

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"/> Slowness of movement (bradykinesia) | <input type="checkbox"/> Difficulty with balance |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sleep disturbances |
| <input type="checkbox"/> Memory problems | <input type="checkbox"/> "Restless legs" |
| <input type="checkbox"/> Speech problems (vocal softness, slurred and indistinct words) | <input type="checkbox"/> "Masked face" showing little or no emotion with a staring expression |
| <input type="checkbox"/> Drooling | <input type="checkbox"/> Difficulty swallowing, choking |
| <input type="checkbox"/> Constipation | <input type="checkbox"/> Difficulty in urinating |
| <input type="checkbox"/> Dizziness, lightheadedness | <input type="checkbox"/> Stooped posture |
| <input type="checkbox"/> Swollen feet | <input type="checkbox"/> Excessive sweating |
| <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"/> Difficulty with walking (a decrease in the natural arm swing, short shuffling steps, difficulty turning, abrupt "freezing" spells) |

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

- ☐ I have a DBS (deep brain stimulation) implant. Questions should be directed to my DBS provider _____ 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.

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Patient Name: _____

Date Updated: _____

COMPLICATING FACTORS

Factors that may worsen my condition are:

- not getting medications (particularly carbidopa-levodopa, aka Sinemet®, Parcopa®) on time
- taking carbidopa-levodopa with protein or iron
- taking carbidopa-levodopa more than 15 minutes from the prescribed time
- stress, anxiety, pain, lack of exercise and/or the need for rest, infection
- being prescribed new or incompatible medications (see contraindicated medications below)

MY MEDICATIONS

Medications commonly used to treat PD:

DOPAMINE

Sinemet® (carbidopa-levodopa)*
Rytary® (carbidopa-levodopa IR/ER)
Parcopa® (dissolvable carbidopa-levodopa)
Duopa® (enteral)

COM-T INHIBITORS

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

ANTI-VIRAL

Symmetrel® (amantadine)

ANTI-CHOLINERGICS

Artane® (trihexiphenidyl)

MAO-B INHIBITORS

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

DOPAMINE AGONISTS

Requip® (ropinirole)*
Mirapex® (pramipexole)*
Neupro® (rotigotine)-patch
Apokyn® (apomorphine)-injection

List ALL medications and supplements. If you need more room, please attach a detailed list.

Medication	Dose (mg)	# of pills / dose	Times taken	Reason for medication

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 (see page 4).

ATTN: NURSING STAFF

- **TIMING IS CRITICAL.** The timing of my medication is very important because a late or missing medication may cause me to become immobile and unable to assist in my own care. Thus, 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 to have it administered by my caregiver. 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.
- **Medication changes** are often necessary with PD and everyone responds differently to PD medications. Please document when my medications do not work in relation to the timing of my last or next dose.
- **If I am not able to swallow**, my medications may need to be crushed and administered by a stomach or naso-gastic tube (exception: extended release formulations) or the dissolvable form should be requested. If I am on carbidopa-levodopa and Intravenous Protein (TPA) is proposed, my neurologist must first be contacted because the dosage may need to be adjusted.

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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 stopped.
- **Dopamine Agonists:** Watch for obsessive behavior (e.g. gambling, sexual hyperactivity, excessive spending, etc), hallucinations, and psychosis.
- **Narcotics:** Although pain control is the top priority, be aware that PD patients have a lower threshold response to analgesics (sedation/pain medications) and could experience confusion and hallucinations. However, this is not a contraindication (reason to avoid) their administration.
- **Atypical anti-psychotics (Seroquel®/quetiapine; Clozaril®/clozapine):** These are the only two anti-psychotic drugs utilized to help control behavioral problems in people with PD, but only after careful consideration by the treating neurologist, family and patient.

PD & SURGERY:

1. See note above regarding stopping selegiline/rasagiline 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 selegiline, rasagiline) as soon as possible after surgery even if NPO.
4. See narcotics above.

Other medications which may worsen Parkinsonian symptoms and should not be prescribed:

NEUROLEPTICS

All atypical and typical antipsychotic medications are contraindicated (e.g. Haldol®, Thorazine®, Risperdal®, etc) except as noted above.

GI / ANTI-NAUSEA RX

metoclopramide (Reglan®)
prochlorperazine (Compazine®)
promethazine (Phenegran®)

For a complete listing of contraindicated medications, go to www.awareincare.org.

ADDITIONAL CONSULTATIONS

Parkinson's disease is best treated by a team of healthcare providers. I (and my caregiver) can benefit from consultations with the following providers.

- Physical Therapist: To assist with gross motor movements, especially walking, balance, turning in bed, exercise programs.
- Occupational Therapist: To assist with fine motor movements, self care, fatigue management, ,
- Speech Therapist: To assist with treatment for low speech, communication limitations, swallowing issues, and cognitive management.
- Registered Dietitian: Since protein and iron can interfere with the effectiveness of carbidopa-levodopa the consultation with a RD can help to ensure I receive sufficient protein for healing and maintenance.
- Social Worker: my caregiver may not be able to care for me at home immediately following hospitalization because of her/his own care issues. Please be sure a social worker helps us with discharge planning.

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

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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.

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# _____

For more information and a free hospitalization information kit, please visit: www.awareincare.org.

The content provided here is for informational purposes only, and was not designed to diagnose or treat a health problem or disease, or replace the professional medical advice you receive from your physician. Please consult your physician with any questions or concerns you may have regarding your condition.

* * * * *

This form was developed by...

Parkinson's Resources of Oregon (PRO)
800-426-6806
www.parkinsonsresources.org

OHSU Parkinson Center
503-494-7231
www.ohsubrain.com/pco

Drawing from experience, we recommend that for this information to be most effective, you should:

UPDATE OFTEN -- MAKE COPIES -- SHARE EVERYWHERE

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