

Houston Parkinson's Disease Research, Education and Clinical Center

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Caring for the Caregiver

Who is a Caregiver?

It's a difficult term to define since many of us are caregivers who don't think of ourselves that way. Consider these questions:

Do you help by providing personal assistance with activities such as bathing or dressing, if only on occasion? Do you feel responsible for providing emotional support?

Do you provide transportation for errands, exercise class and/or appointments?

Do you provide support or assistance to the person who lives in a long-term care or assisted living facility? If you answered YES to any of these questions or others more common to your experience, you may consider yourself a caregiver.

How Can the PADRECC Help?

1. The physicians and nurses at the PADRECC are more than willing to listen and assist you with your concerns. Our monthly PADRECC support group provides another opportunity to talk with others who share similar experiences.

2. On Friday, October 1 from 12:30-2:30 pm, our program for the Patient and Family Forum at the MED-VAMC will focus on "How to Care for Self While Caring for Others." We will discuss common reactions that face caregivers whose loved ones have been diagnosed with PD. Examples of emotional strains include guilt, anger, loneliness, fatigue, and sadness. We will also present ways to maintain physical and emotional health and suggest ways to cope with caregiving responsibilities.

3.PADRECC and the Houston Area Parkinson Society will host a one-day **conference on Saturday**, **December 4** at the United Way of Houston. The conference will highlight **practical aspects of caregiving**, including changes in mobility, motor functioning, thinking/cognition, and speech/ swallowing. The program will include community resources and stress reduction techniques.

We look forward to seeing you, and will mail you more information.

Hints for Caregiving

- **P** -- Pay attention to your health your most important responsibility.
- A Absorb all you can learn about PD.
- **R** Reach out to others for support and assistance.
- **K** Kindly take care of yourself through exercise and good nutrition.
- Imagine that you will be able to do what is required of you.
- **N** Nature contemplation while walking is a diversion from other tasks.
- **S** Support groups are a good way to share concerns.
- **O** Only you can determine the limits of your time, energy, and health.
- **N** Name the stressors that you feel and talk to someone about them.
- **S** Stress reduction through activity and socializing is essential. *Naomi Nelson, RN, PhD, PADRECC Co-Associate Director of Education*



Anne Thobe, Executive Director of the Houston Area Parkinson's Society, and Dr. Eugene Lai, Houston PADRECC Director, attended the DBS Conference.

Exercises for the Legs: Part 1

As a regular reader of the PADRECC Pathways, you may have already undertaken your "pathway to wellness" by participating in exercise routines highlighted within earlier issues. Even if you are a new reader, I hope you are interested in maintaining your flexibility and strength as long as possible. There is no better place to start than to concentrate on the larger muscles in your legs! Part 1 of this 2 part series will concentrate on stretches and movements that can and should be done while sitting in a firm chair, while Part 2 will emphasize the exercises best done in a supported standing position. Needless to say, the following exercises should be done at least once daily.

Marching in place while sitting – With your hips positioned near the front edge of a firm chair, sit up tall and tense your stomach muscles by actively pulling your belly button back in the direction of your spine. That effort should help your abdominal muscles stabilize your trunk as you do the following set of movements, so be sure to keep those tummy muscles contracting as you:

- 1) bend your right hip and lift your right knee toward your right shoulder,
- 2) lower your right foot back to the floor,
- 3) bend your left hip and lift your left knee toward your left shoulder,
- 4) lower your left foot back to the floor,
- 5) alternately lift your right knee and left knee toward your chest , doing 5 repetitions with each leg.

To make this exercise more beneficial, do 5 more repetitions with each knee alternately lifting up as you twist your upper body and bring your opposite elbow to the lifting knee. Thus, as your right knee is lifting, your left elbow is reaching across the center of your body to touch it, and as your left knee is lifting, your right elbow is reaching across the center of your body to touch it. This crossing over the center of your body to touch something on the opposite side can feel awkward at first, but if you start slowly and then gradually speed up, you should be able to get more comfortable with this coordination activity over time.

Knee extension while sitting – With your hips positioned near the back of a firm chair, straighten your knees just enough for you to comfortably rest your heels on the floor in front of you. Starting with the right leg, straighten out or extend your knee as you lift the right foot completely off the floor. Take a moment at the end of the straightening movement to tighten the muscle on top of your thigh to pull your kneecap up. Release and lower your right foot to the floor. Do *10 repetitions* of the knee straightening exercise with the right leg and then switch to do *10 repetitions with the left leg*. As a secondary challenge to keep up both the strength and coordination of these knee extension movements, do *another set of 10 exercises* on each leg as you **now alternate lifting each foot in a rhythmic manner**, so that the movement becomes right leg, left leg, right leg, left leg, etc for 10 times on each side. Don't forget to fully straighten each knee each time!

Ankle pumps/rotations – With your hips positioned near the back of a firm chair, fully straighten your right knee and hold your foot completely off the floor. Lift your toes up toward your nose while contracting the muscles on the top side of your ankle and then point your toes away from you while contracting the muscles on the back side of your calf. Pump your right ankle up and down 8 *times* before switching to do the same set of movements and repetitions with your left ankle. Be sure to move your ankles as far in each direction as possible, especially when lifting your toes toward your nose, so that you feel the muscles on the back of your calves stretching each time. When you have completed 8 ankle pumps with the left leg, then lift the right foot off the floor again and begin to make circular movements with the ankle by moving your forefoot in a counter-

Exercises for the Legs: Part 1 (Cont'd)

clockwise direction (i.e., foot lifts up, turns inward, points down, and turns outward) for *3 repetitions*. Immediately reverse the movement to rotate clockwise (i.e., foot lifts up, turns outward, points down, and turns inward) for *3 repetitions*. Switch legs and repeat the same series of movements with the left foot *3 times in each direction*.

Hamstring stretch in sitting – What better way to complete a series of exercises than to stretch out muscles that like to stiffen up on you? For our purposes, the muscles to target while sitting are the hamstrings, which run along the back side of your thighs from above your hip joints to below your knees. Since this muscle group passes over 2 joints, the best strategy for stretching the muscle is to have it getting longer over both of those joints simultaneously.

Begin by sitting at the front edge of a firm chair and straightening out your right leg as far as possible. You want the back of your thigh to be free of the chair and your knee to be as straight as possible, so that your straightened leg is resting on your heel. Sit up extra tall and then begin to bend forward through your hip so that your entire trunk is moving forward and over your straightened leg. Go forward as far as possible (yes, you will be feeling the muscle stretching as your body moves more forward over it!) and then reach down to touch your ankle or toes. *Hold the end position for 30 seconds*, which can be timed while watching a clock or by counting slowly to 30. Slowly sit up, bend your right knee back under you for support, and straighten out the left leg in preparation for the stretching activity.

Again, you want to sit up tall before bending forward through your hip to bring your body forward and over the left leg. Once you have reached down for your ankle or toes, then hold the position for *30 seconds*. That may sound or feel like a long time, but the benefit is that you only have to do one stretch per day rather than a whole series of shorter stretches.

If done in sequence, these preceding 4 exercises targeting your hips, knees, and ankles should only take about 10 minutes per day and represent a good start for keeping your leg muscles active and your movements coordinated. (That's not the end of our story. *Exercises for the Legs: Part 2* in the next issue will show you how to increase the challenge and the benefits associated with leg exercises done in standing.) Betty MacNeill, PT, DPT

Associate Professor, Texas Woman's University School of Physical Therapy

Important Dates

Friday, October 1: How to Care for Self While Caring for Others PADRECC Patient and Family Forum 12:30 to 2:30 pm

Saturday, December 4: Practical Aspects of Caregiving PADRECC/HAPS Caregiver Conference 8:45 am to 1:45 pm

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Houston PADRECC Director's Corner

On June 3, 2010, The New England Journal of Medicine published the results of the largest, randomized, controlled study of deep brain stimulation (DBS) for advanced Parkinson's disease conducted by the Department of Veterans Affairs (VA) Parkinson's Disease Research, Educational and Clinical Centers. The study, authored by the PA-DRECC Directors, found that DBS, when placed in two different areas of the brain called the subthalamic nucleus (STN) and the globus pallidus interna (GPi), causes similar motor and quality of life improvements for veterans with Parkinson's disease. Of course, when we recommend DBS for our patients, we make decisions on what will work best for the individual based upon his or her symptoms and unique problems. You will be hearing more about this and similar studies in the near future.

On **Saturday, December 4**, PADRECC and the Houston Area Parkinson Society will present a special conference for spouses and caregivers of patients with PD. I particularly want to thank our **PADRECC Education Committee**, Betty MacNeill, Ruth Zabransky, Kathleen Crist, and our PADRECC associate directors of education for the time and effort they put into organizing these events. I look forward to seeing all our family members and caregivers there.

Eugene C. Lai, MD, PhD, Director, Houston PADRECC



PADRECC and the Houston Area Parkinson Society (HAPS) presented a oneday conference, "Deep Brain Stimulation: Is It for You or Your Loved One?" on November 14, 2009 at the United Way of Greater Houston. Pictured above left to right, Farah Atassi, MD, MPH (PADRECC research health scientist) who provided support and assistance, and conference speakers Michele York, PhD (PADRECC psychologist), Aliya Sarwar, MD (PADRECC neurologist and Assoc. Director of Clinical Services), Richard Simpson, MD, PhD (neurosurgeon), Laura Marsh, MD (Mental Health Care Line Executive, MED-VAMC). 2nd Row L to R: PADRECC Director Eugene Lai, MD, PhD, Marilyn Trail (PADRECC Co-Assoc. Dir. of Education and conference chair), Dr. Sarwar, Naomi Nelson, RN, PhD (PADRECC Co-Assoc. Dir. of Education and conference co-chair), Gabriel Hou, MD, PhD (PADRECC neurologist and Assoc. Dir. of Research), Betty McNeill, PT, DPT (Assoc Prof of Physical Therapy, TWU, & conference organizer), and AnneThobae (Executive Director of HAPS).

The Department of Veterans Affairs (VA) has announced that Parkinson's Disease has been included as a disease associated with Agent Orange. For information, go to the VA website at http://www.publichealth.va.gov/exposures/agentorange/ or call 1-800-749-8387, press 3 to obtain more information. Call 1-800-827-1000 to receive the "VA's guide to Agent Orange Claims.

Exercise and nutrition were topics of discussion at the May 21, 2010 PADRECC Patient/Family Forum. Eugene Lai, MD, PhD, PADRECC Director (above), demonstrates stretching exercises, and Shawna Johnson, RN, PADRECC Clinical Coordinator, and Linda Fincher, RN, PADRECC Assistant Clinical Director, present patient/caregiver resources and information.

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