



PARKINSON ASSOCIATION of Northern California

BUILDING COMMUNITY FOR THE JOURNEY

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

Undergoing a medical procedure has the potential to negatively impact a person with Parkinson's (PD). 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.

This packet of forms was developed by PANC, in conjunction with the Parkinson's Association of San Diego. The forms can be filled out online, downloaded, and completed with your Movement Disorder Specialist/Neurologist. The forms include:

- % Physician Letter** – to be completed and signed by your neurologist. The physician letter provides information on PD and emphasizes:
 - U** The need for compliance with medication dosing times and formulations according to your home regimen, and that PD medications must be taken within 15 minutes of the at-home schedule.
 - V** Important information regarding contraindicated medications and appropriate, safe substitutions.
 - W** Recommendations for physical activity, swallow monitoring, a review of potential complications related to constipation, pneumonia/infection, and the use of nasal gastric tubes (often necessary after surgery).
- & Deep Brain Stimulation Form** (if applicable).
- ' Duopa Form** – with details related to carbidopa/levodopa enteral suspension (if applicable).
- (Special Consideration Rytary Form** – to be completed with and signed by your neurologist (if applicable).
-) Medication List**
- * Personal Contact List**
- + Medical Contacts**

Next Steps:

1. Review and complete the following forms:
 - **Physician Letter**
 - **DBS and/or Duopa Forms** (if applicable).
 - **Special Considerations Regarding Rytary Form** (if applicable)
2. Review and complete the following with your care partner:
 - **Medication List:** note name of medication, dose and time of dosing
 - **Personal and Medical 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 appointments, on admission to the Emergency department, and prior to any procedures
 - **Complete set of medications** in their original RX bottles (if possible)
 - **Phone charger**
 - **Advanced Healthcare Directive and/or POLST**
 - **Bottle of water and some snacks**
 - **Eye mask and ear plugs**
5. Place your To-Go Kit near your front door for emergency visits and place an extra set of forms in your vehicle(s). Make sure your care partner and/or emergency contacts have a set too.

Remember !

You are an important part of the medical team.

Share a set of completed forms, and that you or the person you care for has Parkinson's with the hospital staff.

Patient Name: _____

Date of Birth: _____ MRN _____



Parkinson Association
of Northern California

Physician's Letter: Parkinson's Medical Safety Needs

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

_____ has Parkinson's disease (PD). Their symptoms are managed through a highly individualized medication regimen.

Please see the attached Medication Schedule and Device Form for specifics.

Parkinson's symptoms can be greatly exacerbated by 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 to be aware of, including:

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

Important: People with PD may 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 on a regular schedule, per the attached form

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

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.

Patient Name: _____

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 anti-psychotic medications other than those listed above as safe.

Note: most “atypical” anti-psychotics will still block dopamine receptors and drastically worsen Parkinson’s disease

In-hospital Delirium/agitation

Avoid all anti-psychotic 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 anti-psychotics. Also avoid anticholinergic medications.

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

PD patients taking MAO-B inhibitors (rasagiline, selegiline, or safinamide) avoid:

- Meperidine (Demerol)
- Propoxyphene (Darvon)
- Cyclobenzaprine
- Methadone

Note: PD patients 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

Patient Name: _____

4. The PD patient needs to move their body as safely and regularly as possible

- Have them walk or move their body 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

5. Any swallowing issues should be noted on admission and dealt with accordingly.

6. Key points to reduce patient complications:

- **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
- **UTI's and dehydration** can cause hallucinations, confusion and/or abnormal behavior

If you have any 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 Association of Northern California **Medical Safety Kit**.
For more information, go to **www.panctoday.org**



Parkinson Association
of Northern California

Patient Name: _____

Date of Birth: _____ MRN: _____

I HAVE A DEEP BRAIN STIMULATION DEVICE

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 _____

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 representative 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 their own device programmer.

Patient Name: _____

Date of Birth: _____ MRN: _____

I USE CARBIDOPA/LEVODOPA ENTERAL SUSPENSION (DUOPA)

Surgery and Device Details:

Movement Disorder Neurologist: _____

MDS Phone: _____

Surgeon: _____

Date of Implantation: _____

Daily Dosage Schedule (set out refrigerated cassette 20 mins 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's 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 _____

Date of Birth: _____ MRN: _____

List all medications you are taking for Parkinson's and other conditions, including over-the-counter medications and supplements.

Additional blank copies may be accessed at www.panctoday.org

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 Movement Disorder Specialist (MDS)

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: _____

The Parkinson Association of Northern California has produced these Medical Safety forms in collaboration with and assistance of the Parkinson's Association of San Diego.