



Hospital Safety Guide

Your Step-by-Step Resource for Better Parkinson's Care in the Hospital



About This Guide

Based on the Parkinson's Foundation Hospital Care Recommendations, this guide is designed for people with Parkinson's disease (PD), their care partners and loved ones to prepare for and navigate a hospital stay.

This guide is designed to help you:

- Understand the risks people with PD face in the hospital.
- Prepare to play an active role in the hospital before a crisis occurs.
- Organize care information to use in the hospital, whether it is a planned or emergency visit.
- Reference step-by-step instructions in real time to get your PD needs met.

The Parkinson's Foundation is here to help. As you and your loved ones review this guide, direct any questions to our Helpline information specialists. Call 1-800-4PD-INFO (1-800-473-4636) or email Helpline@Parkinson.org.

Acknowledgements

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The Importance of Hospital Safety for People with PD

People with Parkinson's disease (PD) are at a higher risk of hospitalization and face many challenges while in the hospital. It is important for all people with PD to be aware of the risks, prepare ahead of time and know how to advocate for their needs while in the hospital.

This year alone, **4 of every 12 people with Parkinson's** will be hospitalized.









3 of the **4** will not get the right medicine on time.

2 of the **3** will have complications as a result.







The Symptom Spiral

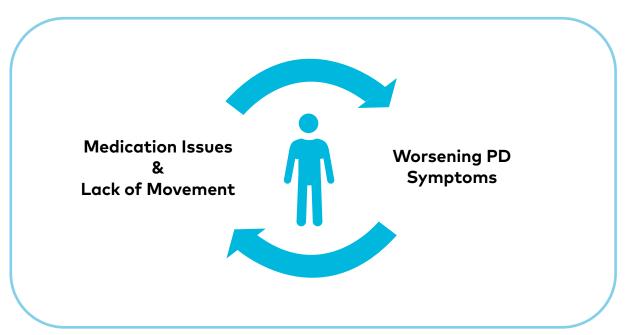
For most people, being in the hospital is a stressful experience. People are usually sick or experiencing some kind of a health crisis. For people with PD, symptoms may get worse, and new symptoms, like confusion or thinking changes, can develop because of stress, infection, fatigue, sleep disturbances, surgery or new medications.

Already a delicate balance, PD symptom management can be even trickier in the hospital because of the following:

- People often do not get enough movement opportunities.
- Parkinson's medications may not be given following the at-home schedule.
- Medications that worsen PD are sometimes prescribed.
- Medication doses may be delayed or missed.

These issues can lead to additional complications and set up a vicious cycle that puts you at risk for falls, swallowing changes, muscle deterioration, medication side effects, mental and physical decline or decreased independence. This is known as The Symptom Spiral.

The Symptom Spiral



Your Step-by-Step Hospital Planner

A hospital stay — whether planned or unplanned — can be especially challenging for people living with Parkinson's disease (PD). Hospital staff may not be experienced with PD. This means you and your care partner will likely need to play an active role in advocating for your Parkinson's needs. Use this planner to be prepared ahead of time.

Preparing for a Hospital Stay Check off each item as you complete it.	✓
Carry Parkinson's identification in case of an emergency. Use the Medical Alert Card at the back of this book or purchase a medical alert bracelet. You can also use the Medical ID feature on your smartphone.	
 Prepare a hospital "go bag." Gather these items: Your Parkinson's Foundation Hospital Safety Guide Completed Medication Form, signed Doctor's Letter (page 24) Current medications in labeled pharmacy bottles (2+day supply) Completed Advance Directives (page 8) Your DBS remote, if applicable 	
Keep your "go bag" by the door. Take it with you when you go and let family and friends know where to find it in case you need to go to the hospital unexpectedly.	
Choose a hospital care partner to accompany you in the hospital. Learn more about how to pick a hospital care partner and how to prepare that person to advocate for you in the hospital on page 8.	
Grab your "go bag" with completed forms and medication bottles Ask someone reliable to bring any forgotten items to the hospital.	

Once You Arrive at the Hospital Check off each item as you complete it.	✓
 Speak up. Each unit will focus on what brought you there. Plan to communicate the urgency of your Parkinson's needs. Share the Parkinson's Care Summary (page 31). Remind staff you have PD before each procedure or surgery and if new medications are prescribed. Let your care team know if you have a DBS or Duopa device. Contact your PD doctor. Let your doctor know why you are in the hospital and ask about the best way to reach out for extra support if pended.	
Stick to your regular medication schedule. Delayed medications can lead to severe complications.	
 Share your <u>Medication Form</u> (pages 27-28) and explain the importance of receiving your medications within 15 minutes of your usual schedule. 	
 Ask to use your own supply if the pharmacy doesn't carry your medication, or you are waiting too long for your next dose. 	
Ask for referrals to other specialties, such as physical, occupational, speech/swallowing therapies, neurology or nutritional services. Each has a different role supporting your needs.	
Review the Real-Time Steps for getting your five Parkinson's care needs met throughout your hospital stay (pages 10-19).	

Preparing to Leave the Hospital

Make sure you understand and agree with the discharge plan. Ask questions if anything is not clear.

- If you are going **home without home care**, talk to the hospital social worker about supportive resources.
- If your discharge plan includes one of the following, use your Hospital Safety Guide to continue advocating for your PD needs.
 - **Home with home care** care professionals come to your house to provide recovery assistance.
 - **Short-term inpatient rehabilitation** you will receive care at a rehabilitation facility or hospital until it is safe to go home.
 - **Long-term care** you will go to a care community, such as an assisted living or skilled nursing facility for the care you need.

Meet the Hospital Care Team

Hospitals have a team of nurses, doctors, specialists and consultants who work together to address your care needs and help your recovery. Knowing each member's role can help you ask for referrals when you need extra support.

Main/Primary Nurse

Gives medications, monitors and provides care.

Charge Nurse

Supervises the nursing team and may address treatment concerns.

Hospital Doctor (Hospitalist)

Leads the care team and makes decisions about treatment.

Pharmacist

Reviews and fills medication orders and consults on medication safety.

Social Worker/Case Manager

Provides support, information, education and discharge planning.

Patient Representative/Advocate

Handles concerns and complaints from patients and loved ones.

Speech-Language Pathologist (Speech Therapist)

Evaluates and treats speech and swallowing issues and can provide communication strategies.

Registered Dietitian

Can make an individualized diet plan to help support your nutritional needs.

Occupational Therapist

Evaluates and develops a treatment plan to improve daily activity skills like eating, dressing and using the bathroom.

Physical Therapist

Evaluates and develops a treatment plan to improve strength, coordination and movement.

If you have trouble communicating your needs or have a care concern...

- Discuss your concern with your primary nurse.
- 2. Involve the charge nurse.
- 3. Ask to meet with the hospital doctor, who may consult with the hospital neurologist or pharmacist or contact your Parkinson's doctor.
- 4. If needed, ask that your concern be noted in your chart and speak with the Patient Representative/Advocate.



Tips for Communicating and Collaborating with Your Hospital Care Team

- Assume your care team is doing the best they can
 with the information and tools they have. Their goal
 is to help you get better and return home safely.
- Be honest, direct and respectful when communicating your needs.

The Role of Care Partners in the Hospital

Hospital stays can be stressful, especially with Parkinson's disease (PD), which often involves managing complex symptoms and timely medication schedules. While in the hospital, you may be unable to communicate as well as usual. Try to have someone you trust with you to listen to treatment instructions, make sure your medication schedule is being followed and help communicate your needs. **Don't wait for an emergency**; talk with family and friends as soon as possible to choose the best person for this role.

Be sure to think about all your options when selecting people to support and advocate for you in the hospital. If you have one, your primary care partner may be the obvious choice, but you could also include an adult child, a sibling or a close friend who understands you and your Parkinson's. You may also consider a professional advocate. Go to Aginglifecare.org for referrals.

The ideal hospital care partners:

- Understand your care needs and medication schedule.
- Can speak on your behalf if needed.
- Are assertive and respectful when communicating your needs.
- Can stay at the hospital to support you as much as possible.
- Remain calm in stressful situations.

Setting Your Hospital Care Partner Up for Success

For your care partner to successfully support and advocate for you in the hospital, be sure to sign any required documents in advance to ensure they can speak on your behalf.

Advance Directives are legal documents that contain your medical care preferences in case you are unable to communicate your wishes.

- A HIPAA Waiver is a legal document that will allow your hospital care partner to access your medical information. Learn more and start the process at Parkinson.org/AdvancedCarePlan.
- A Medical Power of Attorney is a legal form prepared by an attorney in advance
 of a health crisis. It allows you to appoint an agent, also called a healthcare
 representative or surrogate, to access your medical records, speak to healthcare
 professionals about your care and make medical decisions on your behalf if you
 are unable to do so. Often the healthcare representative is your spouse or a family
 member someone you trust and who is reachable in an emergency.

Communicating Your Parkinson's Care Needs

Hospitals provide all levels of care — from same-day procedures to emergency, life-saving treatment. Your hospital care team will focus on the health condition that brought you in, which may be unrelated to Parkinson's disease (PD).

Hospital staff may not be familiar enough with PD to understand your symptoms, know why they change or realize they can worsen if you do not receive your Parkinson's medications on time. Lack of understanding the importance of timely, accurate PD medications can result in life-threatening complications.

Preparation and clear communication can help you minimize complications and recovery time. The Parkinson's Foundation along with key members of the PD community developed standards to guide clinicians in providing quality care to people with PD in the hospital. We adapted these standards to the below Five Parkinson's Care Needs to help you and your care partner communicate during a hospital visit.

My Five Parkinson's Care Needs



NEED 1: I need my hospital chart to include my exact medications and match my at-home schedule.



NEED 2: I need to take my Parkinson's medications within 15 minutes of my usual schedule.



NEED 3: I need to avoid medications that make my Parkinson's worse. These medications include those that block dopamine, sedatives and certain pain medications.



NEED 4: I need to move my body as safely and regularly as possible, ideally three times a day.



NEED 5: I need to be screened for swallowing changes to safely maintain my medication routine and minimize my risk of aspiration pneumonia and weight loss.



NEED 1:

I need my hospital chart to include my exact medications and match my at-home schedule.

Why is this important?

People with Parkinson's typically take different medications at specific times throughout the day (and sometimes at night) to function at their best. As PD progresses, medication routines often become more complex. For example, a person with PD may go from taking medication twice a day to taking it every two hours to maintain consistent dopamine levels in the brain.

REAL-TIME STEPS

Share Important Forms

- Give important documents (page 24) to staff, including:
 - Parkinson's Care Summary
 - Doctor's Letter
 - Medication Form
- **Review Medications & Timing** Verbally review your hospital medication list and schedule with the hospital care team. You can also request a printout.
- Offer Home PD Prescriptions If the pharmacy does not stock one of your medications, ask if you can provide your own supply in the original bottles.

If you are having trouble getting your medications listed correctly, review pages 6-7 for next steps.

CHALLENGES

- Hospitals often follow standardized medication schedules to ensure timely administration for most patients. Special care is needed to prevent these schedules from replacing your unique medication schedule.
- If the hospital pharmacy does not carry your specific medication, the pharmacist may try to make a substitution. A different type or dose of the same medication may not provide enough symptom relief or may increase your side effects.



Understanding Hospital Medication Schedules

Make sure the hospital records your exact medication times rather than the number of times per day you take them. Otherwise, the hospital will follow *their* schedule instead of *yours*. See below for how much the hospital schedule could vary from your own:

Sample Home	Standard Hospital		
Schedule:	4x/Day Schedule:		
8 a.m.	6 a.m.		
noon	noon		
4 p.m.	6 p.m.		
8 p.m.	midnight		



My husband was hospitalized for two weeks for a broken hip following a fall. It was extremely difficult to get his same PD meds and doses since prescriptions from home were not permitted. Once we got the correct prescriptions, receiving them on his home schedule was also a challenge. I had to speak with each new shift nurse every day to confirm what meds were to be given and their scheduled timing. A sheet noting his meds and their schedule was provided to nursing staff, who ultimately added it to my husband's chart.

- Tamara, care partner



NEED 2:

I need to take my Parkinson's medications within 15 minutes of my usual schedule.

Why is this important?

Parkinson's symptoms return when dopamine-replacing medications "wear off" in between doses. Depending on the individual, even small changes to medication timing can worsen symptom control and slow recovery. Delayed or missed doses can lead to falls, difficulty participating in rehabilitation and being less prepared to go home after leaving the hospital.

REAL-TIME STEPS

- **Explain the Impact**
 - Describe your symptoms and how they are affected when you do not receive medication on time, every time.
- Offer Reminders Let the nurse know when it's almost time for your medication.
- Follow Up Reconfirm your medication schedule with your nurse and share the following documents (page 24) again if necessary:
 - Parkinson's Care Summary
 - Doctor's Letter
 - Medication Form

If you are having trouble getting your medications on time, review pages 6-7 for next steps.

CHALLENGES

- Many hospitals allow nurses to give medications up to an hour before or after the scheduled time. Taking your PD medication more than 15 minutes before or after your scheduled time may affect your ability to move and function.
- The hospital is a busy place. Between members of your care team checking on you, rehabilitation, and diagnostic testing or surgical procedures, taking your medications on time may get a little bit trickier.

Understanding How to Prepare for Surgery

Scan the **QR code** to listen to a podcast in which a movement disorders specialist explains how to prepare for a routine outpatient procedure.

TIP: Schedule the procedure first thing in the morning or when your medications are working best to minimize medication schedule interruptions.



Read about more ways to prepare for a surgery on pages 20-21.



While in the hospital for a hip replacement, I went for an extended period of time without my meds despite our constant reminders. We had to follow up again and again! We learned that we have to be our own advocates and the Foundation's advice on how to prepare came in very handy.

- Bubba, person with Parkinson's



NEED 3:

I need to avoid medications that make my Parkinson's worse. These medications include those that block dopamine, sedatives and certain pain medications.

Why is this important?

Lack of dopamine in the brain is the primary cause of Parkinson's movement symptoms. Dopamine-blocking medications, such as antipsychotics like haloperidol (Haldol) and olanzapine (Zyprexa, Zyprexa Zydis), and anti-nausea medications like metoclopramide (Reglan) and prochlorperazine (Compazine), can worsen these symptoms and cause harmful side effects. Other medications commonly prescribed in the hospital may cause or increase confusion and sleepiness and result in falls.

REAL-TIME STEPS

Identify Harmful Medications

View the list of harmful medications on the Parkinson's Care Summary (page 31) with your hospital care team.

Review Possible Interactions Chack if any of your prescribes

Check if any of your prescribed medications are on the list of contraindicated medications (page 32). Watch out for medications prescribed before or after surgery, as well as those prescribed for confusion and behavioral changes.

Seek Appropriate Alternatives

If you are prescribed a medication not appropriate for a person with PD, ask for a safe alternative.

If you are having trouble getting a safe medication alternative, review pages 6-7 for next steps.

CHALLENGES

Some medications used in the hospital to treat nausea, confusion and psychosis (hallucinations and delusions) can worsen Parkinson's symptoms. Staff may be unfamiliar with safe PD medication alternatives.

Understanding Confusion in the Hospital

Medication side effects, infection, lack of sleep, an unfamiliar setting or a surgery can cause confusion. Sometimes this leads to behavioral changes, such as aggression, refusal to take pills or psychosis. If an antipsychotic is necessary, pimavanserin, clozapine or quetiapine are the only options recommended for people with PD.

These symptoms often disappear once the underlying cause is treated, whether by addressing an infection or reducing or eliminating certain medications. Please note, some PD medications need to be decreased slowly.



While hospitalized, I learned I was going to receive a shot of Abilify, an antipsychotic that can make PD symptoms worse. I called the Parkinson's Foundation Helpline and the information specialist was able to fax the Parkinson's Care Summary for Health Professionals to my doctor, who read that Abilify is contraindicated and then chose a more appropriate medication.

- Anonymous Helpline Caller, person with Parkinson's



NEED 4:

I need to move my body as safely and regularly as possible, ideally three times a day.

Why is this important?

Staying active in the hospital is key to maintaining abilities and recovering faster. Regular movement has many benefits, including reducing muscle loss, helping with sleep, improving focus and managing constipation.

For people with PD, regular movement — often coupled with physical and occupational therapy — is important for controlling PD symptoms, preventing falls and minimizing complications.

REAL-TIME STEPS

Communicate Your Needs

Share the Parkinson's Care Summary and the Doctor's Letter (page 24) with your hospital care team and point out that you need to move regularly to manage your PD symptoms. Describe your typical physical activity and ask for safe alternatives.

- Continue Safe Movement If safe, continue daily activities, such as dressing, walking to the bathroom, sitting in a chair for meals and taking short walks. If you can't get up, you may be able to exercise in bed or in a chair.
- Request Expert Help Ask for rehabilitation therapy (physical and occupational therapy) if you need help moving safely.

If you are having trouble getting a referral to physical or occupational therapy, review pages 6-7 for next steps.

CHALLENGES

- Nursing staff may not be aware of the important role Parkinson's medications have in helping people with PD move. They may also not know that lack of movement can worsen tremor, stiffness, balance and walking problems.
- Your care team may limit your movement to keep you safe, especially if you are weak after surgery, have low blood pressure or have other issues that put you at risk of falling. You also may require assistance to get out of bed, but sometimes nurses get busy, and hospital staff may not feel it is safe for family to help.



Your health condition could make it challenging to keep moving. If standing or walking are not safe, ask your care team if you can do seated or bed exercises. Here are some options they may recommend:

Arm Alphabet: With your arm straight out in front of you, write the alphabet or your name in the air as big as you can. Repeat with the other arm.

Ankle Circles: Kick your foot out in front of you and move your foot in slow circles. Repeat with the other foot.

Head Turns: Slowly rotate your head from left to right 5x making sure you feel a slight stretch on each side. Repeat right to left. Next, nod your head up and down 5x.

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My wife was in the hospital due to a constipation issue, a common symptom of Parkinson's. Once she was settled into her room she was asked if she was able to get up and walk on her own. She responded "Yes, with the help of a walker." A physical therapist came in to check her out and provided the walker. She was able get out of bed and walk on her own.

- Geri, care partner



NEED 5:

I need to be screened for swallowing changes to safely maintain my medication routine and minimize my risk of aspiration pneumonia and weight loss.

Why is this important?

Difficulty swallowing, called dysphagia, is common for people with Parkinson's. It can cause problems eating, drinking or taking pills. Dysphagia can lead to choking or aspiration pneumonia — an infection caused by food or liquid entering the lungs. Aspiration pneumonia is a common cause of death for people with PD.

A bedside swallow screening and consultation with a speech-language pathologist can identify issues early and provide safety measures to decrease risks.

REAL-TIME STEPS

Share Swallowing Issues

Tell staff if you have had problems swallowing in the past and ask for a speech-language pathology consultation.

Avoid Medication Pauses

Discuss safe ways to continue taking your medications with your nurse, such as with a sip of water or crushed with applesauce (page 22).

Minimize Risks

To decrease risk of aspiration pneumonia, eat when PD meds are working and you have energy. Sit up for meals. Take smaller bites. Brush your teeth, tongue and mouth before and after eating to reduce bacteria.

If you are having trouble getting a speech-language therapy consultation or finding safe ways to continue to take your medications, review pages 6-7 for next steps.

CHALLENGES

- People with PD may have undetected or minor swallowing issues that could worsen and create severe complications during a hospital stay. A swallowing screening and a speech-language pathologist evaluation can help identify dysphagia but may not be routinely ordered.
- To decrease choking or aspirating, staff may order "NPO" (nothing by mouth), meaning food, liquids and medications cannot be swallowed. If the medication is not given in another way, it may be stopped completely. Staff may not realize this could worsen your PD symptoms and swallowing issues, and lead to unintentional weight loss. Read more on page 23.



Aspiration is when something you swallow goes down the wrong way and enters your airways or lungs. Aspiration pneumonia is when bacteria from your mouth gets pulled down into the lungs and causes an infection.

Reducing the risk of aspiration pneumonia is a two-part process that involves not only preventing swallowing issues, but also reducing bacteria in your mouth by cleaning teeth and mouth regularly.

My friend had a medical emergency and had to go to the hospital. He usually takes Parcopa, but it wasn't available in the hospital pharmacy. I called the Parkinson's Foundation Helpline looking for another way he could get his meds. I was just wondering what other people do in this situation. The Helpline specialist suggested asking the nurse about crushing his medication and putting it in applesauce. I let his wife know about this option.

- Cathy, friend of a person with Parkinson's

Tips for Surgery

People with Parkinson's disease (PD) are more likely to take longer to recover after surgical procedures than other people their age. This is related to the following factors:

Surgery may interrupt the normal PD medication schedule, which can worsen Parkinson's symptoms.



Fasting or "NPO" (nothing by mouth) is often ordered prior to procedures requiring general anesthesia or sedation to prevent food or liquids accidentally going into the airways or lungs (called aspiration). Sometimes tests, such as blood work, may also require fasting to ensure accurate results.

- Anti-nausea, gastrointestinal and pain medications, which are routinely given before and after surgery, can worsen existing PD symptoms or cause new, temporary symptoms like delirium — a serious change in a person's mental state.
- Anesthesia or sedation, often used to prevent pain during surgical procedures, can impact people with health issues or advanced age more negatively than others.

For people with Parkinson's, shorter and lighter anesthesia typically causes fewer side effects. Work with your surgical team to find the right option for you.

- **Sedation** helps the person relax or fall asleep.
- **Local anesthesia** numbs just the surgery site.
- Regional anesthesia, such as an epidural, numbs a larger area of the body.
- General anesthesia keeps the person asleep and pain free during the procedure.

Preparing for Surgery

Review these recommendations before surgery and refer to them on surgery day.

- Meet with your surgical team before surgery to discuss:
 - How your symptoms might interfere with or be impacted by surgery.
 - Sticking to your PD medication schedule as much as possible.
 - Anesthesia options (see page 20).
 - Medications to avoid. For safe alternative see page 32.
- 2. Encourage your surgical team to consult with your Parkinson's doctor.
- 3. Confirm your exact medications are available in the hospital pharmacy. If not, ask to supply your own medications in their original bottles.
- **4.** Continue your PD medications up to your surgery whenever possible (see page 22). Ask to schedule surgery early in the morning to minimize gaps in your medication schedule.
- **5**. Ask if you can restart your PD medications directly after surgery in the recovery room — even before you are allowed to eat. Explain that getting back on your regular medication routine will help manage your PD symptoms and reduce recovery time.
- **6. Get moving as soon as possible.** Let your rehabilitation team know you have Parkinson's so they can consider your PD symptoms in the treatment plan.

Other Ways to Take Your Medication

You may need to temporarily stop eating and drinking if you have a serious swallowing issue (dysphagia) or are scheduled for a medical procedure that requires fasting. In both situations, ask to continue taking your Parkinson's medications with a small sip of water to avoid complications.

When swallowing issues are severe, crushing your pills or a different type of medication may be necessary for safety. Most immediate-release tablets can be crushed, but most extended-release tablets cannot.

Talk to the hospital pharmacist, speech-language pathologist and neurologist to explore medication alternatives, which may include one or more of the following:

- Immediate-release tablets, such as carbidopa/levodopa immediate release (Sinemet), can be crushed and either added to a thickened liquid like applesauce or given through a nasogastric (NG) tube (see blue box below).
- Carbidopa/levodopa extended-release (Rytary) capsules can be opened and sprinkled over applesauce.
- Rotigotine transdermal patch (Neupro), a dopamine agonist, doesn't require swallowing pills.
- Amantadine capsules can be opened and the contents mixed with water or soft food. An oral amantadine formulation is also available.

A nasogastric (NG) tube is a thin tube that goes in through your nose and down your throat into your stomach used for a temporary swallowing problem. It won't affect your ability to breathe or speak.

An NG tube can be used even if you have decided during advance care planning not to use a **feeding tube**, a more permanent surgical solution used to prolong life.

If you have been using any of the following non-oral medications, ask to use your home supply as prescribed if it is unavailable through the hospital pharmacy.

- Apomorphine subcutaneous injections (Apokyn)
- Levodopa inhalation powder (Inbrija) via inhaler
- Levodopa enteral suspension (Duopa) via surgically implanted tube between the stomach and small intestine

Tips to Minimize Unintended Weight Loss

It can be challenging to maintain your weight in the hospital if you are not feeling well, adjusting to new routines or experiencing medication side effects. Older adults and people with chronic illnesses, like Parkinson's disease (PD) are even more likely to struggle with weight loss and malnutrition during a hospital stay.

Some of the things that can make eating difficult for people with PD include:

- PD symptoms such as tremor, constipation, depression and anxiety
- PD medication issues, including delays, pauses or substitutions
- Medication side effects, such as nausea, reduced appetite, confusion or drowsiness
- Meal interruptions or unfamiliar foods
- Swallowing issues or fear of choking

Not eating enough can quickly lead to muscle loss, particularly for older adults, which can impact strength and mobility and increase the risk of falling. It can also cause skin to break down, slow healing and extend a hospital stay.

If you have nutrition or eating concerns, consider the following tips:

- 1. Discuss concerns about eating with your hospital care team.
 - A speech-language pathologist (SLP) can recommend a safe diet and provide swallowing rehabilitation.
 - A registered dietitian (RD) can make an individualized diet plan to help support your nutritional needs. RDs and SLPs often work together.
 - An occupational therapist (OT) can suggest tools, such as adaptive utensils and techniques to make eating easier.
- **2.** Work with your hospital care team to avoid medication delays, pauses and substitutions, which can worsen your PD and make eating more difficult.
- **3.** Alert hospital staff if you need help eating, drinking or opening food packaging. Family and friends might also be able to assist.
- **4. Tell your care team** if you have nausea or do not feel hungry. They can help figure out the cause.



Remember the importance of hydration. Ask your care team how much liquid you need and to help keep you on track. If you are fasting or have significant swallowing issues, alternative hydration options may be necessary.

Hospital Safety Forms Index

Use the following pages to share important details about your Parkinson's with your care team. In addition to copies of each form that remain in this guide, you will find tear-out forms that you can complete, remove and give to your care team during your hospitalization.

Additional copies of each of these forms can be printed at Parkinson.org/HospitalSafety.

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Personal Care Details

Use this section to keep track of information that is specific to you and your care. Many of these details may change over time. When that happens, we recommend you update the information and keep it folded (like a bookmark) so that it is easy to access.

Personal Contacts Medical Contacts Emergency Contact Primary Care Doctor Name: Name: Relationship: Relationship: Phone: Phone: Email: Email: Parkinson's Doctor Hospital Care Partner (page 8) Name: Name: Relationship: Relationship: Phone: Phone: Email: Email: Additional Personal Contact Additional Medical Contact Name: Name: Relationship: Relationship: Phone: Phone: Email: Email: Additional Personal Contact Additional Medical Contact Name: Name: Relationship: Relationship: Phone: Phone: Email: Email:



To print additional copies of the Personal Care Details page, visit Parkinson.org/HospitalSafety.

Device-Specific Needs

If you have received any surgical treatments, fill out this form and be sure to keep any device-specific information with this guide.

I have a DBS device.					
Surgery & Device Details					
Neurosurgery Center:					
Center Phone:					
Neurosurgeon:					
Date of Surgery:					
Product Name (IPG Model):					
Manufacturer Name:					
Manufacturer Phone:					
Lead Location: Right Brain Left Brain					
Battery Type: Rechargeable Non-rechargeable					
Battery Location: Right Chest Left Chest Other					
I use carbidopa/levodopa enteral suspension (Duopa).	I use carbidopa/levodopa enteral suspension (Duopa).				
Daily Dosage Schedule					
☐ Morning Dose Time:					
☐ Continuous Dose Time:					
☐ Extra Dose(s) Time:					

Using the Medication Form

Use the Medication Form to list all your medications for Parkinson's and other conditions, including over-the counter medications and supplements in the order that you take them each day. Your list should be clearly labeled with the dosage (usually mg or milligrams) and the specific time you take each medication.

Update your form any time your medications change — even slightly. You may also be able to print a list of your current medications from your patient portal. If not, ask your doctor to print these details at the end of each visit. Attach your completed, upto-date Medication Form and the printout from your doctor to your Doctor's Letter.

Sample Medication Form

Time	Medication	Dose	Notes
8 am	Carbidopa/levodopa immediate-release (IR) tablets (Sinemet)	25/250 mg	
8 am	Entacapone (Comtan)	200 mg	Must be taken with carbidopa-levodopa
8 am	Loratadine (Claritin)	10 mg	Not time specific but usually taken with morning PD meds
With breakfast	polyethylene glycol 3350 (MiraLax)	17 g	Mix with water or juice, drink with breakfast
12 pm	Carbidopa/levodopa IR tablets (Sinemet)	25/250 mg	
12 pm	Entacapone (Comtan)	200 mg	Must be taken with carbidopa-levodopa
4 pm	Carbidopa-levodopa IR tablets (Sinemet)	25/250 mg	
4 pm	Entacapone (Comtan)	200 mg	Must be taken with carbidopa-levodopa
8 pm	Carbidopa-levodopa IR tablets (Sinemet)	25/250 mg	
8 pm	Entacapone (Comtan)	200 mg	Must be taken with carbidopa-levodopa
As needed bedtime	Senna S Dual Action	50-8.6 mg	When constipated for 2 days
As needed	Levodopa inhalation powder (Inbrija)	42mg	Use up to 5 times/day for OFF time

Medication Form

(Tear-out forms on pages 33-40).

Complete this form and attach it to your signed Doctor's Letter. Give both to your hospital care team. Fill out a new form when your prescriptions change and keep an updated version in your Hospital Safety Guide. YOUR NAME DATE FORM FILLED **Important names and numbers** CARE PARTNER RELATIONSHIP PHONE PARKINSON'S DOCTOR PHONE PRIMARY CARE **DOCTOR** PHONE **PHARMACY** PHONE I was diagnosed with Parkinson's disease in (year). **Special Considerations** O I have a deep brain stimulation device. O I have balance issues. O I have trouble swallowing. O I have a Duopa pump. O I experience hallucinations or delusions as part O I have dementia. of my Parkinson's. O I get dizzy or feel faint. O I sometimes feel disoriented or confused. O I have special dietary needs. O Other: I also have the following conditions (list them below): Medication List (continued on back) List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements. See page 27 for an example and more information. TIME **MEDICATION**

Patient Name:	
Date of Birth:	(Tear-out forms on pages 41-42).

Doctor's Letter: Parkinson's Hospital Care Needs

Ask your Parkinson's doctor to sign this letter and to print and attach a co	urrent record of
your medication schedule with specific formulations and timing.	

Their symptoms are managed through an individualized medication regimen. Please see the attached medication schedule for specifics.

Below I've outlined five care priorities for this patient:

1. The patient needs their medication ordered in an individualized fashion, according to how they take them at home.

Dosing times and medication formulations are specific to each individual patient because of the complexity of the disease. Adherence to this regimen without substitutions is imperative to avoid unnecessary pain or other severe complications.

2. The patient needs to take their PD medications within 15 minutes of their at-home schedule.

If this is not possible, <u>please give the patient and/or their care partner authorization to self-administer medications while in the hospital</u>.

If surgery is necessary, please allow patient to take their PD medications as close to the time of surgery as possible, with a sip of water or crushed in applesauce, unless it is unsafe. They should resume their PD medication as soon after surgery as is safe.

3. The patient needs to avoid medications that make their Parkinson's worse, including dopamine-blocking medications, sedatives and certain medications for pain.

People with Parkinson's are more prone to pneumonias and infections, which can cause sudden changes in behavior and motor function, increasing their risk of serious complications.

Should delirium occur, <u>avoid haloperidol (Haldol) and most neuroleptics</u>. Instead, use pimavanserin (Nuplazid), Seroquel (quetiapine) and Clozaril (clozapine).

Prochlorperazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan) and droperidol (Inapsine) are contraindicated for use in Parkinson disease.

Should an antiemetic be required, Zofran (ondansetron) is a safe alternative. For additional contraindicated medications, refer to the Parkinson's Care Summary for Health Professionals.

4. The patient needs to move their body as safely and regularly as possible, ideally three times a day.

Bed rest should be used as a last resort. Consult with physical and occupational therapy to determine what is safe.

5. The patient needs to be screened for swallowing changes to minimize the risk of aspiration pneumonia and weight loss.

Avoid withholding medications whenever possible. Consult with speech-language pathology as needed.

The below strategies can also help reduce complications:

- People with PD are prone to constipation. A good bowel regimen can improve medication absorption.
- Should they require an NG tube, carbidopa/levodopa 25/100 immediate-release tablets can be crushed and administered via the tube.

Should you have additional questions or concerns, please don't hesitate to contact me.

Doctor's Signature: Doctor's Email:	Doctor's Printed Name:	Doctor's Phone Number:
	Doctor's Signature:	Doctor's Email:

This letter is part of the Parkinson's Foundation Hospital Safety Guide. For more information, go to Parkinson.org/HospitalSafety.

Parkinson's Care Summary for Health Professionals

Parkinson's disease (PD) is a complex, progressive neurological disorder characterized by a loss of dopamine-generating cells in the brain. PD is primarily known for movement symptoms, such as tremor, bradykinesia and rigidity/stiffness, but there are many other motor and non-motor symptoms, including:

- Freezing
- Lack of facial expression
- Low voice or muffled speech
- Instability and falls
- Dysphagia and drooling
- Dyskinesia (involuntary movements)
- Pain

- Mood changes
- Cognitive issues
- Constipation and incontinence
- Hallucinations and delusions
- Impulse control disorders
- Orthostatic hypotension
- Sleep disturbances

5 Parkinson's Care Considerations

People with PD have longer hospital stays, more secondary complications and complex care needs.

Customize All Medication Orders

Follow patient's at-home PD medication regimen. People with PD typically take multiple doses of medication at specific times throughout the day to manage symptoms. Different strengths and formulations of the same medication are often not interchangeable.

Prevent Medication Delays

Administer medications within ±15 minutes of at-home schedule. Delayed medications can make movement difficult, leading to falls, skin breakdown, incontinence, eating difficulties, emotional distress and inaccurate skilling of discharge needs.

Beware of symptoms of neuroleptic malignant syndrome (NMS), which can result from stopping levodopa abruptly. Resume medications immediately after procedures when safe.

Avoid Contraindicated Medications

Avoid medications that can worsen PD symptoms, including haloperidol (Haldol), prochlorperazine (Compazine) and metoclopramide (Reglan). See back for full list.

Prioritize Regular Movement

Ambulate as soon as medically safe. Physical activity is key to maintaining mobility and reducing fall risk for someone with PD. PT/OT consultation recommended.

Address Risk of Dysphagia and Aspiration

Avoid withholding medications whenever possible but be aware that swallowing issues are very common for people with PD and aspiration pneumonia is the leading cause of death. Swallow screening and SLP consultations recommended for safe medication strategies.

Safe & Contraindicated Medications

	Safe Medications	Medications to Avoid
Antipsychotics	Pimavanserin (Nuplazid) Quetiapine (Seroquel) Clozapine (Clozaril)	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics other than those identified in the safe column.
Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, anesthesiologist and surgeon to determine the best treatment plan whenever possible. Local or regional anesthesia generally have fewer side effects than general anesthesia for people with PD and should be used as an alternative when appropriate.	Beware of mixing MAO-B inhibitors with the following pain medications: • Meperidine (Demerol) • Tramadol (Rybix, Ryzolt, Ultram) • Droperidol (Inapsine) • Methadone (Dolophine, Methadose) • Propoxyphene (Darvon, PP-Cap) • Cyclobenzaprine (Amrix, Fexmid, Flexeril)
Gastrointestinal (GI) & Nausea Medications	 Domperidone (Motilium) Ondansetron (Zofran) Dolasetron (Anzemet) Granisetron (Kytril) Aprepitant (Emend) 	 Prochlorperazine (Compazine) Metoclopramide (Reglan) Promethazine (Phenergan) Droperidol (Inapsine) Olanzapine (Zyprexa)

Caution: Benzodiazepines, muscle relaxants, bladder control medications and other medications used for sleep and pain may lead to confusion, hallucinations, falls and other symptoms. Also, though most antidepressants are safe to use, amoxapine (Asendin) may lead to worsening movement symptoms for people with PD.

If a patient has a deep brain stimulation (DBS) device there are requirements for MRI scans, EKGs and EEGs.

Contact the device manufacturer or the patient's Parkinson's doctor for more information:

Abbott: 1-800-727-7846

Boston Scientific: 1-833-327-4636

Medtronic: 1-800-510-6735

If a patient has an existing Duopa device, clinicians should:

- Allow patients to bring in medication cassettes, which are often not part of the hospital formulary.
- Turn the device off, disconnect it and remove it from the room during imaging.

Go to Duopa.com or call 1-844-386-4968 to speak with registered nurses about the pump, tubing or medication cassettes.



Medication Form

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Safety Guide.				
YOUR NAME		DATE FOR	M FILLED	
Important names and nur	mbers			
CARE PARTNER	RELATI:	ONSHIP	PHONE	
PARKINSON'S DOCTOR			PHONE	
DOCTOR			PHONE	
PRIMARY CARE			DUONE	
DOCTOR			PHONE	
PHARMACY			PHONE	
I was diagnosed with Par	kinson's disease in	(year).		
Special Considerations				
O I have a deep brain stim	nulation device.	O I have balance	issues	
O I have a Duopa pump.	Torquiori device.	O I have trouble		
O I have dementia.			allucinations or delusions as part	
O I get dizzy or feel faint.		of my Parkinso	· ·	
O I have special dietary ne	eds.	O I sometimes feel disoriented or confused.		
		O Other:		
I also have the following o	conditions (list them be	low):		
Taise have the renewing	Jonaidions (iist tilein be			
Medication List (continue				
List all medications you a medications and supplem			s, including over-the-counter	
TIME	MEDICATION	DOSE	NOTES	
TIME	MEDICATION	DOSE	NOTES	

Medication List

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



To print additional copies of the Medication Form, visit <u>Parkinson.org/HospitalSafety</u>.

Medication Form

Complete this form and attach it to your signed Doctor's Letter. Give both to your hospital care team. Fill out a new form when your prescriptions change and keep an updated version in your Hospital Safety Guide. YOUR NAME DATE FORM FILLED Important names and numbers **CARE** PARTNER RELATIONSHIP PHONE **PARKINSON'S DOCTOR** PHONE **PRIMARY CARE DOCTOR** PHONE **PHARMACY** PHONE I was diagnosed with Parkinson's disease in _____ (year). **Special Considerations** O I have a deep brain stimulation device. O I have balance issues. O I have trouble swallowing. O I have a Duopa pump. O I have dementia. O I experience hallucinations or delusions as part of my Parkinson's. O I get dizzy or feel faint. O I sometimes feel disoriented or confused. O I have special dietary needs. O Other: I also have the following conditions (list them below): Medication List (continued on back) List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements. See page 27 for an example and more information. TIME **MEDICATION DOSE**

Medication List

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



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Medication Form

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Medication List

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



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Medication Form

Complete this form and att Fill out a new form when you Safety Guide.				to your hospital care team. Version in your Hospital
YOUR NAME		DATE FO	DRM FI	LLED
Important names and numb	ers			
CARE				
PARTNER	RELATION	ONSHIP		PHONE
PARKINSON'S DOCTOR				PHONE
DOCTOR				TTIONE
PRIMARY CARE				DUONE
DOCTOR				PHONE
PHARMACY				PHONE
				1110112
I was diagnosed with Parkir	nson's disease in	(year).		
Special Considerations				
O I have a deep brain stimul	ation device.	O I have balar		
O I have a Duopa pump.		O I have troub		-
O I have dementia.		O I experience of my Parkii		nations or delusions as part
O I get dizzy or feel faint.	٨٥	•		soriented or confused.
O I have special dietary need	15.	O Other:		
I also have the following co	nditions (list them be	low):		
Medication List (continued List all medications you are medications and supplemen	taking for Parkinson			
TIME	MEDICATION	DOSE		NOTES

Medication List

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



To print additional copies of the Medication Form, visit <u>Parkinson.org/HospitalSafety</u>.

Patient Name:	
Date of Birth:	

Doctor's Letter: Parkinson's Hospital Care Needs

Ask your Parkinson's doctor to sign this letter and to print and attach a current record of your medication schedule with specific formulations and timing.
lives with Parkinson's disease (PD). Their symptoms are managed through an individualized medication regimen. Please see the attached medication schedule for specifics.

Below I've outlined five care priorities for this patient:

1. The patient needs their medication ordered in an individualized fashion, according to how they take them at home.

Dosing times and medication formulations are specific to each individual patient because of the complexity of the disease. Adherence to this regimen without substitutions is imperative to avoid unnecessary pain or other severe complications.

2. The patient needs to take their PD medications within 15 minutes of their at-home schedule.

If this is not possible, <u>please give the patient and/or their care partner authorization to self-administer medications while in the hospital</u>.

If surgery is necessary, please allow patient to take their PD medications as close to the time of surgery as possible, with a sip of water or crushed in applesauce, unless it is unsafe. They should resume their PD medication as soon after surgery as is safe.

3. The patient needs to avoid medications that make their Parkinson's worse, including dopamine-blocking medications, sedatives and certain medications for pain.

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Should delirium occur, <u>avoid haloperidol (Haldol) and most neuroleptics</u>. Instead, use pimavanserin (Nuplazid), Seroquel (quetiapine) and Clozaril (clozapine).

Prochlorperazine (Compazine), metoclopramide (Reglan), promethazine (Phenergan) and droperidol (Inapsine) are contraindicated for use in Parkinson disease.

Should an antiemetic be required, Zofran (ondansetron) is a safe alternative. For additional contraindicated medications, refer to the Parkinson's Care Summary for Health Professionals.

4.	The patient needs to move their body as safely and regularly as possible, ideally three times a day.
Ве	ed rest should be used as a last resort. Consult with physical and occupational

therapy to determine what is safe.

5. The patient needs to be screened for swallowing changes to minimize the risk of aspiration pneumonia and weight loss.

Avoid withholding medications whenever possible. Consult with speech-language pathology as needed.

The below strategies can also help reduce complications:

- People with PD are prone to constipation. A good bowel regimen can improve medication absorption.
- Should they require an NG tube, carbidopa/levodopa 25/100 immediaterelease tablets can be crushed and administered via the tube.

Should you have additional questions or concerns, please don't hesitate to contact me.

Doctor's Printed Name:	Doctor's Phone Number:
Doctor's Signature:	Doctor's Email:

This letter is part of the Parkinson's Foundation Hospital Safety Guide. For more information, go to <u>Parkinson.org/HospitalSafety</u>.

Parkinson's disease (PD) is a complex, progressive neurological disorder characterized by a loss of dopamine-generating cells in the brain. PD is primarily known for movement symptoms, such as **tremor**, **bradykinesia and rigidity/stiffness**, but there are many other motor and non-motor symptoms, including:

- Freezing
- Lack of facial expression
- Low voice or muffled speech
- Instability and falls
- Dysphagia and drooling
- Dyskinesia (involuntary movements)
- Pain

- Mood changes
- Cognitive issues
- Constipation and incontinence
- Hallucinations and delusions
- Impulse control disorders
- Orthostatic hypotension
- Sleep disturbances

5 Parkinson's Care Considerations

People with PD have longer hospital stays, more secondary complications and complex care needs.

Customize All Medication Orders

Follow patient's at-home PD medication regimen. People with PD typically take multiple doses of medication at specific times throughout the day to manage symptoms. Different strengths and formulations of the same medication are often not interchangeable.

Prevent Medication Delays

Administer medications within ±15 minutes of at-home schedule. Delayed medications can make movement difficult, leading to falls, skin breakdown, incontinence, eating difficulties, emotional distress and inaccurate skilling of discharge needs.

Beware of symptoms of neuroleptic malignant syndrome (NMS), which can result from stopping levodopa abruptly.

Resume medications immediately after procedures when safe.

Avoid Contraindicated Medications

Avoid medications that can worsen PD symptoms, including haloperidol (Haldol), prochlorperazine (Compazine) and metoclopramide (Reglan). See back for full list.

Prioritize Regular Movement

Ambulate as soon as medically safe. Physical activity is key to maintaining mobility and reducing fall risk for someone with PD. **PT/OT consultation recommended.**

Address Risk of Dysphagia and Aspiration

	Safe Medications	Medications to Avoid
Antipsychotics	Pimavanserin (Nuplazid) Quetiapine (Seroquel) Clozapine (Clozaril)	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics other than those identified in the safe column.
Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, anesthesiologist and surgeon to determine the best treatment plan whenever possible. Local or regional anesthesia generally have fewer side effects than general anesthesia for people with PD and should be used as an alternative when appropriate.	Beware of mixing MAO-B inhibitors with the following pain medications: • Meperidine (Demerol) • Tramadol (Rybix, Ryzolt, Ultram) • Droperidol (Inapsine) • Methadone (Dolophine, Methadose) • Propoxyphene (Darvon, PP-Cap) • Cyclobenzaprine (Amrix, Fexmid, Flexeril)
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If a patient has a deep brain stimulation (DBS) device there are requirements for MRI scans, EKGs and EEGs.

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Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, anesthesiologist and surgeon to determine the best treatment plan whenever possible. Local or regional anesthesia generally have fewer side effects than general anesthesia for people with PD and should be used as an alternative when appropriate.	Beware of mixing MAO-B inhibitors with the following pain medications: • Meperidine (Demerol) • Tramadol (Rybix, Ryzolt, Ultram) • Droperidol (Inapsine) • Methadone (Dolophine, Methadose) • Propoxyphene (Darvon, PP-Cap) • Cyclobenzaprine (Amrix, Fexmid, Flexeril)
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Beware of symptoms of neuroleptic malignant syndrome (NMS), which can result from stopping levodopa abruptly. Resume medications immediately after procedures when safe.

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Using the Medical Alert Card

Fill in your card with emergency contact information, tear it out of this book and place it in your wallet. Download and print this card at Parkinson.org/ HospitalSafety or call our Helpline at 1-800-4PD-INFO (1-800-473-4636).

MEDICAL ALERT

I have PARKINSON'S DISEASE which could make me move slowly and have difficulty standing or speaking.

I AM NOT INTOXICATED.

Please call my family or physician for help.



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MYNAME		
HOME ADDRESS		
EMERGENCY CONTACT	PHONE	
PHYSICIAN	PHONE	
ALLERGIES/OTHER MEDICAL CONDITIONS		

Important Information to Communicate in an Emergency

- I have Parkinson's disease.
- I need my medications on time, every time. Otherwise, my Parkinson's symptoms may become severe and uncontrollable.
- Any Parkinson's medication changes need to be discussed with my doctor.
- Many common medications for pain, nausea, depression, sleep and psychosis are not safe for people. If an antipsychotic is necessary, use pimavanserin (Nuplazid), quetiapine (Seroquel) or clozapine (Clozaril).

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Safe & Contraindicated Medications in Parkinson's Disease

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Antipsychotics	
Pimavanserin (Nuplazid)Quetiapine (Seroquel)Clozapine (Clozaril)	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics other than those identified in the safe column.

Anesthesia & Pain Medication

Consult with the patient's PD doctor or hospital neurologist, anesthesiologist and surgeon to determine the best treatment plan whenever possible.

Local or regional anesthesia generally have fewer side effects than general anesthesia for people with PD and should

be used as an alternative when appropriate.

Beware of mixing MAO-B inhibitors with the following pain medications:

- Meperidine (Demerol)
- Tramadol (Rybix, Ryzolt, Ultram)
- Droperidol (Inapsine
- Methadone (Dolophine,
- Methadose)
- Propoxyphene (Darvon, PP-Cap)
- Cyclobenzaprine (Amrix, Fexmid, Flexeril)

Gastrointestinal (GI) & Nausea Medications

- Domperidone (Motilium)
- Ondansetron (Zofran)
- Dolasetron (Anzemet)
- Granisetron (Kytril) Aprepitant (Emend)
- Prochlorperazine (Compazine)
- Metoclopramide (Reglan)
- Promethazine (Phenergan)
- Droperidol (Inapsine)
- Olanzapine (Zyprexa)

Caution: Benzodiazepines, muscle relaxants, bladder control medications and other medications used for sleep and pain may lead to confusion, hallucinations, falls and other symptoms. Also, though most antidepressants are safe to use, amoxapine (Asendin) may lead to worsening movement symptoms for people with PD.

If a patient has a deep brain stimulation (DBS) device there are requirements for MRI scans, EKGs and EEGs.

Contact the device manufacturer or the patient's Parkinson's doctor for more information:

- Abbott: 1-800-727-7846
- Boston Scientific: 1-833-327-4636
- Medtronic: 800-510-6735

If a patient has an existing Duopa device, clinicians should:

Turn the device off, disconnect it and remove it from the room during imaging.

Go to Duopa.com or call 1-844-386-4968 to speak with registered nurses about the pump, tubing or medication cassettes.

About the Parkinson's Foundation

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure.

In everything we do, we build on the energy, experience and passion of our global Parkinson's community. A wealth of information about Parkinson's and about our activities and resources is available on our website, Parkinson.org.

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HELPLINE:

1.800.4PD.INFO (1.800.473.4636) helpline@parkinson.org



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