



Community Empowerment *Aware in Care Kit*

Aware in Care Ambassador

Gloria Friedman

Gloria@gsfriedman.com

www.gsfriedman.com

Better Lives. Together.

The Parkinson's Foundation Mission

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.



What We Do:

For Today

Improving care for everyone living with Parkinson's disease

For Tomorrow

Advancing research toward a cure

For Us All

Building on the energy, experience and passion of our global community



For Today: Learn More To Live Better

We help people live well with PD by providing families with free resources including: educational books, webinars, podcasts, a life-saving hospitalization kit and our toll-free Helpline, staffed by Parkinson's specialists who answer nearly **20,000 calls annually**.



For Tomorrow: Investing In Breakthroughs

We invest more than **\$10 million annually** to support the most talented minds to explore what causes PD, how to treat it and how to cure it.



For Us All: Connecting Our Community

The Parkinson's Foundation is the nation's largest **community for people living with PD**. Consisting of Centers of Excellence, local chapters, volunteers, advocates and staff across the country who advance our research, care, advocacy and education efforts to improve lives and advance research toward a cure.



The Aware in Care initiative is designed to help people with Parkinson's get the best possible care in the hospital.



Hospitals are safe, right?

True or False

~~"They will steal all my
neurologist"~~

**"The pharmacy will
have only PD
medications"**





**"Not all staff
understand the
symptoms of PD."**

"They will give me my medication on time."



**"They will know the
contraindicated
medications."**

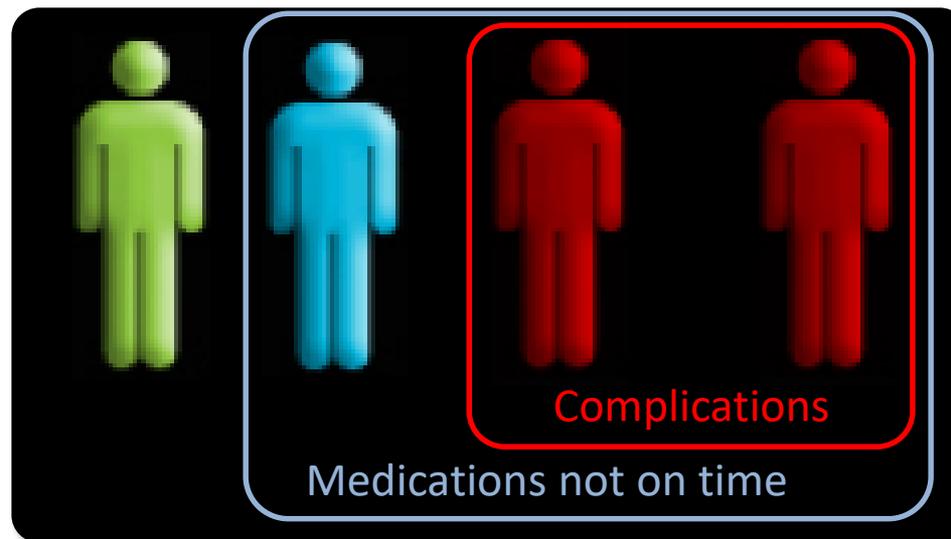


- People with Parkinson's are hospitalized 44% more than their peers without Parkinson's.¹
- People with Parkinson's suffer avoidable complications at a higher rate than non-PD patients.^{1,2,3}
- This yields longer hospital stays than non-PD patients.^{1,3}

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.

This summer a friend was hospitalized for heart problems. He was sent to a rehab and the rehab sent him back to the hospital because of blood pressure fluctuations. It took three days for the hospital to determine it as a Parkinson's issue.

My back surgery

- Didn't record instructions off medicines
- Didn't have Azilect
- Before surgery Sinemet

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.

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**.
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.

What have we learned today?

I need to use the kit during planned
Hospital stays



I need to use the kit during
emergency
Hospital visits



I need to bring the kit to my
annual doctor appointment



Thank You!



Newly Diagnosed: The Need

- More than **60,000 individuals** are diagnosed with PD every year.
- **Close to 50% of people with Parkinson's and their care partners** leave the doctor's office following a diagnosis without resources or information on what the future holds.
- No one should face a diagnosis without **the tools and information they need** to begin to make sense of the disease and what it means for them.
- To close the gap, The Parkinson's Foundation announced the **Newly Diagnosed: Building a Better Life with Parkinson's Disease** campaign to arm people who are newly diagnosed with the knowledge, tools and resources they need as they begin their own personal journey with the disease.



Targeted Tools and Resources to Begin Your Journey to Living Well with PD

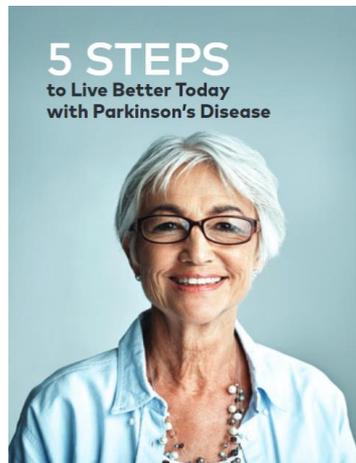
Newly Diagnosed Website Landing Page



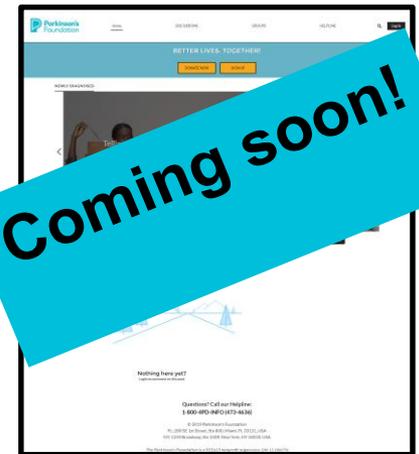
Video: Advice for those Newly Diagnosed with PD



Newly Diagnosed Kit

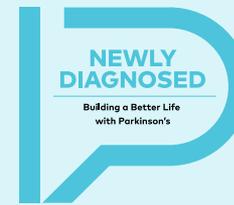


Online Community Forum



And other targeted content including podcast series, Expert Briefings, and additional relevant resources for someone newly diagnosed.

You are not alone. We are here to help.



Find newly diagnosed resources and connections through the Parkinson's Foundation:



Talk with a PD information specialist by calling **1.800.4PD.INFO (473.4636)** (English/Español)



Access resources tailored to those newly diagnosed at **[Parkinson.org/NewlyDiagnosed](https://www.parkinson.org/NewlyDiagnosed)**



Connect with others living with PD through our online community (connect through **[Parkinson.org](https://www.parkinson.org)**)

Or email us at **NewlyDiagnosed@Parkinson.org**