

## 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.



This guide is not a substitute for medical advice and may not cover all situations. Always work with your Parkinson's care team for the best care.

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.

#### **Parkinson's Foundation Resources**

Explore our books, fact sheets, webinars and podcasts in our PD library at **Parkinson.org/Library**.

#### **Acknowledgments**

This guide has been reviewed by Michael Okun, MD, National Medical Advisor for the Parkinson's Foundation, as well as Parkinson's specialists, hospital clinicians and members of the Parkinson's community.

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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

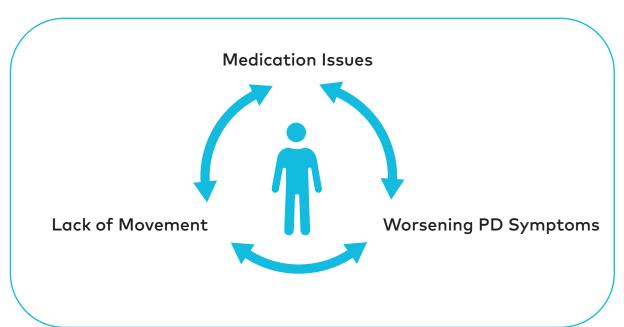
For most people, being in the hospital is a stressful experience. People are usually sick or experiencing a health crisis. For people with PD, symptoms may get worse, and new symptoms, like confusion or thinking changes, can develop because of stress, infection, fatigue, sleep disturbances, surgery or 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.	<b>✓</b>
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.  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.	<b>✓</b>
<ul> <li>Speak up. Each unit will focus on what brought you there. Plan to communicate the urgency of your Parkinson's needs.</li> <li>Share the Parkinson's Care Summary (page 31).</li> <li>Remind staff you have PD before each procedure or surgery and if new medications are prescribed.</li> <li>Let your care team know if you have device-specific needs.</li> </ul>	
<b>Contact your PD doctor.</b> Let your doctor know why you are in the hospital and ask about the best way to reach out for extra support if needed.	
<b>Stick to your regular medication schedule.</b> Delayed medications can lead to severe complications.	
<ul> <li>Share your Medication Form (pages 27-28) and explain the importance of receiving your medications within 15 minutes of your usual schedule.</li> </ul>	
<ul> <li>Ask to use your own supply if the pharmacy doesn't carry your medication, or you are waiting too long for your next dose.</li> </ul>	
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.	
<b>Review the Real-Time Steps</b> for getting your five Parkinson's care needs met throughout your hospital stay (pages 9-19).	

#### 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, teaches communication strategies and may screen for thinking changes.

#### 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 care needs. 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 in the Hospital

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. Understanding the importance of timely, accurate PD medications, can help avoid 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 manage symptoms.

#### **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 the medications and schedule listed in your hospital chart with the 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. For
  example, carbidopa/levodopa extended release (Rytary) is not interchangeable
  with other levodopa medications.



#### **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 person, even small changes to medication timing can worsen movement and non-movement symptoms 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. My wife and I had to follow up again and again! We learned that we have to be our own advocates. In the end, I was able to take the medications I brought from home.

- Bubba, person with Parkinson's





#### NEED 3:

I need to avoid medications that make my Parkinson's worse, including 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 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** 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 and changes in thinking or behavior can make Parkinson's symptoms worse. **Hospital staff might not always know which medications are safest for people with PD.** 

#### Understanding Delirium in the Hospital

Delirium is a temporary change in thinking or behavior that develops over hours or days. It is common in the hospital, especially after surgery, but can also occur during recovery at home. Older adults and people with PD are more likely to experience it. Factors such as infections, medication changes, poor sleep, dehydration and unfamiliar surroundings can trigger delirium.

What are the signs of delirium? Confusion, agitation, aggression, trouble focusing and psychosis, such as visual hallucinations (seeing things that are not there) and delusions (false beliefs).

**How is delirium treated?** Symptoms usually improve once the underlying cause is treated — such as managing an infection or adjusting medications. If medications are needed, the only approved antipsychotics for people with PD are pimavanserin, clozapine or quetiapine.

#### How can I minimize the risk of delirium in the hospital?

- · Avoid medications that are unsafe for PD.
- Take PD medications within 15 minutes of at-home schedule.
- Ensure the right dose, strength and form of PD medications are ordered.
- Stay hydrated (water, broth, Jello, etc.).
- Stick to a regular schedule for meals and rest.
- Bring familiar items from home to reduce confusion and stress.
- Keep the care team updated on any changes or concerns.

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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 provided the Parkinson's Care Summary for Health Professionals, which lists safe medication alternatives.

- 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 managing 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 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.

#### **Understanding Your Exercise Options**

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.



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.

- Jerry, 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.

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My friend had a medical emergency and had to go to the hospital. His swallowing worsened and he was told he couldn't continue taking pills. I called the Parkinson's Foundation Helpline looking for another way he could get his meds. 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

#### **Surgery Challenges**

Surgery can be difficult for anyone. Age, dementia, chronic conditions, like Parkinson's disease (PD), and other underlying health issues can increase recovery time after surgical procedures.

- 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. If medications are stopped, PD symptoms can worsen.



- 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. Learn more about delirium on page 15.
- Anesthesia or sedation, often used to prevent pain during surgical procedures, may cause confusion and increase recovery time — particularly for people with PD.

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.

#### Tips for 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.
- **b.** Plan to get moving as soon as possible. Let your rehabilitation team know you have PD so they can consider your symptoms in the treatment plan.
- 7. Take care of your body in the days leading up to surgery. Prioritize sleep, eat healthy foods and drink plenty of fluids. Follow any instructions about when to stop eating or drinking before surgery.

#### 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
- Foscarbidopa/foslevodopa (Vyalev) for subcutaneous infusion

#### 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.



Staying hydrated is important! Ask your care team how much liquid you need and for reminders. 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.

Print additional copies of each of these forms or fill them out online 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 or to complete the form online, 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 a device to deliver my medication.			
Device Details			
Medication Name:			
Manufacturer Name:			
Manufacturer Phone:			
Daily Dosage Schedule			
Be sure to list the continuous dose, any extra doses and the time range for taking them on the medication form (pages 33-40).			



To print additional copies of Device-Specific Needs, or to complete the form online, visit **Parkinson.org/HospitalSafety**.

#### **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 Entries

Time	Medication	Dose	Notes
8 am	Carbidopa/levodopa immediate-release (IR) tablets (Sinemet)	25/250 mg	
With breakfast	polyethylene glycol 3350 (MiraLax)	17 g	Mix with water or juice, drink with breakfast

#### PD Medications for Movement Symptoms

If you do not have a list of your medications handy, you can use the list below for reference.

Levodopa		Dopamine Agonists	
Carbidopa/levodopa imme	Ropinirole		
Carbidopa/levodopa contr	olled release	Pramipexole (Mirapex)	
Carbidopa/levodopa/entac	Carbidopa/levodopa/entacapone (Stalevo)		
Carbidopa/levodopa exten	(Neupro)		
Carbidopa/levodopa enter	<b>Apomorphine injection</b> (Apokyn)		
Foscarbidopa/foslevodopa			
infusion			
Levodopa inhalation powd	<b>er</b> (Inbrija)		
-	·		
COMT Inhibitors	MAO-B Inhibitors	Others	
(only prescribed with	Rasagiline (Azilect)	Amantadine immediate release	
levodopa medications)	Selegiline (L-deprenyl,	Amantadine extended release	
Entacapone (Comtan)	Eldepryl)	(Gocovri, Osmolex ER)	
Opicapone (Ongentys)	Selegiline oral disintegrating	Istradefylline (Nourianz)	
Tolcapone (Tasmar)	(Zelapar)		
	Safinamide (Xadago)		
	_		



## 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 guide.

YOUR NAME	D	ATE FORM F	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 disec	ise in	(year).	
Special Considerations			
O I have a deep brain stimulation device	e. O I hav	e balance iss	ues.
O I have a device to deliver my medicat	ion. O I hav	n. O I have trouble swallowing.	
O I have dementia.	-	O I experience hallucinations or delusions as pa	
O I get dizzy or feel faint.		of my Parkinson's. O I sometimes feel disoriented or confused.	
O I have special dietary needs.	O Othe		disoriented of comosed.
I also have the following conditions (lis	t them below):		
Medication List (continued on back)	Dandinaan <i>l</i> a and athan		
List all medications you are taking for medications and supplements. See page			•
TIME MEDICAT	ΓΙΟΝ	DOSE	NOTES



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 your medication schedule with specific formulations	,
Their symptoms are managed through an individua the attached medication schedule for specifics.	ves with Parkinson's disease (PD). Ilized medication regimen. Please see

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

1. The patient needs their medications 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. Some patients need to take their levodopa medication 30-60 minutes before meals to ensure absorption. 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) or Clozaril (clozapine).

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

Should an antiemetic be required, ondansetron (Zofran) 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, ide	eally
	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.

If you have additional questions or concerns, please 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, or to complete the form online, 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) After non-drug de-escalation or re-direction and addressing underlying causes: For acute agitation: A low dose of benzodiazepine may be needed. For hyperactive delirium: Stop unnecessary deliriogenic medications, consider quetiapine. Parenteral benzodiazepines may be needed for safety. Limit repeat use to avoid worsening confusion.	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics not listed in the "safe" column, such as olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify).	
Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, surgeon and anesthesiologist to determine best treatment plan.  Local or regional anesthesia usually 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 these pain medications:  • Morphine  • Hydrocodone +/- acetaminophen (Norco)  • Oxycodone +/- acetaminophen (Percocet)  • Fentanyl  • Tramadol (Ultram)  • Methadone  • Cyclobenzaprine (Flexeril)	
Gastrointestinal (GI) & Nausea Medications	<ul> <li>Ondansetron (Zofran)</li> <li>Dolasetron (Anzemet)</li> <li>Granisetron (Kytril)</li> <li>Aprepitant (Emend)</li> <li>Trimethobenzamide</li> </ul>	<ul> <li>Prochlorperazine (Compazine)</li> <li>Metoclopramide (Reglan)</li> <li>Promethazine (Phenergan)</li> <li>Droperidol (Inapsine)</li> </ul>	



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

#### PD Medications for Movement Symptoms

- Medications, even in the same class, are usually not interchangeable.
- Patients should be allowed to supply their own medications if not on formulary.
- Scan QR code or visit Parkinson.org/Medications for PD medication information.



#### If the patient has a deep brain stimulation (DBS) device or uses a medication device:

- Review specific imaging requirements.
- Use patient-supplied medication if it is not available through the hospital pharmacy.
- Contact the patient's Parkinson's doctor or device manufacturer for more information.



Updated March 2025. For the most current version and to print additional copies of the Parkinson's Care Summary for Health Professionals, visit **Parkinson.org/HospitalSafety**.

## 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 guide.

		DATE FO	DATE FORM FILLED			
Important names and num	bers					
CARE PARTNER	RELATIC	NSHIP	PHONE			
PARKINSON'S DOCTOR			PHONE			
PRIMARY CARE DOCTOR			PHONE			
PHARMACY			PHONE			
Larra d'arra a da del Bardo	<i>I</i>	( )				
I was diagnosed with Parki Special Considerations	nson's disease in	(year).				
O I have a deep brain stimu	lation device.	O I have balan	ve balance issues.			
O I have a device to deliver		O I have troub	ave trouble swallowing.			
O I have dementia.		O I experience	hallucinations or delusions of	as par		
O I get dizzy or feel faint.		of my Parkir				
O I have special dietary nee	ds.	O I sometimes feel disoriented or confused. O Other:		d.		
I also have the following co	onditions (list them bel	ow):				
<b>Medication List</b> (continued List all medications you are medications and supplement	e taking for Parkinson's		ions, including over-the-cour re information.	nter		
List all medications you are	e taking for Parkinson's		re information.	nter		



#### **Medication List**

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



To print additional copies of the Medication Form, or to complete the form online, visit **Parkinson.org/HospitalSafety**.



# 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 guide.

		DATE FO	ORM FILLED
Important names and	d numbers		
CARE PARTNER	RELAT	IONSHIP	PHONE
PARKINSON'S DOCTOR			PHONE
PRIMARY CARE DOCTOR			PHONE
PHARMACY			PHONE
I was diagnosed with	Parkinson's disease in	(vear).	
Special Consideration		(/ 641 ).	
•		O I have balan	en issues
O I have a deep brain O I have a device to de		O I have troub	
O I have dementia.	chiver my medicación.		hallucinations or delusions as
O I get dizzy or feel fa	iint.	of my Parkir	
O I have special dieta			feel disoriented or confused.
I also have the follow	ing conditions (list them b	elow):	
	************		
	cinued on back) ou are taking for Parkinsor plements. See page 27 for		
List all medications y	ou are taking for Parkinsor		re information.



## **Medication List**

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



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# 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 guide.

		DATE FO	ORM FILLED
Important names and	d numbers		
CARE PARTNER	RELAT	IONSHIP	PHONE
PARKINSON'S DOCTOR			PHONE
PRIMARY CARE DOCTOR			PHONE
PHARMACY			PHONE
I was diagnosed with	Parkinson's disease in	(vear).	
Special Consideration		(/ 641 ).	
•		O I have balan	en issues
O I have a deep brain O I have a device to de		O I have troub	
O I have dementia.	chiver my medicación.		hallucinations or delusions as
O I get dizzy or feel fa	iint.	of my Parkir	
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I also have the follow	ing conditions (list them b	elow):	
	************		
	cinued on back) ou are taking for Parkinsor plements. See page 27 for		
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Continue listing all medications and supplements here.

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		DATE FO	ORM FILLED
Important names and	d numbers		
CARE PARTNER	RELAT	IONSHIP	PHONE
PARKINSON'S DOCTOR			PHONE
PRIMARY CARE DOCTOR			PHONE
PHARMACY			PHONE
I was diagnosed with	Parkinson's disease in	(vear).	
Special Consideration		(/ 641 ).	
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O I have dementia.	chiver my medicación.		hallucinations or delusions as
O I get dizzy or feel fa	iint.	of my Parkir	
O I have special dieta			feel disoriented or confused.
I also have the follow	ing conditions (list them b	elow):	
	************		
	cinued on back) ou are taking for Parkinsor plements. See page 27 for		
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## **Medication List**

Continue listing all medications and supplements here.

TIME	MEDICATION	DOSE	NOTES



To print additional copies of the Medication Form, or to complete the form online, visit **Parkinson.org/HospitalSafety**.



Patient Name:	
Date of Birth:	



## Doctor's Letter: Parkinson's Hospital Care Needs

Ask your Parkinson's doctor to sign this letter and to your medication schedule with specific formulations	,
Their symptoms are managed through an individua the attached medication schedule for specifics.	res with Parkinson's disease (PD). lized medication regimen. Please see
the attached medication schedule for specifics.	

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

 The patient needs their medications 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. Some patients need to take their levodopa medication 30-60 minutes before meals to ensure absorption. 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) or Clozaril (clozapine).

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

Should an antiemetic be required, ondansetron (Zofran) 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 immediaterelease tablets can be crushed and administered via the tube.

If you have additional questions or concerns, please contact me.

Doctor's Signature: Doctor's	Email:

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

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) After non-drug de-escalation or re-direction and addressing underlying causes: For acute agitation: A low dose of benzodiazepine may be needed. For hyperactive delirium: Stop unnecessary deliriogenic medications, consider quetiapine. Parenteral benzodiazepines may be needed for safety. Limit repeat use to avoid worsening confusion.	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics not listed in the "safe" column, such as olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify).
Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, surgeon and anesthesiologist to determine best treatment plan.  Local or regional anesthesia usually 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 these pain medications:  • Morphine  • Hydrocodone +/- acetaminophen (Norco)  • Oxycodone +/- acetaminophen (Percocet)  • Fentanyl  • Tramadol (Ultram)  • Methadone  • Cyclobenzaprine (Flexeril)
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**Caution:** Benzodiazepines, muscle relaxants, bladder control medications and other drugs for sleep and pain may lead to confusion, hallucinations, falls and other symptoms. Also, though most antidepressants are safe to use, amoxapine (Asendin) may worsen movement symptoms.

## **PD Medications for Movement Symptoms**

- Medications, even in the same class, are usually not interchangeable.
- Patients should be allowed to supply their own medications if not on formulary.
- Scan QR code or visit **Parkinson.org/Medications** for PD medication information.



## If the patient has a deep brain stimulation (DBS) device or uses a medication device:

- · Review specific imaging requirements.
- Use patient-supplied medication if it is not available through the hospital pharmacy.
- Contact the patient's Parkinson's doctor or device manufacturer for more information.





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- Mood changes
- Cognitive issues
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**Caution:** Benzodiazepines, muscle relaxants, bladder control medications and other drugs for sleep and pain may lead to confusion, hallucinations, falls and other symptoms. Also, though most antidepressants are safe to use, amoxapine (Asendin) may worsen movement symptoms.

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- Pain

- Mood changes
- Cognitive issues
- Constipation and incontinence
- Hallucinations and delusions
- Impulse control disorders
- Orthostatic hypotension
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	Safe Medications	Medications to Avoid
Antipsychotics	Pimavanserin (Nuplazid) Quetiapine (Seroquel) Clozapine (Clozaril) After non-drug de-escalation or re-direction and addressing underlying causes: For acute agitation: A low dose of benzodiazepine may be needed. For hyperactive delirium: Stop unnecessary deliriogenic medications, consider quetiapine. Parenteral benzodiazepines may be needed for safety. Limit repeat use to avoid worsening confusion.	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics not listed in the "safe" column, such as olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify).
Anesthesia & Pain Medication	Consult with the patient's PD doctor or hospital neurologist, surgeon and anesthesiologist to determine best treatment plan.  Local or regional anesthesia usually 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 these pain medications:  • Morphine  • Hydrocodone +/- acetaminophen (Norco)  • Oxycodone +/- acetaminophen (Percocet)  • Fentanyl  • Tramadol (Ultram)  • Methadone  • Cyclobenzaprine (Flexeril)
Gastrointestinal (GI) & Nausea Medications	<ul><li>Ondansetron (Zofran)</li><li>Dolasetron (Anzemet)</li><li>Granisetron (Kytril)</li><li>Aprepitant (Emend)</li><li>Trimethobenzamide</li></ul>	<ul><li>Prochlorperazine (Compazine)</li><li>Metoclopramide (Reglan)</li><li>Promethazine (Phenergan)</li><li>Droperidol (Inapsine)</li></ul>



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

### **PD Medications for Movement Symptoms**

- Medications, even in the same class, are usually not interchangeable.
- Patients should be allowed to supply their own medications if not on formulary.
- Scan QR code or visit **Parkinson.org/Medications** for PD medication information.



### If the patient has a deep brain stimulation (DBS) device or uses a medication device:

- Review specific imaging requirements.
- Use patient-supplied medication if it is not available through the hospital pharmacy.
- Contact the patient's Parkinson's doctor or device manufacturer for more information.





## **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. Purchasing and wearing a medical alert bracelet can also be beneficial in case of an emergency.

To download and print the most current version of this card, visit 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 unsteady, move slowly and have difficulty speaking.

#### I AM NOT INTOXICATED.

Please call my family or doctor for help.



1-800-4PD-INFO (473-4636) www.parkinson.org

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PHONE
PHONE

#### 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 with PD. If an antipsychotic is necessary, use pimavanserin (Nuplazid), quetiapine (Seroquel) or clozapine (Clozaril).

Please turn over this card for a list of contraindicated medications.

HOME ADDRESS		
EMERGENCY CONTACT	PHONE	
DOCTOR	PHONE	

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## Using Medical ID on your Smartphone

Medical ID is a tool on Apple and Android smartphones that is used by first responders if you are unable to communicate and have your phone with you. Visit **Parkinson.org/MedicalID** for more information.

#### Safe & Contraindicated Medications in Parkinson's Disease

Safe Medications		Medications to Avoid
Antipsychotics		
•	Pimavanserin (Nuplazid) Quetiapine (Seroquel) Clozapine (Clozaril)	Haloperidol (Haldol) and other typical antipsychotics. Atypical antipsychotics not listed in the "safe" column, such as olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify).

#### 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 usually 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:

- Morphine
- Hydrocodone +/acetaminophen (Norco)
- Oxycodone +/acetaminophen (Percocet)
- Fentanyl
- Tramadol (Ultram)
- Methadone
- Cyclobenzaprine (Flexeril)

#### Gastrointestinal (GI) & Nausea Medications

- Ondansetron (Zofran) Dolasetron (Anzemet)
- Granisetron (Kytril) Aprepitant (Emend) Trimethobenzamide
- Prochlorperazine
- (Compazine)
- Metoclopramide (Reglan)
- Promethazine (Phenergan)

Updated March 2025

Droperidol (Inapsine)

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 the patient has a deep brain stimulation (DBS) device or uses a medication device:

- Review specific imaging requirements.
- Use patient-supplied medication if it is not available through the hospital pharmacy.
- Contact the patient's Parkinson's doctor or device manufacturer for more information.

# **Antipsychotics**

- Pimavanserin (Nuplazid) Quetiapine (Seroquel)
- Clozapine (Clozaril)

Safe Medications

#### antipsychotics not listed in the "safe" column, such as olanzapine (Zyprexa), risperidone (Risperdal) and aripiprazole (Abilify).

Haloperidol (Haldol) and other

typical antipsychotics. Atypical

**Medications to Avoid** 

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Safe & Contraindicated Medications in Parkinson's Disease

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#### Gastrointestinal (GI) & Nausea Medications

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- Prochlorperazine
- (Compazine)
- Metoclopramide (Reglan)
- Promethazine (Phenergan) Droperidol (Inapsine)

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Updated March 2025

#### 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. Information about Parkinson's and resources are available at **Parkinson.org.** 

## Your generosity makes this publication possible.

The Parkinson's Foundation is proud to provide this guide and other educational materials at no cost to people around the world. If you found this resource helpful, please consider a donation to help us continue to offer up-to-date, high quality educational materials about Parkinson's, as well as fund innovative research and support services.

## Choose how you want to give:

Online: Mail: Scan QR Code:

Parkinson.org/Donate Parkinson's Foundation

5757 Waterford District Drive,

**Tax ID:** 13 -1866796 Suite 310

Miami, FL 33126

Volunteer: Phone:

Parkinson.org/Volunteer 1-800-4PD-INFO

(1-800-473-4636)

# THANK YOU FOR YOUR SUPPORT!



PARKINSON, ORG

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## **HELPLINE:**

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

