



The Parkinsonian

Summer Issue, 2010



Northwest PADRECC

Parkinson's Disease Research, Education & Clinical Center

Easy and Common Practices for Good Sleep

When you think of healthy habits for a healthy lifestyle, what is the first thing that comes to mind? If you are like most people, things like healthy eating habits, exercise, or avoiding tobacco come to mind first. But what about sleep? More and more research is shedding light on just how important quality sleep is to our everyday lives. According to the National Sleep Foundation (NSF), poor sleep affects many parts of our health and our lives. People who do not get enough sleep are more likely to have problems with memory, concentration, learning, reasoning, weight, and a variety of serious health and mental health problems. The NSF estimates that about two thirds of older adults suffer from sleep problems. You've probably heard that as we age we need less sleep, right? It turns out that this is a myth; our sleep needs remain pretty constant throughout our adult lives.

It is well known and documented that people with Parkinson's disease (PWP) have difficulty getting quality sleep consistently. From stiffness and rigidity to drowsiness from medications and REM sleep behavior disorder, getting regular and quality sleep for PWP can be very difficult. But what about the caregiver for the person with Parkinson's disease? How can he or she get better sleep? Below you will find some tips for good sleep hygiene that anyone can use to help make it more likely that you will get more quality sleep.

- 1. Stick to a Sleep Routine/Schedule:** Go to bed and get up at the same time each day, including weekends. Routine is important; you want to train your mind/body with a good sleep routine.
- 2. Create a good sleeping environment:** No daytime activities in bed. This means no TV, eating, computer, or telephone. Train yourself to limit your bed-related activities and your mind/body will "think" sleep in bed.
- 3. Relaxing ritual before sleep:** Reading, taking a bath, listening to music...Whatever it is for you, do something comforting and relaxing before sleep.
- 4. Avoid Stimulants:** Generally speaking, you want to avoid caffeine 3-4 hours prior to sleep.
- 5. Limit food intake:** Avoid large meals or foods that cause indigestion prior to sleep.
- 6. Limit liquid intake:** Generally avoid too much liquid intake 3-4 hours prior to sleep. This helps avoid having to get up due to nighttime urgency. This includes alcohol.
- 7. Bedroom temperature:** A cooler room is better for sleeping.
- 8. Naps:** Try to avoid naps later in the day. Generally speaking, no naps after 3 p.m.
- 9. Different beds:** Though this may not be the most appealing idea at first, you may want to try sleeping in a different bed than your spouse, particularly if your spouse acts out his or her dreams.

Many of these tips for good sleep hygiene take some practice and some "getting used to" before they are helpful. Keep at it; it can take some time to change your routines and habits. After you have given it a try and you are finding that you are still having trouble getting enough quality sleep it may be a good idea to speak with your doctor.

Jason Malcom, MSW, VA PADRECC

(Reference: The National Sleep Foundation. For more information go to www.sleepfoundation.org)

Summertime Exercise

With summer fast approaching, now is a great time to take advantage of the beautiful weather, get out and get moving. While exercise will not alter the progression of Parkinson's, it is very important in order to maintain your quality of life. Proper exercise can help to reduce depression and stress and help to prevent poor posture, loss of flexibility, and poor balance. Three key elements help to manage the symptoms of Parkinson's:

1. Stretching - to increase flexibility and range of motion in joints.
2. Aerobic activity (such as walking, biking, and swimming) - to strengthen the heart and lungs.
3. Weight training - to strengthen the muscles of the body.

Around the Pacific Northwest, there are many opportunities to get out during the summer months and to practice all three of these elements.

Suggestions for summertime exercise include:

- National and State Parks - Many parks offer walking paths of various distances. The National Park Service offers a lifetime pass for US citizens aged 62 or over which provides the pass holder with discounts throughout national parks. A lifetime pass is also available for citizens with permanent disabilities. For more information visit www.nps.gov
- Team Parkinson's - at Northwest Parkinson's Foundation (NWPf), Parkinson's patients, family members, caregivers and friends make their journey toward hope and wellness. Team members participate in local events or other personal fitness challenges. Members are welcome regardless of whether they're a novice, intermediate, or experienced athlete. Call (866) 822-2873 or visit www.team-parkinson.org for more information.
- Look for walking paths closer to home. Guide books and websites, such as www.portlandhikers.org, allow you to search for paths by difficulty, interests, elevation, and distance.
- Join a local pool - many pools offer classes of varying ability as well as offer several lap times throughout the day.
- There are many ways to stay active around home. Hobbies, such as vegetable or flower gardening, allow you to be active outdoors without leaving the comfort of your home.

Be sure to only choose activities that you feel safe doing. It is always wise to check with your doctor before starting an exercise program.

Natasha Carney, MA, VA PADRECC
Resources: www.pdf.org, www.parkinson.org, www.nwpf.org

Things to remember when exercising:











- * Drink plenty of fluids
- * Avoid midday sun
- * Wear sunscreen
- * Take it slow

Want to Contribute?

This newsletter is yours, and we think you should be involved. If you have any art, poems, stories, or articles you would like to share with other Parkinson's patients, please send them to the address listed below or e-mail them to nwpadrecc@va.gov with "Newsletter submission" as the subject line.

**Portland VA Medical Center
Attention: Susan O'Connor
P3-PADRECC
3710 SW US Veterans Hospital Rd.
Portland, OR 97239**

Parkinson's disease summer reading list:

-  **The Stranger Comes at Sundown: Living and Dying with Parkinson's Disease** by Jane Kriete Awalt
-  **Living Well, Running Hard: Lessons Learned from Living with Parkinson's Disease** by John Ball
-  **What's Shakin': An Insider's Look at the Humorous Side of Parkinson's Disease** by John S Brissette
-  **Life with a Battery-Operated Brain: A Patient's Guide to Deep Brain Stimulation Surgery for Parkinson's Disease** by Jackie Hunt Christensen
-  **Every Victory Counts: Essential Information and Inspiration for a Lifetime of Wellness with Parkinson's Disease** by Davis Phinney Foundation, Dr. Monique Giroux, and PA-C MPAS Sierra Farris
-  **Always Looking Up** by Michael J. Fox
-  **Lucky Man** by Michael J. Fox
-  **Life in the Balance: A Physician's Memoir** by Thomas Graboys, MD
-  **A Life Shaken** by Joel Havemann
-  **Saving Milly: Love, Politics, and Parkinson's Disease** by Morton Kondracke

Visit www.everyvictorycounts.org/resources for additional suggestions

The Washington State Parkinson's Disease Registry (VA IRB # 31675)

If you have a diagnosis of Parkinson's Disease or atypical parkinsonism, you are eligible to participate in the Washington state Parkinson's Disease Registry which is co-directed by Cyrus Zabetian, M.D., M.S. and James Leverenz, M.D. This is a research registry which notifies participants about clinical studies in which they may be eligible to participate. Enrollment occurs by phone and consists of 15 screening questions and an interview about diagnosis, symptoms, medications and family history. This usually takes less than 30 minutes. For information on how to participate, call toll free (888) 365-9901 or visit our website at www.registerparkinsons.org, where you can start the screening process online.

Recruiting VA Studies

Memory and Movement Disorders Demonstration Project (VA IRB ID: 1585 VA IRB Grant Number: #02-2202)

Joseph Quinn, M.D., is conducting this research study in order to track the frequency and types of changes in mental functioning that occur over time in Parkinson's patients. Participants would be asked to attend one or more study visits. All study visits would take place at the Portland VA Medical Center. The first visit would take less than twenty minutes. If asked to continue in the study there would be a second 90-minute visit and then follow-up examinations once a year for the next 3 years. All patients in the Parkinson's Disease Research, Education and Clinic Center (PADRECC) are invited to participate in this study. You may or may not personally benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Susan O'Connor, RN, at (503) 721-1091.

Parkinson Associate Risk Study (PARS): Evaluating Potential Screening Tools for Parkinson Disease (VA IRB ID: 2021; VA IRB Grant Number: # 05-0307)

Kathryn Chung, M.D., is conducting this research study to estimate the frequency of olfactory loss in first-degree relatives of Parkinson's patients. Participation by a first-degree relative of a Parkinson's patient would require six one-hour annual visits to the Portland VA Medical Center and completion of six annual smell tests by mail. The sub-study would require travel to Connecticut for a brain imaging procedure. All costs for travel to Connecticut will be paid by the study sponsor. All first-degree relatives of Parkinson's Disease (PD) patients above the age of 50 or within ten years of the age of diagnosis of PD are invited to participate. This is a research study and not treatment or diagnosis of PD. You may not benefit from participating in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future. For more information on how to participate, please contact Susan O'Connor, RN, at (503) 721-1091.

Recruiting OHSU Studies

Quantification of the Antidyskinetic Effect of Amantadine and Topiramate in Parkinson Disease Study OHSU eIRB# 4717

Principal Investigator: Kathryn Chung, M.D.

The purpose of this research study is to measure the reduction of dyskinesia in Parkinson's Disease (PD). In order to take part in the study, participants must: (1) have Parkinson's Disease, (2) have either mild, moderate to severe dyskinesia, and (3) also be taking oral Levodopa, Sinemet medications for their PD. There are four visits for this study. The first visit is a screening visit and includes a neurological examination and completion of several questionnaires. The second, third, and fourth visits are overnight stays in the Oregon Clinical and Translational Research Institute (OCTRI) at Oregon Health & Science University (OHSU). Subjects will be admitted to the OCTRI the evening before study tests begin. Their usual PD medications will not be given over night, so that the Levodopa cycle may be observed the next day. You will take one of three drugs, a sugar pill, Amantadine 300 mg, or Amantadine 300 mg plus Topiramate between each overnight visit. Subjects will be studied on a force plate during performance of simple mental task and will wear inertial sensors throughout the testing day. The inertial sensors are similar to a watch. There is no direct benefit to the participant, but Parkinson's Disease patients may benefit in the future. You will be paid \$25.00 for each overnight visit you complete. Participation in this study will last 2.5 months and will involve you taking medication for 2 weeks between the 3 overnight visits.

Kathryn Chung, M.D., is the clinical investigator responsible for this study and Brenna Lobb is the study coordinator. If you are interested in participating, please call Brenna Lobb at (503) 220-8262 ext. 51871 or you can reach Kathryn Chung, MD, at (503) 220-8262 ext. 53233.

Calendar of Events

Portland Patient Education Talks

All talks listed will be held in the Portland VA Medical Center Auditorium. Please arrive early for parking. For more information or to register call (503) 721-1091.

Friday, July 9, 2010, 10 a.m. to 11:30 a.m.:

Caregivers - Jason Malcom, SW

****Please note time change****

Parkinson's Resources of Oregon

Friday, June 18, 2010, noon to 1 p.m.: Lunchtime

Lecture: Finding a Helping Hand: Are you confused or at a loss in locating help from government and community agencies? This presentation with Abby Lottridge Maier, LCSW will explain where to go for help and how to best access it. Call (503) 594-0901 to register.

September 2010: Sole Support for Parkinson's

September 18 - Medford, OR

September 19 - Eugene, OR

September 26 - Portland, OR

Please visit www.solesupport.org for event information.

Movement Classes: Weekly fitness classes held in a variety of locations providing instruction for people with Parkinson's. Call: (800) 426-6806

Communication Programs: Classes and groups to help people learn how to keep their voices and expressions loud and strong. Current locations include Corvallis and Portland, OR. Call: (800) 426-6806

Have a Question? Ask the Doctor.

Do you have a question about Parkinson's Disease that you would like to see answered in our newsletter by one of our doctors or nurses? If so, please submit your question to nwpadrecc@va.gov or call (503) 721-1091. You can also mail requests to the Portland VA Medical Center address listed below.

Parkinson's Center of Oregon (PCO)

Newly Diagnosed Educational Session: Occurs every other month. A three-hour session for people recently diagnosed with PD and their spouse or family member. Participants may ask any questions of a PD specialist and long-time patient. \$20/person; refreshments served. For more information, call (503) 494-9054.

September 25, 2010 - 27th Annual Options & Opportunities Symposium - Red Lion Hotel at Jantzen Beach, Portland, OR. Join us to hear the experts present the latest information on research, treatment, and care for people with Parkinson's disease, their families, healthcare providers, and anyone wanting to learn more about PD. For more information call (503) 494-7231

PADRECC Website

The PADRECC website provides information about Parkinson's Disease and other movement disorders, as well as services available to veterans and their caregivers. Here are some things you can find on the website:

- ◆ PADRECC clinic, staff, and contact information
- ◆ Information about Parkinson's Disease and its treatments
- ◆ Information about support groups and outside resources
- ◆ Patient Education events

Check out the newly updated PADRECC Website at: <http://www.visn20.med.va.gov/portland/PADRECC>

To receive the Parkinsonian by e-mail please forward a request to nwpadrecc@va.gov
Call (503) 721-1091 to be removed from our mailing list



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