act as your spokesperson. If you have a living will or a durable health care power of attorney, these documents should be brought to the hospital and placed in your medical chart.

### CHECKLISTS

Below are two checklists for you to take with you to the hospital: one for you, and one for your doctor/nurse. Remember: You can play an important role in easing the stress of your hospital stay, which can in turn help other PD patients who will follow you.