



# Making Hospitals Safer for People with Parkinson's Disease

The Parkinson's Foundation  
Hospital Care Initiative

# Contents

Message from the CEO	<b>3</b>
Executive Summary	<b>4</b>
Hospital Care Initiative: A Roadmap for Systemic Change	<b>6</b>
Audience	<b>7</b>
Understanding the Issue	<b>8</b>
Key Recommendations to Improve Hospital Care	<b>10</b>
Next Steps: Driving Change and Better Care	<b>19</b>
Acknowledgments	<b>20</b>
Appendix A: Clinical Recommendations for Hospital Care of People with Parkinson's	<b>24</b>
Appendix B: Checklists for Clinicians	<b>33</b>
Appendix C: The Hospital Convening	<b>39</b>
Endnotes	<b>45</b>

# Message from the CEO

Each year, nearly one-third of the one million Americans living with Parkinson's disease (PD) will experience a hospital encounter. Despite the frequency of these encounters, delivery of quality hospital care for people with Parkinson's remains elusive. Research from our Parkinson's Outcomes Project shows that people with PD are not only at increased risk for hospitalization, they are also more likely to have avoidable complications, worsening PD symptoms, longer stays and poorer health outcomes during and following hospitalizations. We can close these gaps in care by aligning the self-advocacy efforts of people with PD with clinical education and standardized care protocols in every hospital. In fact, we consider this work critical to our mission.

The Parkinson's Foundation has a long history of encouraging and supporting self-advocacy for people with Parkinson's and their care partners. Still, we know that self-advocacy is just one piece of this puzzle. Making hospitals safer for people with PD requires changes at the health system level in clinical care, culture, technology, education and policy. Recognizing a need for action, the Foundation launched our **Hospital Care Initiative**, an effort that focuses on improved hospital care for people with PD.

We convened clinicians, hospital care experts, policy makers, experts on Parkinson's disease, and people with Parkinson's and their care partners for data-driven discussions on **establishing best practices designed to increase hospital safety and improve hospital care**. Through this convening, subsequent working group meetings, and ongoing dialogue with clinical experts, community leaders and other key stakeholders, we explored successful models of care and created a set of recommendations and protocols to help hospitals provide better Parkinson's care.

I am pleased to present these recommendations for caring for people with Parkinson's in the hospital setting. We hope that clinical and administrative staff working across health systems will put these practices in place. Improving hospital care quality for people with PD is central to our mission of making life better for people with Parkinson's and their care partners.

Thank you for helping us make hospitals safer for people living with Parkinson's.



**John L. Lehr**  
President & Chief Executive Officer  
Parkinson's Foundation

# Executive Summary

This report highlights the challenges and risks inherent in hospital care for people with Parkinson's disease (PD) and provides recommendations for clinical and administrative staff. These protocols will help hospitals put in place the recommended best practices to make care safer for people with PD and in doing so, aim to improve health outcomes and quality of life.

## The Challenges

The Parkinson's Foundation created its Hospital Care Initiative to improve hospital safety for people with PD. This effort builds on the Foundation's long history of leadership in driving awareness of hospital safety for people with PD and the need to promote further change. During the last decade, the Foundation has moved this work forward through launching tools and programs, such as the Aware in Care hospital safety kit. The Foundation has also provided multidisciplinary clinician training and education, and funded pilot hospital care improvement programs and clinical research.

Today, the Foundation's Hospital Care Initiative continues to build on this work with a focus on three critical challenges faced by people with PD as they encounter a hospitalization:

- **Medication mismanagement:** Each year, an estimated 167,000 people with PD will experience an avoidable complication due to improper medication management in the hospital.
- **Clinical complications:** More than a quarter of hospitalized people with PD will experience motor symptom deterioration.
- **Lack of care standards:** Inconsistent policies and limited understanding of the medication needs of people with PD lead to complications and poorer health outcomes.

## The Recommendations

In 2019, the Foundation held the Hospital Convening, which brought together experts in hospital care and Parkinson's disease, policy makers, and care partners. Through this Convening, subsequent working group meetings, and input from clinical leaders and other stakeholders in the PD community, the Foundation created recommendations in six key focus areas to improve hospital care for people with PD:

## 1. Improve Clinical Care

Recommendations include protocols for fall risk management and medication management at admission and during care.

## 2. Standardize Care Processes and Protocols

Recommendations include checklist protocols for medication reconciliation, hospital admission, perioperative care and hospital discharge.

## 3. Mobilize Technology

Recommendations include protocols for creating visible identifiers in the electronic medical record, notification of the primary PD care provider upon patient admission and consistent distribution of PD medications and warnings about contraindicated medications.

## 4. Promote Education

Recommendations include protocols for implementing patient chart identifiers for people with Parkinson's, training staff on specific PD care needs (including medication timing and improper medication substitutions) and routine education of hospital team members through the Parkinson's Foundation Team Training program.

## 5. Transform Culture

Recommendations include protocols for identifying clinical champions to foster dialogue at the hospital level, honoring the role of the person with Parkinson's and their care partner as experts in managing the disease, implementing policies allowing self-administration of PD medications when appropriate and establishing interdisciplinary team meetings to align specialty care for people with PD.

## 6. Drive Policy

Recommendations include standardizing hospital care delivery practices for people with Parkinson's, establishing a Joint Commission Advanced Certification in Parkinson's Care and improving health outcomes through the uniform adoption, regulation and standardization of Parkinson's care criteria.

## The Next Steps

These recommendations offer a roadmap of actionable solutions designed to make hospital care safer so that more people with Parkinson's have the best health outcomes and quality of life. As a longstanding leader in driving better care, the Parkinson's Foundation is committed to moving these solutions forward by promoting dissemination and implementation of these recommendations, continued evidence generation through research, and ongoing engagement of people with Parkinson's as our partners in these efforts.



# Hospital Care Initiative: A Roadmap for Systemic Change

Each year in the United States, nearly one-third of people with Parkinson's disease (PD) will have a hospital encounter. All too often these visits, whether an unplanned trip to the emergency room or a planned hospital admission, lead to avoidable complications, longer hospital stays and poorer health outcomes. There are multiple factors that lead to this crisis in care, including a lack of uniform policies and standards; inadequate training of clinicians and hospital staff; and low awareness and self-advocacy among people with PD.

As a longstanding leader in driving better care to improve health outcomes and quality of life for people with PD, the **Parkinson's Foundation's Hospital Care Initiative** aims to ensure that all people with PD can trust that the hospital care they receive is of the highest quality and that they are heard, valued and respected as partners in their own care.

The Hospital Care Initiative builds upon more than a decade of experience in improving hospital safety for people with Parkinson's. This work includes engaging the PD community in the importance of self-advocacy through the [Aware in Care](#) initiative; multi-disciplinary clinician training and education; generating research findings through the [Parkinson's Outcomes Project](#); and funding pilot hospital care improvement programs.

The Parkinson's Foundation is driving the systemic change needed to accelerate better health outcomes and improved quality of life for people with Parkinson's who experience hospital encounters. Adoption of the best practices described in this report is expected to lead to greater quality care and a reduction in the cost of health care at the institutional and individual levels.

Central to this effort is the creation of a set of recommendations, with a focus on five core areas: clinical care, technology, education, culture and policy. These recommendations were developed through:

- Internal and external research and survey findings, with a focus on collaboration with our [Global Care Network](#);
- Learnings from the Foundation's work to date;
- Outcomes from a hospital care convening of experts in the field;
- Continued conversations with the Hospital Care Advisory Committee, comprised of clinicians, people with Parkinson's, and their care partners, and;
- Input by stakeholders from across the PD community.

## Audience

These recommendations are intended to be used by hospital staff, including but not limited to physicians, specialty care providers, nurses, and hospital administrators, to improve hospital care for people with Parkinson's disease. They are also intended to serve as a tool for clinicians who work closely with people with PD, as well as a resource for the community of people with Parkinson's and their care partners.

### Being 'Aware in Care' and Staying Safer in the Hospital

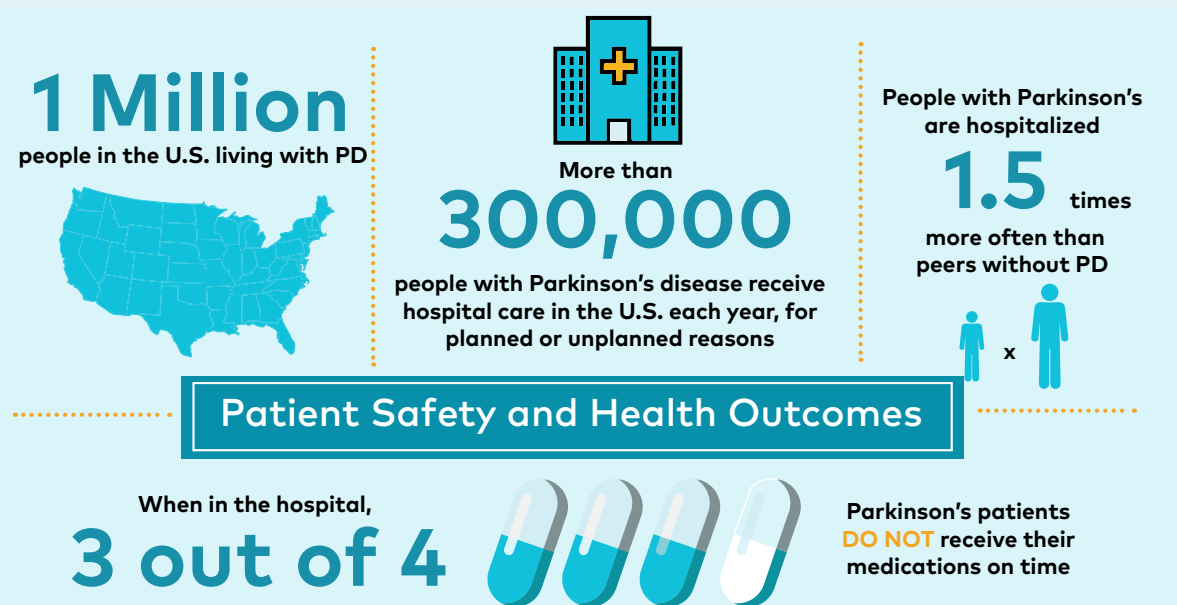
**The Parkinson's Foundation Aware in Care** initiative ensures that people with PD and those who provide support and care have the tools they need to navigate hospital encounters. Central to this effort is the Aware in Care hospital safety kit, with more than 100,000 kits in use today. This initiative leverages the voices of people with PD by training more than 150 volunteer Ambassadors who actively spread the word throughout the community about hospital safety. When surveyed, more than 95 percent of hospital safety kit users found the tool useful, and 80 percent felt confident educating hospital staff about their needs. Learn more at [Parkinson.org/AwareInCare](https://Parkinson.org/AwareInCare).



# Understanding the Issue

In 2009, the Parkinson's Foundation launched the Parkinson's Outcomes Project, a seminal clinical study in partnership with our Global Care Network. This long-term clinical registry captured the experiences of more than 13,000 people with Parkinson's and their care partners over time on topics such as medications, treatment plans, exercise, lifestyle measurements and hospitalizations.

By gathering these individual experiences and looking at them collectively, new and better ways to provide and manage care emerged. In addition, a survey across the Global Care Network found that 94 percent of Centers were not confident that patients received Parkinson's medications on time when hospitalized. These internal findings of people with PD as well as clinical partners were complimented by an analysis of external research findings. Together they paint a clear picture of the challenges and dangers inherent in hospital care for people with Parkinson's.



## Medication Mismanagement

Annually, medication mismanagement affects an estimated 300,000 of the one million people with Parkinson's in the U.S. <sup>a, b</sup> Of these individuals who have had a hospital encounter, it is estimated that 167,000 will experience related complications that could have been avoided with proper medication management. <sup>c</sup>



- Clinical staff do not adhere to a PD patient's at-home medication schedule.<sup>c, d, e, f, g, h, i</sup>
- Medications that worsen PD symptoms are sometimes given with no standard warnings for contraindicated medications.<sup>c, e, f, h, i, j, k, l, m</sup>
- Knowledge gaps exist across hospital staff around the unique medication and care needs of people with PD.<sup>g, l, m, n, o</sup>
- There is no defined process for notifying physicians who care for people with PD that their patient has been admitted to the hospital.<sup>e, g, i, j, k, l, m, p, q</sup>

## Clinical Complications

When compared to people without Parkinson's, those with PD are hospitalized more frequently and typically:

- Experience greater length of hospital stays (up to 14 days longer).<sup>n, r, s, t, u, v, w, x, y, z</sup>
- Experience more complications (28% of hospitalized people with PD experience motor symptom deterioration)<sup>aa</sup> and greater mortality (3.9%).<sup>ab</sup>
- Are more likely to receive post-hospital care at a nursing home or other facility instead of being discharged to their home (62.9% of people with PD).<sup>aa</sup>
- Have higher rates of hospital readmission (more than half return to the hospital or Emergency Department within one year).<sup>b</sup>



Complications result in increased length of stay

Patient hospital length of stay can be up to **14** days longer than their peers without PD



**28%** of patients with Parkinson's experience deterioration of motor symptoms

**Readmissions**



returned to the hospital or ER within one year

**Discharge**



in the U.S. were discharged to a facility

**Mortality**



in the U.S. died during their hospital stay

Parkinson's patients have worse disease severity and symptoms at discharge, compared to admission



## Lack of Care Standards

Inconsistencies across the hospital care continuum are driven by a lack of nationally recognized care standards and hospital protocols for people with PD including:

- A lack of existing “triggers” indicating a patient’s Parkinson’s doctor should be contacted upon hospital admission (just 25% of hospitals currently have such a trigger).<sup>c, e, f, h, i, j, k, o, p</sup>
- A lack of proper surgical intervention policies addressing the administration of Parkinson’s medications, leading to any major interruptions before, during or after surgery.<sup>c, e, f, h, i, k, o, p</sup>
- Limited hospital staff awareness of how certain medications can worsen Parkinson’s motor symptoms — or are contraindicated for people with PD<sup>e, g, h, j, k, l, m, n, o</sup> (70% of hospital staff were unaware of this information).<sup>b</sup>
- Limited understanding of and ability to adequately address the sensitivity of the medication administration needs of people with PD.<sup>c, d, e, f, g, h, i</sup>
- Inadequate staff monitoring of common hospital complications including falls, orthostatic hypotension and delirium.<sup>c, e, f, k</sup>

The lack of care standards and protocols leads to unnecessary complications and poorer health outcomes for people with Parkinson’s and results in more expensive hospital and emergency room care, costing the U.S. healthcare system \$7.19 billion annually.<sup>ac</sup>



## Key Recommendations to Improve Hospital Care

The Parkinson’s Foundation has increased our commitment to improving hospital care, naming the Hospital Care Initiative as one of our top priorities. The following are critical recommendations to improve care through six key focus areas: Clinical Care, Care Processes and Protocols, Technology, Education, Culture and Policy.

## Clinical Care

The full text for each set of clinical recommendations is available in the [Appendix](#).

### Fall Risk Management

**Problem:** Limited movement in people with Parkinson's causes motor symptoms to become more pronounced, which increases fall risk. These motor symptoms include:

- Festination: short, rapid steps during walking
- Freezing: stopping in a certain position while walking or turning
- Neurogenic orthostatic hypotension (nOH): blood pressure drops occurring with changes in position
- Postural instability: difficulty maintaining and regaining balance
- Rigidity: stiffness occurring on one or both sides of the body

#### Recommendations:

- Early mobilization (unless contraindicated) should be part of a nurse-driven mobility protocol.<sup>c, e, j</sup>
- Physical therapy and occupational therapy consultations should occur for all hospitalized people with PD<sup>c</sup> (Note: therapists should consider "on-off time" when scheduling rehabilitation therapy).
- Outpatient rehabilitation therapy referrals should be arranged at discharge (for people who are returning to their home).

### Medication Management

**Problem:** Medications are not managed properly for nearly three-quarters of

### Improving Medication Management (MODS)

Improper medication management during hospital visits is a critical care concern for people with Parkinson's and remains one of the most pervasive challenges for managing their hospitalization.

For people with PD, mismanaged medications fall into four distinct categories: missed, omitted, delayed or substituted (represented below by the acronym MODS).

**Missed (M):** Parkinson's medications are not given. This occurs most often when people with Parkinson's are hospitalized for conditions unrelated to the disease, such as a heart attack or broken bone after a fall.<sup>o, bb, ar, as</sup>

**Omitted (O):** Prior to surgery, clinicians may incorrectly decide to withhold Parkinson's medications because a patient is designated NPO (nothing by mouth).<sup>o, at, au</sup>

**Delayed (D):** Parkinson's medications are given on a different schedule than the dosing schedule designed by a patient's primary PD doctor. Sometimes, hospitals distribute PD medications according to the facility's standard schedule based on the number of doses a patient should receive in 24-hours. In other cases, Parkinson's medication may be given an hour early or late, shifting the timing of medication in a way that is harmful for a person with PD.<sup>o, bb, ee, ff, gg, hh</sup>

**Substituted (S):** Clinicians may assume that certain Parkinson's medications are interchangeable — for example, that a generic formula and a name brand medication are the same — when that is not the case. Clinicians may also assume that an immediate release medication may be substituted for a continuous release formula.<sup>hh</sup>



the 300,000 people with PD who experience a hospital encounter each year. Mismanaged medications can lead to:

- Exacerbated Parkinson's symptoms
- Medical emergencies
- Dyskinesias (involuntary muscle movements)<sup>d, f, h, bb, hh, ad, ae, af, ag, ah, ai</sup>

Additionally, certain medications used in hospitals (notably, antipsychotic, antiemetic, antidepressant, analgesic and anesthetic medications) can worsen PD motor and non-motor symptoms. These medications typically have anticholinergic or dopamine receptor blocking properties or may negatively interact with PD medications. Administration of these inappropriate or contraindicated medications can make Parkinson's symptoms worse and cause complications that lead to poorer health outcomes. Further challenges to managing medications in people with Parkinson's include:

- Dysphagia (swallowing disorders)
- Orders indicating nothing by mouth (NPO) during admission in preparation for testing and in preparation for surgery<sup>a, b, ee, kk, aj</sup>

**Recommendations:** Establish clear and consistent hospital best practices to reduce the risks associated with medication mismanagement. Eliminate rigidity in hospital medication schedules for patients with Parkinson's through clinician education and by ensuring people with PD and their care partners are encouraged to self-advocate.

### At Admission

- Speak with patients about their at-home Parkinson's management and their typical symptoms
- Notify the primary PD care provider that the patient has been admitted
- Complete a medication reconciliation that includes consultation with the patient and/or care partner and verification of the home schedule, any special instructions and any over the counter medications
- Review a list of contraindicated medications and special considerations for PD care

### During Care

- Consult with the primary PD care provider before substituting or stopping Parkinson's medications (including substituting immediate release and continuous medications). Abrupt medication changes may cause parkinsonism-hyperpyrexia syndrome, a life-threatening condition that resembles neuroleptic malignant syndrome.

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**"My husband went to a major well-known hospital for an MRI last week and stayed two days. Staff were given a list of his medications and his medication schedule, but he missed four consecutive doses of his Parkinson's medications. He has now gone back to having problems that took three months to conquer."**

— Care partner for person with Parkinson's

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- Assess whether those with dysphagia or who have nothing by mouth (NPO) status prior to surgery or testing should continue PD medications with a small sip of water. If swallow function is severely impaired, consider alternate medications as appropriate and consult with a nutritionist and speech language pathologist as needed. Refer to the Appendix to see full recommendations regarding alternate medications and methods of delivery.
- Mitigate system-based medication timing errors by updating charts and electronic records to ensure that at-home dosing schedules take precedence over hospital standard distribution schedules. Further, medication timing should consider how dietary factors (for example, eating protein) and patient meal timing impact medication absorption.
- Consider motor fluctuations and "on-off time" when administering medications and scheduling therapies and procedures.
- Educate clinical staff on typical movement patterns during "off time" to avoid inappropriate treatment.

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**"Getting medications on time involves a continuous fight, repeated every shift, to control the administration of my Parkinson's disease medications. This even happens at hospitals with major Parkinson's Foundation Centers of Excellence."**

— Aware in Care kit user

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## Hospital Care Convening

The Parkinson's Foundation held an expert convening on December 6, 2019, in New York, NY, with the goal of better understanding hospital care needs for people with Parkinson's and identifying best practices that enable consistent quality care and improve health outcomes. Participants included clinicians from within and outside the Foundation's Global Care Network, hospital administrators, policy makers, people with PD and care partners. (See Appendix for full list of attendees.)



This convening:

- Identified common barriers to excellent hospital care for people with Parkinson's
- Explored successful institutional care models to understand the drivers behind their achievements
- Reached consensus on top recommendations to improve care
- Developed strategies for successful implementation and adoption of these recommendations

# Standardization of Care Processes and Protocols

**Problem:** Lack of standardized care processes and protocols across hospital systems create inconsistencies in care.

**Recommendation:** Develop and use PD care specific checklists to standardize hospital processes, ensure adherence to medication and care protocols, and more effectively manage care for people with PD.

The Parkinson's Foundation, in collaboration with Hospital Care Convening stakeholders, developed a set of checklists as a companion to the Clinical Care recommendations provided in this report. Checklists include:

- Emergency Department Medication Reconciliation
- Hospital Admission
  - Notify primary Parkinson's care doctor
  - Reconcile medications
  - Assemble team of specialty care providers
- Perioperative
  - Pre-surgical Parkinson's medication plan
  - Medication management for day of surgery
  - Post-surgical Parkinson's medication plan
- Hospital Discharge

[See Appendix](#) for downloadable and printable checklists

## Technology

**Problem:** The lack of technical features to support data capture and best practice PD care combined with the lack of standardized technology used in the hospital setting results in substandard and inconsistent care delivery and care coordination.<sup>ak, al, am, an, ao, ap</sup>

Standardized use of technology, particularly Electronic Health Records (EHR) across hospital systems, is critical to supporting best practices and improving PD hospital care. The Parkinson's Foundation and Epic, one of the largest software companies managing hospital medical records in the country, established a working group to develop a clinical program using standard EHR

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**"The partnership between the Parkinson's Foundation and Epic will simultaneously help us improve PD care and allow for standardization in clinical data gathering that will enable us to understand where expert care is happening versus where it is lacking."**

— Ihtsham ul Haq, MD, FAAN, Division Chief Movement Disorders, Department of Neurology, University of Miami Miller School of Medicine, a Parkinson's Foundation Center of Excellence, Epic and Parkinson's Foundation Work group member

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## Defining Electronic Health Record (EHR) Features and Best Practices in PD Care



Together, the Parkinson's Foundation and the health care software company Epic, responsible for about one-third of the EHR systems in U.S. Hospitals, established the Movement Disorders Sub-committee working group as a part of Epic's Adult Neurology Steering Board. The sub-committee is working to identify and standardize best practices within the Epic technology system and create built in solutions to ensure that quality PD care can be easily implemented across the Epic network. The group's goal is to build solutions within Epic, based on best practices for Parkinson's care, established through the Convening, stakeholder expertise and subsequent work.

features and functionality to improve PD care.

In addition, following a survey of our Centers of Excellence, the Foundation determined that several Centers of Excellence were implementing needed changes to their EHR systems to improve the hospital experience for people with PD. These learnings all informed our technology recommendations.

### Recommendation:

- Create an identifier that is always visible in the patient's electronic record to ensure a person with Parkinson's can be easily identified as having PD throughout their hospital stay, regardless of whether their stay is PD-related
- Establish a mechanism to notify the primary PD care provider (Movement Disorder Specialist/Neurologist) upon the patient's admission
- Create systems to ensure that medications are administered consistent with at-home schedules including the following:
  - Require custom input for all Parkinson's medications, protecting PD medications dosages and schedules against the default hospital administration schedule ('x' times per day")
  - Create system reminders on the importance of distributing medication at the prescribed time, rather than the standard one hour before/after window
  - Require completion of medication reconciliation *prior to* admission
- Establish warnings/redirects for contraindicated medications
- Design a discharge order set/summary sheet to be provided to the person with Parkinson's and sent to their primary Parkinson's care provider

## Education

**Problem:** Current clinician training involves minimal Parkinson's disease-specific curriculum or patient-specific knowledge. <sup>g, l, n, o, p</sup>



## Recommendations:

- Establish and train staff on a methodology for flagging Parkinson's disease in the patient chart, accompanied by a detailed checklist of clinical tasks and action items
- Implement trainings for all hospital departments with a focus on their specific role in caring for people with PD
- Train staff on the critical importance of medication timing for people with Parkinson's including specifically pharmacy-focused training on the importance of medication reconciliation, contraindicated medications and improper substitutions
- Create nurse-specific training on medication distribution, mobility needs, signs of delirium and the impacts of "on time" and "off time"
- Train physical therapists, occupational therapists and speech-language pathologists on the importance of a timely consult and distributing therapy aligned with a patient's "on time"
- Develop surgical team training on the nuances of NPO (no medications taken orally) in people with PD and develop recommendations for anesthesiologists on care planning before, during and after surgery
- Establish protocols for routinely educating hospital team members through the [Parkinson's Foundation Team Training](#)

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**"Parkinson's education for hospital staff is an essential piece of delivering improved care. With greater staff education and awareness of Parkinson's, hospitals can implement practices and policies that enable staff to use this new knowledge and provide better care for their patients with Parkinson's disease."**

— Benjamin Walter, MD, MBA, Movement Disorders Specialist; Section Head, Movement Disorders; Medical Director, DBS Program; Associate Professor of Neurology; Cleveland Clinic

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## Professional Education and Training for Better Hospital Care

The Parkinson's Foundation has trained more than 300 nurse faculty through the [Edmond J. Safra Visiting Nurse Faculty Program](#), a 50-hour accredited "train the trainer" program. This initiative emphasizes hospital safety, and nurse faculty in turn have educated an estimated 24,000 nursing students each year. Many have also been awarded Foundation grants focused on improving hospital care.

Additionally, nearly 2,500 health care professionals have attended the "Hospitalization in Parkinson's Disease" lecture through our [Parkinson's Team Training program](#). Due to the initiative's success, the Foundation replicated and expanded this training model to broader clinicians. In April 2021, the Foundation trained an additional 120 health professionals who provide care annually to more than 12,000 people with PD and an estimated 10,000 care partners.





## Culture

**Problem:** There is misalignment between hospital policies designed to improve care and efficiency and the daily actions of clinical staff. Information “silos” in shift turnovers, existing hospital hierarchies and hospital staff and clinician work culture can amplify this problem.

### Recommendations:

- Identify clinical champions inside the hospital to foster open and transparent dialogue about the importance of understanding PD specific care needs
- Evaluate current policies and practices that could be problematic in providing optimal care for patients with PD
- Create opportunities for ongoing conversations between healthcare system leaders and the Parkinson’s community regarding lived experiences in the community hospital setting
- Recognize patient engagement as a best practice, honoring the role of the patient and care partner as experts in managing Parkinson’s disease and inviting them into the care conversation
- Implement self-administration of Parkinson’s medication when appropriate, recognizing the care partner as an expert in PD medication administration



*Six hospital staff members at the University of Rochester Medical Center, a Parkinson's Foundation Center of Excellence took part in Team Training for Parkinson's through the Centers of Excellence Community Outreach Resource Education (CORE) grant Parkinson's Disease Hospital Optimization Program in October 2019. This grant funds training to help improve the hospital experience and quality of care for people with Parkinson's and their care partners.*

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**“I’ve never run into a situation where someone says, ‘I don’t want to shift to better care.’ I truly think this is an education gap.”**

—Emily P. Peron, PharmD, MS, BCPS, BCGP, FASCP, FCCP, Associate Professor of Geriatrics at Virginia Commonwealth University School of Pharmacy

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## Champions Help Drive Change

Establishing a one or two Parkinson’s care champions within a hospital setting has several purposes. Champions can highlight relevant information for hospital leadership, identify examples of problematic care in their specific hospital, provide appropriate pressure to influence decision making, ensure protocols are implemented and help leaders navigate cost and capacity challenges. Once identified these individuals serve as the team coordinator, working to ensure that new protocols continue to be implemented and can help navigate the logistical challenges around capacity and cost.



- Promote open communication between the clinical care team and pharmacy team to ease administrative and practical burdens in appropriate medication management for people with Parkinson's
- Establish interdisciplinary team meetings to ensure that care goals for people with PD align across administrative, clinical, specialty care and pharmacy teams. Recommended meetings include weekly meetings of physical therapy, occupational therapy, speech therapy, respiratory therapy, nursing staff and rehab physicians, as well as related integrative therapy providers
- Establish clinical recommendations for people with Parkinson's including:
  - Dietary considerations
  - Identifying contraindicated medications
  - Medication management and dosing schedules
  - Mobilization and mitigation of fall risk
- Create policies to bring Parkinson's medications onto the hospital formulary and to facilitate:
  - Consultation with the primary Parkinson's care physician
  - Medication reconciliation
  - Use of patient-supplied medications
  - Medication ordering for admitted patients

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**"Every rehab hospital should understand the importance of timing of delivery of PD medications, but that one-hour window that our initial Joint Commission surveyor told us was acceptable for most places shouldn't be good enough."**

— Christian Benedict, DPT, LSVT-BIG, Physical Therapist, Kansas Rehabilitation Hospital

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## Policy

**Problem:** There is a lack of sufficiently rigorous and standardized PD certification criteria for hospital care that results in inconsistent standards and hospital care delivery practices.<sup>PP</sup>

**Recommendations:** Establish a Joint Commission Advanced Certification in Parkinson's Care.

The Joint Commission accredits and certifies healthcare organizations nationally, mandating specific criteria in select disease areas at both a basic and advanced level. For Parkinson's disease, hospital certification is only available at the basic level which means hospitals define and prioritize their own select criteria for certification. Advanced certification criteria, however, are established by the Joint Commission and result in uniformly adopted, regulated, and standardized disease criteria resulting in better health outcomes and higher quality care.

Advance disease criteria exist for Stroke care,<sup>99</sup> which serves as an example and model of success to follow. The Joint Commission in collaboration with the American

Heart Association and American Stroke Association developed four advanced stroke certifications for hospital care including acute, primary, thrombectomy-capable, and comprehensive stroke center care which have significantly improved care outcomes and reduced healthcare costs for the stroke population.

## Next Steps: Driving Change and Better Care

The Parkinson's Foundation is committed to ensuring that people with Parkinson's who are cared for in a hospital setting have the best outcomes and quality of life. Whenever hospitals are ready to begin working towards improving care, the Foundation will be ready with tools and resources to aid in the process. Over the next four years, the Foundation will implement a cross-cutting strategy to further adoption of the recommendations contained within this report. This path forward includes:

- Improving clinical care through the investment in a targeted campaign to speed the use of the Parkinson's Foundation suite of medication management tools in hospital settings. This campaign will leverage our 47 Centers of Excellence throughout the globe as well as our trained cadre of volunteer Aware in Care Ambassadors who work in communities across the U.S. to engage and educate the Parkinson's community.
- Furthering the implementation of standards of care by funding research to generate evidence linking policy and protocol changes with improved hospital-related health outcomes. The Foundation is currently conducting a two-year Inpatient Hospital Research study in collaboration with the Cleveland Clinic, a Parkinson's Foundation Center of Excellence to examine the impact of adopting the Foundation's recommendations on patient outcomes.
- Accelerating the implementation of technology solutions by leveraging our learnings and collaboration to date with Epic, building on that work, and seeking new partnerships with other leading technology companies that enable the identification of a person with PD while in the hospital and provide critical information to clinicians managing care.
- Promoting Parkinson's education among hospital-based clinical staff through the provision of accredited, continuing medical education that builds on the Foundation's portfolio of health professional trainings that, to date, have reached over 21,000 clinicians and more than 100,000 clinical students. To ensure that the lived hospital experiences of people with PD are incorporated into the educational courses, the training will also be informed by an online survey and interviews of people with PD.
- Fostering culture change by investing in institution-specific solutions that build a hospital safety mind-set. The Foundation provided funding to the University of Rochester Medical Center to launch a Parkinson's Disease Hospital Optimization Program that includes the use of education and culture change strategies to improve clinical care.



- Driving policy change by working with organizations such as the Joint Commission to create certification criteria for hospital care that results in consistent standards and hospital care delivery practices. These sweeping systemic incentives are central to uniform and broad adoption of practices that will improve the health and quality of life of people with Parkinson's.

## Acknowledgments

The work highlighted in this report would not have been possible without collaboration of a broad coalition of advocates, clinicians, researchers and individuals living with Parkinson's. The Parkinson's Foundation recognizes the impact of these many voices and perspectives and the value of these continued conversations. We are also grateful to the Edmond J. Safra Foundation, who has been a partner in improving hospital care for people with Parkinson's since the launch of the Aware in Care initiative.

**We wish to acknowledge and thank the following individuals who, through their expert review and guidance, offered essential contributions in the development of these recommendations.**

Katherine Amodeo, MD, Assistant Professor in Neurology and Psychiatry, Divisions of Movement Disorders and Memory Care Co-Investigator, Lewy Body Dementia Association Research Center of Excellence (LBDA-RCOE), University of Rochester Medical Center

Hooman Azmi, MD, FAANS, Director, Division of Functional and Restorative Neurosurgery Director, Division of Neurotrauma Department of Neurosurgery, Hackensack University Medical Center

Christian Benedict, DPT, LSVT-BIG, Physical Therapist, Kansas Rehabilitation Hospital; Edmond J. Safra Visiting Nurse Faculty Scholar

Lucia Blasucci, RN, BSN, CCRC, Ambulatory Nurse, Rush Movement Disorder Clinic

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## Interested in Partnering?

As we move forward with the Hospital Care Initiative, the Parkinson's Foundation invites and encourages all stakeholders in the Parkinson's community to join us in driving change that will create lasting impact and better lives for people with Parkinson's disease. Access the tools and resources we've created and learn more about the many ways the Parkinson's Foundation can support the work you and your institution are doing to improve hospital care for people with Parkinson's at [Parkinson.org/HospitalCare](https://www.parkinson.org/HospitalCare).



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## **Appendices:**

### **Clinical Recommendations for Hospital Care of People with Parkinson's**

PD Medication Management/MODS

Special Considerations for Medications

Potentially Inappropriate Medications/Contraindicated Medications

Fall Risk and Early Mobilization

### **Clinical Checklists for Clinicians**

Emergency Department Checklist

Admission Checklist

Perioperative Checklist

Discharge Checklist

### **The Hospital Convening**

Featured Implementation Projects

Additional Attendees and Presenters

# Appendix A: Clinical Recommendations for Hospital Care of People with Parkinson's

The following outlines best practices for care of people with PD in the hospital as recommended by the Parkinson's Foundation. These recommendations are based on research and the guidance of experts in both movement disorders and in hospital care.

The Parkinson's Foundation strongly recommends consultation with the Primary PD Care Provider (Movement Disorder Specialist, General Neurologist or Primary Care Physician) whenever possible when treating a patient with PD. Additionally, please be advised that people with PD and their care partners are the experts in their management of PD because it is such an individualized disease in terms of both symptoms and pharmacological treatment.

## PD Medication Management/MODS

Do not substitute PD medications or stop levodopa therapy abruptly. Doing so may cause a life-threatening condition called neuroleptic malignant syndrome (NMS). Symptoms of NMS include rigidity, fever, tachycardia, tachypnea, labile blood pressures, and altered mental status.

The top priority should be to prevent medications from being **M**issed, **O**mitted, **D**elayed, or **S**ubstituted (**MODS**)

- **Missed:** Often when people with PD arrive at the hospital, sometimes for something unrelated to PD like a broken hip or a heart attack, their PD is not mentioned or listed in the Electronic Health Record (EHR) and those medications are missed entirely.
- **Omitted:** Many clinicians incorrectly assume that if someone is not supposed to receive anything by mouth (NPO) before a surgery that PD medications should also be omitted. This could be extremely dangerous. Even in cases of severe difficulty swallowing (dysphagia), medication should not be omitted and alternative sources of medications for PD should be found (see Dysphagia/NPO Protocol below for reference).
- **Delayed:** Medications must be distributed precisely at the home schedule. A one-hour window, while acceptable in most hospital situations, is not acceptable for PD medications. Additionally, the hospital standard distribution schedule (such as three times a day being given at 9:00 a.m., 3:00 p.m., and 9:00 p.m.) is not acceptable for PD patients given the short half lives in the body of many dopaminergic medications. Special attention must be paid to this issue when inputting medications for PD patients to ensure that system-based errors and/or delays do not occur.
- **Substituted:** Because there are so many PD medications, in many cases, the exact form is not available on formulary. Careful attention must be paid to any





medication substitutions and whenever possible substitutions should not be made. Immediate release and continuous should not be substituted without consultation of the patient's Primary PD Care Provider. Nor should name brand be substituted for generic without consultation. For example, Rytary should not be substituted in the same doses as carbidopa/levodopa as they are not equivalent.

In addition to the risk of NMS, consequences of MODS are significant, and place PD patients at risk for:

- **Falls:** Due to rigidity, postural instability, freezing, and bradykinesia
- **Aspiration pneumonia:** Due to dysphagia from impairment in the swallowing muscles
- **Incontinence:** Due to rigidity and bradykinesia which impairs mobility to the bathroom
- **Skin breakdown:** Due to the inability to change position freely
- **Emotional distress:** Due to feelings of helplessness, frustration, anxiety, fear, depression, embarrassment

To ensure that medications are distributed appropriately, medication reconciliation should be performed upon admission. Outreach to the Primary PD Care Provider should be done at this time and adherence to the home regimen should be followed when possible.

## Special Considerations for Medications

### Dietary Considerations

Gastrointestinal, digestion, and constipation issues are common in people with PD. For example, eating protein may impact medication absorption. Some people with PD find that timing meals an hour after their scheduled medication dose is most effective.

Providers should ask whether or not their patients with PD take medication for constipation at home and should continue with these medications whenever possible.

A nutrition consultation may be indicated to address these issues or concerns with swallowing capacity (along with a Speech Language Pathologist).

### Dysphagia/NPO Protocol

If a patient is NPO or has dysphagia, continue PD medications with a small sip of water. If swallow function is severely impaired, consult with the Speech Language Pathologist and consider one of the following options as appropriate:

**If any of these options are in the hospital formulary, consider their use:**

Medication (product brand name in parentheses)	Dosages in Milligrams (mg)	Typical Treatment Regimens	Common Side Effects	Indications for Usage
carbidopa/levodopa orally disintegrating tablets (Parcopa)	10/100, 25/100, 25/250 tablet	150-1000 mg of levodopa total daily dose (divided 3-4 times)	Low blood pressure, nausea, confusion, dyskinesia	Monotherapy or combination therapy for slowness, stiffness, and tremor; need for dissolvable medication in mouth especially if swallowing is impaired
rotigotine transdermal patch (Neupro)	1, 2, 3, 4, 6, 8 patch	4-8 mg once/day	Low blood pressure, nausea, leg swelling and discoloration, confusion, sleep attacks, compulsive behaviors like gambling, skin rashes	Monotherapy or combination therapy for slowness, stiffness and tremor; skin patch delivery an advantage for some

**If the patient is already using any of the following rescue options, they can be considered for use:**

apomorphine subcutaneous injections (Apokyn)	30 mg/3 ml vial	0.2-0.6 ml up to 5 times a day as needed	Low blood pressure, nausea, leg swelling and discoloration, confusion, sleep attacks, compulsive behaviors like gambling; for nausea, may receive anti-nausea medication daily for 3 days before starting medication	Adjunct therapy as needed for "off" periods; the only injectable, fast-acting dopaminergic drug, starts working in 10 minutes and lasts for up to 90 minutes
levodopa inhalation (Inbrija) via inhaler	42 per capsule	84 mg (2 capsules) inhaled by mouth up to 5 times a day as needed	Low blood pressure, nausea, confusion, dyskinesia, cough	As needed for "off" periods; starts working in 10-30 minutes and lasts for up to 60 minutes; regularly scheduled oral carbidopa/levodopa doses should be continued.
carbidopa/levodopa enteral suspension (Duopa) via surgically implanted tube between the stomach and small intestine	4.86 mg/20 ml cassette	Up to 2000 mg of levodopa over 16 hours	Low blood pressure, nausea, confusion, dyskinesia	For the treatment of motor fluctuations in patients with advanced PD



If swallowing is completely compromised and the above options are not available or appropriate, consider the use of Liquid Sinemet:

### Formula for Liquid Sinemet

1 mg levodopa per 1 ml solution

- Sinemet 25/100 tablets 10 tablets (1000 mg levodopa) (do not use Sinemet CR)
  - Ascorbic acid (Vitamin C) crystals ½ tsp. (approximately 2 grams)
  - Tap water or distilled water 1 liter or 1 quart
1. Mix the above ingredients in a liter/quart plastic container with lid (do not use metal).
  2. Rotate or shake gently until tablets dissolve (no need to crush tablets). Tablets may not go completely into solution.
  3. Formula will maintain full strength and purity for 24 to 48 hours in refrigerator.

*Optimal dosing can vary tremendously from one person to another.*

### Dosing Recommendations

(Always establish a dosing plan the Primary PD Care Provider whenever possible)

#### 1. Morning ("Jump Start") dose:

- 60 ml of the formula (60 mg or a little more than ½ of a 25/100 tablet of carbidopa/levodopa) or may use amount comparable to usual tablet dose.
- Adjust dose 5-10 ml up or down every three to five days until you achieve the best "on" response with the least dyskinesia.

#### 2. Hourly dosing:

- 30 ml of the formula on the hour while awake, or hourly proportion of usual tablet dose. (For instance, a person with PD taking one carbidopa/levodopa 25/100 tablet every two hours might try 50 ml per hour of the liquid.)
- Adjust dose 5-10 ml up or down every three to five days until "on" periods are smoother.

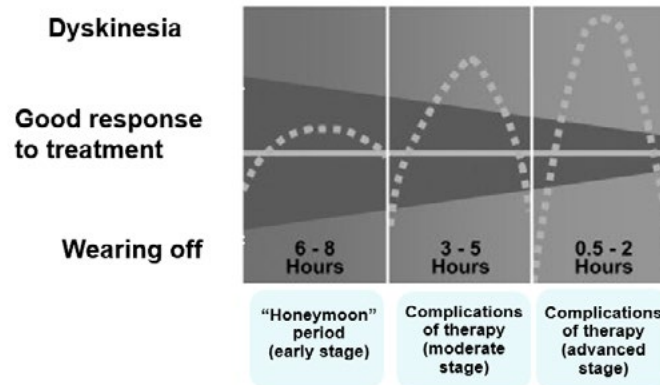
For the best overall result, it is strongly recommended that you adjust the morning jump start dose prior to adjusting the hourly doses. Accuracy of the dose and exact hourly timing between doses is critical for optimal benefit.

If use of a nasogastric (NG) tube is indicated, carbidopa/levodopa (Sinemet) 25/100 mg immediate release tablets can be crushed and administered via the tube.



## Motor Fluctuations and "On-Off" Time

It is normal for a person with mid-to late-stage PD to show a varying degree of symptoms throughout each day. Motor fluctuations, sometimes referred to as "on-off time," are due to the combined effect of disease progression and the shrinking therapeutic window of dopaminergic medications over time. During "on" time medications are working and the patient experiences reasonably good symptom control. During "off" time, medications are not working so well and symptoms of PD (primarily motor symptoms but not exclusively) become more noticeable.



As PD progresses, "on time" decreases and "off time" and troublesome dyskinesias (involuntary, erratic, writhing movements of the face, arms, legs, or trunk) increase. It is important for all care providers to understand this so that additional treatments are not given inappropriately due to what appears to be a sudden change in movement.

Rehabilitation therapies should be scheduled during "on time" to be effective and optimize the impact.

## Psychosis, Hallucinations, and Delirium

Hallucinations and psychosis can be part of the typical progression of PD or can be a side effect of medications for PD.

Many people with PD can feel disoriented or confused in the hospital even when that is not normal for their condition. Infections can cause sudden changes in behavior and motor function. Monitor closely for urinary tract and lower respiratory infections such as pneumonia.

Confusion accompanied by psychosis sometimes requires a simpler medication regimen. Should delirium occur, avoid haloperidol (Haldol) and most other antipsychotics. Only pimavanserin (Nuplazid), quetiapine (Seroquel), and clozapine (Clozaril) are considered appropriate for treating psychosis associated with PD.

About 50-60% of people with PD have rapid eye movement sleep behavior disorder (RBD). Speaking during sleep or acting out dreams should not be confused with

hallucinations or psychosis. It is inappropriate to treat RBD with antipsychotics, and though it is sometimes treated with benzodiazepines this may not be appropriate for those prone to delirium.

## **Potentially Inappropriate Medications/ Contraindicated Medications**

Dopamine-blocking medications, including most antipsychotics, could be added to the allergy list for patients with PD. This acts as an added check for the hospital pharmacist in case a different care provider such as someone on call overnight prescribes the medication inadvertently. Please refer to the following chart before prescribing dopamine-blocking medications (including those indicated for psychosis), pain medication, anesthesia, nausea/gastrointestinal (GI) drugs, or antidepressants to people with PD.

Medical Purpose	Potentially Safer Medications	Medications to Avoid
<b>Antipsychotics</b>	<p><b>pimavanserin</b> (Nuplazid, FDA approved to treat PD psychosis)</p> <p><b>quetiapine</b> (Seroquel)</p> <p><b>clozapine</b> (Clozaril)</p>	avoid all other typical and atypical antipsychotics
<b>Pain Medication</b>	most are safe to use but narcotic medications may cause confusion/psychosis and constipation	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid: <b>meperidine</b> (Demerol)
<b>Anesthesia</b>	request a consultation with the anesthesiologist, surgeon, and Primary PD Care Provider to determine best anesthesia given your PD symptoms and medications	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect), avoid: <p><b>meperidine</b> (Demerol)</p> <p><b>tramadol</b> (Rybox, Ryzolt, Ultram)</p> <p><b>droperidol</b> (Inapsine)</p> <p><b>methadone</b> (Dolophine, Methadose)</p> <p><b>cyclobenzaprine</b> (Amrix, Fexmid, Flexeril)</p> <p><b>halothane</b> (Fluothane)</p>
<b>Nausea/GI Drugs</b>	<p><b>domperidone</b> (Motilium)</p> <p><b>trimethobenzamide</b> (Tigan)</p> <p><b>ondansetron</b> (Zofran)</p> <p><b>dolasetron</b> (Anzemet)</p> <p><b>granisetron</b> (Kytril)</p>	<p><b>prochlorperazine</b> (Compazine)</p> <p><b>metoclopramide</b> (Reglan)</p> <p><b>promethazine</b> (Phenergan)</p> <p><b>droperidol</b> (Inapsine)</p> <p><b>chlorpromazine</b> (Thorazine)</p>
<b>Antidepressants</b>	<p><b>fluoxetine</b> (Prozac)</p> <p><b>sertraline</b> (Zoloft)</p> <p><b>paroxetine</b> (Paxil)</p> <p><b>citalopram</b> (Celexa)</p> <p><b>escitalopram</b> (Lexapro)</p> <p><b>venlafaxine</b> (Effexor)</p>	<b>amoxapine</b> (Asendin)

# Fall Risk and Early Mobilization

## Mobilization

Most motor symptoms of PD will become more pronounced when movement is limited. Early mobilization should be established as part of a nurse-driven mobility protocol unless contraindicated.

Physical Therapy (PT) and Occupational Therapy (OT) consultations should be obtained for all PD patients in the hospital whenever possible.

Consideration should be made in regard to "on-off time" when scheduling rehabilitation therapy. Assessments should be performed during "on time" based on the known amount of each patient's time to respond to medications for PD.

Outpatient referrals to rehabilitation therapy should be provided at discharge if patients are not candidates for inpatient or skilled rehabilitation immediately following a hospital stay.

## Fall risks

Many PD symptoms have the potential to increase fall risk. These include:

- **Festination:** Short, rapid steps taken during walking. May increase the risk of falling and is often seen in association with freezing (see below).
- **Freezing:** Gives the appearance of being stuck in place, especially when initiating a step, turning or navigating through doorways or other tight places.
- **Neurogenic Orthostatic Hypotension (nOH):** A persistent drop in blood pressure that occurs upon moving from a sitting position to standing, or from lying down to either sitting up or standing, is common in PD. It can be caused by a lack of the neurotransmitter norepinephrine due to PD progression or can be caused by certain medications, dehydration. Conditions such as diabetes, adrenal insufficiency, thyroid disease or various heart conditions can also increase this risk.
- **Postural Instability:** Difficulty maintaining and regaining balance
- **Rigidity:** Stiffness that can occur on one or both sides of the body and contribute to a decreased range of motion

Though counterintuitive, effective rehabilitation therapies can decrease fall risk despite these symptoms as physical inactivity often makes these symptoms more severe.

## Summary

We believe that outcomes for hospitalized PD patients can improve when these recommendations involving medication management (timing, drug-drug interactions, and contraindications), reducing fall risk, and facilitating early mobilization are

adhered to closely. The overall goal is to increase awareness in a way that could decrease the chances of complications and help avoid prolonged hospital stays. We urge all providers to review the Aware in Care® content at [Parkinson.org/AwareinCare](https://www.parkinson.org/AwareinCare) including the additional information available about Deep Brain Stimulators, the delivery of carbidopa/levodopa enteral suspension via a Duopa pump, and other special considerations.

Should any questions arise as you implement these recommendations, you are encouraged to reach out to the Parkinson's Foundation Helpline at 1-800-4PD-INFO.



# Appendix B: Checklists for Clinicians

## Emergency Department Checklist

Date: \_\_\_\_\_ Time of arrival: \_\_\_\_\_

Action	Time	Comments
<b>Medication Reconciliation upon admission:</b>		
<input type="checkbox"/> Consultation with the patient/care partner (if this is not possible reach out to their outpatient pharmacy).		
<input type="checkbox"/> Verify the home schedule for medication timing. Input into the Electronic Health Record (EHR) as a custom field, ensuring that it does not default to the hospital schedule.		
<input type="checkbox"/> Verify any special instructions (such as combining medications together, meal timing based on medication distribution, etc.).		
<input type="checkbox"/> Confirm any over-the-counter (OTC) medications, especially for constipation. Continue unless contraindicated.		
<input type="checkbox"/> Administration of their first dose based on the home schedule.		
<input type="checkbox"/> Review contraindicated medications for PD and avoid haloperidol (Haldol).		
<input type="checkbox"/> Review special considerations for PD care from Aware in Care® materials (available at <a href="https://www.parkinson.org/AwareinCare">Parkinson.org/AwareinCare</a> if the patient/care partner does not provide the Nurse Fact Sheet).		
<input type="checkbox"/> Coordinate whether medications for PD not available on hospital formulary could be used in the hospital by having a care partner or other family member retrieve medications in their original labeled bottles from the patient's home or outpatient pharmacy.		

# Admission Checklist

Date: \_\_\_\_\_ Time of arrival: \_\_\_\_\_

Action	Time	Comments
<b>Medication Reconciliation upon admission:</b>		
<input type="checkbox"/> Consultation with the patient/care partner (if this is not possible, then contact their outpatient pharmacy).		
<input type="checkbox"/> Verify the home schedule for medication timing. Input into the electronic medical record (EMR) as a custom field. DO NOT default to the hospital schedule (for example, 9:00 a.m., 3:00 p.m., and 9:00 p.m. for "three times a day").		
<input type="checkbox"/> Verify any special instructions (such as combining medications together, meal timing based on medication distribution, etc.).		
<input type="checkbox"/> Confirm any over-the-counter (OTC) medications, especially for constipation. Continue unless contraindicated.		
<input type="checkbox"/> Administration of their first dose based on the home schedule.		
<input type="checkbox"/> Review Contraindicated Medications for PD.		
<input type="checkbox"/> Review special considerations for PD care.		
<b>Notify Primary Parkinson's Care Provider</b>		
<input type="checkbox"/> Send a message through the EHR when possible.		
<input type="checkbox"/> Discuss any potential medication changes when possible.		

## Provide Interdisciplinary Care throughout Hospitalization

<input type="checkbox"/> Consider Physical Therapy consultation to facilitate early mobility and prevent falls as appropriate.		
<input type="checkbox"/> Implement a nurse-driven mobility protocol, if indicated.		
<input type="checkbox"/> Consider Occupational Therapy consultation to assess need for assistive devices, adaptive equipment, or other modifications for safety and improved functioning.		
<input type="checkbox"/> Consider Speech Language Pathology consultation in most cases to assess swallowing function and cognition.		
<input type="checkbox"/> Consider Nutritionist/Dietitian consultation to assess nutritional status and make recommendations regarding gastrointestinal and digestion issues.		

# Perioperative Checklist

Date: \_\_\_\_\_ Time of arrival: \_\_\_\_\_

Action	Time	Comments
<b>Planning for Surgery: Discuss medication plan for surgery day:</b>		
<input type="checkbox"/> Do not hold PD medications. Patient should take their PD medications with a small sip of water.		
<input type="checkbox"/> Review each PD medication and the time the patient takes the medications. If any medications are not on formulary, confirm with Pharmacy that their medications brought from home will be distributed rather than making a substitution.		
<input type="checkbox"/> Document the exact timing patient takes each medication at home in the Electronic Health Record (EHR).		
<input type="checkbox"/> Consult Primary PD Care Provider (Movement Disorder Specialist, General Neurologist or Primary Care Physician) if any additional questions arise about medications.		
<input type="checkbox"/> Confirm with the patient and family that they are to bring their PD medications with original bottle to the hospital on the day of the surgery.		
<input type="checkbox"/> Alert the anesthesiologist that the patient has PD and to avoid contraindicated medications, (including metoclopramide (Reglan), prochlorperazine (Compazine) and meperidine (Demerol) if on MAO inhibitors).		
<input type="checkbox"/> Ensure that the patient will receive a dose of PD medication upon arriving in the recovery room, which should not wait for the usual oral diet advances.		

## Day of Surgery

<input type="checkbox"/> Allow the patient to take medication on the day of the surgery with a small sip of water, when due.		
<input type="checkbox"/> Mention the importance of avoiding contraindicated medications during the "Operative Briefing" so the anesthesiologist is reminded again.		

## After Surgery

<input type="checkbox"/> Confirm PD medications are ordered post-operatively at the same times as the patient's home regimen.		
<input type="checkbox"/> Avoid ordering contraindicated medications in order sets.		
<input type="checkbox"/> Mobilize early.		
<input type="checkbox"/> Complete the discharge checklist.		

## Discharge Checklist

Date: \_\_\_\_\_ Time of arrival: \_\_\_\_\_

Action	Time	Comments
<input type="checkbox"/> Provide referrals to outpatient Physical Therapist, Occupational Therapist, and Speech Language Pathologist, preferably with specialization in PD or neurological conditions. Include reason for admission and primary diagnosis in referral.		
<input type="checkbox"/> If indicated, include a referral to outpatient dietitian/nutritionist.		
<input type="checkbox"/> Referral to community exercise and support groups (refer to Parkinson's Foundation Helpline if not available: 1-800-4PD-INFO).		
<input type="checkbox"/> Educate the patient and care partner on any medication changes during hospitalization.		
<input type="checkbox"/> Send a copy of the discharge summary to the Primary PD Care Provider.		
<input type="checkbox"/> Communicate that the patient should follow up with the Primary PD Care Provider.		
<input type="checkbox"/> If the patient is transitioning to another care facility, such as inpatient or skilled rehabilitation, communicate the specifics of the medication including timing.		

# Appendix C: The Hospital Convening

## Featured Implementation Projects:

### Hackensack University Medical Center

**Hooman Azmi, MD, FAANS** outlined the work that has been done at Hackensack University Medical Center by utilizing the Joint Commission Parkinson's disease specific Certification.

*"We are aligning the protocol with the Joint Commission platform which is a very, very effective platform for identifying the measures that are meaningful and then following those measures and making sure there is a plan to improve." – Hooman Azmi, MD, FAANS*



### Key first steps to implementing Parkinson's Specific Protocols in an acute care hospital:

- Establish a way to identify all Parkinson's patients within the chart and train staff to understand what it means when a patient is flagged for Parkinson's
- Address the availability of medications on formulary with pharmacy
- Utilize the Electronic Hospital Record (EPIC in their case) to allow for the custom input of each Parkinson's medication
- Conduct widespread and ongoing education around the critical importance of medication timing for Parkinson's patients

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### Kansas Rehabilitation Hospital

**Christian Benedict, DPT** outlined the approach that Rehabilitation Hospitals should take based on his experience at Kansas Rehabilitation Hospital.

*"Every Rehab Hospital should understand the importance of timing of delivery of PD medications, but that one-hour window that our initial Joint Commission surveyor told us was acceptable for most places shouldn't be good enough." – Christian Benedict, DPT*



### Key Elements to Parkinson's care in a Rehabilitation hospital include:

- PD Specific evaluations is completed by a Physical Therapist, Occupational Therapist, and if indicated, Speech Language Pathologist and Nutritionist/dietician.
- Monthly interdisciplinary team meetings
- Patient education that measures whether they are able to teach back information on Parkinson's and on community referrals

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## University of Rochester Medical Center

**Katherine Amodeo, MD & Amy Chesire, LCSW-R, MSG** shared their two-pronged approach to improving hospitalization outcomes through community conversations and hospital engagement at the University of Rochester.

One care partner from their community roundtables shared:

*"I felt like I knew so much more about my husband's PD and it was hard to advocate for his medication needs, in particular. I knew what medications he should not take and yet they wanted to prescribe it and didn't necessarily want to listen to me. I felt very angry and frustrated."*



### Key Elements to Partnerships between movement disorder clinics and their affiliated hospitals:

- Ongoing conversations with the Parkinson's community regarding their lived experiences in specific community hospitals
- Addressing issues with what medications are not on formulary
- Tracking the prescription of Haldol for a month showed hospital leaders that the warnings were necessary
- Hospital team education through the Parkinson's Foundation Team Training

## Presenters and Attendees

- **Elana Clar, MD**, Movement Disorders Neurologist, Hackensack University Medical Center
- **Lisa Coccoziello, APN**, Department of neurosurgery, Hackensack University Medical Center
- **Max Coslov**, Program Director, Edmond J. Safra Philanthropic Foundation
- **Alessandro Di Rocco, MD**, Professor of Neurology, Zucker School of Medicine at Hofstra Northwell System Director - Neurology, Parkinson's and Movement Disorders, Northwell Health.
- **Michael Okun, MD**, Adelaide Lackner Professor and Chair of Neurology, Executive Director, Norman Fixel Institute for Neurological Diseases; National Medical Advisor, Parkinson's Foundation
- **Steve Peters**, Aware in Care Ambassador
- **Patrick Phelan**, Executive Director, Hospital Business Development, The Joint Commission
- **Ritesh Ramdhani, MD**, Director, Deep Brain Stimulation Program, Northwell Health



**Florian P. Thomas, MD, MA, PhD, MS**, Chair, Neuroscience Institute; Chair, Department of Neurology Director, Multiple Sclerosis Center, Director, Hereditary Neuropathy Foundation Center of Excellence, Co Director, Center for Brain Health & Dementia, Hackensack University Medical Center

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- **Leslie Peters, Aware in Care Ambassador**, Former PPAC Vice Chair
- **Stephanie R. Stewart MSN, RN-BC**, Executive Director - Freudenthal Center for Parkinson's Disease; Edmond J. Safra Visiting Nurse Scholar at Parkinson's Foundation 2018

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# Endnotes

- a. Zeldenrust F, Lidstone S, Wu S, et al. Variations in hospitalization rates across Parkinson's Foundation Centers of Excellence. *Parkinsonism Relat Disord*. England; 2020;81:123–128.
- b. Hassan A, Wu SS, Schmidt P, et al. High rates and the risk factors for emergency room visits and hospitalization in Parkinson's disease. *Parkinsonism Relat Disord*. 2013;19:949–954.
- c. Aminoff MJ, Christine CW, Friedman JH, et al. Management of the hospitalized patient with Parkinson's disease: current state of the field and need for guidelines. *Parkinsonism Relat Disord*. 2011;17:139–145.
- d. Oguh O, Videnovic A. Inpatient management of Parkinson disease: current challenges and future directions. *Neurohospitalist*. 2012;2:28–35.
- e. Ramirez-Zamora A, Tsuboi T. Hospital Management of Parkinson Disease Patients. *Clinical Geriatric Medicine United States*. 2020;36:173–181.
- f. Jones SL, Hindle JV. Parkinson's disease in the acute hospital. *Clinical Medicine (Lond)*. 2011;11:84–88.
- g. Wood LD, Neumiller JJ, Carlson J, Setter SM, Corbett CF. Challenges of medication management in hospitalized patients with Parkinson's disease. *Am J Health Syst Pharm*. England. 2010;67:2059–2063.
- h. Katus L, Shtilbans A. Perioperative management of patients with Parkinson's disease. *Am J Med*. United States. 2014;127:275–280.
- i. Probasco J, Sahin B, Tran T, et al. The preoperative neurological evaluation. *Neurohospitalist*. 2013;3:209–220.
- j. Akbar U, Kurkchubasche AG, Friedman JH. Perioperative management of Parkinson's disease. *Expert Rev Neurother*. England; 2017;17:301–308.
- k. Roberts DP, Lewis SJG. Considerations for general anaesthesia in Parkinson's disease. *J Clin Neurosci*. Scotland; 2018;48:34–41.
- l. Cohen MR, Smetzer JL. Delayed Administration and Contraindicated Drugs Place Hospitalized Parkinson's Disease Patients at Risk; Doxorubicin Liposomal Mix-up; Avoid Mix-ups Between Hydroxyprogesterone and Medroxyprogesterone. *Hosp Pharm*. 2015;50:559–563.
- m. Chou KL, Zamudio J, Schmidt P, et al. Hospitalization in Parkinson disease: a survey of National Parkinson Foundation Centers. *Parkinsonism Relat Disord*. 2011;17:440–445.
- n. Magdalinou KN, Martin A, Kessel B. Prescribing medications in Parkinson's disease

- (PD) patients during acute admissions to a District General Hospital. *Parkinsonism Relat Disord*. England; 2007;13:539–540.
- o. Skelly R, Brown L, Fakis A, Walker R. Hospitalization in Parkinson's disease: a survey of UK neurologists, geriatricians and Parkinson's disease nurse specialists. *Parkinsonism Relat Disord*. England; 2015;21:277–281.
- p. Cohen MR, Smetzer JL. Delayed Administration and Contraindicated Drugs Place Hospitalized Parkinson's Disease Patients at Risk; Doxorubicin Liposomal Mix-up; Avoid Mix-ups Between Hydroxyprogesterone and Medroxyprogesterone. *Hosp Pharm*. 2015;50:559–563.
- q. Brennan KA, Genever RW. Managing Parkinson's disease during surgery. *BMJ*. England; 2010;341:c5718.
- r. Perdomo-Lampignano JA, Pana TA, Sleeman I, et al. Parkinson's disease and patient related outcomes in stroke: A matched cohort study. *J Stroke Cerebrovasc Dis*. United States; 2020;29:104826.
- s. Su C-M, Kung C-T, Chen F-C, et al. Manifestations and Outcomes of Patients with Parkinson's Disease and Serious Infection in the Emergency Department. *Biomed Res Int*. 2018;2018:6014896.
- t. Jo T, Yasunaga H, Michihata N, et al. Influence of Parkinsonism on outcomes of elderly pneumonia patients. *Parkinsonism Relat Disord*. England; 2018;54:25–29.
- u. Heinzl S, Berg D, Binder S, et al. Do We Need to Rethink the Epidemiology and Healthcare Utilization of Parkinson's Disease in Germany? *Front Neurol*. 2018;9:500.
- v. Paul SS, Harvey L, Canning CG, et al. Fall-related hospitalization in people with Parkinson's disease. *Eur J Neurol*. England; 2017;24:523–529.
- w. Braga M, Pederzoli M, Antonini A, Beretta F, Crespi V. Reasons for hospitalization in Parkinson's disease: a case-control study. *Parkinsonism Relat Disord*. England; 2014;20:488–492; discussion 488.
- x. Hobson DE, Lix LM, Azimae M, Leslie WD, Burchill C, Hobson S. Healthcare utilization in patients with Parkinson's disease: A population-based analysis. *Parkinsonism & Related Disorders*. 2012;18:930–935.
- y. Huse DM, Schulman K, Orsini L, Castelli-Haley J, Kennedy S, Lenhart G. Burden of illness in Parkinson's disease. *Mov Disord*. United States; 2005;20:1449–1454.
- z. Guttman M, Slaughter PM, Theriault M-E, DeBoer DP, Naylor CD. Burden of parkinsonism: a population-based study. *Mov Disord*. 2003;18:313–319.
- aa. Gerlach OHH, Broen MPG, Weber WEJ. Motor outcomes during hospitalization in Parkinson's disease patients: a prospective study. *Parkinsonism Relat Disord*. England; 2013;19:737–741.

- ab. Mahajan A, Balakrishnan P, Patel A, et al. Epidemiology of inpatient stay in Parkinson's disease in the United States: Insights from the Nationwide Inpatient Sample. *J Clin Neurosci*. Scotland; 2016;31:162–165.
- ac. Lewin Group (R). Economic Burden and Future Impact of Parkinson's Disease Final Report [online]. 2019 Jul. Accessed at: <https://www.parkinson.org/sites/default/files/2019%20Parkinson%27s%20Economic%20Burden%20Study%20-%20FINAL.pdf>. Accessed November 14, 2020.
- ad. Fujioka S, Fukae J, Ogura H, et al. Hospital-based study on emergency admission of patients with Parkinson's disease. *eNeurologicalSci*. Elsevier; 2016;4:19–21.
- ae. Gerlach OHH, Broen MPG, van Domburg PHMF, Vermeij AJ, Weber WEJ. Deterioration of Parkinson's disease during hospitalization: survey of 684 patients. *BMC Neurol*. 2012;12:13.
- af. Mucksavage J, Kim KS. Challenges in ICU Care: The Patient With Parkinson's Disease. *Crit Care Nurs Q*. United States; 2020;43:205–215.
- ag. Shin JY, Habermann B. Medication Adherence in People With Parkinson Disease. *J Neurosci Nurs*. United States; 2016;48:185–194.
- ah. Grosset KA, Reid JL, Grosset DG. Medicine-taking behavior: implications of suboptimal compliance in Parkinson's disease. *Mov Disord*. United States; 2005;20:1397–1404.
- ai. Yu XX, Fernandez HH. Dopamine agonist withdrawal syndrome: A comprehensive review. *J Neurol Sci*. Netherlands; 2017;374:53–55.
- aj. Lertxundi U, Isla A, Solinís MÁ, et al. Medication errors in Parkinson's disease inpatients in the Basque Country. *Parkinsonism Relat Disord*. England; 2017;36:57–62.
- ak. Azmi H, Coccoziello L, Harvey R, et al. Development of a Joint Commission Disease-Specific Care Certification Program for Parkinson Disease in an Acute Care Hospital. *J Neurosci Nurs*. United States; 2019;51:313–319.
- al. Aslam S, Simpson E, Baugh M, Shill H. Interventions to minimize complications in hospitalized patients with Parkinson disease. *Neurol Clin Pract*. 2020;10:23–28.
- am. Nance MA, Boettcher L, Edinger G, et al. Quality Improvement in Parkinson's Disease: A Successful Program to Enhance Timely Administration of Levodopa in the Hospital. *J Parkinsons Dis*. Netherlands; 2020;10:1551–1559.
- an. Lance S, Travers J, Bourke D. Reducing medication errors for hospital inpatients with Parkinsonism. *Intern Med J*. Australia; Epub 2020 Feb 11.
- ao. Corrado J, Jackson O, Baxandall D, et al. Get Parkinson's medications on time: the Leeds QI project. *Age Ageing*. England; 2020;49:865–872.

ap. Hobson P, Roberts S, Davies G. The introduction of a Parkinson's disease email alert system to allow for early specialist team review of inpatients. *BMC Health Serv Res.* 2019;19:271.

aq. The Joint Commission. (2021). Advanced Stroke. Retrieved May 1, 2021, from <https://www.jointcommission.org/accreditation-and-certification/certification/certifications-by-setting/hospital-certifications/stroke-certification/advanced-stroke/>.

ar. Derry CP, Shah KJ, Caie L, Counsell CE. Medication management in people with Parkinson's disease during surgical admissions. *Postgrad Med J.* England; 2010;86:334–337.

as. Carlson JD, Neumiller JJ, Swain LDW, Mark J, McLeod P, Hirschauer J. Postoperative delirium in Parkinson's disease patients following deep brain stimulation surgery. *J Clin Neurosci.* Scotland; 2014;21:1192–1195.

at. Skelly R, Brown L, Fogarty A. Delayed administration of dopaminergic drugs is not associated with prolonged length of stay of hospitalized patients with Parkinson's disease. *Parkinsonism Relat Disord.* 2017;35:25–29.

au. Mill D, Bakker M, Corre L, Page A, Johnson J. A comparison between Parkinson's medication errors identified through retrospective case note review versus via an incident reporting system during hospital admission. *Int J Pharm Pract.* England; 2020;28:663–666.