## 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

1 **Share Important Forms**
Give important documents (page 24) to staff, including:
- Parkinson's Care Summary
- Doctor's Letter
- Medication Form

2 **Review Medications & Timing**
Verbally review the medications and schedule listed in your hospital chart with the care team. You can also request a printout.

3 **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 in the Hospital Safety Guide 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 Schedule:*** | ***Standard Hospital 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

1 **Explain the Impact**
Describe your symptoms and how they are affected when you do not receive medication on time, every time.

2 **Offer Reminders**
Let the nurse know when it's almost time for your medication.

3 **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 in the Hospital Safety Guide 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

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

2. **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.

3. **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 in the Hospital Safety Guide 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.

> “
>
> 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

1 **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.

2 **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.

3 **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 in the Hospital Safety Guide 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

1

**Share Swallowing Issues**

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

2

**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).

3

**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 in the Hospital Safety Guide 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.

### Understanding Aspiration vs. Aspiration Pneumonia

**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. 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