

Five Frequently Asked Questions About Hospitalization

For Patients with Parkinson Disease

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Most people with Parkinson disease will need to be hospitalized at some time. Hospitalization can be stressful for a number of important reasons. The neurologist who takes care of you and manages your Parkinson disease medications may not have privileges at the hospital where you are admitted, and the physicians and nursing staff responsible for your care in the hospital may not know a lot about Parkinson disease. If you need to undergo surgery or other invasive medical procedures, you may not be able to take any medications until the surgery or procedure is complete.

It is important for the patient and the caregiver to plan and anticipate what is likely to happen. This article will answer five of the most frequently asked questions about hospitalization for people with Parkinson disease.

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

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 schedule. Furthermore, many hospitals may have a policy that permits nurses to give medications at times different (generally, one hour before or after) from the scheduled time. This window is provided as a practical compromise because nursing



staffs are busy, and each nurse usually cares for 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, patients with Parkinson disease 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 the dose of each medication is correct. 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 about Parkinson disease than the doctor and the staff, and it is your job to help them understand your situation. While you will still need to be somewhat flexible (there are many other important things 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.



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, you need to bring them from home in their original bottles and give them to the nursing staff. They will then dispense your medications while you are admitted, and there will be no need for substitution. 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 the hospital rule on taking your own medication. Always bring your medications in the original bottles along with a list of the medications, doses, and times of administration.

Pearl: Not everyone in the hospital has experience treating patients with Parkinson disease, so you should share your knowledge 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?



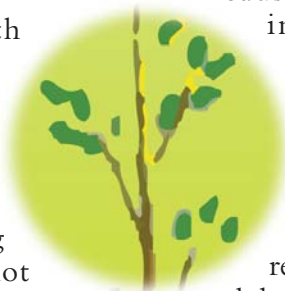
While you are hospitalized, the nursing staff must have control of your medications. This is a safety issue and is standard hospital policy. It is not a reflection of what the staff thinks of you, so don't take it personally.

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

Several explanations are possible. When patients with Parkinson disease 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, their symptoms generally return to baseline. Another symptom that may worsen when patients with Parkinson disease 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 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 the addition of a new medication. Common offenders include antipsychotic drugs or anti-nausea drugs. Haloperidol (Haldol) is a common antipsychotic drug that is used in hospital settings. 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 symptoms of Parkinson disease include prochlorperazine (Compazine), promethazine (Phenergan), and metoclopramide (Reglan). These medications have similar structures to the antipsychotics and should not be used. Trimethobenzamide (Tigan) and ondansetron (Zofran) are suitable alternatives that can be used without fear of worsening symptoms.

Regardless of the cause, all patients with Parkinson disease 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 you to bed rest. 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 Parkinson disease 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 Parkinson disease and became confused in the hospital last time he was there. How can I prevent this?

Many things happen in the hospital that can contribute to confusion. Any infection in a patient with Parkinson disease 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, especially pain medications, frequently results in disorientation and memory problems. Lack of sleep while in the hospital can also contribute to a confusional state. Continuous alarms from IV machines and hallway lights can all result in frequent awakening. Nurses also may regularly enter the room overnight to take vital signs, give medications, or check on a patient. In some patients, especially in the elderly with intermittent confusion at home, the mere 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. The combined effects of anesthesia and medications to treat surgical incision pain are contributing factors in this situation.

Confusion will often disappear once the underlying cause is treated, whether it is 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 use a sitter to promote safety. If there are 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 in patients with Parkinson disease.

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 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 in the hospital, and when the underlying cause is addressed, problems with confusion usually improve dramatically.

5.) I had deep brain stimulators (DBS) placed 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 Parkinson disease 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 things you and your doctors should be aware of. First, if you have had DBS surgery, you can only get an MRI of the brain, and it must be done with something called a head-receive coil. You cannot get an MRI of any other part of the body. This situation exists because the DBS device can become heated and damage the brain tissue during MRI. 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 getting 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 soon after you are discharged from the hospital to recheck your settings.

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.

The above tips and scenarios will hopefully aid in minimizing problems for patients with Parkinson disease who are hospitalized. Be aware that, for unclear reasons, some symptoms worsen following general or local anesthesia, and some patients have even reported feeling as if they never return to their baseline. In general, local anesthesia is thought to be safer than general anesthesia, and if you have problems with thinking and memory, they should be evaluated prior to surgery as they may also worsen.

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 the medical chart.

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



Information Checklist for Hospital Stays

General Points to be Aware of When Entering the Hospital:

- Provide a list of your medications with exact times, frequencies, and dosages. Be prepared to share your knowledge about Parkinson disease, including on-off fluctuations and the importance of taking medications at specific time intervals.
- Bring medication in original bottles.
- Know which drugs can worsen the symptoms of Parkinson disease.
- Research study participants should provide information explaining the experimental drugs and phone the study coordinator to let them know you are in the hospital.
- Speak up when medications are wearing off.
- Do not take medication on your own. Unless you have prearranged permission, the staff should administer all medication.
- Let the staff know if you have a deep brain stimulation (DBS) implant. Bring the access review or magnet device to turn the stimulator on and off for procedures.
- Contact your neurologist letting him/her know you are in the hospital and give the phone number of your neurologist to your doctor in the hospital.



Be mobile, especially during prolonged stays!

- Walk around as much as possible.
- Inquire about physical therapy or occupational therapy. Even passive range of motion exercises can help prevent contractures if you are not mobile.

If you have difficulty swallowing:

- Sit up while eating.
- Ask for a speech-swallowing therapist.
- Alert staff that your medications may need to be crushed and administered through a tube. Make sure medications are administered one hour prior to meals or feedings, especially if medications are crushed.
- There is a dissolvable form of carbidopa/levodopa called Parcopa® that can be given by placing on the tongue.

Know what factors may make your symptoms worse:

- Failing to get medications at specific times and coordinated with meals.
- Dopamine blocking drugs such as haloperidol (Haldol), risperidone (Risperdal) and olanzapine (Zyprexa) can worsen symptoms. If absolutely necessary because of hallucinations, behavior, or sleep, only quetiapine (Seroquel) or clozapine (Clozaril) should be used.
- Anxiety, stress, and sleep deprivation.
- Urinary tract, lung, or other infections (and antibiotics).

Provide Advance Directives:

Power of attorney for health care and living will. Choose an advocate who can ask questions and act as your spokesperson. Make sure this person is aware of your medical wishes so (s)he can assist in speaking for you if needed.

Information for Your Nurse and Doctor when You Enter the Hospital

Name of your Parkinson disease Neurologist: _____

Phone Number of your Parkinson disease Neurologist: _____

The following are some suggestions to make the hospitalization of this person with Parkinson disease smoother:

- Parkinson disease medications often need to be given at specific times of the day. Therefore, when writing medications in the orders, instead of writing TID or QID, please write specific times (e.g. q8AM, q11AM, etc.).
- Patients with Parkinson disease should resume medications immediately following procedures unless vomiting or severely incapacitated.
- If there is confusion, consider urinary or lung infections. Also consider pain medications or benzodiazepines as a potential cause.



- In cases of prolonged confusion, and an antipsychotic is necessary, quetiapine (Seroquel) and clozapine (Clozaril) are the best options. These two drugs minimally affect symptoms. Avoid using haloperidol (Haldol), risperidone (Risperdal), olanzapine (Zyprexa), aripiprazole (Abilify), and ziprasidone (Geodon).
- If the patient has nausea, please avoid the use of prochlorperazine (Compazine), promethazine (Phenergan), or metoclopramide (Reglan), as they can worsen symptoms. Trimethobenzamide (Tigan) and ondansetron (Zofran) are alternatives that can be used safely.
- Do not mix selegiline or rasagiline (MAO-B inhibitors) with meperidine (Demerol), as it can precipitate a serious reaction characterized by blood pressure fluctuations, respiratory depression, convulsions, malignant hyperthermia, and excitation.
- Do not stop carbidopa/levodopa (Sinemet) abruptly, as this can lead to neuroleptic malignant-like syndrome.
- If medications have to be crushed and administered through a tube, give them at least one hour prior to meals and be aware that CR formulations may not work as well. Protein in meals may interfere with the absorption of carbidopa/levodopa (Sinemet). There is a dissolvable form of carbidopa/levodopa called Parcopa® that may be useful in some patients.
- If you are having trouble getting an EKG, EEG, or using heart rate monitors, consider that the patient may have a deep brain stimulator. You may need to ask the patient or family member to turn the device off to avoid electrical interference. ■

