Maintaining Independence in Parkinson’s Disease

By Paulette Olsen

Resources: How, When, Where, and Why?

The activities that you do everyday are very important to maintain your health and independence. In order to preserve independence in activities of daily living, people with Parkinson's disease (PD) should do all that they can for themselves. To be helpful in offering assistance, families can:

- Allow the PWP (People with Parkinson's) to do all the tasks he/she can do for him/herself.
- Offer specific help when asked.
- Realize that PWP’s ability to do tasks can vary significantly throughout the day, or from day to day because of the disease and their response to medications.

Activities of daily living include tasks such as bathing, grooming, dressing, preparing food, writing, eating, caring for the home, timing/management of medications, communication, mobility-sitting, standing, walking, driving, exercise, and recreational activities/hobbies. PWP often have tremors, rigidity or slowness that may interfere with these activities, but help in adapting is available for most every activity of daily living. Knowing how and where to find the right people to help you stay healthy and happy is essential.

Who can help with what?

Neurologist

Seeing a neurologist who is well versed in PD can be beneficial to the medical...
management of your PD. Neurologists are physicians who specialize in diseases of the brain. Some may be more specialized in movement disorders like Parkinson's, either through taking advanced education such as a movement disorder fellowship, or through devoting a significant portion of their medical practice to patients with Parkinson's disease and other movement disorders. Your APDA Information and Referral Center (APDA I & R Center) coordinator can refer you to a physician who specializes in PD.

**Nurse, nurse practitioner or physician assistant:** These professionals may work independently in care management for PWP or in conjunction with a neurologist. They may assist with all aspects of PD management including medication management.

**Physical therapist:** It is helpful to see a physical therapist upon diagnosis of PD for a baseline evaluation and to determine a safe and appropriate exercise program and then regularly thereafter, as needed, to modify it. Physical therapists can also help by teaching strategies to improve physical mobility, which may include:

- Gait aids
  (walkers, canes, wheelchairs/mobility)
- Bed mobility
- Posture
- Car transfers
- Fall prevention
- Stair navigation
- Home modification

**To find a physical therapist contact:**

1) The APDA Exercise Helpline to locate a qualified physical therapist in your area at 888-606-1688 or e-mail rehab@bu.edu.

2) The American Physical Therapy Association, www.apta.org, click on Find a Clinician, and then look for therapists with the initials NCS (Neurological Clinical Specialist) after their names.

3) LSVT® (Lee Silverman Voice Treatment) BIG, www.lsvt.org, and click on BIG, and Find a Clinician. This is a treatment program offered by certified physical and occupational therapists to meet the needs of the PWP.

4) A Parkinson's center, a rehabilitation (rehab) hospital, a rehab clinic or a hospital that serves people with rehab needs.

5) The nearest APDA I & R Center.

**Occupational therapist:** There is some overlap between physical and occupational therapy in some communities. Generally, occupational therapy focuses on daily activities and recommendations for modifications when needed. If you are struggling with any of the activities below, you can get help by obtaining a referral from your doctor to see an occupational therapist.

- Adaptive equipment (kitchen, bath, and bedroom aids)
- Dressing advice
- Toileting/grooming/hygiene
- Meal preparation and feeding
- Technology adaptations (phones/computers/switches)
- Fatigue management
- Recreation adaptations
- Home modification

**To link to an occupational therapist contact:**

1) Your state occupational therapy association.

2) A Parkinson's center, a rehab hospital, a rehab clinic or a hospital that serves people with rehab needs.
3) The nearest APDA I&R Center.

**Speech-language pathologist:** Speech-language pathologists help PWP with communication and adapted communication, voice, and swallowing issues. A quiet voice is a frequent problem. There is a speech-language treatment program for Parkinsonian's available through certified therapists who have been trained in the LSVT® LOUD method. If you are having speech difficulties, you can ask your doctor for a referral. In general speech-language pathologists work with Parkinson's patients on:

- Speech problems
- Swallowing problems
- Adaptations to aid communication such as picture boards.

**To find a speech-language pathologist contact:**

1) The American Speech Language and Hearing Association (ASHA) at www.asha.org/findpro/ and go to Find a Professional with ProSearch.

2) The LSVT® LOUD program at www.lsvt.org, and click on Loud, then Find a Clinician.

3) A Parkinson's center, rehab hospital or rehab clinic, or a hospital that serves people with rehabilitation needs.

4) The nearest APDA I&R Center.

**Support Groups:** Community-based groups offer the opportunity to connect with others who have the disease. Contact your APDA I&R Center to find a support group in your area.

**Primary Care and Specialists:** Generalists and specialists are also part of the Parkinson's team as needed.

- Neurologist
- Internist/Primary Care physician
- Ophthalmologist/Neuro-ophthalmologist
- Urologist
- Gastroenterologist
- Pulmonologist (sleep specialist)
- Neuropsychologist/Psychologist/Psychiatrist

**Resources for Obtaining Adaptive Equipment**

In general, it is best to consult with a professional before buying adaptive equipment, as it can be costly. Working with a professional who can help you determine which equipment is the least costly and most beneficial. People sometimes buy equipment they think they need; only to find that it does not work for their particular problem, or that there was a better solution. Equipment is typically available at medical supply stores, pharmacies, and some big box stores.

**To find rehabilitation or adaptive equipment contact:**

1) A local physical or occupational therapist for advice on how and where to obtain specialized adaptive equipment in your community.

2) The nearest APDA I&R Center.

3) Use an internet browser to search for the equipment item and links to companies and
their contact/ordering information.

APDA's brochure "34 Helpful Hints to Improve the Quality of Life of People with Parkinson's" has tips on bathroom, grooming, dressing, kitchen, and mealtime aids. To obtain a copy contact the nearest APDA I & R Center.

**Don't know where to start?**

APDA's National Resource Center for Rehabilitation is a free service that puts you in contact with a licensed physical therapist who can answer questions about exercise, provide information about programs in your area, and supply free educational materials about the benefits of exercise for people with PD.

If you have questions about when or how to seek a rehab professional, you may contact the APDA Exercise Helpline by calling 888-606-1688 or e-mail rehab@bu.edu or go to www.bu.edu/neurorehab/resourcecenter.

Or you can contact the nearest APDA I & R Center for information regarding rehabilitation professionals, equipment vendors, Parkinson's support groups, and chapters, or contact the American Parkinson Disease Association's national office at 800 223-2732 or www.apdaparkinson.org.

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The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient’s own physician.

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