Parkinson's Foundation

Parkinson's Foundation Hospital Care Recommendations

The Parkinson's Foundation Hospital Care Initiative

APRIL 2023

Developed in collaboration with Hackensack Meridian Health, Henry Ford Health, University of Florida Health, and Manatt Health

Hackensack Meridian Hackensack University Medical Center

HENRY FORD HEALTH Neurosciences

UFHealth NORMAN FIXEL INSTITUTE FOR NEUROLOGICAL DISEASES

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Message from the President and CEO

All people with Parkinson's deserve access to equitable and quality care. This includes all forms of care, from a routine neurology appointment to seeing a specialist to a planned or unplanned hospitalization.

Every year, more than 300,000 people with Parkinson's receive hospital care. And because they have Parkinson's, they are at an increased risk of experiencing avoidable complications that can lead to longer hospital stays, along with worse disease and symptom severity after discharge. We illustrated this harm in our seminal report, Making Hospitals Safer for People with Parkinson's Disease. For example, 75% of the more than 300,000 people with Parkinson's who are hospitalized each year do not receive their medications on time. Of these, 28% experience deterioration of motor symptoms during their hospital stay, with 51% readmitted within one year of discharge.

The vision for the Parkinson's Foundation Hospital Care Initiative is to eliminate this type of preventable harm and promote higher reliability in care for people with Parkinson's in the hospital. The Parkinson's Foundation is dedicated to ensuring that all people with Parkinson's can trust that the hospital care they receive is of the highest quality.

I am pleased to present the Parkinson's Foundation Hospital Care Recommendations developed in partnership with clinical, quality, nursing, and operational leadership from Hackensack Meridian Health, Henry Ford Health, and the University of Florida Health Norman Fixel Institute for Neurological Diseases, with support from Manatt Health. Because of these partnerships, as well as our partnership with the Cleveland Clinic, the Recommendations reflect the realities of care in our health systems, propose feasible solutions to challenges in improving safety, and will advance the vision of our Hospital Care Initiative by addressing major gaps in hospital care.

Access to quality care is at the core of everything we do at the Parkinson's Foundation. Our care initiatives, programs, and fellowships have all guided us to this moment. These Recommendations are the culmination of our long commitment to improving hospital safety as well as the starting point for the next phase of our leadership in this space. Following these Recommendations will make life better for people with Parkinson's.

Sincerely,

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

Message from Peter Pronovost

By joining together, health systems can achieve zero harm. Historically, patient safety initiatives have largely focused on ensuring that patients with a specific admitting diagnosis receive the correct evidence-based therapies, largely using guidelines, checklists, and order sets. However, recent shifts in practice for high-risk patients also emphasize the importance of identifying and mitigating harm that can be caused by disorders outside of the admitting diagnosis. This is a major advancement in patient safety. Additional efforts are needed across health systems for patients with disorders that pose significant risk for patient harm that may be undetected at admittance. People with Parkinson's are the prototype.

There are nearly one million people living with Parkinson's in the U.S., and hospitalization is common. Despite the regularity with which hospitals are caring for people with Parkinson's, awareness of their needs is often limited, and a lack of standard protocols results in significant preventable harm.

There is an urgent need to make these defects in Parkinson's care more visible and to design systems that eliminate preventable harm. We recognize this is not an easy task, especially in our constrained health care environment. Yet we must and we can; not only do current practices cause avoidable suffering and death, but also, they significantly increase costs.

No doubt we have much to learn. We need more evidence to demonstrate just how often these patients are harmed and the impact on mortality, morbidity, and costs. The Parkinson's Foundation is committed to leading this charge—and we need health systems and the private sector to innovate with us.

So, join the journey. Let us work together to quantify the harm and the costs in patients hospitalized with Parkinson's. Let us learn from one another so we can learn and improve faster. Let us eliminate harm in people with Parkinson's. No one group can do it alone.

An Aspen Institute on education reform discussed how in any collective endeavor, there comes a moment—a moment when diverse voices align around a common purpose; a moment when together we learn so much about what to do; a moment when we can make the potential real. For the Parkinson's community, that moment is now.

So, my friends, join us on the journey toward zero harm among people with Parkinson's.

Sincerely,

Peter J. Pronovost, MD, PhD, FCCM
Chief Quality & Clinical Transformation Officer
University Hospitals
Special Advisor to Manatt Health

Executive Summary

The Need for Parkinson's Foundation Hospital Care Recommendations

The mission of the Parkinson's Foundation is to make life better for people with Parkinson's by improving care and advancing research toward a cure. Since its founding in 1957, the Parkinson's Foundation has been a leader in funding national and international research and has served as a trusted source for all those impacted by Parkinson's. The vision of its **Hospital Care Initiative** is to eliminate preventable harm and promote higher reliability in care for people with Parkinson's in the hospital. The Parkinson's Foundation is committed to ensuring that all people with Parkinson's can trust that the hospital care they receive is of the highest quality and that people with Parkinson's are heard, valued, and respected as partners in their own care.

Recommendations Development

Through the seminal report **Making Hospitals Safer for People with Parkinson's Disease**, the Parkinson's Foundation illustrated that people with Parkinson's in the hospital consistently experience preventable harm. For example, 75% of the more than 300,000 people with Parkinson's who are hospitalized each year do not receive their medications on time. Of these, 28% experience deterioration of motor symptoms during their hospital stay, with 51% readmitted within one year of discharge. These gaps in effective care delivery contribute to increased morbidity and mortality for patients and increased costs for hospitals and health systems. The findings and focus areas in the report are supported by qualitative and quantitative evidence gathered from people with Parkinson's by the Parkinson's Foundation during the development of the report and throughout years of patient advocacy and engagement. The **Parkinson's Foundation Hospital Care Recommendations** build on the framework outlined in the report.

The Recommendations were developed by the Parkinson's Foundation in partnership with clinical, quality, nursing, and operational leadership from Hackensack Meridian Health, Henry Ford Health, and the University of Florida Health Norman Fixel Institute for Neurological Diseases, with support from Manatt Health.

The Recommendations will advance the vision of the Parkinson's Foundation Hospital Care Initiative by addressing major gaps in hospital care related to medication management through system-level changes in clinical care, management, culture, technology, education, and policy. The Recommendations will facilitate improved care for the hundreds of thousands of people with Parkinson's who are hospitalized in the U.S. each year and are at increased risk of preventable harm.

Care Standards

The Recommendations describe five measurable standards, as well as an implementation management system with associated requirements, and implementation steps for meeting those standards. Tactics are flexible and can be adapted according to organizational context and resource availability. Achieving these standards will be a steadfast, long-term effort requiring organizational leadership, culture change, and workflow redesign. Though a complex undertaking, achieving these standards will meaningfully and dramatically improve health outcomes for people with Parkinson's, in turn decreasing the cost of care. The Parkinson's Foundation is committed to partnering with institutions large and small throughout the coming years as we work to improve hospital care for every American living with Parkinson's.

All Parkinson's medications are ordered in a custom fashion, according to patients' at-home regimen.

All Parkinson's medications are administered within ± 15 minutes of patients' at-home regimen, 100% of the time.

Potentially harmful medication events are eliminated, particularly in dopamine-blocking medications, agents for pain, and sedatives.

All people with Parkinson's should mobilize 3 times a day if clinically appropriate and under professional supervision if necessary.

All people with Parkinson's should undergo screening for dysphagia within 24 hours, with measures taken to minimize the risk of aspiration pneumonia, as needed.

Next Steps

While the Recommendations are evidence-based and address known deficiencies in Parkinson's care, the evidence is less mature regarding how best to implement the Recommendations and the impact of the Recommendations on clinical and economic outcomes. The Parkinson's Foundation is committed to providing leadership to expand the evidence base for the Recommendations and to supporting hospitals and health systems in achieving the changes in clinical care, management, culture, technology, education, and policy required to make hospital care safer for people with Parkinson's. To that end, the Parkinson's Foundation plans to invest in the research, shared learning, education, and training needed to support the adoption and realization of the Recommendations in the coming years.

Who We Are

The mission of the Parkinson's Foundation is to make life better for people with Parkinson's disease by improving care and advancing research toward a cure. It is the nation's leading community for people living with Parkinson's, those who love them, and those who are working to end the disease.

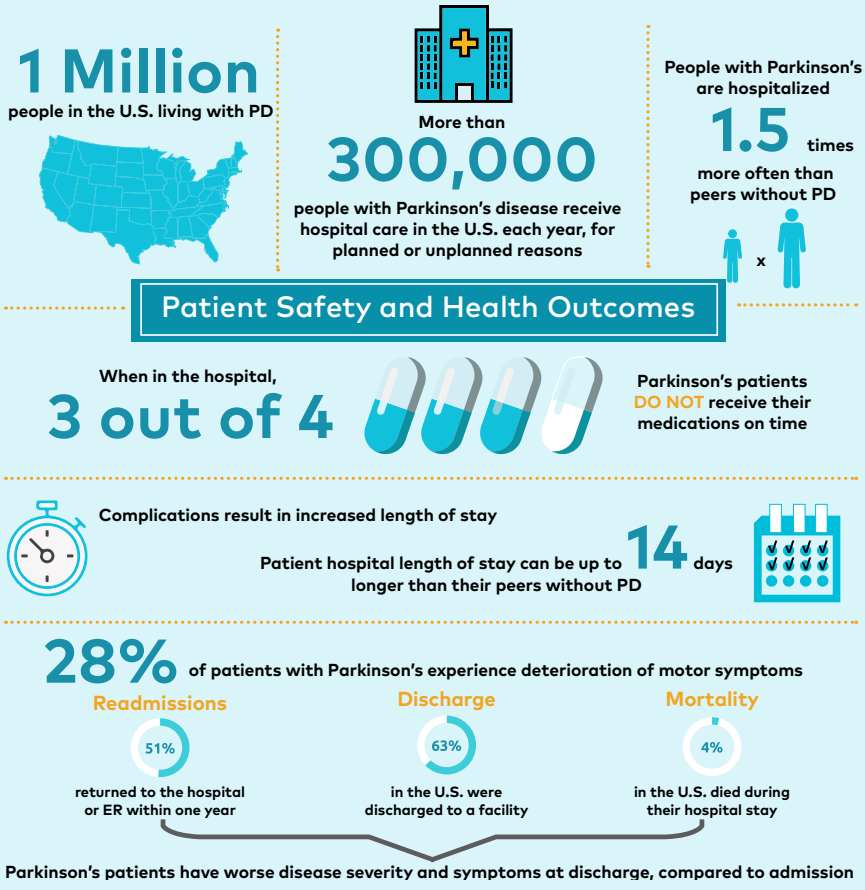
The Parkinson's Foundation's vision for the Hospital Care Initiative is to eliminate preventable harm and promote higher reliability in care for people with Parkinson's in the hospital. Through this initiative, the Parkinson's Foundation has developed key tools and resources for patients and providers alike. As part of its Aware in Care Hospital Safety campaign to help people with Parkinson's advocate for their best care when hospitalized, the Parkinson's Foundation has published resources, such as the **Hospital Action Plan** and **Medication Form**, and distributed more than 130,000 hospital safety kits since 2011.

For providers, the Parkinson's Foundation has developed **clinical checklists** and several educational resources and trainings to help defend against gaps related to hospital care for people with Parkinson's. The Parkinson's Foundation continues to advance its hospital care improvement work and provide critical leadership in this area through publication of these Recommendations, representing their continued dedication to improving hospital care for people with Parkinson's. The Recommendations will serve as an anchor for the Parkinson's Foundation's future work in support of hospital quality improvement.

An Acute Case for Change

The Parkinson's Foundation published the seminal **Making Hospitals Safer for People with Parkinson's Disease** report in April 2022, outlining gaps in hospital care and recommendations for hospital administration and staff to improve hospital care for people with Parkinson's. Building on the *Making Hospitals Safer* report, the Parkinson's Foundation convened a series of workshops with clinical, quality, and operational leaders at Hackensack Meridian Health, Henry Ford Health, and the University of Florida Health Norman Fixel Institute for Neurological Diseases to develop the Parkinson's Foundation Hospital Care Recommendations for organizations committed to achieving zero harm and higher reliability in hospital care for people with Parkinson's. The Recommendations were developed with support from Manatt Health and Dr. Peter Pronovost, a national quality expert.

Figure 1: Preventable Harm for People with Parkinson's Who Experience a Hospital Encounter Each Year[A]



The Recommendations aim to address major gaps in hospital care for people with Parkinson's related to medication management, mobility, and dysphagia management through changes in care delivery patterns, accountability, management, culture, technology, education, and policy. These gaps materially increase the risk of patient harm.

1. **Gaps in Medication Management:**

    - Harm is often caused when the hospital does not carry a patient's Parkinson's medication or when medications are given per the hospital rounds schedule, which is different from a patient's home regimen.[B] These missed, delayed, or substituted medications during hospital stays may stem from a lack of provider awareness about the importance of proper medication management for people with Parkinson's and may be compounded by challenges in staffing ratios.[A] Three out of four people with Parkinson's do not receive their medication on time when in the hospital.[C]
    - Omission of Parkinson's medications occurs frequently for patients with dysphagia and "nothing by mouth" (NPO) status because staff do not understand the importance of continuing these medications or know that people with Parkinson's may be able to take medications with a small sip of water or use alternative medications or alternative delivery systems (e.g., nasogastric tube).[D] Problems may also arise in patients who cannot swallow at all.[A] See "Gaps in Preventing and Managing Dysphagia" below.
    - Potentially harmful medications may be administered, particularly commonly used antipsychotic, antiemetic, antidepressant, analgesic, and anesthetic medications that may interact with Parkinson's medications and/or make Parkinson's symptoms worse.[E]

2. **Gaps in Mobility:** Bed rest and lack of mobility are contributors to complications and rapid deconditioning among hospitalized people with Parkinson's, putting them at an increased risk of fall injury when compared to the general population and potentially a prolonged length of stay or discharge to a rehabilitation facility rather than the home.[F]

3. **Gaps in Preventing and Managing Dysphagia:** Aspiration pneumonia associated with dysphagia is the leading cause of mortality among people with Parkinson's, accounting for 25% of deaths.[G] A recent study reported higher incidence (3.01 events per 1,000 person-years) and higher risk (hazard ratio = 4.21) of aspiration pneumonia among people with Parkinson's compared to those without.[H] These findings are exacerbated by the fact that after the first aspiration pneumonia event, the mortality rate after one year was 65.2%.[H] However, attempting to mitigate aspiration risk by omitting Parkinson's medications puts many patients at higher risk of aspiration. Suddenly stopping Parkinson's medications when dysphagia occurs worsens difficulties with swallowing because medication plays an important role in maintaining swallowing ability.

The Recommendations fill an important gap in efforts to eliminate patient harm. Most efforts to improve safety focus on patients admitted with a specific diagnosis or focus on specific harms like healthcare-associated infections. In Parkinson's, the problem may be more complex. Many patients may be admitted for one condition (e.g., stroke) while having another that substantially increases their risk for harm (e.g., Parkinson's). Because many hospitals and health systems lack mechanisms to consistently identify these patients and mitigate their risks, when people with Parkinson's are admitted, they often suffer preventable harm and have higher lengths of stay and costs. These Recommendations aim to eliminate preventable harm to hospitalized people with Parkinson's.

The Recommendations

The Recommendations are composed of:

1. **Care Standards:** Measurable clinical goals that hospitals and health systems must meet to eliminate harm and attain higher reliability in care.

2. **Implementation Management System:** Actionable requirements, tactics, and implementation steps that address areas such as education and training, standard processes, IT solutions (e.g., EHR optimization), and data analytics.

    - **Requirements and Tactics:** Requirements to meet care standards and suggested tactics that health systems may utilize to fulfill the requirements.
    - **Implementation Steps:** An outline of the process to successfully implement the Recommendations and meet the standards of care.

Figure 2: Care Standards and Implementation Management System

Care Standards				
All Parkinson's medications are ordered in a custom fashion, according to patients' at-home regimen.	All Parkinson's medications are administered within ± 15 minutes of patients' at-home regimen, 100% of the time.	Potentially harmful medication events are eliminated, particularly in dopamine-blocking medications, agents for pain, and sedatives.	All people with Parkinson's should mobilize 3 times a day if clinically appropriate and under professional supervision if necessary.	All people with Parkinson's should undergo screening for dysphagia within 24 hours, with measures taken to minimize the risk of aspiration pneumonia, as needed.
Implementation Management System: Requirements, Tactics, and Implementation Steps				
Education and Training	Standard Processes	IT Solutions	Data Analytics	

Care Standards

A. **All Parkinson's medications are ordered in a custom fashion, according to patients' at-home regimen.** Hospital standard distribution schedules (e.g., three times a day at 9:00 a.m., 3:00 p.m., and 9:00 p.m.) are not acceptable for people with Parkinson's given the short half-lives of many dopaminergic medications and potentially severe deterioration in motor symptoms that accompany deviations from at-home medication schedules and dosages. Because there is no standard Parkinson's medication regimen, it is critical to adhere to the at-home schedules of people with Parkinson's by ordering their Parkinson's medications in a custom fashion to prevent complications associated with medication mismanagement. Ordering medications in a custom fashion allows clinicians to provide exact timing on the order.

Tactics and implementation steps are not exhaustive. Hospitals are encouraged to select and modify tactics and implementation steps in accordance with their available resources, technology, and organizational contexts. The tactics and steps are intended to demonstrate what is possible; however, the Parkinson's Foundation acknowledges that there can be no prescriptive pathways for achieving the Recommendations—innovation is encouraged and required.

B. **All Parkinson's medications are administered within ± 15 minutes of patients' at-home regimen, 100% of the time.** Delivering medication on time every time is essential to preventing harm to people with Parkinson's, whose symptoms are tightly managed via prescribed patient schedules. Medication timing contributes significantly to in-hospital complications, with one study reporting that 61% of people with Parkinson's who had an altered medication schedule had significant sequalae and another study reporting that those who received incorrect Parkinson's medications were 5.8 times more likely to experience Parkinson's deterioration than those who did not.[C,I] Due to limitations in existing research and the wide diversity of Parkinson's symptoms and medications, there is no defined medication administration window to prevent worse outcomes, but they can appear when medications are delivered early or late by 30–60 minutes. Therefore, a more rigorous 15-minute standard for medication administration timeliness must be established to prevent the most clinical harm.

A note on including patients in the implementation of Recommendations. Patient engagement should be recognized as a best practice, and organizations should honor the role of the patient and care partner as experts in managing their disease by inviting them into the care conversation. This may include engaging the broader Parkinson's community in quality improvement activities and inviting people with Parkinson's and their care partners to participate in the implementation of Recommendations.

C. **Potentially harmful medication events are eliminated, particularly in dopamine-blocking medications, agents for pain, and sedatives.** Certain routine and normally benign medications can worsen Parkinson's symptoms due to their interaction with Parkinson's medications and the Parkinson's disease process. Haloperidol, metoclopramide, and prochlorperazine are among the most important contraindicated medications to avoid in the care of people with Parkinson's to prevent harm. Other medicines are potentially harmful but not necessarily contraindicated by medicolegal definition (e.g., the drug label does not include a contraindicated warning for Parkinson's). Typical neuroleptics are usually contraindicated. Occasionally, atypical neuroleptics may be used when the severity of symptoms greatly outweighs risk. Most pain medications and sedatives may worsen cognition and should be avoided or minimized. Pain medications may also exacerbate constipation and contribute to length of hospital stay.

D. **All people with Parkinson's should mobilize three times a day if clinically appropriate and under professional supervision if necessary.** Limited movement in people with Parkinson's can make motor symptoms like festination, freezing, and rigidity more pronounced, which increases fall risk. Early mobilization and effective rehabilitation strategies can reduce movement limitations, decrease fall risk, and prevent secondary complications associated with hospitalization.

E. **All people with Parkinson's should undergo screening for dysphagia within 24 hours, with measures taken to minimize the risk of aspiration pneumonia, as needed.** Oropharyngeal dysphagia is quite common among people with Parkinson's (80%), yet many people with Parkinson's are not aware they have it (33%).[J] Given the underreporting of dysphagia and the high risk of mortality associated with aspiration pneumonia, screening is essential to ensure both providers and people with Parkinson's are aware of any risks related to swallowing. It is equally imperative that providers recognize the role that medication management plays in aspiration prevention, even when dysphagia is identified. Careful consideration of alternative medication delivery must be part of standard Parkinson's hospital care. The Parkinson's Foundation published a dysphagia/NPO protocol for patients with dysphagia/NPO status with options for safe medication administration.

Implementation Management System

Requirements and Tactics

Requirements have been articulated to meet each standard. Tactics are potential implementation methods to meet the requirements.

Standard: All Parkinson's medications are ordered in a custom fashion, according to patients' at-home regimen.	
Requirements	**Tactics**
Determine patients' at-home regimen and consequences of delayed medication upon admission as part of the medication reconciliation process.	• Designate a professional (i.e., transition of care pharmacist, neuro unit registered nurse) to complete all medication reconciliations for people with Parkinson's using a protocol to review the at-home regimen. • Require verbal confirmation of the medication regimen recorded in the EHR from the patient, care partner, or family.
Enable custom input for Parkinson's medications to align with at-home regimens rather than use default EHR medication schedules.	• Remove once a day (QD), two times a day (BID), and three times a day (TID) ordering options from the EHR for all Parkinson's medications (some EHR configurations may not allow this). • Create an order set for all admitted people with Parkinson's with required custom input of medication schedules for all Parkinson's medications.
Improve hospital-wide awareness of preventable harm for people with Parkinson's.	• Hold annual Parkinson's-focused grand rounds or other group talks for departments, hospital units, and pharmacy staff who have a high probability of encountering people with Parkinson's, with modules on Parkinson's medication management (emphasizing the importance of medication timing, medication reconciliation, and contraindications), early mobilization, new standard processes, and EHR tools. These group talks should involve multiple specialties (medicine, neurology, geriatrics, psychiatry, surgery, and nursing).

Standard: All Parkinson's medications are administered within ± 15 minutes of patients' at-home regimen, 100% of the time.

Requirements	Tactics
Implement data collection and review mechanisms that track and assess the discrepancy between patients' at-home regimen and in-hospital medication administration.	• Automate reporting of all medication administration events and delays for people with Parkinson's, including primary and secondary diagnoses and Parkinsonism (ICD-10 G20). • Automate and distribute monthly reports to designated clinical champions followed by a review with the working group at standing meetings.
Implement standard processes for reducing delays in medication administration.	• Require annual discipline-/profession-specific training on medication timing, common contraindicated medications and their impact, the impacts of "on time" (medication is working well and symptoms are controlled) and "off time" Parkinson's symptoms (e.g., signs and causes of delirium, tremor, stiffness), and the need to prioritize people with Parkinson's in hospital mobility protocols and medication administration. • Permit self-administration of Parkinson's medications by the patient if willing and able or administration by the care partner if willing and able.* • Encourage surgical procedures to be performed in early morning to limit the number of potentially missed medication doses.
Avoid unnecessary NPO status.	• Complete order for a speech language pathologist (SLP) swallow evaluation and SLP assessment before NPO status is initiated related to swallowing. • If NPO status is confirmed, find an alternative way to administer medication (e.g., nasogastric tube, alternative formulation of drugs). • Develop surgical team training on the nuances of NPO (no medications taken orally) in people with Parkinson's disease and necessary care planning before, during, and after surgery. • Establish EHR-based safeguards to avoid unnecessary NPO status related to standard perioperative care.

*The Joint Commission (TJC), and by virtue CMS, allows self-administration of medication by patients and their family members through a written protocol and establishment of competence (see MM.06.01.03 of TJC Hospital Accreditation Manual). The hospital or system may exercise latitude in drug class and types of medication to administer. Self-administration is a powerful tool for ensuring timely delivery of Parkinson's medications in resource-constrained environments and amid national workforce shortages.

Example: University Hospitals' Policy on Self-Administration.

University Hospitals permits self-administration of medications (provided by the hospital pharmacy or home medications), assuming:

(1) home medications are verified by the pharmacy; (2) prescription medications are securely stored; (3) the provider permits and documents self-administration in the medication order after an evaluation of clinical status, cognitive function, motor skills, and health literacy with potential re-evaluation after changes to clinical status; (4) the provider documents patient or caregiver ability to safely self-administer medications; (5) patients or caregivers are educated on self-administration; and (6) medications are appropriately labeled.

Standard: Potentially harmful medication events are eliminated, particularly in dopamine-blocking medications, agents for pain, and sedatives.	
Requirements	**Tactics**
Identify potentially contraindicated or potentially harmful medications related to both Parkinson's disease and the use of MAO-B inhibitors (with anesthetics or pain medications) during the medication reconciliation process.	• Designate a specific role (i.e., transition of care pharmacist, neuro unit registered nurse) to complete all reconciliations for people with Parkinson's using a protocol to review contraindicated medications.
Establish EHR-based safeguards to avoid the prescription and administration of contraindicated medications.	• Include reference to contraindicated medications in the identification mechanism for all people with Parkinson's. • Create EHR warnings/redirects (i.e., best practice alerts (BPAs)) for contraindicated medication orders. • Include safe potential treatment options in the admission order set.
Avoid inappropriate treatment of psychosis, confusion, or delirium with contraindicated antipsychotics.	• Suggest an early consultation with the patient's primary Parkinson's care provider or a designated member of the inpatient neurology team if any new psychotic symptoms are detected, before administering contraindicated medication to treat "higher priority symptoms." • Create EHR warnings/redirects (i.e., BPAs) for contraindicated antipsychotics orders.
Avoid contraindicated nausea/GI medications prescribed as part of standard postoperative care.	• Create EHR warnings/redirects (i.e., BPAs) for contraindicated nausea/GI medication orders and suggest safer alternatives.
Avoid unnecessary medication substitutions.	• Ensure common Parkinson's medications are on formulary by evaluating the formulary at all health system locations. The focus should be on carrying more carbidopa/levodopa forms to prevent the need for nonequivalent substitutions and medication options for NPO patients (e.g., dissolvable). • Permit the use of patient home medications if their specific Parkinson's medications are not on formulary, through clear and standard processes for checking and approving medications through the pharmacy.

Standard: All people with Parkinson's should mobilize three times a day if clinically appropriate and under professional supervision if necessary.	
Requirements	**Tactics**
Provide opportunities for patients to move safely and frequently in the hospital environment.	• Conduct nurse assessment of mobility upon admission to determine prior level of function in the home environment and home medication schedule for optimal movement. • Assess current mobility, recognizing any possible new limitations resulting from the hospital admission. • Determine whether family can assist with mobilization and allow family assistance when appropriate. • Provide the highest level of mobility opportunities, with a target of increased time out of bed during waking hours and ambulation three times/day.
Provide PT and OT orders for people with Parkinson's.	• Establish physician-ordering practices, where people with Parkinson's receive orders for PT and OT. • Consider including in an order set or care pathway advisories to alert nurses and/or physicians to the need for PT and OT consults. • Offer PT and OT evaluation at or before admission. • Ensure PT and OT competency as related to Parkinson's, including the importance of mobility during medication "on time."
Provide opportunities for communication and collaboration regarding patient mobility.	• Create communication opportunities regarding mobility and fall prevention, including, but not limited to, communication mechanisms within the EHR, phone communication, and/or interdisciplinary rounds.

Standard: All people with Parkinson's should undergo screening for dysphagia within 24 hours, with measures taken to minimize the risk of aspiration pneumonia, as needed.	
Requirements	**Tactics**
Establish standard protocol for screening of swallowing abilities for all people with Parkinson's.	• Require a nurse to complete bedside swallow screening for all people with Parkinson's. • Notify the admitting provider of abnormal results from the swallow screening, and request that they order an SLP evaluation.
Establish a protocol for minimizing the risk of aspiration pneumonia.	• Ensure patients sit upright in a chair instead of in their bed when eating a meal. If a patient is confined to a bed, ensure the head of the bed is as upright as possible. • Supervise patients screened for dysphagia and at high risk of aspiration pneumonia based on their SLP evaluation.
Establish a protocol for medication management in people with Parkinson's experiencing varying degrees of dysphagia that prioritizes the closest adherence to their home medication regimen as is possible.	• Consult neurology (or a movement disorders specialist) when considering withholding Parkinson's medications because of concern for possible dysphagia. • Include reference to dysphagia/NPO protocol in the identification mechanism for all people with Parkinson's.

Implementation Steps

Successful implementation of the Recommendations will rely on generating broad stakeholder buy-in and accountability, ensuring the necessary IT solutions are in place to identify people with Parkinson's and track metrics, and building an evidence base for the tactics through continuous improvement.

Stage A. Self-Assessment and Planning

Step 1: Convene a working group of clinical, administrative, operational, and quality leaders.

Working Group Membership

- Physician leaders
- General neurologists
- Movement disorder specialists
- Nursing leaders
- Pharmacy leaders
- Quality leaders
- PT/OT/SLP leaders
- Multidisciplinary councils or committees (as needed)
- Data analytics/technology leaders

See "Forming an Effective Working Group" below for recommendations on messaging when engaging working group members and clinical quality champions.

Working Group Responsibilities

- Define goals, roles, and success measures for the Recommendations, including the individual directly responsible for their implementation.
- Develop an institutional case for change based on a self-assessment of hospital care for people with Parkinson's utilizing the self-assessment tool.
- Identify system-level needs to enable tracking and reporting of outcomes and cost metrics to system leadership and the Parkinson's Foundation (see phased approach described under Stage B).
- Develop and iterate tactics to meet the care standards according to the local context.

Step 2: Identify and empower clinical quality champions.

Clinical Quality Champions

- Unit leaders accountable to someone on the quality team (either chief quality officer or designee) who is responsible for this effort.

Clinical Quality Champion Responsibilities

- Share the institutional case for change developed by the working group.
- Identify unit-level needs, to enable tracking and reporting outcomes to the working group (see phased approach described under Stage B).

Step 3: Ensure the health system can identify and flag every patient with a Parkinson's diagnosis via a visible identifier in the EHR.

Ensure the identifier in the EHR includes people with Parkinson's and those with Parkinsonism (ICD-10 G20) to ensure broad application.

Step 4: Ensure the health system can reliably measure and report on Recommendations standards, working with clinical decision support/IT as needed.

Care Standards	Requirements
All Parkinson's Medications are ordered in a custom fashion, according to patients' at-home regimen.	Track custom medication orders.
All Parkinson's medications are administered within ± 15 minutes of patients' at-home regimen, 100% of the time.	Leverage medication barcode scanning data to evaluate whether medications are administered early, on time, or late.
Potentially harmful medication events are eliminated, particularly in dopamine-blocking medications, agents for pain, and sedatives.	Track contraindicated medication events.
All people with Parkinson's should mobilize 3 times a day if clinically appropriate and under professional supervision if necessary.	Track mobilization events.
All people with Parkinson's should undergo screening for dysphagia within 24 hours, with measures taken to minimize the risk of aspiration pneumonia, as needed.	Track dysphagia screenings.

Stage B. Phased Implementation

Step 5: Select or create tactic(s) to pilot.

- Define success metrics.
- Determine whether to implement systemwide or in a single/cohort of hospitals.
- Automate regular reports to be reviewed on an agreed-upon schedule by clinical quality champions.
- Identify a pilot cohort of people with Parkinson's among whom to quickly implement the Recommendations (e.g., all people with Parkinson's or Parkinsonism admitted within a certain department).

Step 6: Review impact.

- Review pilot results.
- Celebrate progress.
- Agree how to refine and/or expand tactics.
- When appropriate, add new tactic(s) and repeat to meet requirements and standards.
- Leverage Lean, Agile, or any other quality/process improvement framework typically used in the health system to refine tactics through rapid cycles of solution implementation, and track progress against Recommendations metrics.

Stage C. Broad Implementation

Step 7: Expand implementation.

Scale efforts based on pilot results and learnings across the health system.

Getting Started: Forming a Working Group and Completing a Self-Assessment

Forming an Effective Working Group

Assembling an effective working group of professionals and clinical quality champions will require targeted messaging that speaks to their specific values and responsibilities and ensures their active participation. Messaging can be reinforced by the completion of the self-assessment tool, which includes a section on health outcomes and costs among people with Parkinson's as compared to the general patient population.

Figure 3: An Effective Working Group of Professionals and the Parkinson's Community

Stakeholder Group	Values and Responsibilities	Messaging
Hospital Leadership, Physician Leadership, and Movement Disorder Specialists	• Achieving zero harm and higher reliability in care for people with Parkinson's.	• People with Parkinson's experience worse outcomes in the hospital when compared to the general patient population.[A] • Of the 300,000 people with Parkinson's who are hospitalized each year in the U.S., preventable complications due to medication mismanagement and lack of mobility result in 51% readmissions and 4% mortality.[K,L]
Nursing Leadership	• Delivering medications safely and on time. • Adhering to hospital and nurse-driven mobility protocols to prevent falls and facilitate early mobility.	• People with Parkinson's are at increased risk of missed, omitted, delayed, or substituted medications.[A] • Providers and staff should work to monitor, prevent, and treat in-hospital complications such as falls, orthostatic hypotension, and delirium.[M,N] • People with Parkinson's should be mobilized early in their hospitalization, including after surgery.[O] • People with Parkinson's are also at increased risk for fall injuries because of medication mismanagement and lack of mobility.[P]
Parkinson's Community	• Patient engagement in care and research is a best practice; patient community should be invited into the care conversation. • People with Parkinson's and care partners/families are experts in managing Parkinson's.	• People with Parkinson's and their care partners are experts in managing their own care.[A] • People with Parkinson's should feel heard, valued, and respected as contributors to their own healthcare.[A] • The perspective of people living with Parkinson's should be prioritized in all conversations about Parkinson's care.[A]

Stakeholder Group	Values and Responsibilities	Messaging
Pharmacy Leadership	• Ensuring safe and timely delivery of medication. • Assessing and preventing use of potentially harmful and contraindicated medications.	• People with Parkinson's require strict adherence to an individualized, timed medication regimen of antiparkinsonian agents.[D] • One in three hospitalized people with Parkinson's is prescribed at least one contraindicated medication.[D] Serious neuropsychiatric complications occurred in more than half of these patients.[D]
Quality Leadership	• Achieve zero harm and higher reliability in care. • Mitigate regulatory and financial risks related to care.	• Reimbursement and quality metrics are negatively impacted by poor hospital care for people with Parkinson's due to increased risk of readmissions (51%), increased risk of fall injury (2.4 times the odds of falls in-hospital compared to controls), and costs ($14,000 on average) of fall injury.[K,P,Q] The Joint Commission tracks fall injuries as sentinel events and as part of their National Patient Safety Goals.[Q,R] • Systematic interventions are required to improve care for people with Parkinson's and mitigate regulatory and financial risks.
PT and OT Leadership	• Ensure timely PT and OT evaluations. • Collaborate with care team on safe mobilization and strategies for prevention of worsening motor symptoms. • Ensure PT and OT staff remain competent in Parkinson's sequela.	• Early mobilization during "on time" is essential to prevent worsening of motor symptoms for people with Parkinson's during their hospital stay. PT and OT consults, in combination with nurse-driven protocols, will help prevent risk of fall injury.[O]
SLP Leadership	• Ensure timely SLP evaluations. • Ensure collaboration with care team on safe and functional swallowing.	• People with Parkinson's with NPO status require their medications on time every time. SLP consults help confirm whether patients with NPO status can take oral medication safely with a small sip of water or a substitution is required.[J]

Completing the Self-Assessment

This two-part baseline self-assessment tool was designed to help hospital and health system working groups implementing the Recommendations to develop an institutional case for change that encourages widespread adoption. By understanding these specific data points, you will be able to identify your priorities for intervention and track your progress. Please complete to the best of your ability, and if it becomes clear that certain data points do not exist, please reach out to the Parkinson's Foundation to brainstorm.

Part 1: Current State Programmatic Assessment

Current programs, processes, technologies, and pathways related to caring for people with Parkinson's when they are admitted to your hospital(s):

Instructions: To understand the current practices in caring for people with Parkinson's, please work with the appropriate clinical, IT, administrative, and financial staff to complete the following steps in your preferred format (e.g., Word, PowerPoint, Excel).

1. Working Group Identification
Who have you identified to convene as part of the working group that will address this quality improvement initiative?
Hospital Leadership
Informatics and Analytics Representative(s):
Operational Representative(s):
Quality Representative(s):
Clinical Leadership
Inpatient Physician(s):
Nursing:
Occupational Therapy:
Outpatient Movement Disorders Clinic:
Pharmacy:
Physical Therapy:
Speech Language Pathology:
Parkinson's Community Members:
Care Partner:
People with Parkinson's:

Who from this group will fulfill the following roles?	
Project Coordinator:	
Quality Champion 1:	
Quality Champion 2:	
2. Universal Awareness	
Are you confident that all people with Parkinson's or Parkinsonism have that diagnosis documented in the EHR (Y/N)?	Y/N?
If yes, please provide additional detail on how Parkinson's diagnoses are documented.	
Do you have an easy way of identifying a patient with Parkinson's in the EHR (Y/N)? For example, if a person with Parkinson's comes in with an impacted bowel, how would the Gastroenterology unit see a Parkinson's diagnosis?	Y/N?
3. Clinical Pathways	
Are there clinical pathways/protocols or inpatient care management programs for the treatment of people with Parkinson's (Y/N)?	Y/N?
If yes, please provide additional detail on existing clinical pathways/protocols.	
Are any best practice alerts (BPAs) or educational prompts currently active in the EHR to avoid contraindicated antipsychotics or nausea/GI medications (Y/N)?	Y/N?
If yes, please describe how they are used and address how they have changed clinician behavior.	
4. Optimal Medication Management	
Are you able to align a patient's medication administration schedule with their pre-admission home schedule using custom times instead of standard options (once a day, twice a day, or three times a day) (Y/N)?	Y/N?
If yes, please provide additional detail on how medication administration schedules can or cannot be aligned with the home-based regimen (e.g., modifying time intervals for medication administration in the EHR).	

Do you currently consult with a patient's primary Parkinson's care provider before substituting or stopping any Parkinson's medications (Y/N)? Are any other consultations standard before making these medication changes (Y/N)?	Y/N?
If yes, please provide additional detail on consultations ahead of medication changes.	
Are providers aware of contraindicated and potentially harmful medications for people with Parkinson's (Y/N)?	Y/N?
If yes, please provide additional detail on the level of provider awareness (e.g., what contraindicated medications are listed in the EHR, CME offered, grand rounds, quality improvement initiatives, EHR warnings and redirects).	

5. Pharmacy

How are the times of medication distribution tracked (i.e., scanning a barcode at the time of delivery)?

What Parkinson's medications do you have on your hospital's formulary?

Carbidopa/Levodopa	
Carbidopa/levodopa immediate-release tablets (Sinemet)	Y/N?
Carbidopa/levodopa immediate-release orally disintegrating (Parcopa)	Y/N?
Carbidopa/levodopa controlled-release (formerly Sinemet CR)	Y/N?
Carbidopa/levodopa extended-release (Rytary)	Y/N?
Carbidopa/levodopa/entacapone tablets (Stalevo)	Y/N?
Carbidopa/levodopa enteral suspension (Duopa) via surgically implanted tube in small intestine	Y/N?
Levodopa inhalation powder (Inbrija)	Y/N?

Dopamine Agonists	
Rotigotine (Neupro)	Y/N?
Apomorphine HCl injection (Apokyn)	Y/N?
Apomorphine HCl sublingual film (Kynmobi)	Y/N?
MAO-B Inhibitors	
Selegiline (formerly Eldepryl)	Y/N?
Rasagiline (Azilect)	Y/N?
Selegiline HCL orally disintegrating (Zelapar)	Y/N?
Safinamide (Xadago)	Y/N?
6. Quality Measurement	
Do you use any tools to get insights into the quality of care you're providing to people with Parkinson's (Y/N)?	Y/N?
If yes, please provide additional information about these tools and whether they have demonstrated measurable improvements in the care of people with Parkinson's.	
Do you trust the quality and integrity of available data (Y/N)?	Y/N?
Please explain, including information on how data does or does not reflect clinical pathways and workflows.	
Are quality improvement initiatives selected or started at a certain time of year, or presented to a particular committee for approval (Y/N)?	Y/N?
If yes, please provide additional details.	

Are there any other institutional policies or protocols related to quality improvement initiatives that should be noted (Y/N)?	Y/N?
If yes, please provide additional details.	
7. PT, OT, and SLP	
Do you have a way to measure patient mobility occurrences across disciplines (e.g., nursing, PT, OT, support personnel) (Y/N)?	Y/N?
If yes, please provide additional details.	
Do you have a way to measure PT/OT orders, including time of evaluation from the consult order (Y/N)?	Y/N?
If yes, please provide additional details.	
8. Dysphagia	
Do you have a standardized bedside swallow assessment and workflow for consulting SLP when indicated?	Y/N?
If yes, please provide additional details.	
Do you have a way to measure SLP orders, including time of evaluation from the consult order?	Y/N?
If yes, please provide additional details.	

Part 2: Patient Outcomes and Cost Impact of Current Practices

Instructions: To understand the cost implications of caring for people with Parkinson's, please work with the appropriate clinical, IT, administrative, and financial staff to complete the following steps in your preferred format (e.g., Word, PowerPoint, Excel). To do so, you will need to leverage claims data to define the Parkinson's cohort: patients with primary and secondary diagnoses of Parkinson's and Parkinsonism (ICD-10 G20). We recommend that you exclude patients who were hospitalized for deep brain stimulation implants from the Parkinson's cohort to avoid skewing certain metrics (e.g., length of stay), especially if this is a common procedure.

Required Data		
	Adult Population	**Parkinson's Population**
Total number of admissions		
Average length of stay		
30-day readmission rate		
Total cost per adjusted discharge		
Fall injuries (number)		
Fall injuries (rate)		
Contraindicated medication events (number)		
Contraindicated medication events (rate)		
Patients who have 3 mobility occurrences per day during their hospital stay (number)		
Patients who have 3 mobility occurrences per day during their hospital stay (rate)		
Prevalence of early medication administration (± 30 minutes)		
Prevalence of late medication administration (before or after 30 minutes)		

Recommended Data		
	Adult Population	**Parkinson's Population**
Patients with a PT consultation (number)		
Patients with a PT consultation (rate)		
Patients with an OT consultation (number)		
Patients with an OT consultation (rate)		
Patients with an SLP consultation who have NPO orders (number)		
Patients with an SLP consultation who have NPO orders (rate)		
Number of patients who received at least one dose of each of the following commonly contraindicated medications		
	Number of Patients	**Percent of Patients**
Olanzapine		
Haloperidol		
Aripiprazole		
Risperidone		
Fluphenazine		
Chlorpromazine		
Prochlorperazine		
Metoclopramide		
Droperidol		
Promethazine		

Appendix A – Contributors

The Recommendations were developed in partnership with the following clinical, quality, nursing, and operational leaders.

Hackensack Meridian Health	
Name	**Title**
Jose Azar	Executive Vice President and Chief Quality Officer
Hooman Azmi	Director, Division of Functional and Restorative Neurosurgery; Associate Professor, Neurosurgery
Lisa Cocoziello	Advanced Practice Nurse, Neurosurgery
Maria Coello	Vice President, Care Transformation Services
Blessy Jacob	Transition of Care Pharmacist
Ken McArdle	Vice President, Chief Clinical Data Officer
Manisha Parulekar	Division Chief, Geriatrics; Co-Director, Center for Memory Loss and Brain Health; Director, Geriatrics Fellowship
Lucy Pereira-Argenziano	Vice President and Chief Quality Officer, Northern Region
Ihor Sawczuk	President, Academics, Research, and Innovation, Hackensack Meridian School of Medicine
Florian P. Thomas	Chair, Department of Neurology and Neuroscience Institute; Co-Director, Center for Memory Loss and Brain Health; Founding Chair of Neurology
Jewell Thomas	Manager, Medication and Safety Education; Transition of Care Pharmacist
Neal Wigod	Manager, Quality Operations, Patient Safety and Quality Department

Henry Ford Health	
Name	**Title**
Ellen Air	Vice Chair for Operations, Residency Program Director, and Co-Director Functional Neurosurgery, Department of Neurosurgery; Interim Division Head, Movement Disorders, Department of Neurology
Kelly Clarkson	Director, Epic Inpatient Clinical Applications and Third-Party Clinical Applications
Michael Eichenhorn	Division Head Emeritus, Pulmonary & Critical Care Medicine; Director of Medical Informatics
Mathew Jones	Pharmacy Specialist, Neurosurgical Intensive Care
Peter LeWitt	Sastry Foundation Endowed Chair in Neurology; Program Director, Movement Disorders Fellowship; Professor of Neurology, Wayne State University School of Medicine
Krista Mcintosh	Manager, Analytics Delivery
Stacy Pettit	Epic Training Manager and Security Manager
Edward Pollak	Chief Quality Officer and Chief Medical Officer-Associate

University of Florida Health	
Name	**Title**
Irene Alexaitis	Chief Nursing Officer
Matthew Barabas	Physician Assistant, Norman Fixel Institute for Neurological Diseases
Traci d'Auguste	Chief Operating Officer
Pattie deBear	Director, Inpatient Rehabilitation
Ariane Carpentier	Movement Disorders Fellow, Norman Fixel Institute for Neurological Diseases
Robert (Bob) Donnell	Chief Medical Information Officer; Assistant Dean, Clinical Informatics; Associate Professor, Urology
Tom Johns	Associate Vice President, Operations
Irene Malaty	Barbara Padgett Dein Professorship in Parkinson's; Professor, Neurology; Medical Director, National Parkinson Foundation Center of Excellence; Director, University of Florida Health Tourette Syndrome Association Center of Excellence

University of Florida Health	
Name	**Title**
Michelle Musalo	Rehab Division Manager, Inpatient Rehabilitation; Physical Therapist; Board-Certified Clinical Specialist in Neurologic Physical Therapy
Michael Okun	Chair and Professor, Neurology; Executive Director, Norman Fixel Institute for Neurological Diseases; National Medical Advisor, Parkinson's Foundation
Ashley Rawls	Assistant Professor, Neurology
Amy Rosenberg	Director, Inpatient Pharmacy Services
Millie Russin	Director, Quality
Heather Simpson	Occupational Therapist, University of Florida Rehab Center, Norman Fixel Institute for Neurological Diseases; Coordinator, Tourette Association of America's Centers of Excellence; Co-Coordinator, Parkinson's Foundation Centers of Excellence
Amita Singh	Physician Director, Quality; Assistant Professor, Neurology

Parkinson's Foundation	
Name	**Title**
Annie Brooks	Director, Strategic Initiatives
Emily Buetow	Associate Director, Strategic Initiatives
Sheera Rosenfeld	Vice President, Strategic Initiatives

Manatt Health	
Name	**Title**
Jared Augenstein	Managing Director
Eboné Carrington	Managing Director
Tom Enders	Senior Managing Director
Peter Pronovost	Chief Quality & Clinical Transformation Officer, University Hospitals; Special Advisor to Manatt Health
Michael Siao Tick Chong	Manager

Appendix B – Parkinson's Foundation Hospital Care Initiative: Professional Education

Parkinson's Foundation Learning Lab

The Parkinson's Foundation Learning Lab is a virtual learning community dedicated to advancing knowledge about Parkinson's. Designed to help expand your professional knowledge of Parkinson's, our online accredited self-paced courses are just a click away!

Hospital Care Courses

Available at Education.Parkinson.org/HospitalCare

Optimizing Hospital Care for People with Parkinson's. This course highlights key recommendations and strategies to promote optimal care and health outcomes for people with Parkinson's during planned and unplanned hospital stays. This can include an inpatient, outpatient, and emergency department hospital encounters. *Up to 3.25 IPCE credits available for physicians, nurses, pharmacists/pharmacy technicians, physician assistants, psychologists, and social workers.*

Professional Ed Talks: Hospitalization. This course highlights the link between research, clinical medicine, and community health improvement by providing health professionals with the latest information in evolving, yet essential, areas that may be outside their core practice. *Up to 2 IPCE credits available for physicians, nurses, and social workers.*

Hospitalization in PD. This course outlines how 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. Watch this activity to learn about the challenges that people with Parkinson's face in the hospital and what the interprofessional team can do to provide better care to this vulnerable population. *Up to 1.25 credits available for physicians, nurses, physician assistants, psychologists, and social workers.*

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In support of improving patient care, Parkinson's Foundation is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing.

Endnotes

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About 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. For more information, visit **https://www.parkinson.org**.

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