



*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 the needed 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.

## To be *Aware in Care*.

# Aware In Care Advisory Committee

## Aware In Care Advisory Committee

- This committee of six is be comprised of expert clinicians and members of the Parkinson's community.
- Our role is to advise on the content and disbursement of educational materials as part of the Aware in Care initiative.
- The goal of the Aware in Care initiative is to make hospitals a safer place for People with Parkinson's.

# Debra Mayer, MSN, RN, CNE



- Registered Nurse specializing in critical care and emergency nursing for the past 29 years.
- I currently hold a tenure position as nursing faculty at Anoka Ramsey Community College which is part of the Minnesota Alliance for Nursing Education (MANE) Baccalaureate Nursing program.

- In 2018 I was selected to participate in the esteemed Edmond J. Safra Visiting Nurse Faculty Program at the Parkinson's Foundation.
- I have both a personal and professional interest in promoting further Parkinson Disease education, by working with my faculty peers to augment student learning.

# Hospitals Are Safe, Right?

“They will call my  
neurologist.”

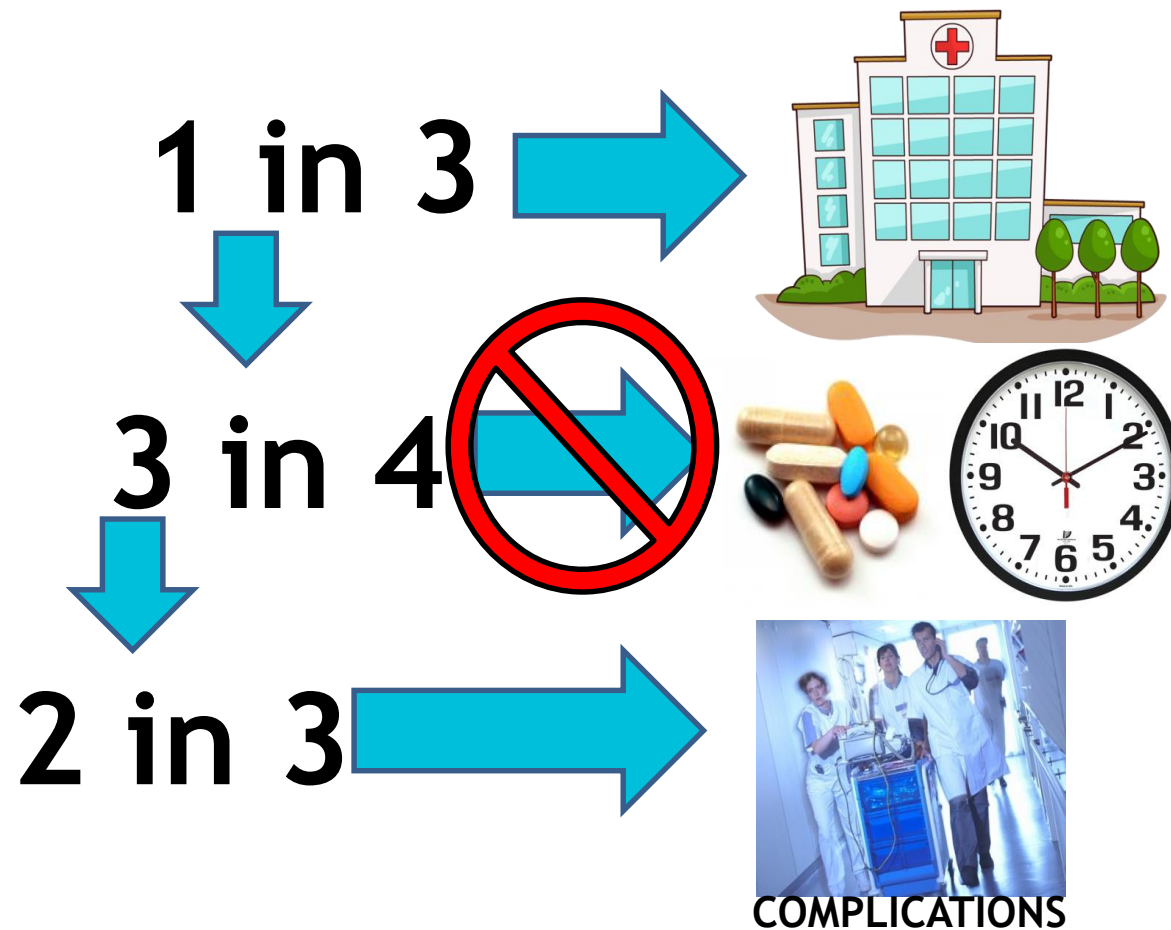
“The pharmacy will  
have my PD meds.”

“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



100 patients	1 Million PWP
<b>33</b> admissions	<b>330,000</b> admissions
<b>25</b> Medications changed	<b>247,500</b> Medications Changed
<b>16</b> complications	<b>163,350</b> complications

MJ Aminoff, et al. *Parkinsonism and Rel. Disord.* 2011. 17:139-145. KN Magdalinos, et al. *Parkinsonism and Rel. Disord.* 2007 Dec;13(8):539-40. OHH Gerlach, et al. *BMC Neurol.* 2012.

- People with Parkinson's are hospitalized 44% more than their peers without Parkinson's.<sup>1</sup>
- People with Parkinson's 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>

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.



# 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.

# Why Is This Happening?

**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.

# 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.

# How PD Patients Enter Hospitals

## Emergency Admissions

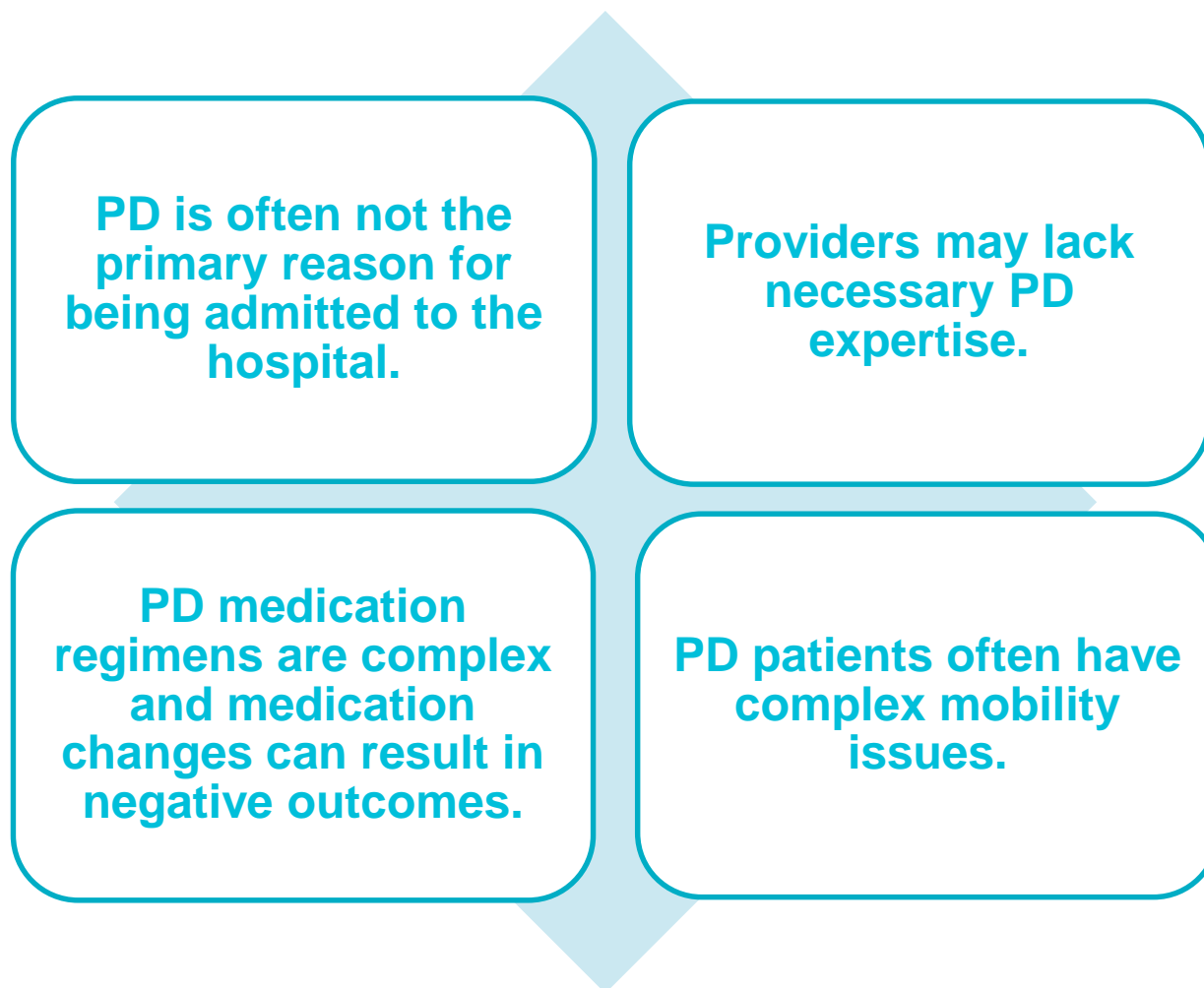
- First Responders
- ER Nurses
- ER Physicians

## Planned Admissions

- 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



# 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.**

## 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

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

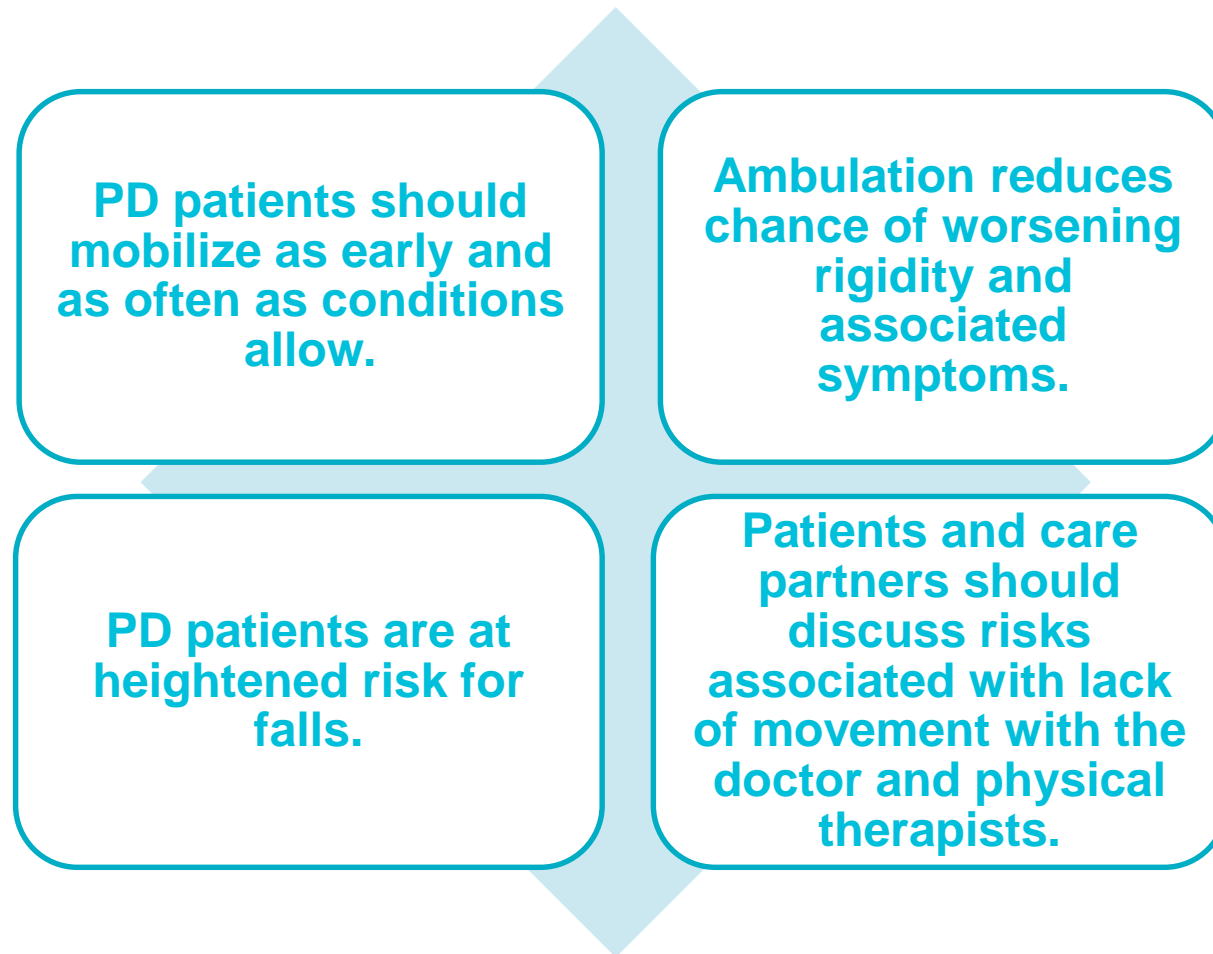


Anti-Parkinson medications are as necessary to a Parkinson's patient as insulin is to a diabetic.

“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.”

MJ Aminoff\*, et al., Management of the hospitalized patient with Parkinson's disease: Current state of the field and need for guidelines. *Parkinsonism and Related Disorders*. 2011

# Mobility Challenges



# 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.**

# ***Aware in Care* Is Here to Help**

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.

**Aware  
in Care**  
Parkinson's Foundation

**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.



## The right\* medications, on time



***\*No contraindicated medications-  
Never Haldol***

# 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](https://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 question 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!



# 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.).



## Learn more:

- Watch the archived *Aware in Care* webinar.
- Download the support group discussion guide.
- Order your kit.
- Spread the word!
- <https://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/Patient-Safety-Kit/Kit-Contents>

Call Our HELPLINE: 1-800-4PD-INFO (473-4436) [Español](#) [About Us](#) [In Your Area](#) [Search](#) [Donate](#)

**Parkinson's Foundation**  
Understanding Parkinson's Living with Parkinson's Expert Care Research Get Involved Ways to Give

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### Helpline

[Ask the Doctor Forums](#)  
[Expert Briefings Webinars](#)  
[Patient Safety Kit](#)  
- Kit Contents  
- Resources  
- Who Can Use the Kit  
- Order a Kit  
[Podcasts: Substantial Matters](#)  
[The Edmond J. Safra National Parkinson's Wellness Initiative](#)  
[Order Publications](#)

### Patient Safety Kit

The Parkinson's Foundation launched the *Aware in Care* campaign in 2011 to help people with Parkinson's disease (PD) get the best care possible during a hospital stay. According to a recent study, three out of four people with Parkinson's do not receive medications on time when staying in the hospital. With more frequent hospital visits and a high sensitivity to the timing and dosing of PD medications, people with Parkinson's face great risks in the hospital.

To protect, prepare and empower people with Parkinson's before, during and after a hospital visit, we developed the free *Aware in Care* kit with tools and information to share with hospital staff during a planned or emergency hospital visit.

*Aware in Care* kits can be requested from your [local Parkinson's Foundation Chapter or Center of Excellence](#). If you do not live in an area with a Chapter or center, you can order a kit online.


If you live in Canada, call [Parkinson Alberta](#) at 1-877-243-9992 or [Parkinson Society British Columbia](#) at 1-800-668-3330 to order your kit.

### Online Seminar

Register for our next Expert Briefings webinar: *Depression & PD: Treatment Options*, taking place Nov. 21, 2018.

[Register Now](#)

**Aware in Care: Real Stories**





## **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.

# 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.

**Learn more online at [Parkinson.org](https://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.***



# *Aware in Care Is Made Possible by...*



EDMOND J. SAFRA  
PHILANTHROPIC FOUNDATION

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ACADIA<sup>®</sup>  
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**Medtronic**

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