Aware in Care

National Parkinson Foundation
Why Are We Here Today?

• To help people with Parkinson’s:
  – Understand the risks associated with hospital stays
  – Plan for your next hospital stay, whether it is scheduled or an emergency
  – Develop strategies to get better care in the hospital

Let’s learn about Aware in Care!
Hospitals Are Safe, Right?

“They will call my neurologist.”

“The pharmacy will have my PD meds.”

“Staff will understand PD symptoms.”

“They will bring me my meds on time.”

“They will know the drugs that are unsafe.”
The Reality

• People with Parkinson’s are hospitalized 50% more than their peers without Parkinson’s,¹ and they suffer avoidable complications at a higher rate than non-PD patients.¹,²,³

• This yields longer hospital stays than non-PD patients...¹,³

• …and results in a 44% higher risk-adjusted mortality.¹,³

The Reality

- 3 out of 4 people with Parkinson’s disease do not receive medications on time in the hospital.¹
- 61% of patients who did not get their medications on time had serious complications from it.¹

The Reality

- Only 25% of hospitals have a mechanism in place to contact a patient’s Parkinson’s doctor upon admission.¹

- 70% of hospital staff are unaware of the drugs that worsen PD motor symptoms or are contraindicated for people with Parkinson’s.¹

Why Is This Happening?

• Lack of understanding of Parkinson’s disease - symptoms, treatment, etc. - *even in the very best hospitals in the U.S.*

• 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
Why Is This Happening?

• Hospital pharmacies that do not stock the full array of PD medications

• Lack of awareness that poorly-managed PD might result in mental confusion and other serious symptoms
Aware in Care Is Here to Help

• You are the best advocate for your own care!

• Your new *Aware in Care* kit will help you plan and advocate for better care during a hospital stay.

Let’s take a look at what’s in the kit...
What’s in the Kit?

1. **Bag**: Pack the bag with your Parkinson’s medication and *Aware in Care* materials.

2. **Hospital Action Plan**: Read about how to prepare for your next hospital visit, whether it is planned or an emergency.

3. **Parkinson’s Disease ID Bracelet**: Wear your bracelet at all times in case you are in an emergency situation and cannot communicate.

4. **Medical Alert Card**: Fill in the card with emergency contact information, and put it in your wallet.
What’s in the Kit?

5. **Medication Form:** Complete this form and keep copies in the bag.

6. **Parkinson’s Disease Fact Sheet:** Share the facts about Parkinson’s with hospital staff, and ask that a copy be placed in your chart.

7. **I Have Parkinson’s Reminder Slips:** Share vital information about Parkinson’s disease with every member of your care team in the hospital.

8. **Magnet:** Use this magnet to display a copy of your Medication Form in your room.

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**www.awareincare.org**
**1.800.4PD.INFO (473-4636)**

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**Medication Form**

**Parkinson’s Disease Fact Sheet**

**I Have Parkinson’s Reminder Slips**

**Magnet**
10 Steps to Optimum Care
Take Action at Home

• **Step 1: Line Up Help**
  – Assemble your care team: care partner, Parkinson’s doctor, primary care physician.
  – Who else is part of your care team?

• **Step 2: Pack Your Aware in Care Kit**
  – Review materials and know what’s in the kit.
  – 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.
Take Action at Home

• **Step 3: Prepare for the Unexpected**
  – Wear your Parkinson’s ID Bracelet.
  – Put the Medical Alert Card in your wallet.
  – Establish and share an emergency plan.

• **Step 4: Find a Good Hospital**
  – Contact local hospitals and ask questions.
  – Select a hospital that will meet your needs as a person with PD.
When You Are in the Hospital

• **Step 5: Be Vocal**
  – Use the Parkinson’s Fact Sheet and I Have Parkinson’s slips to educate staff.
  – Let them know you need your Parkinson’s medications on time, every time.
  – If you have trouble speaking, ask your care partner to speak up on your behalf.

• **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.
When You Are in the Hospital

• **Step 7: Get Moving**
  - Start moving as soon as possible after your procedure.
  - Ask for physical therapy 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**
  - Engage your care partner in monitoring all aspects of your care.
  - Pay attention to the medications, treatments and tests you get in the hospital.
  - Know the medications that are unsafe for people with PD.
  - **Speak up if you think something is wrong.**
When You Are Back 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.
  – Prepare your kit for your next hospital stay.

• **Step 10: Connect with Others in the Parkinson’s Community**
  – Reach out to join a local support group.
  – Need a local referral? Call the NPF Helpline:
When Should I Use the Kit?

- **Planned Hospital Stay**
  - Bring it with you to every consult appointment.
  - Pack and bring the kit with you when you go to the hospital.

- **Emergency Visit**
  - Ask a family member or friend to bring your packed kit to the ER.

- **Annual Check-In with Your Parkinson’s Doctor**
  - Bring the kit with you, and share the program with your doctor.
**Aware in Care Is About You!**

- Use your kit during your next hospital stay.

- Tell others with Parkinson’s about *Aware in Care*.

- Order a free kit for a friend at [www.awareincare.org](http://www.awareincare.org).

- Organize an *Aware in Care* event at your next support group meeting. We’ll send you kits and materials to share with members.
Aware in Care Is Made Possible By:

The Eleanor M. and Herbert D. Katz Family Foundation

...And individuals like you. Thank you for your support.
National Parkinson Foundation

- 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.

- 41 NPF Centers of Excellence at top medical institutes deliver care to more than 50,000 people with Parkinson’s, and NPF programs touch more than one million people a year through our U.S. chapters, support groups and our online resource, Parkinson.org.

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

- Learn more online at www.parkinson.org or call 1.800.4PD.INFO.