

# Nurse to Nurse

Oregon's community-based care nursing newsletter



Winter 2010

Vol. 6 No. 3

## It's flu season again!

It seems just like yesterday we were all focused on H1N1. **The good news** — There is plenty of vaccine available, and more people know the importance of getting vaccinated and how to prevent the spread of disease. Just look around at how many businesses now offer wipes for carts or alcohol hand sanitizers at the door. The 2010-2011 flu vaccine is readily available and includes coverage for H1N1. The vaccine is also offered by most pharmacies at low or no cost (based on insurance coverage). **The bad news** — The flu season is upon us again.

You can help prevent the spread of the flu virus by following these guidelines:

- Wash your hands frequently with soap and water or, if hands are not visibly soiled, use alcohol-based hand sanitizers.
- Sneeze or cough into your sleeve or tissue. Dispose of the tissue immediately in a proper container. Wash your hands immediately.

- Get an annual flu vaccine and encourage your family, friends and coworkers to get their flu vaccine too.
- Get plenty of rest.
- Eat properly and drink plenty of fluids.
- Exercise routinely.
- Clean surfaces frequently at home and work. Don't forget the door knobs and TV remote control.
- If you are sick, stay home.

Share this information with coworkers, clients, friends and family members. We all need gentle reminders to keep up with good habits. Additional information and resources can be found at [www.flu.oregon.gov](http://www.flu.oregon.gov). The website has a ZIP code search function to locate businesses offering the flu vaccination.

# Parkinson's and Medication

## What is Parkinson's Disease?



Parkinson's Disease is a chronic, progressive, neurological movement disorder. The symptoms arise from changes in the brain and how the brain sends messages to the body.

Once someone has developed PD it will never go away and it will progressively get worse over time. Unfortunately, there is no known cure or way to slow the progression. Many research studies are currently working towards new knowledge of the cause and mechanism so that we can hopefully develop a cure. The average age of onset is 60 years old, but people can be diagnosed at any age.

For people who live with PD, treatment is focused on managing the symptoms. One of the primary challenges is that symptoms vary in severity throughout the course of the day, week, and as time progresses. In addition, each person reacts differently to medications and therapies so treatment plans must be tailored to that individual person, as well as being up to date for symptom severity and appropriately selected for the symptoms that are of greatest concern.

The four primary motor symptoms of PD are:

- Tremor, or shaking
- Bradykinesia, or slowness movement
- Rigidity, or a stiffness in the arms, legs, and trunk
- Postural instability, or impaired balance

Additional symptoms include "freezing", masked face showing little expression, low speech volume, and a distinctive shuffling walk. Parkinson's can also produce a number of non-motor changes including depression, anxiety, slowed thinking, trouble with sleep, constipation, and urinary urgency and frequency.

## What causes the symptoms?

In Parkinson's disease, there is a breakdown of communication in the brain because cells have died or stopped working. Loss of brain cells in the substantia nigra, within the basal ganglia, leads to a loss of the chemical (neurotransmitter) dopamine. Dopamine relays signals from the substantia nigra to brain regions that control speed of movement, balance, and coordination. Changes in dopamine can impact the balance of other chemicals in the brain affecting a variety of functions including cognition and mood.

## Medications

It is probably not surprising that medications used to relieve symptoms target the lost dopamine. Anti-parkinson drugs work primarily through the following three strategies:

Replace dopamine to restore concentrations to near normal levels for optimal functioning.

Mimic the action of dopamine to maintain communication between cells. These are called dopamine agonists.

Prevent breakdown of dopamine or levodopa to increase the amount that is available in the brain for as long as possible before the body breaks it down and recycles it. Drugs that prevent the breakdown of dopamine include MAO-B inhibitors, and drugs that prevent the breakdown of levodopa include COMT-Inhibitors.

Additional drugs currently used to treat PD include Symmetrel® (amantadine,) an anti-viral.

The timing of medications for Parkinson's is extremely important. Medication schedules are often a delicate balance between achieving as much "on" time as possible, (time when the person with Parkinson's is functioning well,) while avoiding adverse affects from increased doses. This is especially important for carbidopa/levodopa because of the short mode of action.

If a medication dose is given too early or too late, it can disrupt the balance and can have severe consequences for the person with Parkinson's. This may include not only discomfort and loss of function and independence for the rest of the day or even longer, but can also lead to falls or other potentially dangerous situations. A good guideline for timing is to keep within 15 minutes of the prescribed time.

Some people are fortunate to find a medication schedule that provides adequate relief without many noticeable side effects. However, many people must work with their neurologist and health care team to decide if certain side effects are an acceptable "trade-off" in order to achieve relief from symptoms.

One of the most well-known side effects of carbidopa/levodopa is the potential development of dyskinesia, an abnormal writhing movement that occurs when dopamine levels are at their highest. While these movements can be very tiring and embarrassing, a person may be able to function better with dyskinesia than if he or she is stiff and slow without taking the medication. This is a perfect example of how individual concerns and goals can come in to play, and why it's important for people with PD to be clear about what's important to them and be an engaged partner in medication decisions.

Parkinson's Resources of Oregon has partnered with the Parkinson Center of Oregon at OHSU to develop an important information packet that helps communicate the most critical information about medication interactions, timing, and precautions for health care professionals to know before caring for a person with PD. Additional copies of this document, as well as information and referral to other helpful information, can be found by contacting Parkinson's Resources of Oregon at 1-800-426-6806 or [info@parkinsonsresources.org](mailto:info@parkinsonsresources.org).

(Adapted from Parkinson's Disease Professional Training Series, a program of Parkinson's Resources of Oregon by Anna Sanger Reed)

**Anna Sanger Reed** is the education and outreach coordinator for Parkinson's Resources. She received her BA in psychology from the University of Washington and joined Parkinson's Resources shortly thereafter, in February of 2008. Anna has enjoyed a variety of volunteer roles, and has experience as a volunteer coordinator for the American Red Cross. Her current responsibilities include overseeing Parkinson's Resources' network of support groups, exercise classes, annual conference and monthly education programs and training for long-term care professionals.

*Note: I had the pleasure of hearing Anna speak at the 3rd Annual Community-Based Nursing Conference this summer. After the conference I walked away with two key messages I routinely share when I'm discussing medication management: The effect of not giving medications on time can mean the difference between controlling their symptoms or misery for hours or longer; and side effects of some medications used for Parkinson's may look worse to us but can improve their quality of life. I invite you to check out Parkinson's Resources' website for more information: [www.parkinsonsresources.org](http://www.parkinsonsresources.org).*

***Parkinson's Resources of Oregon provided the information that follows in this newsletter.***



**PARKINSON'S  
RESOURCES**  
of OREGON  
National Parkinson Foundation  
Affiliate Chapter



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

Enclosed you will find a copy of *Critical Information for Caring for the Parkinson's Patient*, a document that was recently developed by Parkinson's Resources of Oregon and the Parkinson Center of Oregon at Oregon Health & Science University to assist patients and medical professionals in providing optimal care for those with Parkinson's disease.

As you may know, Parkinson's disease symptoms and treatment regimens are often complex, requiring strict adherence to medication and dietary schedules. It is hoped that this document will serve as a useful tool to help you communicate this importance with care professionals.

While not legally binding, *Critical Information for Caring for the Parkinson's Patient* provides you with an opportunity to express your unique needs/symptoms and also can serve as an education tool for care staff you may interact with. Because symptoms and medication regimens frequently change, it will be important that you periodically review and update this information.

Should you (or your loved one) require additional care and support either at home or in an institutional setting, we urge you to ask that this document be included with the patient's Care Plan as well as attached to medical records. You may need to make several copies so that all relevant parties have ready access to the information.

If you have additional questions regarding the use of this document, please contact either of us at the number(s) listed below.

Sincerely,

*Holly Chaimov*

Holly Chaimov, Director  
Parkinson's Resources of Oregon  
(800) 426-6806

*Lisa Mann*

Lisa Mann, Nurse & Education Coordinator  
Parkinson Center of Oregon  
(503) 494-5620

Patient Name: \_\_\_\_\_

Date Updated: \_\_\_\_\_

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# 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.

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

- 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)
- Zelapar® (selegiline)

#### DOPAMINE AGONISTS

- Requip ® (ropinirole)
- Requip XL ® (ropinirole)
- Mirapex ® (pramipexole)
- Apokyn® (apomorphine)

#### Withdrawn or not recommended:

- ~~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/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.
- **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®)

Patient Name: \_\_\_\_\_

Date Updated: \_\_\_\_\_

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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.

**LOCAL PARKINSON CENTER CONTACT INFORMATION:**

*\* 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.*



Developed by Parkinson's Resources of Oregon and OHSU's Parkinson Center of Oregon.  
**Parkinson's Resources of Oregon (PRO)**  
[www.parkinsonsresources.org](http://www.parkinsonsresources.org)  
*PRO provides support and educational resources for people and families dealing with Parkinson's disease.*

**Parkinson Center of Oregon (PCO) at Oregon Health & Sciences University - [www.ohsu.edu/pcu](http://www.ohsu.edu/pcu)**  
*The PCO is a national leader in medical care, research, and education for people and families living with Parkinson's.*



Patient Name: \_\_\_\_\_

Date Updated: \_\_\_\_\_

## **Nurse to Nurse**

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