

Aware In Care Hospital Action Plan



 **Aware
in Care**

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Many of the world's leading medical institutions that treat Parkinson's disease are affiliated with the Parkinson's Foundation, and they are known collectively as Parkinson's Foundation Centers of Excellence. These institutions are setting new standards for quality care for people with Parkinson's, while also conducting cutting edge research and providing outreach services to individuals and families living with the disease. These esteemed institutions collaborated on two research papers that summarize best practices in caring for people with Parkinson's in the hospital:

- Kelvin Chou, MD, and others: Hospitalization in Parkinson Disease: A Survey of National Parkinson Foundation Centers (*Parkinsonism and Related Disorders*, 2011).
- Michael Aminoff, MD, and others: Management of the Hospitalized Patient with Parkinson's Disease: Current State of the Field and Need for Guidelines (*Parkinsonism and Related Disorders*, 2011).

The concept for the **Aware in Care** campaign was inspired by the **Get it On Time Campaign**, an awareness initiative undertaken by Parkinson's UK, the leading advocacy organization in the United Kingdom. We are grateful to the Parkinson's UK advocacy team for sharing insights and lessons learned to inform our efforts.

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Introduction

As you already know, getting diagnosed with Parkinson's disease is a life-changing experience. What you may not know is that people with Parkinson's disease are admitted to the hospital 50 percent more than their peers. And, once admitted, they typically have longer hospital stays.

Fortunately, there is a lot you can do to change that. When your Parkinson's is well controlled—you get your medication on time, you receive consistently good medical care and you are an active participant in your treatment team—you are more likely to stay well. This lowers your chance of being hospitalized and improves your ability to recover more quickly from illness or surgery.

To help you get the high-quality hospital care you deserve, the Parkinson's Foundation created a program called the **Aware in Care** campaign. This initiative is one of many that we have undertaken to help you gain control of your health. We believe that one of the first steps is education—including educating your doctors and nurses on how to take good care of you during a hospital stay.

This is your guide to prepare for both planned hospital visits and emergency treatment. The information in this kit is relevant even if your visit to the hospital is unrelated to your Parkinson's diagnosis. In addition, these materials are useful beyond hospital walls. Bring your kit with you for any in-patient stay, whether it is a rehabilitation, assisted living, skilled nursing or other care facility.

Included in this guide are useful tips on how to use your **Aware in Care** kit to get the right care at the right time. We hope this blueprint to better care will help you and your family on your Parkinson's journey. Read on to get started today.



10 Steps to Optimum Care

TAKE ACTION AT HOME

The best way to avoid medication-related problems and other complications during a hospital stay is to prepare beforehand. Here's what you can do.

Step 1: Line Up Help

Are your symptoms being treated optimally right now? To ensure you achieve the best symptom control, your Parkinson's care team should include a neurologist or movement disorders specialist, a primary care physician and a trusted pharmacist. It may be useful to consult with a mental health specialist, a speech pathologist, a social worker, or a neuropsychologist. Complementary

health practitioners also can be beneficial (yoga, massage therapy and acupuncture are examples of complementary therapies that may ease symptoms). A care partner—a close friend or family member you can count on to accompany you to the hospital and doctor appointments—should play a pivotal role on your Parkinson's care team, as well.

Step 2: Pack Your *Aware in Care* Kit



In addition to helping you understand how to get the best care possible in the hospital, your **Aware in Care** kit can be useful in helping you **prepare** for a hospital

stay. Take your kit with you every time you go to the hospital. But first, make sure your kit is complete by including these key items:

1 **Emergency Contact List.** Create a contact list that includes names, phone numbers, emails and addresses of your primary care physician, Parkinson's doctor, other specialists (if applicable), your care partner and close family members. Put a copy of the contact list in your **Aware in Care** kit. Review and update the list every six months.

2 **Parkinson's Medications.** Keep an extra supply of all your current medications in your **Aware in Care** kit. That way, if you have a medical emergency, you can pick up the bag and leave in a hurry, knowing you have everything you need. Make sure all medications are stored in their original bottles and your name is marked on each label. Then check that the dose written on the label matches what you are actually taking.

- **Medication Form.** During a hospital stay, nurses and doctors need to know all the medications you are taking and the exact times you are taking them. To help communicate this information in the most effective way, fill out the **Medication Form**. Write down all of your prescriptions and over-the-counter medications for Parkinson's and any other medical conditions. Then make five copies of the **Medication Form**, and put the original and the copies back in your **Aware in Care** kit. When your prescriptions change, be sure to fill out a new form, then make copies and replace the outdated ones in your kit.

ACTION PLAN

Step 1:

Assess your current situation. If you don't have all these people in place, sit down with your primary care physician and ask for a recommendation to a neurologist or other health professional who can help you better manage your symptoms. If you need a referral to a specialist in your area, please call the Parkinson's Foundation at **1-800-4PD-INFO (473-4636)**.



Step 2:

Make your kit complete by creating an emergency contact list, storing an extra supply of all your Parkinson's medication, completing the **Medication Form** and including a copy of your **Health Care Proxy Card**.

TAKE ACTION AT HOME (CONT.)

4 Health Care Proxy Card. No one wants to think about it, but if you become incapacitated and unable to express yourself, who do you want to carry out your wishes? Work with a lawyer to create a **Health Care Proxy Form** that complies with your

state guidelines to identify the individual(s) who is authorized to make medical decisions for you. Consider various scenarios such as end-of-life care and hospice. Keep a copy of your signed **Health Care Proxy Form** in your kit.

Step 3: Prepare for the Unexpected

Even the best-laid plan can be upset by life's unexpected events. That is why your kit includes two items that are meant to protect you in case of an emergency: a **Parkinson's Disease ID Bracelet** and a **Medical Alert Card**. By wearing your bracelet at all times and carrying your card in your wallet, you are safeguarding your health in the case of an emergency should you be unable to tell law enforcement or community or medical professionals that you have Parkinson's disease.

- **Wear your Parkinson's Disease ID Bracelet at all times.** The bracelet is hypo-allergenic, durable and designed to be worn continuously. The front of the bracelet alerts medical professionals to the fact that you have Parkinson's disease and also refers them to the wallet card for more information. The back of the bracelet has the toll-free Helpline number for the Parkinson's Foundation – 1-800-4PD-INFO (473-4636). Encourage hospital staff to call the number if they have questions about Parkinson's.

- **Fill out the Medical Alert Card.** This card includes vital information about treating people with Parkinson's disease, including medications that are not safe. Complete the back of the **Medical Alert Card**. Write down your name and the contact information for your doctor and care partner. Put the card in your wallet.
- **Share with your loved ones.** Let your care partner and family know that you are wearing the bracelet in case of an emergency. Also show them the **Medical Alert Card**. Then talk about the medications that are unsafe for people with Parkinson's so they understand what information they need to communicate to doctors and nurses if you are unable to speak for yourself.
- **Keep your Aware in Care kit handy.** Tell your care partner where you are storing the kit in case they need to get it for you in a hurry.

Step 4: Find a Good Hospital

Get to know the hospitals in your community before you need one. Map out where you will go if an emergency requires you to go to the hospital. It is your right as a patient to ask questions, so call ahead and ask:

- Do you have a neurologist available for patient consultation in the hospital?
- Do you stock a wide range of Parkinson's medications in the pharmacy?
- What is your rule on Parkinson's patients taking their own medications?
- How do you accommodate requests for medications at specific times during the day?
- How do you accommodate special dietary requests?
- Do you have staff trained in Parkinson's disease management?
- Do you provide outpatient care for Parkinson's patients?

ACTION PLAN

Step 3:

Put your **Parkinson's Disease ID Bracelet** on your wrist and your **Medical Alert Card** in your wallet. Keep your **Aware in Care** kit updated and in a location that is easy to access. Talk to your care partner and family about these safety measures which will protect you in case of an emergency.



Step 4:

Contact local hospitals and ask questions. Their answers can help you determine which hospital may provide you with good care.



WHEN YOU ARE IN THE HOSPITAL

Whether your hospital visit is planned or urgent, make sure these vital steps are never left out. Here is how to get the most from your care team.

Step 5: Be Vocal

The best way to help your healthcare team fully understand the importance of getting you your medications **on time, every time** is to be prepared. That means you and your care partner (or the person who is staying with you in the hospital) will need to be ready to share information about Parkinson's during each phase of your hospital stay.

Here is what you should do:

- Request a consultation with a neurologist. Provide the neurologist with a copy of your **Medication Form** and discuss your medical condition with him or her. Make sure the neurologist is consulted on all medication and treatment decisions during your entire hospital stay.
- Ask your Parkinson's doctor to contact the doctor in charge of your care in the hospital. He or she should provide the key facts about Parkinson's disease as well as detailed information about your medical condition and medications.
- Share your knowledge about Parkinson's disease with the nurse(s) and doctor(s) in charge of your care during your stay. Use the **"I Have Parkinson's Disease" Reminder Slips** in your kit to share vital information about your needs as a patient with Parkinson's. Each kit has 50 reminder slips, so there are plenty for you to tear off and pass out.
- Each time you are asked about the medications you take, provide a copy of the **Medication Form**. You may have to supply this information multiple times. Although this can be frustrating, it is critical that you hand each person that asks a complete list of your medications. Also explain to every new person you meet that you need your medications delivered **on time, every time** to control your Parkinson's symptoms.
- If you brought your medications with you in their original bottles to the hospital, let your nurses and doctors know. Ask if all of your medications are available in the hospital pharmacy. If not, find out what the hospital's policy is for using your own supply during your hospital stay. Some hospitals will allow this.
- Whenever you are asked to provide your **Medication Form**, ask the nurse or doctor to make a copy of the **Parkinson's Disease Fact Sheet** included in your kit. The fact sheet provides basic information about Parkinson's and may be useful to medical staff unfamiliar with the symptoms and the special

circumstances they need to take into account when treating a person with Parkinson's disease.

Step 6: Be Persistent

It can be difficult to let others know what you need, but it's critical to give clear direction upon your arrival. Talk with the nurses and doctors who are taking care of you in the hospital about your symptoms and how you feel. Say, for example, "My voice is low and I often lack facial expressions due to Parkinson's, but this doesn't mean I'm ignoring you or I don't understand." Or, "I need time to answer your questions." If you experience "on-off" fluctuations, explain that you may need help with basic tasks at times.

If the length of your hospital stay is longer than one day, you will probably encounter new staff each day. Assume that each person you meet has little experience with Parkinson's disease and likely does not understand your symptoms, the importance of getting you your medications **on time, every time** or the medications you should avoid.

The best way to share information is to present each member of your care team with an **"I Have Parkinson's Disease" Reminder Slip**.

ACTION PLAN

Step 5:

Request a consultation with a neurologist and make sure he or she is consulted on any medication or treatment decisions that occur while you are in the hospital. Ask your Parkinson's doctor to contact the doctor in charge of your care in the hospital. When you are asked about the medications you take, provide a copy of the **Medication Form** as well as the **Parkinson's Disease Fact Sheet**.

Talk to the nurses and doctors about your medication schedule and any prescriptions you brought from home. If you have difficulty communicating, ask your care partner to speak on your behalf. Verify that you will receive your prescription drugs as scheduled.



Step 6:

Be sure to keep your **I Have Parkinson's Disease Reminder Slips** nearby. Hand a slip to every member of your care team then talk about your symptoms and special needs. Ask for help if you feel no one is listening.

WHEN YOU ARE IN THE HOSPITAL (CONT.)

When you hand a reminder slip to a new person, you might say, "Hi, my name is _____, and I have Parkinson's disease. I want to share some of the key information about Parkinson's. Most important, I need my medications **on time, every time** to ensure my symptoms are well-controlled. I can answer any questions you might have, and there is a Parkinson's helpline you might want to call 1-800-4PD-INFO (473-4636). Thank you for your help."

Most people you meet will appreciate your efforts to share your knowledge about Parkinson's. However, if you feel your nurse or doctor isn't listening to you, it is important to take action. If you have trouble speaking, ask your care partner, friend or family member to speak up for you. Here are some ways to keep your care on track.

- **Ask to speak to the nurse in charge of the unit or floor.** Explain to him or her that you have Parkinson's. Share the information in your kit. Talk about your symptoms and how you feel.
- **Tell the nurses to come back 30 minutes after giving you your medication.** They might not understand how much the drugs affect your ability to move until they see it for themselves.
- **Call your Parkinson's doctor.** Tell him or her about your concerns and ask if he or she will call the doctor in charge of your care in the hospital.

- **Ask to see a patient advocate.** Many hospitals have a patient advocate or patient representative department. These professionals are available to help patients navigate the hospital system and to coordinate care when necessary.

On the other hand, many hospitals have programs in which they recognize and award staff members who provide outstanding patient care. Ask if your hospital has such a program, then share the name of the person you feel went above and beyond the call of duty to help you during your hospital stay.

Step 7: Get Moving

Soon after your medical procedure, it is vital that you get out of bed and start moving, if possible. Even if you are unable to get out of bed, there are exercises you can do that will help speed your recovery. The doctor who is treating you may recommend physical, occupational or speech therapy, depending on your symptoms and needs. During your stay, take the opportunity to have an experienced professional show you how to build your physical skills and strength. Ask your doctor if you qualify to receive physical therapy at home after you are discharged.

Find out what exercises you can do at home to continue to improve your condition. For more information about continuing

exercise and speech therapy after a hospital visit, please contact the Parkinson's Foundation's Helpline at 1-800-4PD-INFO (473-4636).

Step 8: Stay on Top of Your Care

It is essential to pay attention to the medications, treatments and tests you get throughout your stay. Never agree to any treatment that you are not certain about. Talk openly about any and all concerns. For example, if you have a deep brain stimulation device, make sure you let the doctors and nurses know. Before getting an MRI or any diagnostic test, tell your doctor, nurse and MRI technician that there are specific protocols that need to be followed.

Know which medications are safe: Many common medications for pain, nausea, anesthesia, depression, sleep and psychosis may not be safe for people with Parkinson's. Review the list at the end of this book. Before taking any medications, double check the list and if you have questions, ask to speak to your doctor.

Dietary considerations: Gastrointestinal, digestion and constipation issues are common in people with Parkinson's. For example, eating protein may impact medication absorption. Some people find that taking their Parkinson's medications an hour before mealtime is most effective. If you have issues with swallowing and drooling, request modifications to the food you receive and avoid foods that

ACTION PLAN

Step 7:

Start moving as soon as possible after your procedure. Find out if you qualify to receive physical therapy at home once you are discharged.



Step 8:

Monitor every step of your care. Know the basics about safe and unsafe medications for people with Parkinson's, especially if you are experiencing problems with pain, nausea, anesthesia, depression, sleep, or psychosis. If you have a deep brain stimulation device, ask your doctor to review the information on brain devices listed on your **Parkinson's Disease Fact Sheet**. Review your discharge instructions so you can discuss them with your primary care physician after you leave the hospital. Before you leave, remember to thank any members of the medical team who provided outstanding care.



WHEN YOU ARE IN THE HOSPITAL (CONT.)

contribute to drooling (such as sweets). Also, if you take medication for constipation at home, be sure to list this on your **Medication Form** so that you will continue to receive stool softeners while you are in the hospital.

Ask for a nutrition consultation if you have special dietary needs that impact the absorption of your medications. Tell the nutritionist what works best for you, and make

sure he or she communicates these special needs to the doctors and nurses who are caring for you.

Discharge plan and instructions: At the end of your stay, your doctor and nurse should provide you with a set of instructions to follow when you get home. Make sure you and your care partner understand the plan and never hesitate to ask questions if something is not clear.

WHEN YOU ARE BACK HOME

At home, the process of healing and recuperation continues.

Step 9: Follow Up and Provide Feedback

Contact your Parkinson's doctor and your primary care physician and give them a progress report. If possible, fax or mail them a copy of your discharge instructions. Find out what follow-up care you will need and what things you can do at home to help control and improve your condition. Based on your situation, ask whether you could benefit from medication, equipment or additional care such as physical therapy or home care, if these have not already been set up by the hospital.

Did you receive attentive care? If not, pick up the phone or send an email to the hospital's patient advocate or community relations department. Explain why you are dissatisfied with your hospital stay. Your effort will help point hospital staff in the right direction. If you had a good experience, write a letter praising the nurses, doctors and other staff members who cared for you in the hospital. Include how important it is to you, and the Parkinson's community, to receive proper care.

Step 10: Connect With Others in the Parkinson's Community

It is natural to be uneasy about facing challenges on your own. Both you and your care partner may benefit from community programs, social groups and other resources. Consider the kind of support you will find most helpful. This may include complementary therapies such as yoga and massage, mental health counseling or spiritual guidance.



ACTION PLAN

Step 9:

Make sure both your Parkinson's doctor and primary physician get a full report. Discuss next steps with your physicians. Contact the hospital and let them know about the quality of care they provided during your hospital stay.



Step 10:

Turn to people who can help you. Contact local and online support groups as well as hospitals for more information on classes and resources for people with Parkinson's disease. Call the Parkinson's Foundation at 1-800-4PD-INFO (473-4636) for assistance with local referrals.

Checklist for a Planned Hospital Stay

BEFORE YOUR HOSPITAL STAY

Before you have surgery or undergo any procedure, here's what you should do:

- **Notify your healthcare team.** Contact your Parkinson's doctor and let him or her know about your scheduled hospital visit. Ask your Parkinson's doctor to contact the specialist or surgeon who is performing the procedure prior to your scheduled hospital stay to share pertinent information about Parkinson's disease and any other medical conditions.

- **Share important information.** Schedule a meeting with your surgeon or specialist prior to your hospital visit and take time to review your Parkinson's symptoms and medications as well as any other conditions you may have. Ask your doctor to make copies of your **Medication Form** and the **Parkinson's Disease Fact Sheet**. Discuss the medications that are not safe for people with Parkinson's disease.
 - If you are ordered to stop taking certain drugs before surgery, be sure to find out exactly when to resume taking them.
 - Provide the name and number of your Parkinson's doctor, and request that the surgeon or specialist contact them.

- **Ask these key questions before surgery or any major treatment or procedure:**
 - Are my medications stocked in the hospital pharmacy? If not, will you allow me to bring my medications into the hospital?
 - Will I require anesthesia for my procedure? If so, ask your Parkinson's doctor to consult with your surgeon/specialist and the anesthesiologist who will be assisting with the procedure. Many people with Parkinson's have serious complications from anesthesia, and it is important that these conversations take place prior to the procedure taking place (for example, MAO-B inhibitors may interact with anesthesia).
 - What if I can't swallow my medications after surgery? Explain that medications may need to be crushed and administered by a stomach tube or in dissolvable form (Parcopa); carbidopa-levodopa should be ordered and administered in a way that ensures absorption. Make sure any changes are discussed with your Parkinson's doctor and your surgeon/specialist prior to surgery or other procedures. In some cases injectable apomorphine can be used.

- Will physical therapy be a part of my recovery? If so, ask if there is a physical therapist with experience working with people with Parkinson's disease or other movement disorders.

□ **Prepare your medications.** Before you leave for the hospital, gather a 48-hour supply (or more when appropriate) of all your medications. They should be stored in their original bottles and clearly labeled with your name and the dosing schedule. Use your **Aware in Care** kit to carry your medicines to the hospital.

DURING YOUR HOSPITAL STAY

Once you are admitted, here is what you should do:

□ **Request a consultation with the hospital's neurologist.** Provide the neurologist with a copy of your **Medication Form** and discuss your medical condition with him or her. Make sure the neurologist is consulted on all medication and treatment decisions during your entire hospital visit even if you are hospitalized for a non-neurological reason.

□ **Discuss your medication schedule.** As soon as you're admitted, set up a visit with the nurse overseeing your care. Explain why it is critical for you to get your medications **on time, every time**. Use your **Aware in Care Magnet** to post a copy of your **Medication Form** on the white board in the hospital so your medication schedule is clearly visible. Be prepared to remind staff when your drugs are due. You can bring an alarm clock or a timer with you to help keep track of time.

□ **Ask about medication management.** Find out how your medicines will be managed. Each hospital has a different policy on drug administration. If the hospital pharmacy doesn't stock your prescription medications, ask if you can supply your own.

□ **Introduce yourself.** When you meet a new member of your care team, introduce yourself and say, "My name is ____ and I have Parkinson's." Give that person one of your **"I Have Parkinson's Disease" Reminder Slips** and share your chief symptoms. Remember to say this even if the reason you are hospitalized is unrelated to your Parkinson's diagnosis.

□ **Ask questions before taking any new medications.** Before accepting any new medications, review the safe/unsafe medications list at the end of this booklet. Never be afraid to ask questions or to share the list of unsafe medications with the nurses and doctors in the hospital.

□ **Get an explanation.** If a staff member will not allow you the chance to provide important information about your medication timing or symptoms, request that the medical staff contact your neurologist or personal physician.

DURING YOUR HOSPITAL STAY (CONT.)

- **Request physical therapy evaluation and treatment.** Soon after your medical procedure, it is vital that you get out of bed and start moving, if possible. Ask the doctor who is treating you to recommend physical, occupational or speech therapy, depending on your symptoms and needs.
- **Call for help.** If you are having trouble swallowing, ask for a nutrition consult and a swallow study. There are dietary modifications that can be made to help you. If you feel confused or your loved ones notice changes in your behavior, share this information with your doctor and nurse. Make sure your healthcare team knows that confusion and disorientation are commonly caused by multiple drugs, and that these side effects are more common in people with Parkinson's.



Checklist for an Emergency Situation

ADVANCED PREPARATION

Before an emergency can happen, here is what you should do to prepare:

- **Devise an emergency plan.** Gather your care partner and close family and friends and draft an emergency plan. Go over key procedures such as how to use the **Aware in Care** kit and where you will store your second set of Parkinson's medications. Make sure everyone knows who will accompany you to the hospital, where you keep the kit and who will bring it to the hospital.

AT THE HOSPITAL

Once you are admitted, here is what you should do:

- **Notify your Parkinson's doctor.** Ask him or her to contact the medical staff in the ER as soon as possible to help coordinate your care.
- **Bring your Aware in Care kit.** Ask your care partner or a family member or friend to bring the kit to the hospital as soon as possible. Keep an extra supply of all your medications in your **Aware in Care** kit, or leave them in a convenient place at home. That way, you or your care partner will be able to get to them in case of an emergency. Remember, you should always have a 48-hour supply (or more when appropriate) of your medicines, and they should be stored in their original bottles, clearly labeled with your name and the dosage.
- **Have someone stay with you in the emergency room.** Your care partner, a family member or friend can make a critical difference during a medical emergency by relaying important information about your Parkinson's symptoms and medication schedule. If you are able, tell the emergency room staff that you have Parkinson's, and provide them with a copy of your **Medication Form** and **Parkinson's Disease Fact Sheet**. This is important to do even if you are in the ER for a condition unrelated to your Parkinson's diagnosis.

Special Considerations



I have a deep brain stimulation device.

Some people with Parkinson's disease

have a deep brain stimulation (DBS) device that helps to control symptoms. A deep brain stimulator is a surgically implanted, battery-operated neurostimulator and includes a pacemaker located in the chest region with a wire leading to the brain.

Share this with your doctor

If you have a deep brain stimulation (DBS) device:

MRI Warning

- MRI should not be performed unless the hospital has MRI experience imaging a DBS device safely.
- MRI should never be performed if the pacemaker is placed anywhere other than the chest or abdomen.
- Under certain conditions, some DBS devices are safe for full-body MRI and do not need to be turned off. In other cases, devices should be turned to 0.0 volts and MRI should not be used to image structures of the body lower than the head, as dangerous heating of the lead could occur.
- Always check with your DBS team before having an MRI to make sure the procedure will be safe for you.

EKG and EEG Warning

- Turn off the DBS device before conducting EKG or EEG.
- Diathermy should be avoided.



I have trouble swallowing.

Problems with swallowing

(dysphagia) are common in people with Parkinson's. If you have trouble swallowing, it is important to share this information with hospital staff as early as possible. Here are some important tips:

- Sit up while eating.
- Tuck in your chin each time you swallow.
- Ask for a speech-swallowing therapist if you are having problems swallowing. Make sure you are evaluated when you are in your medication "on" state.
- Ask the therapist to make necessary dietary changes so the food you are eating is easier to swallow.
- 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 feeding, especially if medications are crushed.
- Another option is to use the dissolvable form of carbidopa-levodopa called Parcopa, which can be given by placing on the tongue.
- Make sure any changes of this nature are discussed with your Parkinson's doctor prior to surgery.



I have special dietary needs.

Gastrointestinal, digestion and

constipation issues are common in people with Parkinson's disease.

- Eating protein may impact medication absorption.
- Ask for a nutrition consultation if you have special dietary needs that impact the absorption of your medications.
- Watch out for dehydration. Ask for a large, sturdy cup or glass to make drinking fluids easier.
- Some foods, such as sweets, cause drooling for people with Parkinson's. This can make speech and swallowing more difficult. Ask the nutritionist to guide your food selection or call 1-800-4PD-INFO (473-4636) for more information.



I am dizzy or feel faint.

Low blood pressure (hypotension) is

common in people with Parkinson's and may cause dizzy or fainting spells.

- If you feel dizzy or have issues with fainting, tell the doctor or nurse immediately.



I have balance issues.

Balance issues also are common in people with Parkinson's.

- Make sure you tell medical staff that you have balance issues or that you fall often.
- Ask medical staff to help you get out of bed, move around the room, go to the bathroom or exercise.
- Ask for physical therapy in your hospital room if you have any of the above problems.



I feel disoriented or confused.

Many people with Parkinson's feel

disoriented or confused in the hospital. If you feel this way, share the following list of likely causes with your doctor:

- Urinary tract infection or pneumonia.
- Infections can worsen confusion.
- Pain medications can worsen confusion and cause constipation.
- Confusion accompanied by psychosis sometimes requires a simpler medication regimen and/or the addition of "safe" antipsychotic medications such as pimavanserin (Nuplazid), quetiapine (Seroquel) or clozapine (Clozaril).

Medications That May Be Contraindicated in Parkinson's Disease

Medical Purpose:	Safe Medications:	Medications to Avoid:
Antipsychotics	pimavanserin (Nuplazid, FDA approved to treat Parkinson's disease psychosis), quetiapine (Seroquel), clozapine (Clozaril)	avoid all other typical and atypical antipsychotics
Pain Medication	most are safe to use, but narcotic medications may cause confusion/psychosis and constipation	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid meperidine (Demerol)
Anesthesia	request a consult with the anesthesiologist, surgeon and Parkinson's doctor to determine best anesthesia given your Parkinson's symptoms and medications	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid: meperidine (Demerol), tramadol (Rybitz, Ryzolt, Ultram), droperidol (Inapsine), methadone (Dolophine, Methadose), propoxyphene (Darvon, PP-Cap), cyclobenzaprine (Amrix, Fexmid, Flexeril), halothane (Fluothane)
Nausea / GI Drugs	domperidone (Motilium), trimethobenzamide (Tigan), ondansetron (Zofran), dolasetron (Anzemet), granisetron (Kytril)	prochlormethazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan), droperidol (Inapsine)
Antidepressants	fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil), citalopram (Celexa), escitalopram (Lexapro), venlafaxine (Effexor)	amoxapine (Asendin)



Aware in Care

Parkinson's Foundation

The Parkinson Foundation's *Aware In Care* campaign aims to help people with Parkinson's get the best care possible during a hospital stay.

For more information please visit [Parkinson.org/awareincare](https://www.parkinson.org/awareincare) or call 1-800-4PD-INFO.