



*Aware in Care*

**Better Lives. Together.**

# 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.”

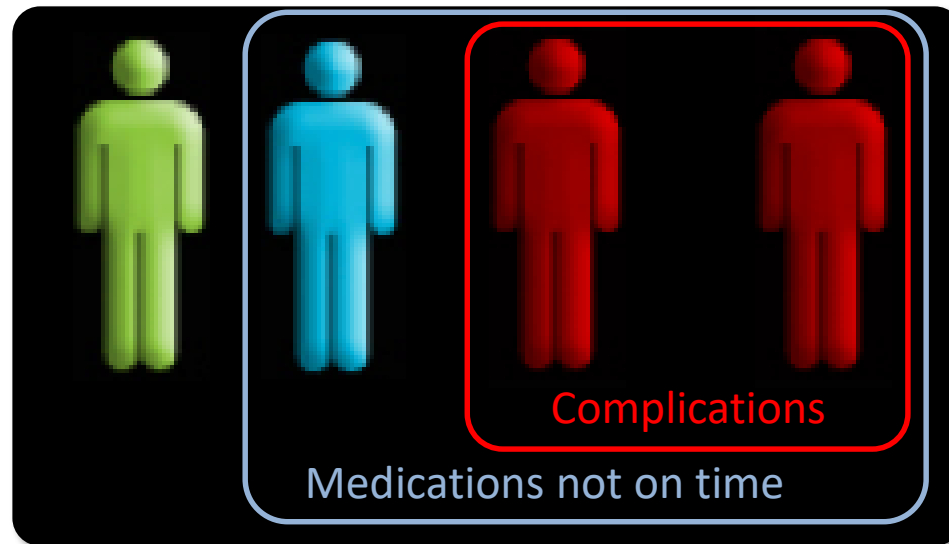
“They will know the drugs that are unsafe.”

- People with Parkinson's:
  - Are hospitalized 50% more than their peers without Parkinson's.<sup>1</sup>
  - Suffer avoidable complications at a higher rate than non-PD patients.<sup>1,2,3</sup>
- This yields longer hospital stays than non-PD patients.<sup>1,3</sup>
- ...and results in a 44% higher risk-adjusted mortality.

1. Aminoff MJ., et al. Parkinsonism and Related Disorders, 2010.
2. Derry CP, et al. Postgrad Med J., 2010. 86 (1016): 334-7
3. Guttman M, et al. Movement Disorders, 2004 19(1):49-53.

# 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.



KN Magdalinou, et al. Prescribing medications in Parkinson's disease (PD) patients during acute admissions to a District General Hospital. *Parkinsonism and Related Disorders*. 2007 Dec;13(8):539-40.

# 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.

Chou, Kelvin L., et al. Best Care Practices in NPF Centers: Care of the Hospitalized Parkinson's Disease Patient. Parkinsonism and Related Disorders, 2011.

# 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?

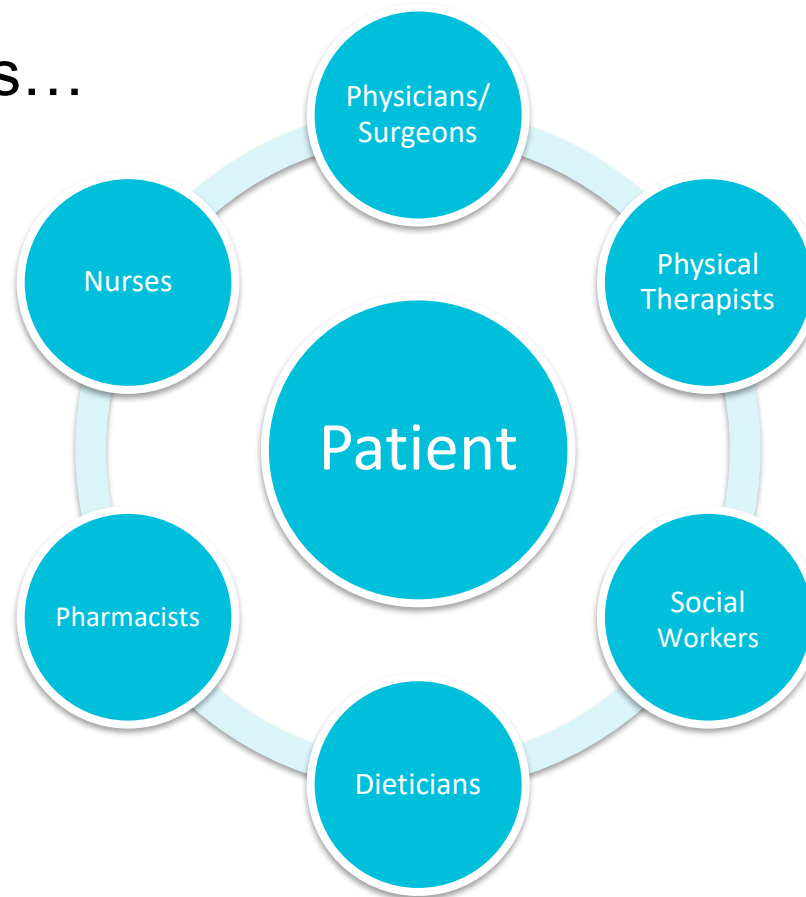
## Lack of awareness:

- 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...



# 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!

# Patient and Care Partner Stories



Ruth B.

We were able to explain my needs and our concerns. The anesthesiologist thanked us for being prepared, providing information, and asking questions.

# Patient and Care Partner Stories

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?

### Parkinson's Medication Form of

Complete this form, make copies and keep them in your *Aware in Care* Kit. At the hospital, show your completed Medication Form when you are asked to provide a list of medications. Fill out a new form when your prescriptions change and keep this updated version in your kit. **Important names and numbers:**

YOUR NAME HERE

First Name \_\_\_\_\_ Last Name \_\_\_\_\_

DOB: \_\_\_\_\_

Primary Care Physician: \_\_\_\_\_

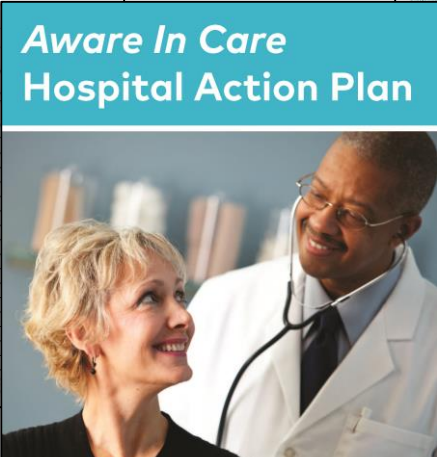
Neurologist: \_\_\_\_\_

Special Information: Have you been diagnosed with Parkinson's disease?  Yes  No. If Yes, how long have you had the disease? \_\_\_\_\_

Other conditions:  Diabetes  Heart Disease  Depression  COPD  High Blood Pressure  Other: \_\_\_\_\_

Medication List: List all medications you are taking for Parkinson's and all other medical conditions, including over-the-counter medications and supplements.

Medication	Dosage	Frequency/Timing



## Aware In Care Hospital Action Plan

### Parkinson's Disease Fact Sheet

**About Parkinson's Disease:** Parkinson's disease is a progressive, incurable neurological disorder associated with a loss of dopamine-generating cells in the brain. It is primarily associated with progressive loss of motor control, but it results in a complex array of symptoms, including many non-motor symptoms. Parkinson's impacts an estimated one million people in the United States.

**Special Care Considerations:** Parkinson's disease has serious side effects. Parkinson's patients need their medications on time, every time – do not skip or postpone doses. Write down the exact times of day medications are to be administered so doses are given on the same schedule the patient follows at home. Do not substitute Parkinson's medications or stop levodopa therapy abruptly. If you have any questions about your medications, ask your doctor or pharmacist immediately following procedures, unless vomiting or severely incapacitated.

**Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia.** Ambulate as soon as medically safe. Patients may require assistance.

**Symptoms of Parkinson's Disease:**

- Tremor
- Slowing or tripping on feet
- Stiffness or freezing (feeling "stuck" or "not moving")
- Postural instability (trouble with balance and falls)
- Speech problems (trouble speaking)
- Swallowing problems (trouble swallowing)
- Constipation
- Depression
- Cognitive decline and dementia
- Impulse control disorders
- Orthostatic hypotension
- Risk

**Non-Motor:**

- Depression
- Anxiety
- Constipation
- Cognitive decline and dementia
- Impulse control disorders
- Orthostatic hypotension
- Risk

**Medications:**

Depression: \_\_\_\_\_  
Anxiety: \_\_\_\_\_  
Constipation: \_\_\_\_\_  
Cognitive decline and dementia: \_\_\_\_\_  
Impulse control disorders: \_\_\_\_\_  
Orthostatic hypotension: \_\_\_\_\_  
Risk: \_\_\_\_\_

### MEDICAL ALERT

I have **PARKINSON'S DISEASE** which could make me move slowly and have difficulty standing or speaking.

I AM NOT INTOXICATED.  
Please call my family or physician for help.

### Parkinson's Foundation

Hello my name is \_\_\_\_\_ and I have Parkinson's disease.

**Important things to remember when caring for people with Parkinson's:**

- To avoid serious side effects, provide Parkinson's medications on time, every time – do not skip or postpone doses.
- Write down the exact times of day medications are to be administered so doses are given on the same schedule the patient follows at home.
- Do not substitute Parkinson's medications.
- Do not stop levodopa therapy abruptly.
- Resume medications immediately following procedures, unless vomiting or severely incapacitated.
- If an antipsychotic is necessary, use pimozide (Relpax), quetiapine (Seroquel) or clozapine (Clozaril).
- Be alert for symptoms of dysphagia (trouble swallowing) and risk of pneumonia.
- Ambulate as soon as medically safe. Patients may require assistance.



I need my Parkinson's medications **ON TIME, EVERY TIME**

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



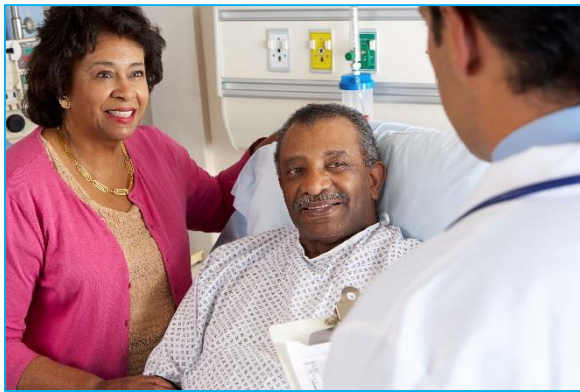
# What's in the Kit?

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

## 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

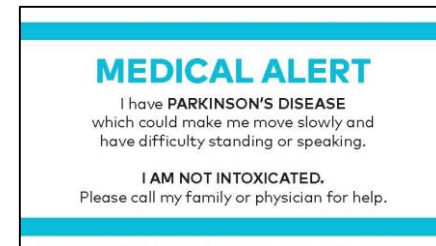
- Review materials and know what's in the kit.
- Add an **emergency contact list**, an extra supply of your Parkinson's medications, a completed **Medication Form**, and a copy of your healthcare proxy card.



# 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](http://www.qualitycheck.org/consumer)
  - [www.hospitalcompare.hhs.gov](http://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.



The right\* medications, on time



Aware  
in Care  
Parkinson's Foundation

I need my Parkinson's medications  
**ON TIME, EVERY TIME**

For more information please visit  
[Parkinson.org/awareincare](http://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](https://www.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](https://parkinson.org/awareincare)

The screenshot shows the Parkinson's Foundation website. At the top, there is a navigation bar with the following items: 'Call Our HELPLINE: 1-800-4PD-INFO (473-4636)', 'Español', 'About Us', 'In Your Area', 'Search', and 'Donate'. Below this is the Parkinson's Foundation logo and a secondary navigation bar with links: 'Understanding Parkinson's', 'Living with Parkinson's', 'Expert Care', 'Research', 'Get Involved', and 'Ways to Give'. The main content area is titled 'Patient Safety Kit' and includes sections for 'Helpline', 'Ask the Doctor Forums', 'Expert Briefings Webinars', 'Patient Safety Kit' (with sub-links for Kit Contents, Resources, Who Can Use the Kit, and Order a Kit), 'Podcast: Substantial Matters', 'The Edmond J. Safra National Parkinson's Wellness Initiative', and 'Order Publications'. A video player is embedded at the bottom, showing a man in a red shirt holding a black bag labeled 'Aware in Care'. The video title is 'Aware in Care: Real Stories'.

# Aware in Care Is Made Possible by...



EDMOND J. SAFRA  
PHILANTHROPIC FOUNDATION

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*...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](https://www.parkinson.org) or call 1-800-4PD-INFO.

**GET A KIT. KNOW THE FACTS.  
BE *AWARE IN CARE*.**