

Essential information about my Parkinson's Disease:

Name: _____ DOB: _____

Family Contact: _____ Phone#: _____

I have Parkinson's disease (PD) which doctors diagnosed in _____ (year). It is important that those who care for me have a basic understanding of the disease so that my symptoms can be accurately recognized and treated.

WHAT IS PARKINSON'S DISEASE?

Parkinson's disease is a slowly progressive disorder, generally associated with tremor, stiffness, rigidity of the muscles and slowness of movement. Patients with PD have low dopamine levels in the brain. The medications for PD increase the level of dopamine. When the PD medications are not working (off-time), the tremor and stiffness will return. Patients may have wiggly or writhing movements (dyskinesias). When the patient is experiencing dyskinesias it usually indicates that the Sinemet (carbidopa-levodopa) and/or Stalevo level is high.

CHARACTERISTICS OF PARKINSON'S DISEASE

I may personally exhibit those symptoms which have been checked below.

- | | |
|---|--|
| <input type="checkbox"/> Tremor | <input type="checkbox"/> Dementia / Hallucinations / Confusion |
| <input type="checkbox"/> Rigidity / Stiffness of muscles | <input type="checkbox"/> Speech problems (reduced volume / slurred) |
| <input type="checkbox"/> Bradykinesia (slowness of movement) | <input type="checkbox"/> Constipation & Urinary symptoms |
| <input type="checkbox"/> Stooped posture | <input type="checkbox"/> Drooling |
| <input type="checkbox"/> Low blood pressure | <input type="checkbox"/> Sleep disturbances (daytime somnolence, night time insomnia, acting out dreams) |
| <input type="checkbox"/> Difficulty walking / imbalance & falls | <input type="checkbox"/> "Masked face" (Flattened affect) |
| <input type="checkbox"/> Difficulty swallowing | |

FACTORS THAT WORSEN PD SYMPTOMS

- not getting medications on time
- taking Carbidopa/Levodopa, Sinemet®, Parcopa® with protein or iron
- stress, anxiety, lack of exercise and/or the need for rest
- being prescribed incompatible medications
- Infection

ALERT!! I have a DBS (deep brain stimulation) implant.

Questions should be directed to my DBS nurse at: _____ or to Medtronic at 1-800-328-0810.

-WARNING: Diathermy (therapy which uses high-frequency current) is completely contraindicated; MRIs can only be done following strict guidelines.

PD AND MEDICATIONS

Medications commonly used to treat PD:

DOPAMINE

- Sinemet®(carbidopa/levodopa))
- Parcopa®
- Stalevo® (Comtan + Sinemet)

MAO-B INHIBITORS

- Eldepryl® (selegiline)
- Zelapar® (selegiline)
- Azilect® (rasagiline)

DOPAMINE

AGONISTS

- Requip ®
(ropinirole)
- Mirapex ®
(pramipexole)
- Parlodel®
(bromocriptine)

COM-T INHIBITORS

- Comtan® (entacapone)
- Tasmart® (tolcapone)

ANTI-VIRAL

- Symmetrel ®
(amantadine)

INJECTIONS

- Apokyn® (apomorphine)

Current PD medications I am taking:

Medication	Dose	# of pills each dose	Times taken	Why I take this medication...

Common potential side effects of PD medications:

• nausea	• dizziness	• hypotension
• confusion	• hallucinations	• orthostatic hypotension
• Dyskinesias	• compulsive behavior	•

Potential *SERIOUS* PD medication side effects:

• **MAO-B Inhibitors (selegeline, rasagiline, Zelapar): DEMEROL MUST NEVER BE GIVEN WITH MAO-B inhibitors!**

IF POSSIBLE, MAO-B inhibitors should be stopped for two weeks prior to *surgery*. It is imperative that the attending physicians verify and stipulate this interval. THESE medications may be given with SSRI's safely.

• **COM-T Inhibitors (Stalevo, Comtan, Tasmar):**

These medications can cause severe *diarrhea* which will resolve once the medication is changed.

• **Dopamine Agonists (Requip, Mirapex, Parlodel):**

Watch for obsessive-compulsive behavior, hallucinations, swelling, and psychosis.

• **Atypical Anti-psychotics (Seroquel, Clozapine):**

These drugs are utilized to help control hallucinations and delusions. May cause *hypotension*, clozapine must be monitored with weekly CBC's/diff for *neutropenia*

MEDICATIONS *CONTRAINDICATED* for use in PD patients:

NEUROLEPTICS

Haloperidol (Haldol)
Chlorpromazine (Thorazine)
Thioridazine (Mellaril)
Molindone (Moban)
Perphenazine (Trilafon)
Perphenazine and amitriptyline (Triavil)
Benzodiazapines

Thiothixene (Navane)
Flufenazine (Prolixin)
Risperdal
Zyprexa
Geodon
Abilify

GI Drugs

Promethazine/phenergan
Prochlorperazine

Metoclopramide (Reglan)

Others

Dextromethorphan*
Benadryl *

*These can worsen confusion, particularly in elderly PD patients.

MEDICATION DOSING AND DIETARY INFORMATION

Medication dosing, timing, and administration:

The timing of my medication is very important to help minimize my symptoms and “off” times. I must be given my medication(s) promptly at the times specified. If this is not possible, consult my admitting physician for authorization to administer my own medication, or alternatively, to have it administered by my caregiver.

IN PARTICULAR, my carbidopa/levodopa (or Sinemet) must be taken 30-60 minutes before or two hours after my meals, because protein prevents the maximum amount of dopamine from reaching the brain. The relationship of protein consumption and medication timing greatly affects my condition.

If I am not able to swallow, my medications may need to be crushed and administered by a stomach tube (exception: Sinemet CR must not be crushed) or the dissolvable form—Parcopa®—should be ordered. If I am on Sinemet and Intravenous Protein (TPA) is proposed, my neurologist must first be contacted because the dosage may need to be adjusted.

PD and Surgery

1. If possible, stop MAO-B Inhibitors (Eldepryl/selegiline, Azilect, Zelapar) two weeks prior to surgery.
2. Pre-operative dosing instructions: There should be no reason to skip PD medications prior to surgery even if directions are NPO (nothing by mouth) for 6-10 hours prior to surgery. Discuss with surgeon or anesthesiologist.
3. Restart PD medications post-surgery (except MAO-B Inhibitors) as soon as possible even if NPO; discuss with surgeon.
4. Be aware that PD patients have a lower threshold response to analgesics (sedation/pain medications) and could experience hallucinations; however, this is not a contraindication (reason to avoid) their administration.

Additional concerns / comments / other conditions for which I am being treated:

NEUROLOGICAL ADVISORY

Ready access to a neurologist/doctor who is familiar with my condition is very important.

My neurologist is: _____ Phone # _____

My DBS nurse is: _____ Phone # _____

My family doctor is: _____ Phone# _____

My home caregiver is: _____ Phone# _____

Additional medical support:

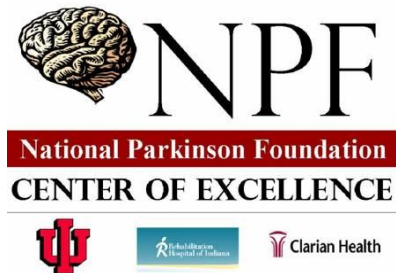
_____ Phone# _____
_____ Phone# _____

Optional: I concur with the above considerations: _____
Physician's Signature

Please Note: This guide does not replace the orders of my admitting physician (s). I have chosen to use this guide to encourage communication among all my physicians, nursing staff and myself. Thank you for taking the time to review this document in order to improve my care.

- I have an Advanced Directive. I have a Healthcare Power of Attorney.

Created by:
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** Drawing from the experiences of those who have contributed to this publication, we recommend that, if hospitalized, you or your caregiver have sufficient copies of this leaflet to distribute: one to your admitting physician, one for the nurse on each shift (4), one for the attending surgeon if surgery is to be done, and one for the anesthesiologist.*