



**PARKINSON CENTER
OF OREGON**
*National Parkinson
Foundation*
Center of Excellence

CRITICAL INFORMATION FOR CARING FOR THE PARKINSON'S PATIENT

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 trembling of the limbs, stiffness, rigidity of the muscles and slowness of movement. An accelerated loss of the brain chemical dopamine (a neurotransmitter which activates the message system from the brain to control movements) causes this. To date there is no known cause and no cure. Researchers believe that both environmental and genetic factors may play a role in the development of the disease.

CHARACTERISTICS OF PARKINSON'S DISEASE

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

- | | |
|---|--|
| <input type="checkbox"/> Rigidity
<input type="checkbox"/> Tremor
<input type="checkbox"/> Bradykinesia (slowness of movement)
<input type="checkbox"/> Difficulty with balance
<input type="checkbox"/> Depression
<input type="checkbox"/> Sleep disturbances
<input type="checkbox"/> Dementia
<input type="checkbox"/> "Restless legs"
<input type="checkbox"/> Speech problems (vocal softness, slurred and indistinct words)
<input type="checkbox"/> "On-off" symptoms (able to perform one minute, but not the next; this may be related to timing of medications) | <input type="checkbox"/> "Masked face" showing little or no emotion with a staring expression
<input type="checkbox"/> Drooling
<input type="checkbox"/> Difficulty swallowing
<input type="checkbox"/> Constipation
<input type="checkbox"/> Difficulty in voiding
<input type="checkbox"/> Dizziness
<input type="checkbox"/> Stooped posture
<input type="checkbox"/> Swollen feet
<input type="checkbox"/> Excessive sweating
<input type="checkbox"/> Difficulty with walking (a decrease in the natural arm swing, short shuffling steps, difficulty turning, abrupt "freezing" spells) |
| <input type="checkbox"/> _____
<input type="checkbox"/> _____ | <input type="checkbox"/> _____
<input type="checkbox"/> _____ |

- 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.

Patient Name: _____

Date Updated: _____

COMPLICATING FACTORS

Factors that may worsen my condition are:

- not getting medications (particularly Sinemet®, Carbidopa/Levodopa) on time
- taking Sinemet® with protein or iron
- taking Sinemet® too soon or too late (more than 15 minutes) from the prescribed time
- stress, anxiety, lack of exercise and/or the need for rest
- being prescribed incompatible medications (see below)

MY MEDICATION & DIETARY SCHEDULE

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. The timing of my medication is very important to help minimize my symptoms and “off” times. For example, **my 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.

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.

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

Medications commonly used to treat PD:

DOPAMINE

- Sinemet®(carbidopa/levodopa)
- Parcopa®

MAO-B INHIBITORS

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

DOPAMINE AGONISTS

- Requip ® (ropinirole)
- Mirapex ® (pramipexole)
- Apokyn® (apomorphine)
- Neupro® (rotigotine)
- Permax® (pergolide)
- Parlodel® (bromocriptine)

COM-T INHIBITORS

- Comtan® (entacapone)
- Tasmar® (tolcapone)
- Stalevo® (Comtan + Sinemet)

ANTI-VIRAL

- Symmetrel ® (amantadine)

NUTRITION CONSULTATION

If this hospital or facility has a nutritionist, it would be helpful for me or my home caregiver to speak directly with him/her. The relationship of protein consumption and medication timing greatly affects my condition.

Patient Name: _____

Date Updated: _____

MEDICATION SIDE EFFECTS

Parkinson's medications all have very similar side effects: nausea, dizziness, mental changes, hallucinations, confusion, involuntary movements, loss of appetite, dryness of mouth, lowered blood pressure. If these should occur or other medication issues arise, please contact my neurologist's nurse at _____.

Medication changes are often necessary with Parkinson's disease and everyone responds differently to the medications. The doctor will need to know what has changed, how and when my medications work (reduced symptoms), and the timing of when they do not work. A medication diary noting changes may be helpful.

IMPORTANT MEDICATION INFORMATION

Medication concerns are not limited to the notes below; however, these are some of the more common medication reactions that some healthcare providers are not aware of.

- **MAO-B Inhibitors (selegiline, rasagiline):** DEMEROL MUST NEVER BE GIVEN WITH MAO-B inhibitors! To be safe, MAO-B inhibitors should be stopped for two weeks prior to surgery. It is imperative that the attending physicians verify and stipulate this interval.
- **COM-T Inhibitors (Stalevo/Comtan/Tasmar):** These medications can cause severe diarrhea which will resolve once the medication is changed. Contact the prescribing physician for directions.
- **Dopamine Agonists (see list on page 2):** Watch for obsessive behavior, hallucinations, and psychosis. Contact the prescribing physician for directions.
- **Atypical Anti-psychotics (Seroquel / Clozapine):** These drugs are utilized to help control behavioral problems in people with PD, but only after careful consideration by the treating neurologist, family and patient.
- **Narcotics:** Although pain control is the top priority, be aware that narcotics can more easily precipitate confusion in people with Parkinson's disease.

PD & SURGERY:

1. See note above regarding stopping Eldepryl/selegiline two weeks prior to surgery.
2. 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 (except eldepryl) as soon as possible after surgery 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.

Other medications which may worsen Parkinsonian symptoms and should not, in general, be prescribed for a person with PD include:

NEUROLEPTICS

Haloperidol (Haldol®)
Chlorpromazine (Thorazine®)
Thioridazine (Mellaril®)
Molindone (Moban®)
Perphenazine (Trilafon®)
Perphenazine and amitriptyline (Triavil®)
Thiothixene (Navane®)
Flufenazine (Prolixin®)

GI / ANTI-NAUSEA RX

metoclopramide (Reglan®)
prochlorperazine (Compazine®)
trimethobenzamide (Tigan®)

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

NEUROLOGICAL ADVISORY

I feel that having ready access to a neurologist/doctor who is familiar with my condition is very important.

My neurologist 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 is not intended to 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.

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

* * * * *

Developed by Parkinson's Resources of Oregon and OHSU's Parkinson Center of Oregon.

Parkinson's Resources of Oregon (PRO)
2145 N.W. Overton Street
Portland, OR 97210
503-413-7717
800-426-6806
www.parkinsonsresources.org
PRO provides support and educational resources for people and families dealing with Parkinson's disease.

Parkinson Center of Oregon (PCO)
Oregon Health & Sciences University
3181 S.W. Sam Jackson Park Rd, OP-32
Portland, OR 97239
503-494-7230
www.ohsu.edu/pco
The PCO is a national leader in medical care, research, and education for people and families living with Parkinson's.

** 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.*

Patient Name: _____

Date Updated: _____