Critical Information for Caring for Residents with Parkinson's

The information that follows was developed jointly by Parkinson's Resources of Oregon and Oregon Health & Sciences University's (OHSU) Parkinson Center of Oregon to aid people with Parkinson's disease and their caregivers.

Name: _____ DOB: _____
Family Contact: _____Phone#:_____

Mr./Mrs./Ms. _____ has Parkinson's disease (PD), which doctors diagnosed in _____ (year). It is important that those who care for this resident have a basic understanding of the disease so that his/her symptoms can be accurately recognized and treated.

What Is Parkinson's Disease?
PD 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 that activates the message system from the brain to control movements) causes the disease.

Characteristics Of Parkinson's Disease
Mr./Mrs./Ms. _____ may exhibit these signs or symptoms listed below:

☐ Rigidity
☐ Masked face (shows little or no emotion with a staring expression)
☐ Tremor
☐ Drooling
☐ Bradykinesia (slow movements)
☐ Difficulty swallowing
☐ Difficulty with balance
☐ Constipation
☐ Depression
☐ Difficulty voiding
☐ Sleep disturbances
☐ Dizziness
☐ Dementia
☐ Stooped posture
☐ Restless legs
☐ Swollen feet
☐ Speech problems (vocal softness, slurred and indistinct words)
☐ Excessive sweating
☐ On-off symptoms (able to perform 1 minute but not the next; may be related to timing of medications)
☐ Difficulty walking (decrease in the natural arm swing, short shuffling steps, difficulty turning, abrupt "freezing" spells)

☐ Mr./Mrs./Ms. _____has a DBS (deep brain stimulation) implant. Questions should be directed to his/her DBS nurse _____ at _____ or to Medtronic at 1-800-328-0810.

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

Complicating Factors
Factors that may worsen the resident's 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

Medication and Dietary Schedule
The resident must receive medication(s) promptly at the times specified to help minimize symptoms and "off" times. For example, **Sinemet must be taken 30 to 60 minutes before or 2 hours after meals** because protein prevents the maximum amount of dopamine from reaching the brain. If the resident is not able to swallow, the 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 the resident takes Sinemet and intravenous protein (TPA) is proposed, first contact the resident's neurologist.

Medications	Dose	Number of pills in each dose	Times taken	Reason for medication

Medications Commonly Used to Treat PD:

Dopamine	Dopamine Agonists	COM-T Inhibitors
☐ carbidopa/levodopa (Sinemet)	☐ ropinirole (Requip)	☐ entacapone (Comtan)
☐ Parcopa	☐ pramipexole (Mirapex)	☐ tolcapone (Tasmar)
MAO-B Inhibitors	☐ apomorphine (Apokyn)	☐ Comtan + Sinemet (Stalevo)
☐ selegiline (Eldepryl)	☐ rotigotine (Neupro)	**Antiviral**
☐ rasagiline (Azilect)	☐ pergolide (Permax)	☐ amantadine (Symmetrel)
	☐ bromocriptine (Parlodel)	

Proposed Changes to Parkinson's Disease Guidelines

Parkinson's disease (PD), a progressive neurological disorder, robs the body of its ability to move freely and purposefully. Numerous complicating factors, which may include cognitive changes and dementia, make people with PD prime candidates for long-term care (LTC) day care or assisted living residency.

Parkinson's Resources of Oregon (PRO) is a regional nonprofit organization working to provide support and services to families dealing with a diagnosis of PD. Oregon Health & Sciences University's (OHSU) Parkinson Center of Oregon is a nationally recognized leader in PD care and research.

Under the leadership of the Parkinson's Advocacy Committee, whose members demonstrate personal as well as professional experience with PD, we ask the Seniors and People with Disabilities of the Department of Health and Human Services (SPD/DHS) to adopt changes in Administrative Rules for (various) LTC settings that have the potential to dramatically improve functioning for residents living with PD and decrease facility employee workload.

Summary of Proposed Rules Changes

To raise and standardize the level of care people with PD receive in a residential setting to a minimally acceptable level, PRO, with the support of the medical experts at OHSU's Parkinson Center of Oregon, submits that the following changes be adopted on a state-wide level:

1. **Medication Timing:** Maximum efficacy of many PD medications requires that they be administered on a tightly coordinated schedule. **Insert language to allow for variations in timing no greater than 15 minutes.**
2. **Nutrition Services:** Medication absorption is highly correlated with levels of protein and iron existing in the blood stream. **Insert guidelines to support coordination of dietary services to avoid protein and iron supplement consumption 1 hour before or 2 hours after medication.**
3. **Training:** PD symptom manifestation is highly variable from individual to individual. **Provide that all staff members involved with the care of a person with PD have a basic understanding of the complexities of PD and how to manage symptoms to maximize wellness for the resident.**

Background

Of all the symptoms of PD, motor fluctuations rank among the most distressing, disabling, and difficult to manage. The need to closely control medication dosage and timing and protein consumption has long been understood by researchers and physicians skilled in treating people with PD.

Clearly, medication administration and timing, and nutrition services play an important and interrelated role in maximizing functional ability for people with PD. Proper medication administration can mean the difference between a resident frozen in place or one mobile and able to demonstrate independence of care or the need for reduced assistance.

The current guidelines and practice can result in grossly and even dangerously inadequate care because of preventable immobility. We recognize that there may be hurdles to implementing these changes—not the least of which include concerns over an already stretched staff force in the majority of impacted care settings. However, a more mobile resident can lessen employee workload and prevent emergent patient care situations.

Nutrition Consultation

If a nutritionist is available to the resident, it is helpful to have him or her speak directly to the resident. The relationship of protein consumption and medication timing greatly affects this condition.

Medication Side Effects

PD medications all have very similar side effects: nausea, dizziness, mental changes, hallucinations, confusion, involuntary movements, loss of appetite, dryness of mouth, lowered blood pressure. Medication changes are often necessary with PD and everyone responds differently to the medications. The doctor will need to know what has changed, how and when the medications work (reduced symptoms), and the timing of when they do not work.

Important Medication Information

- **MAO-B Inhibitors (selegiline, rasagiline)**: DEMEROL MUST NEVER BE GIVEN WITH MAO-B inhibitors! To be safe, MAO-B inhibitors should be stopped for 2 weeks prior to surgery.
- **COM-T Inhibitors (Stalevo/Comtan/Tasmar)**: These medications can cause severe diarrhea that will resolve once the medication is changed. Contact the prescribing physician for directions.
- **Dopamine Agonists**: 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 person.

- **Narcotics**: Although pain control is the top priority, be aware that narcotics can more easily precipitate confusion in people with PD.

Parkinson's and Surgery:

1. See note above regarding stopping Eldepryl/selegiline 2 weeks prior to surgery.
2. There should be no reason to skip medications prior to surgery even if directions are NPO (nothing by mouth) for 6-10 hours prior to surgery.
3. Restart 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 to use.

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

Neuroleptics	GI/Antinausea Drugs
haloperidol (Haldol)	metoclopramide (Reglan)
chlorpromazine (Thorazine)	prochlorperazine (Compazine)
thioridazine (Mellaril)	trimethobenzamide (Tigan)
molindone (Moban)	
perphenazine (Trilafon)	
perphenazine and amitriptyline (Triavil)	
thiothixene (Navane)	
fluphenazine (Prolixin)	

Additional concerns/comments/other conditions for which the resident is being treated: _____

_____

Neurological Advisory

The resident's neurologist is _____
Phone # _____
The resident's family doctor is _____
Phone# _____
Additional medical support:
_____ Phone#_____
_____ Phone#_____
Physician's Signature: _____

☐ The resident has an Advanced Directive.
☐ The resident has a Healthcare Power of Attorney.

Adapted with permission from a patient-focused publication developed by Parkinson's Resources of Oregon and Oregon Health & Sciences University's Parkinson Center of Oregon. For more information see www.parkinsonsresources.org or www.ohsu.edu/pco.

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