

## Medical Safety Information and Forms for Persons with Parkinson's and their Care Partners

Receipt of medical services, for any reason, has the potential to negatively impact a person with Parkinson's. Changes to your medication schedule may occur and result in complications that could lengthen your recovery, stay in the hospital, or necessitate follow up care in a nursing facility.

PASD has developed these forms that can be filled out online, downloaded, and completed with the Movement Disorder Specialist/Neurologist. These forms include a:

1. **Physician Letter** – to be completed and signed by your Neurologist. The Physician Letter provides information on PD and emphasizes:
  - a. The need for compliance with medication dosing times and formulations according to your home regimen.
  - b. That PD medications must be taken within 15 minutes of the at-home schedule. There is information regarding contraindicated medications and appropriate, safe substitutions.
  - c. Recommendations for physical activity, swallow screening, a review of potential complications related to constipation, pneumonia/infection, and the use of NG tubes (often necessary after surgery).
2. **Deep Brain Stimulation Form** (if applicable).
3. **Duopa Form** – with details related to Carbidopa/Levodopa Enteral Suspension (if applicable).
4. **Special Consideration Regarding Rytary Form** – to be completed with and signed by your Neurologist (if applicable).
5. **Medication List**
6. **Personal Contact List**
7. **Medical Contacts**

Next Steps:

1. Review and complete, with the clinician who provides your Parkinson's care, the:
  - **Physician Letter:** have him/her sign, date, add phone number and email.
  - **DBS and/or Duopa Forms** (if applicable).
  - **Special Considerations Regarding Rytary Form:** have him/her sign and add phone number (if applicable).
2. Review and complete the:
  - **Medication List:** note name of medication, dose, time of dosing, and any notes.
  - **Personal Contacts List.**
3. Make copies of all forms and assemble into several sets.
4. Create a **"To-Go Kit"** containing:
  - Sets of forms – share a set at Pre-Op appts, on admission to the ED, and on a hospital floor
  - Eye mask and ear plugs
  - Complete set of medications in their original RX bottles
  - Phone charger
  - Advanced Healthcare Directive and/or POLST
  - Bottle of water
5. Place your To-Go Kit near your front door for emergency visits and place an extra set of forms on your refrigerator and in your vehicle(s).

### Remember !

You are an important part of the medical team.  
Share with staff a set of completed forms,  
and that you, or the person you care for, has Parkinson's.

Patient Name: \_\_\_\_\_



Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

## Physician's Letter: Parkinson's Medical Safety Needs

*Ask your Parkinson's doctor to sign this letter. Print and attach a current record of your Medication Schedule, Device Form and Patient Contact form.*

\_\_\_\_\_ lives with Parkinson's disease (PD). Their symptoms are managed through a highly individualized medication regimen. Please see the attached Medication Schedule & Device Form for specifics.

Parkinson's symptoms can be greatly exacerbated by both the presenting medical condition, as well as environmental factors. Keep any stimulus, visual and/or auditory (this includes alarms), to a minimum, and place patient in a single room, whenever possible.

PD is a complex, progressive neurological disorder characterized by a loss of dopamine-generating cells in the brain. PD is primarily known for movement symptoms, such as tremor, bradykinesia, and rigidity/stiffness, but there are many other motor and non-motor symptoms of which to be aware, including:

- Cognitive dysfunction
- Freezing of gait
- Instability and falls
- Dyskinesia (involuntary movements)
- Dysphagia and drooling
- Low voice and muffled speech
- Lack of facial expression
- Orthostatic hypotension
- Hallucinations and delusions
- Constipation and incontinence
- Anxiety and/or depression
- Impulse control disorders
- Pain
- Sleep disturbances

**Important:** People with PD have longer hospital stays, more secondary complications and complex care needs. Below are the top five care priorities to aid in safe management of this patient:

### 1. The patient needs their medication ordered in an individualized fashion, according to how they take them at home.

Dosing times and medication formulations are specific to each individual patient because of the complexity of their disease. **Adherence to this regimen *without substitutions* is imperative to avoid severe complications.**

### 2. The patient must take their PD medications ***within 15 minutes*** of their at-home schedule.

If this is not possible, please write orders giving the patient and/or their care partner authorization to administer medications while in the hospital.

If surgery is scheduled, please allow patient to take their PD medications as close to the time of surgery as possible, with a sip of water or crushed in applesauce (if not extended release). They should resume their PD medications as soon after surgery as is safe. If NPO at any point, immediately implement orally dissolvable medication dosing to match existing schedule.

### **3. Certain medications significantly worsen PD symptoms:**

#### **Antipsychotics**

##### **Safe medications:**

- Quetiapine (Seroquel)
- Clozapine (Clozaril)
- Pimavanserin (Nuplazid)

##### **Medications to avoid:**

- haloperidol
- aripiprazole
- olanzapine
- risperidone
- ziprasidone
- lurasidone
- cariprazine
- brexpiprazole
- fluphenazine
- and all other antipsychotic medications other than those listed above as safe.

Note: most “atypical” antipsychotics will still block dopamine receptors and drastically worsen Parkinson’s disease..

#### **In-hospital delirium/agitation**

Avoid all antipsychotic medications other than quetiapine or clozapine. Quetiapine 12.5 to 25 mg is a good initial as-needed choice. If quetiapine is insufficient, benzodiazepines such as lorazepam, diazepam, or clonazepam are actually preferable to the other antipsychotics. Also avoid anticholinergic medications.

Note: Though brexpiprazole (Brexulti) has been approved as a treatment for agitation in Alzheimer disease it is contraindicated in Parkinson disease

#### **Gastrointestinal and anti-nausea medications:**

##### **Safe medications:**

- ondansetron (Zofran)
- granisetron (Kytril)
- trimethobenzamide (Tigan)
- domperidone

##### **Medications to avoid:**

- metoclopramide (Reglan)
- prochlorperazine (Compazine)
- promethazine (Phenergan)

#### **Pain Medications:**

*In persons with PD taking MAO-B inhibitors (rasagiline, selegiline, or safinamide) avoid:*

- meperidine (Demerol)
- propoxyphene (Darvon)
- cyclobenzaprine
- methadone

*Persons with PD taking taking MAO-B inhibitors (rasagiline, selegiline, or safinamide) should hold the MAO-B inhibitor 2 weeks prior and 2 weeks after general anesthesia to avoid potential interactions*

**4. The patient needs to move their body as safely and regularly as possible, ideally TID**

Ambulate as soon as medically safe. Bed rest should be used as a last resort. Physical activity is key to maintaining mobility and reducing fall risk. Consult with physical and occupational therapy to determine what is safe and with whom.

**5. The patient should be screened upon admission for swallowing changes and determination of safe medication/food routes to minimize the risks of choking, aspiration pneumonia and/or weight loss. At the same time, keep in mind that many persons with PD live with a mild to moderate degree of chronic swallowing dysfunction and have elected against a feeding tube. Poor performance on a dysphagia evaluation should not result in a reflex action NPO order. Oral PD medications may not be withheld. Consult with the care team and consider the overall context.**

**Key points to reduce patient complications:**

People with PD are prone to:

- **constipation.** A good bowel regimen can improve medication absorption.
- **pneumonia and infection,** causing sudden changes in behavior and motor function. Initial and ongoing SLP evaluation is important to help identify and reduce these risks.
- Should the patient require an **NG tube,** carbidopa/levodopa 25/100 immediate-release tablets can be crushed and administered via the tube.

**Should you have additional questions or concerns, please don't hesitate to contact me.**

Doctor's Printed Name:

\_\_\_\_\_

Doctor's Signature:

\_\_\_\_\_

Doctor's Phone Number:

\_\_\_\_\_

Doctor's Email:

\_\_\_\_\_

This letter is part of the Parkinson Foundation Western Pennsylvania's (PFWPA) **Medical Safety Kit.** For more information, go to [pfpwpa.org](http://pfpwpa.org).

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

**I HAVE A DEEP BRAIN STIMULATION DEVICE:**

Yes \_\_\_\_\_

No \_\_\_\_\_

If yes:

Surgery and Device Details:

Movement Disorder Neurologist: \_\_\_\_\_

Movement Disorder Neurologist Phone: \_\_\_\_\_

Neurosurgeon: \_\_\_\_\_

Date of Implantation: \_\_\_\_\_

Manufacturer Name: \_\_\_\_\_

Product Name (IPG Model): \_\_\_\_\_

Device Rep Name: \_\_\_\_\_

Device Rep Phone: \_\_\_\_\_

Lead Location: Right Brain \_\_\_\_\_ Left Brain \_\_\_\_\_

Battery Type: Rechargeable \_\_\_\_\_ Non-rechargeable \_\_\_\_\_

Battery Location: Right Chest \_\_\_\_\_ Left Chest \_\_\_\_\_ Other \_\_\_\_\_

Date of last battery replacement \_\_\_\_\_

**Considerations for DBS safety:**

Contact manufacturer or movement disorder neurologist/neurosurgeon for device specific instructions for diagnostic and/or therapeutic procedures, including but not limited to:

- MRI
- Electrocautery
- Laser procedures
- Diathermy
- Lithotripsy

Artifact may occur on EKG and EEG reports. If these studies are critical, contact the patient's neurologist and/or the device Rep to see if DBS can be temporarily deactivated during the study

Avoid sudden cessation of DBS stimulation. Contact device manufacturer for assistance and instructions on device management, MRI safe mode, and turning device on/off (i.e. for surgery.) Patient may have own device programmer.

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

**I USE CARBIDOPA/LEVODOPA ENTERAL SUSPENSION (DUOPA):**

Yes \_\_\_\_\_

No \_\_\_\_\_

If yes:

Surgery and Device Details:

Movement Disorder Neurologist: \_\_\_\_\_

Movement Disorder Neurologist Phone: \_\_\_\_\_

Surgeon: \_\_\_\_\_

Date of Implantation: \_\_\_\_\_

Daily Dosage Schedule (set out refrigerated cassette 20" before connecting)

Start Time: \_\_\_\_\_ Morning Dose: \_\_\_\_\_

Stop Time: \_\_\_\_\_ Continuous Dose Rate: \_\_\_\_\_

Extra Dose: \_\_\_\_\_ Time/s: \_\_\_\_\_

Titrated Dose/s: \_\_\_\_\_ Time/s: \_\_\_\_\_

Type of Tubing: AbbVie: \_\_\_\_\_ ENFit \_\_\_\_\_

Date Last Tube Replacement: \_\_\_\_\_

*Due to a fixed, interior bumper plate, AbbVie tubing should be removed endoscopically, if replacement is indicated.*

DuoConnect RN Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Device Rep Name: \_\_\_\_\_

Device Rep Phone: \_\_\_\_\_

My PEG-J tube for this device was implanted by a

Gastroenterologist \_\_\_\_\_

Interventional Radiologist \_\_\_\_\_

General Surgeon \_\_\_\_\_

Name: \_\_\_\_\_ Phone: \_\_\_\_\_ (for tubing system complications)

- The DUOPA cassettes must be kept refrigerated (between 36°F to 46°F; do not freeze), but should be used at room temperature.
- 20 minutes prior to use, remove a cassette from the refrigerator. An opened cassette should not be re-used. If the cassette contents are yellowed, do not use.
- Avoid sudden discontinuation or rapid dose reduction in patients taking DUOPA.
- If pump is disconnected for less than 2 hours, do not supplement with oral medications.
- If imaging studies (ultrasound, ECG, CT scan, X-Ray, MRI) are required, turn off the pump and detach from patient and remove the pump from the procedure room.

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

**SPECIAL CONSIDERATION REGARDING RYTARY**

For my Parkinson Disease I take Rytary which is a specialized extended-release formulation of carbidopa levodopa. The pharmacokinetics of Rytary are different from immediate release carbidopa levodopa (Sinemet) in that Rytary requires roughly 2-3 times the levodopa dose in Sinemet to achieve an equivalent peak plasma dopamine level. As such, a dose conversion must be applied if a temporary switch is made from Rytary to Sinemet. This requires different dosing and more frequent administration.

**Rytary capsules should be swallowed whole to preserve their extended/timed-release properties.**

My current Rytary regimen:

\_\_\_\_\_

If Rytary is not on the hospital formulary, if possible allow the patient's care partner(s) to bring in their home supply to be administered according to the normal outpatient regimen.

If the administration of Rytary is not possible (i.e. temporarily unavailable or patient is only receiving enteral intake via NG tube) please substitute the following temporary regimen of immediate release carbidopa levodopa (aka Sinemet or Parcopa):

\_\_\_\_\_

(completed by the patient's outpatient PD Neurologist)

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

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





Patient Name \_\_\_\_\_

Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

### PERSONAL CONTACTS

#### Emergency Contact

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

#### Hospital Care Partner

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

#### Additional Personal Contact

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

#### Additional Personal Contact

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Patient Name: \_\_\_\_\_

Date of Birth: \_\_\_\_\_ MRN: \_\_\_\_\_

### MEDICAL CONTACTS

Parkinson's Neurologist (Doctor)

Name: \_\_\_\_\_

Medical Affiliation or Hospital: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Parkinson's Neurologist (APP)

Name: \_\_\_\_\_

Medical Affiliation or Hospital: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Primary Care Physician

Name: \_\_\_\_\_

Medical Affiliation or Hospital: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Pharmacy

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

Additional Medical Contact

Name: \_\_\_\_\_

Medical Affiliation or Hospital: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_