Aware in Care
Discussion Guide

A program of the
NATIONAL PARKINSON FOUNDATION®
Table of Contents

Welcome Letter from Joyce Oberdorf, President and CEO, National Parkinson Foundation ..................................... Page 3

Aware in Care Background ...................................................... Page 4

Aware in Care Discussion Guide for Support Group Leaders ........... Page 7

About the National Parkinson Foundation ................................. Page 11

The National Parkinson Foundation’s Aware In Care campaign aims to help people with Parkinson’s get the best care possible during a hospital stay. For more information please visit www.awareincare.org or call 1.800.4PD.INFO (473-4636).
Welcome to Aware in Care
Thank you for helping us spread the word!

Dear Friends:

On behalf of all of us at the National Parkinson Foundation, thank you for your dedication to helping improve the lives of people with Parkinson’s disease.

NPF launched the Aware in Care campaign in 2011 to draw attention to the fact that many people with Parkinson’s are not getting quality care when they are in the hospital. This results in more frequent and longer hospital visits and serious health setbacks for hundreds of thousands of individuals living with Parkinson’s disease. It is critical to make families aware of this issue and empower them to take action.

NPF’s Aware in Care campaign aims to help people with Parkinson’s get the best care possible during a hospital stay.

NPF created the Aware in Care kit to help people with Parkinson’s prepare for a hospital stay and to advocate for better care. Ideally, each time a kit is distributed, a discussion takes place that illustrates the critical nature of this issue.

This Discussion Guide is intended to be used by staff or volunteers who are speaking with people with Parkinson’s and their care partners about Aware in Care.

We deeply appreciate the efforts you are making to spread the word and welcome your feedback on how we can improve this campaign. Thank you for all you are doing to partner with NPF to help people with Parkinson’s become Aware in Care.

Sincerely,

Joyce Oberdorf
President and Chief Executive Officer
What Is Parkinson’s Disease?

Parkinson’s disease (PD) is an incurable progressive neurological disorder associated with a loss of dopamine-generating cells in the brain. The disease results in a complex array of symptoms, but is primarily associated with progressive loss of motor control. Parkinson’s affects an estimated one million individuals in the United States and between four and six million individuals over the age of 50 worldwide, a number expected to double by the year 2030. Medications for Parkinson’s are effective, but their continued, regular, and scheduled dosing is important both for symptom control and patient safety. As Parkinson’s advances, complications of motor function and cognition/mood can reach the point where they become disabling.

Why Are People with Parkinson’s at Risk in the Hospital?

People with Parkinson’s are hospitalized more frequently than their peers, especially in the later stages of the disease.

The most common reasons for hospital visits include complications resulting from falls or aspirational pneumonia, or because of unrelated conditions common with advancing age.

With more frequent hospital visits and a high sensitivity to the timing and dosing of Parkinson’s medications, people with Parkinson’s face great risks in the hospital.

Issues associated with higher risk include:

- Lack of understanding of Parkinson’s disease—symptoms, treatment, etc.—even in the very best hospitals in the United States
- Lack of awareness about the critical importance of Parkinson’s medication timing
- Lack of awareness that many common medications for pain, nausea, depression and psychosis are unsafe for people with Parkinson’s
- Hospital pharmacies that do not stock the full array of Parkinson’s medications
- Lack of awareness that poorly managed Parkinson’s might result in mental confusion and other serious symptoms
What the Research Says

Everyone with Parkinson’s knows how critical medication timing is to controlling symptoms. However, studies indicate that three out of four patients (74%) with Parkinson’s do not receive their medications on time during their hospital stays.  

According to a survey of National Parkinson Foundation Centers of Excellence:

- Only 25% of hospitals have a mechanism in place to contact a PD patient’s neurologist upon admission.
- 70% of hospital staff do not understood the drugs that worsen PD motor symptoms, or that certain psychosis drugs are contraindicated for PD.

A paper published in the journal Parkinsonism and Related Disorders found that:

- Parkinson’s patients are admitted to the hospital 50% more than their peers.
- Parkinson’s patients have longer hospital stays than the general population.

What Is Aware in Care?

Aware in Care consists of:

- A national awareness campaign to alert people with Parkinson’s and their care partners about the critical need to be prepared before a hospital visit
- A kit filled with useful information and tools to protect, prepare and empower people with Parkinson’s before, during and after a hospital visit
- Useful information for people with Parkinson’s to share with hospital staff during a planned or emergency hospital stay
- An educational initiative aimed at hospital-based health care staff to improve knowledge and understanding of the special needs of people with Parkinson’s

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The National Parkinson Foundation’s Aware In Care campaign aims to help people with Parkinson’s get the best care possible during a hospital stay. For more information please visit www.awareincare.org or call 1.800.4PD.INFO (473-4636).
Where Can I Find Aware in Care Information?

Learn more about kit contents, resources and what you can do at [www.awareincare.org](http://www.awareincare.org).

How Can I Help Promote Aware in Care?

In addition to this discussion guide, NPF created the following tools to help promote Aware in Care:

- Posters for display in hospitals, chapters or areas where support groups meet
- Postcards to share campaign information and details on how to order a kit
- Educational PowerPoint designed to be presented to people with Parkinson’s and care partners to help them prepare for the next hospital stay
- Web banners and promotional language to spread the word about Aware in Care on social media and organizational websites

Order Your Aware in Care Kit

For bulk orders, please call 1.800.4PD.INFO (473-4636).

For individual orders, go to [www.awareincare.org](http://www.awareincare.org).
Dear Support Group Leader:

Thank you for sharing Aware in Care with members of your Parkinson’s support group. This meeting will raise awareness of the need for people with Parkinson’s and care partners to be prepared before a hospital stay in order to get the best care possible.

Before facilitating a discussion of this topic, please read this entire discussion guide. We also suggest you review information available at www.awareincare.org.

Thanks again,

Your friends at the National Parkinson Foundation

Meeting Topic

Get the Best Care Possible in the Hospital
The National Parkinson Foundation’s
Aware in Care Campaign

Meeting Goal

Each person who attends the meeting will:

• Understand the risks associated with hospitalization for people with Parkinson’s;
• Be knowledgeable of the strategies that can be used to get better care during the next hospital visit, whether it is planned or an emergency; and
• Receive an Aware in Care kit from the National Parkinson Foundation or find out how to order the kit online at www.awareincare.org.
Meeting Format

1. **Start with a Story**

   Ask a member who has had a negative experience in the hospital to share his or her story. Keep it brief, but highlight the issues (common issues include not getting Parkinson’s medications on time; withdrawal of all medications; the hospital pharmacy substituting Parkinson’s medications; receiving pain, nausea, anesthesia, psychosis or depression medications that are unsafe for people with Parkinson’s disease; hospital staff not understanding the symptoms of Parkinson’s; etc.) as well as the problems that resulted (longer hospital stay, Parkinson’s symptoms much worse after hospital stay, serious complications from medications, serious issues with psychosis, etc.).

2. **Share the Facts about Hospitalization**

   Everyone with Parkinson’s knows how critical medication timing is to controlling symptoms. However, a recent study indicated that three out of four patients (74%) with Parkinson’s do not receive their medications on time during their hospital stays.

   According to a survey conducted by the National Parkinson Foundation, only 25% of hospitals have a mechanism in place to contact a PD patient’s neurologist upon admission. Furthermore, the hospitals indicated that 70% of hospital staff do not understand the drugs that worsen PD motor symptoms, or that certain psychosis drugs are contraindicated for PD.

   A paper published in the journal *Parkinsonism and Related Disorders* found that Parkinson’s patients are admitted to the hospital 50% more than their peers and have longer hospital stays than the general population.

3. **Why Are People with Parkinson’s at Risk in the Hospital?**

   With more frequent hospital visits and a high sensitivity to the timing and dosing of Parkinson’s medications, people with Parkinson’s face great risks in the hospital.

   Issues include:
   - Lack of understanding of Parkinson’s disease (symptoms, treatment, etc.), even in the very best hospitals in the United States
   - Lack of awareness about the critical importance of Parkinson’s medication timing
   - Lack of awareness that many common medications for pain, nausea, depression and psychosis are unsafe for people with Parkinson’s
   - Hospital pharmacies that do not stock the full array of Parkinson’s medications
   - Lack of awareness that poorly-managed Parkinson’s might result in mental confusion and other serious symptoms

The National Parkinson Foundation’s *Aware In Care* campaign aims to help people with Parkinson’s get the best care possible during a hospital stay. For more information please visit [www.awareincare.org](http://www.awareincare.org) or call 1.800.4PD.INFO (473-4636).
4. **Present the Solution: Aware in Care**

We’re here today to talk about how to be a part of the solution to improve care for people with Parkinson’s in the hospital.

The National Parkinson Foundation has created materials to help you be prepared for your next hospital visit, whether it is a planned visit or an emergency. The program is called *Aware in Care*.

The *Aware in Care* kit has materials and information to help you get ready for your next hospital visit. Let’s walk through the 10 steps outlined in the Hospital Action Plan that is in your kit.

**Before Your Next Hospital Visit**

**Step 1 - Line Up Help:** Do you have your Parkinson’s team in place? It should include your care partner, a Parkinson’s doctor, a family physician and a trusted pharmacist.

**Step 2 - Pack Your Aware in Care Kit:** This kit is meant to help you prepare for your next hospital stay. After you review information in the kit, take extra time to add an emergency contact list, an extra supply of your Parkinson’s medications, a completed *Medication Form* and a copy of your health care proxy card. Keep your kit in a visible place and tell your care partner where you are storing the kit in case of an emergency.

**Step 3 - Prepare for the Unexpected:** There are two items in the kit that will help protect you in the case of an emergency. Put the *Parkinson’s ID Bracelet* on your wrist and the *Medical Alert Card* in your wallet. The bracelet alerts emergency responders that you have PD and refers them to your wallet card for more information.

**Step 4 - Find a Good Hospital:** Contact local hospitals and ask questions. Find a hospital that is dedicated to meeting the needs of each patient and is willing to take the time to understand the special needs you have as a person with Parkinson’s.

**When You Are in the Hospital**

**Step 5 - Be Vocal:** Use the information in the kit to educate staff about Parkinson’s. Let them know you need your *medications on time, every time*. Request a neurology consult or ask your Parkinson’s doctor to speak with the physician in the hospital in charge of your care. If you have trouble speaking, ask your care partner to speak up on your behalf to make sure you are getting the care you need and deserve.
Step 6 - Be Persistent: Talk to each member of your care team about your symptoms and special needs. Ask for help if you feel no one is listening.

Step 7 - Get Moving: Start moving as soon as possible after your procedure. Physical therapy should be covered in the hospital. Find out if you qualify to receive physical therapy at home once you are discharged.

Step 8 - Stay on Top of Your Care: You and your care partner need to pay attention to the medications, treatments and tests you get in the hospital. Know the medications that are unsafe for people with Parkinson’s, and don’t be afraid to speak up if you feel you are being given a drug that is not safe.

When You Are At Home

Step 9 - Follow Up and Provide Feedback: Contact your Parkinson’s doctor and share your discharge instructions. Contact the hospital and let them know about the quality of care they provided during your hospital stay.

Step 10 - Connect with Others in the Parkinson’s Community: Reach out to join a local support group. If you need a referral, call the National Parkinson Foundation Helpline at 1.800.4PD.INFO (473-4636).

5. Preparing for Your Next Hospital Visit

Every person is unique, and every person with Parkinson’s has different symptoms and different needs.

Take the time to review the Hospital Action Plan booklet in your kit. There are tips for people with DBS devices, people with swallowing issues or special dietary needs and people with balance problems.

Most important, prepare your Aware in Care kit so that the next time you go into the hospital, you have everything you need to get the best care possible.

6. Facilitated Discussion

Were the facts and figures around Parkinson’s and hospitalization surprising to you? What surprised you the most?

How are you going to prepare for your next hospital visit?

What do you think is the most important need to communicate to hospital staff? (Parkinson’s medication on time, every time is the right answer!)

The National Parkinson Foundation’s Aware In Care campaign aims to help people with Parkinson’s get the best care possible during a hospital stay. For more information please visit www.awareincare.org or call 1.800.4PD.INFO (473-4636).
Founded in 1957, the National Parkinson Foundation (NPF) is the only organization with a singular focus of improving the quality of Parkinson’s care through research, education and outreach. We continue to bring help and hope to this generation of the estimated one million individuals in the United States, four to six million worldwide, who are living with Parkinson’s disease (PD). Here are some of the highlights of our organization:

→ NPF has funded more than $189 million in research and support services to improve the lives of people with Parkinson’s. We continue to be a major funder of research programs, such as our Quality Improvement Initiative, part of the Parkinson’s Outcomes Project, designed to change the course of the disease.

→ NPF Centers of Excellence, at top medical institutes, comprise the first international network to focus on how to improve care delivered to Parkinson’s patients. The network includes 41 Centers of Excellence that deliver care to more than 50,000 Parkinson’s patients.

→ NPF Chapters, throughout the United States, provide access to local resources and services, such as support groups, exercise and wellness classes, education programs and more.

→ NPF Programs touch more than one million people a year through our U.S. chapters, support groups and our online resource, Parkinson.org.

→ NPF helps people with Parkinson’s every day through our popular “Ask the Doctor” online forum, our series of free educational manuals that are distributed to patients and families around the world and through our national Helpline, 1-800-4PD-INFO (473-4636).

→ Many of today’s leading scientists in the field of PD research received their initial funding through a NPF grant. Among the accomplishments of NPF-supported research:

  • Genetic research that led to discovery of the importance of the alpha-synuclein gene in PD.
  • Research that led to the identification of novel pathways in the basal ganglia that are now targets for drug development efforts.

→ NPF has trained more than 1600 medical and health care professionals in “best practices” for Parkinson’s patient care through our signature professional training initiative, Allied Team Training for Parkinson (ATTP). ATTP prepares allied health care professionals to deliver integrated specialized care in a team setting to individuals with PD.