Why Are We Here Today?

To help people affected by Parkinson’s:

– Understand the risks associated with hospital stays.
– Get tools to play an active role in your care.
– Be prepared for a hospital visit, whether planned or unplanned.
– Develop strategies to get the best possible 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
  
  • 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.

The Reality

– 3 out of 4 of people with Parkinson’s do not receive medications on time in the hospital.
– Almost 2/3 of people who did not receive their meds on time had serious complications from it.

The Reality

– Only 25% of hospitals have a mechanism in place to contact a person’s Parkinson’s doctor upon admission.

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

Why Is This Happening?

– Lack of understanding of Parkinson’s disease and its symptoms and treatment – even at the best hospitals.

– Hospital pharmacies do not always stock the full array of Parkinson’s medications.
Why Is This Happening?

Lack of awareness:

– Of the critical importance of Parkinson’s medication timing.

– That many common medications for pain, nausea, depression and psychosis are unsafe for people with Parkinson’s.

– That poorly managed Parkinson’s might result in mental confusion and other serious symptoms.
Hospitals Can Be Complicated

Many providers…

- Physicians/Surgeons
- Physical Therapists
- Social Workers
- Dieticians
- Pharmacists
- Nurses

Patient
Role of Patient and Care Partner

– Share knowledge of your Parkinson’s experience and other conditions, including special needs and challenges.

– Bring your own medications (in original containers) and schedule with you to show hospital staff.

– Be your own advocate!
Aware in Care is here to help

Aware in Care can help EVERYONE be better informed:

– Person with Parkinson’s
– Care partner and family
– Healthcare providers
– Hospital staff

You are the best advocate for your own care!
We were able to explain my needs and our concerns. The anesthesiologist thanked us for being prepared, providing information, and asking questions.

Ruth B.
The doctor was about to give me Demerol... I said I looked it up in my kit and it’s not appropriate for people with PD.

Information specialist: Dianett Ojeda, RN
Nurse
Patient and Care Partner Stories

This was my first time at a hospital when a nurse was aware of the importance of meds being on time for Parkinson's patients.

Information specialist: Sharon Metz, MS, RN
Nurse
What’s in the Kit?

I need my Parkinson’s medications ON TIME, EVERY TIME

For more information please visit Parkinson.org/awareincare or call 1-800-4PD-INFO (473-4636).
What’s in the Kit?

1. **Kit bag:** Along with *Aware in Care* materials, pack your bag with your current medications and supplements in original bottles.

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 your card with emergency contact information and place in your wallet.
What’s in the Kit?

5. **Medication Form**: Keep this form up-to-date and make copies. You can print additional copies from [parkinson.org/awareincare](http://parkinson.org/awareincare).

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 hospital room.
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? Identify those professionals, family or friends who may be active in your care.

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 healthcare 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 an emergency plan and share it.

Step 4: Find a Good Hospital
– Contact your local hospital(s) and ask questions.
– If your community has multiple hospitals, select one that will best meet your needs as a person with PD. These websites may be helpful:
  • www.qualitycheck.org/consumer
  • www.hospitalcompare.hhs.gov
Take Action in the Hospital

Step 5: Be Vocal
– Use the Parkinson’s Fact Sheet and “I Have Parkinson’s” reminder slips to educate staff about Parkinson’s.
– 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.
Take Action 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 receive in the hospital.
– Ask about medications that may be unsafe for people with Parkinson’s.

Speak up if you think something is wrong!
Take Action 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.
– Prepare your kit for your next hospital stay.

Step 10: Connect with Others
– Reach out to join a local support group.
– Need a local referral?
  Call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636).
When Should I Use the Kit?

Planned Hospital Stay
– Bring it with you for every physician or consult appointment.
– Pack and bring the kit with you when you go to the hospital.

Emergency Visit
– Ask a relative or friend to bring your packed kit to the ER.

Annual Check-Up with Your Parkinson’s Doctor
– Bring the kit with you, and share the program with your doctor at your next scheduled appointment.
Changing Outcomes

The right* medications, on time

I need my Parkinson’s medications ON TIME, EVERY TIME

For more information please visit Parkinson.org/awareincare or call 1-800-4PD-INFO (473-4636).

*No contraindicated medications
Remember…

Anti-Parkinson medications are as necessary to a Parkinson’s patient as insulin is to a diabetic.
Aware in Care is about you!

– Use your kit during your next hospital stay.

– Share your thoughts with us at Parkinson.org/feedback.

– Tell others with Parkinson’s about Aware in Care.

– Organize an Aware in Care event at your next support group meeting. We will send you materials to share with members.
Learn More

– Watch the archived *Aware in Care* webinar.
– Download the support group discussion guide.
– Order your kit.
– Spread the word!

Parkinson.org/awareincare
Aware in Care Is Made Possible by…

...And individuals like you. Thank you for your support.
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.

We are leaders in ensuring expert Parkinson’s disease (PD) care; educating and empowering the Parkinson’s community; and driving the understanding of Parkinson’s through research. As a national organization with a local presence and impact, we bring help and hope to the estimated one million individuals in the United States, 10 million worldwide, who are living with Parkinson’s.

Learn more online at Parkinson.org or call 1-800-4PD-INFO.
GET A KIT. KNOW THE FACTS. 
BE AWARE IN CARE.