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 their care.
– Be prepared for a hospital visit, whether planned or unplanned.
– Develop strategies to get the best possible care in the hospital.

To be Aware in Care.
Care Transitions: Hospital to Home

For most people, the transition from hospital to home is the challenging part.

For people with Parkinson’s, it’s the reverse.
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.”
Parkinson’s and Hospitalization

1 in 3

3 in 4

2 in 3


<table>
<thead>
<tr>
<th>100 patients</th>
<th>1 Million PWP</th>
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</thead>
<tbody>
<tr>
<td>33 admissions</td>
<td>330,000 admissions</td>
</tr>
<tr>
<td>25 Medications changed</td>
<td>247,500 Medications Changed</td>
</tr>
<tr>
<td>16 complications</td>
<td>163,350 complications</td>
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The Reality

– People with Parkinson’s are hospitalized 44% more than their peers without Parkinson’s.¹

– People with Parkinson’s 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

Why Is This Happening?

Even in the best hospitals, there can be a lack of understanding of Parkinson’s disease.

Non-PD specialists may not be fully aware of the critical importance of Parkinson’s medication timing.

Hospital pharmacies may not stock all PD medications.

Hospital staff may not know that many common medications can be unsafe for people with Parkinson’s.
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.

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…

- Patient
- Physicians/Surgeons
- Physical Therapists
- Social Workers
- Dieticians
- Pharmacists
- Nurses
How PD Patients Enter Hospitals

- First Responders
- ER Nurses
- ER Physicians

- PD Patient MD
- Unit Nurses

Seemingly minor errors by any of these people can mean a crisis for people with PD entering the Hospital.
Challenges in Parkinson’s Care

- PD is often not the primary reason for being admitted to the hospital.
- Providers may lack necessary PD expertise.
- PD medication regimens are complex and medication changes can result in negative outcomes.
- PD patients often have complex mobility issues.
Medication Challenges

Multiple medications are used to treat Parkinson’s.

Contraindicated medications are not often recognized.

Changes in times/dosing of medications can affect patient status.

Compromised swallowing ability may dictate a change in medication formulation.
Mobility Challenges

- PD patients should mobilize as early and as often as conditions allow.
- Ambulation reduces chance of worsening rigidity and associated symptoms.
- PD patients are at heightened risk for falls.
- Patients and care partners should discuss risks associated with lack of movement with the doctor and physical therapists.
Why the problem is so difficult to solve

Complexity of medication regimens

- More frequent dosing than most meds
- Default schedules typically not appropriate
- Non-specialists unfamiliar with crucial differences between different formulations
  - Continuous Release vs Immediate Release
  - Generic vs. Name Brand
- Complex mix of medications needed to stabilize motor fluctuations
EMR & Hospital culture

“The patient is wrong, the computer is right” mentality

Time pressures: It’s faster to get information from the computer than from patients and care partners

- The outpatient medication list is often not specific to timing, or contains errors
- What the patient does at home is how it needs to be ordered in the hospital
- Investing time to talk to the patient and care partner about what is actually happening at home, rather than relying on the computer, is essential for accuracy
Stopping PD meds can be fatal!

Levodopa withdrawal-emergent syndrome (a.k.a. Parkinsonism-hyperpyrexia)

Clinically identical to Neuroleptic Malignant Malignant Syndrome, but occurs in patients with PD after abrupt stop of (or significant reduction in) dopaminergic medications

- Rigidity
  - Particularly prominent axial rigidity (neck and trunk)
  - Can be accompanied by dystonia
- Fever
- Tachycardia, tachypnea, labile BP
- Altered mental status → more likely to prescribe UNNECESSARY and DAMAGING anti-psychotics
Role of Patient and Care Partner

Each person with PD has the best knowledge of their disease and other conditions.

Each person with PD has a unique combination of medications and listed regimen.

Each person with PD is most knowledgeable about their own special needs but may have communications challenges.

Care partners can have all of the above information and advocate for the Parkinson’s patient.
Changing Outcomes

The right* medications, on time

*No contraindicated medications—Never Haldol

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).
Medications

Anti-Parkinson medications are as necessary to a Parkinson’s patient as insulin is to a diabetic.

“Often, PD medication schedules are changed in the hospital...This change may result in greater risk for disability and consequently an increased risk of accidents and other complications. The acute discontinuation of PD medications...can be life-threatening.”

The Parkinson’s Foundation’s *Aware in Care* campaign can help EVERYONE be better informed:

- Person with Parkinson’s
- Healthcare providers
- Care partner and family
- Hospital/facility staff

The *Aware in Care* kit helps patients and families plan for a hospital visit and advocate for the best possible care during the stay.
Stories from the Helpline

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

“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.”
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 complete and print additional copies from parkinson.org/awareincare.

6. **Nurse Disease Fact Sheet Pad:** Share the facts about Parkinson’s with every member of your care team in the hospital and ask that a copy be placed in your chart.

7. **Magnet:** Use this magnet to display a copy of your Medication Form in your hospital room.
Six Steps to Optimum Care – At Home

Step 1: Prepare Your Aware in Care Kit
- Make sure the contents provided with your kit are completed and up to date.

Step 2: Find a Good Hospital
- Get to know the hospitals in your community before you need one.
- Map out where you will go if an emergency requires you to go to the hospital.
- It is your right as a patient to ask questions ahead!
Step 3: Be Vocal

- Each time you are asked about the medications you take, provide a copy of the Medication Form.
- If you brought your medications with you in their original bottles to the hospital, let your nurses and doctors know.
- Ask to see a patient advocate.

Step 4: Get Moving

- Soon after your medical procedure, it is vital that you get out of bed and start moving, if possible.
- You should ask for physical, occupational or speech therapy, depending on your symptoms and needs.
Step 5: Stay on Top of Your Care

- It is essential to pay attention to the medications, treatments and tests you get throughout your stay.

Step 6: Follow Up and Provide Feedback

- Contact your Parkinson’s doctor and your primary care physician and give them a progress report.
- Find out what follow-up care you will need and what things you can do at home to help control and improve your condition.
Remember Your Kit When You Go!
Learn more:
- Watch the archived *Aware in Care* webinar.
- Download the support group discussion guide.
- Order your kit.
- Spread the word!
**Aware in Care Summary**

*Aware in Care* is a national campaign to:

Prepare and empower people with Parkinson’s disease, through tools and information, to be your own advocate in the hospital setting, and an engaged partner in your healthcare overall.

Educate healthcare providers and staff to help people with Parkinson’s get the best possible care while in the hospital (or other in-patient setting – rehab, LTC, etc.).
Aware in Care Ambassadors

Educate the Community -
If people with Parkinson’s know what they need, they are more likely to get appropriate care.

Educate Clinicians who treat Parkinson’s -
If clinicians help spread the word about resources, we can share them with more people with Parkinson’s.

Educate the Hospital Staff -
If staff know what people with Parkinson’s need and why, they are more likely to adjust the care given.
Aware in Care Is Made Possible by…

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

Learn more online at Parkinson.org or call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO.
Questions?

Get a kit.
Know the facts.

Be Aware in Care.