



PADRECC Bulletin

A Special Edition for Persons with Parkinson's Disease and their Families



Houston Parkinson's Disease Research, Education and Clinical Center
Michael E. DeBakey VA Medical Center, Neurology Care Line

Medication Safety Suggestions

- 1) Learn all that you can about the medications you take. This includes knowing the names of the medications, dosages (strengths), and schedules. Ask your pharmacist about reactions with other medications, foods, and beverages.
 - 2) Always carry a list of all of the medicine you take, including herbal supplements and home remedies, plus any allergies to medications or food products.
 - 3) Check the medications you receive from the pharmacy to ensure the pills are what the doctor ordered. (Note the name of the medication, the dosage, the recommended time schedule, and any other instructions.) Put printed information in a special location.
 - 4) Question anything you don't understand or that doesn't seem correct, especially if the strength or appearance has changed.
 - 5) Repeat your understanding about your medications to someone else (pharmacist, health care provider, or family member) as an extra safety precaution.
 - 6) Organize your medications. Purchase a large capacity pill organizer at a pharmacy (or adapt an egg carton) that has room for 4 doses a day and with enough space for a week's supply. Have someone else check your organizer for accuracy.
 - 7) Build in a reminder system to take your medications. Use a pillbox or a watch that can be set to ring or vibrate at selected times. Ask your pharmacist about products and see our resource list on page 8. Your partner may also give you reminders.
 - 8) If grandchildren visit or if someone in your home has memory problems, use safety-resistant closures on medications bottles.
 - 9) Try keeping a journal and list side effects and when they occur.
 - 10) Take your medicines with you to doctor visits.
- For further information, contact the VA Pharmacy Helpline at (713) 794-7653 or a PADRECC nurse at (713) 794-7841**

Food and PD Medications: Do they mix?

Your physician or nurse will tell you to take your Parkinson's medications before or after a meal but not with a meal containing protein such as beef, fish, or eggs and high fat such as cheese or ice cream. Why is this a good recommendation? Carbidopa /levodopa (Sinemet) is absorbed into the small intestine, sometimes called the gut. This absorption may become slower or may be blocked when levodopa is taken with foods that have a high fat or a high protein content. Protein and fat can affect the action of levodopa on the brain which in then affects your motor func-

tioning.

While protein is an important nutrient, if you take carbidopa / levodopa, you should space your protein throughout the day and not near your medication times. Your doctor will give you specific times to take your Parkinson's medications—usually at least 30 minutes before or one hour after you eat, and it is important to follow those instructions. If you have questions about your medications, talk to your neurologist or call the PADRECC nurses at (713) 794-7841.

FALLS and PD

According to recent research, 68% of patients with Parkinson's disease (PD) suffer falls. Patients usually fall indoors, during transfers (such as getting into bed or on the toilet), or while performing two tasks at the same time (walking and carrying a laundry basket; walking and talking). In another study, researchers found that 55% of those with PD fall because of problems walking, especially turning. Other reasons for falls include poor balance and difficulty reaching. Sometimes medications play a role. Studies suggest that about 40% of patient fear falling and as a result, cut down their activities.

Patients with PD tend to have difficulty doing two things at once—such as walking and carrying a cup or walking and talking, or walking and thinking about plans for the weekend—and fall as a result. Try to avoid doing two tasks at the same time. Wear an apron or shirt with pockets, try a waist pack, or have someone else transport things for

you. We are all in danger when we walk across a street while searching for our car keys in a pocket or purse!

Although most patients fall because of problems associated with the disease itself, the environment also plays a role. Look at your home, your office, your yard and your garage. Make your surroundings as safe as possible. Throw rugs, uneven surfaces, clutter, and other hazards cause falls and by making changes in the home (put grab bars in the bathroom, remove clutter) or at work, many can be avoided.

Report all falls to your physician. A physical therapist can teach you an exercise program specifically suited to your needs or recommend a few therapy sessions to help correct the underlying problems such as poor balance or gait. An occupational therapist can suggest safety equipment or help you make changes at home and work.

What are SLPs, OTs, and PTs?

Speech/language pathologists (SLP)—sometimes called speech therapists—are trained professionals who treat speech and language disorders as well as swallowing problems. To learn more, go to www.asha.org or call 1-800-638-8255.

An **occupational therapist (OT)** is a skilled professional who will evaluate your ability to engage in self-care (such as bathing, dressing, writing) and other daily activities (cooking, shopping, gardening, etc.), hobbies, and work. OTs can recommend ways to help you cope with difficulties caused by PD. An OT might suggest equipment (such as a shower seat, grab bars), community resources, and home adaptations, and teach you ways to save energy, avoid falls and be more efficient with your body. Find out more about OT go to www.aota.org or call 1-800-377-8555.

A **physical therapist (PT)** is a trained professional who will evaluate your walking, balance, coordination, strength, and range of motion. A PT can instruct you in exercises for flexibility, strength, and endurance and teach you ways to get in and out of a chair, roll in bed, and how to overcome freezing and other mobility problems caused by PD. For more information go to www.apta.org or call 1-800-999-2782.

Safety Tips

- ◆ **Use nightlights; keep flashlights handy—near phones, beds, and circuit box**
- ◆ **If you live alone, carry a phone**
- ◆ **Remove scatter rugs & floor mats**
- ◆ **Install grab bars around shower/tub, toilet & other areas**
- ◆ **Never use towel bars for support**
- ◆ **Keep a fire extinguisher in kitchen; install smoke detectors**
- ◆ **Post emergency numbers in visible areas and near telephone**
- ◆ **Decrease temperature setting on hot water heater to prevent burns**
- ◆ **Subscribe to an emergency response service if you live alone**
- ◆ **Lower or remove door thresholds**
- ◆ **Use a chair that is higher and firmer than a standard one**

Facts about Driving and PD

Discussions about driving concerns need to begin after a patient receives a diagnosis of Parkinson's disease (PD). The patient and family should talk at regular intervals due to changes in motor abilities and cognition caused by PD.

We know that, aside from teenagers, older drivers have the highest accident rates. As we age our vision dims, our reactions slow, our joints stiffen, and our memory fades. Patients with PD face additional challenges. The good news is that older drivers are more likely to wear their safety belts, tend to drive when conditions are safest, and are less likely to drink and drive than younger drivers.

Freezing episodes, slowed reaction time, stiffness of the trunk and neck, balance problems, and visual difficulties lead to driving problems. Research shows that those with PD have difficulty turning their heads, moving their feet between the brake and the

accelerator, and steering. Changing lanes, monitoring the blind spot, backing up, and dealing with traffic lights also prove challenging. People with PD tend to drive too slow rather than too fast.

Consider a training program or safety class that focuses upon the special needs of older drivers, or contact a driving rehabilitation specialist who works with patients who have special needs. (See resources listed throughout the Bulletin.)

Participation in community activities is important for us all, but particularly for those with PD. For many of us, driving symbolizes independence, and we need to drive to carry out our daily activities. If you or your family members have concerns about your driving safety, speak with your physician, seek out community resources, and get the help you need.

DRIVING WITH CARE

- ◆ **A right turn is always safer than a left**
- ◆ **Drive the speed limit**
- ◆ **Driving too slow is as dangerous as driving too fast**
- ◆ **Keep enough space, at least 2 car lengths, between your car and the one in front of you**
- ◆ **Check rear view mirror to be aware of the traffic behind you**
- ◆ **Keep headlights clean and aligned**
- ◆ **Check windshield wiper blades and replace when needed**
- ◆ **Keep plenty of gas in the tank**
- ◆ **Keep a cloth/towel in car for cleaning windows**
- ◆ **Be careful at intersections—use turn signals and look *left-right-left***
- ◆ **When changing lanes remember to check rear view mirror, look over your shoulder & signal**
- ◆ **Keep windshields and mirrors clean**

Driving Safety

- ◆ **Adjust driver's seat so your chest is 10" or more from the steering wheel**
- ◆ **Adjust your posture by moving steering wheel or seat or sit on a cushion to get your eyes 3" higher than top of steering wheel**
- ◆ **Adjust side view mirrors to minimize the blind spot**
- ◆ **Wear your seat belt correctly**
- ◆ **Avoid distractions such as listening to radio or having a conversation—this is particularly important for PD patients**
- ◆ **Turn off your cell phone, don't eat or drink, or try to do multiple tasks**
- ◆ **Keep headlights on at all times**
- ◆ **Don't drive when you are stressed or tired**
- ◆ **Be aware of medication effects**
- ◆ **Avoid driving in bad weather such as rain, fog, sleet, etc and during heavy traffic**
- ◆ **Avoid night driving and take familiar roads**

Voice, Speech, and Swallowing Problems Associated with PD

by Jean M. Whitehead, MA, CCC/SLP, Speech/language Pathologist

Many patients who have Parkinson's disease (PD) will eventually have problems with their voice, speech, and/or swallowing. The difficulties vary from person to person, but for some, these problems can impair quality of life. Swallowing problems can also pose a problem with nutrition and hydration.

Patients with PD often have soft voice with reduced loudness, and it may sound hoarse or breathy. They typically have little variability in loudness (monoloudness) and pitch (monopitch) and may sound monotonous. Speech can be imprecise and spoken in short rapid rushes. The speech disorder commonly associated with PD is called hypokinetic dysarthria. You may not be aware that you have a voice or speech problem or deny it when others ask about it. If you experience speech, voice, or swallowing problems, an evaluation by a speech/language pathologist might be helpful.

Signs of a Possible Voice or Speech Problem

- ◆ Others ask you to repeat what you said
- ◆ People don't understand you or look confused when you speak
- ◆ Listeners say you are mumbling or ask you to speak up
- ◆ You feel others are ignoring you or talk when you're talking
- ◆ You think your listeners need a hearing aid
- ◆ You avoid situations that require you to speak
- ◆ You avoid talking on the telephone
- ◆ You find yourself talking less and less.

Strategies to Improve Communication

- ◆ Get the attention of the person you are speaking to before you start to talk
- ◆ Get physically closer to your listener
- ◆ Have good eye contact with your listeners. Let them see your face when you're talking
- ◆ Reduce any background noise that may interfere. Turn down/off the TV, close car windows or get away from the noise
- ◆ Sit so that the light is on your face rather than a bright light behind you casting a shadow over your face
- ◆ Hold your head up when you speak
- ◆ Consider getting an amplified telephone
- ◆ Speak up!

Resources —Emergency Alerts

Med Alert (800) 985-4357 — ID bracelets

Medical alert systems and alarms <http://www.1800medalert.com>

Voice, Speech, and Swallowing Problems Associated with PD

(Continued from page 4)

Signs of a Possible Swallowing Problem

- ◆ You cough or choke when drinking or eating
- ◆ You take a long time to finish a meal
- ◆ You have lost weight without trying
- ◆ You drool
- ◆ You have trouble keeping food or liquid in your mouth
- ◆ You have trouble moving food to the back of your mouth
- ◆ You have trouble swallowing your pills
- ◆ You have food left in your mouth after the meal
- ◆ Your voice sounds wet or gurgly after drinking or eating
- ◆ You have unexplained fevers

Suggestions to Help with Swallowing

- ◆ Reduce distractions when eating
- ◆ Sit upright when eating or drinking
- ◆ Remain sitting upright for about 20-30 minutes after you eat
- ◆ Take small size bites and sips one at a time
- ◆ Chew food well and swallow everything in your mouth before taking another bite or sip
- ◆ Alternate bites of food and sips of liquid
- ◆ Take only one sip at a time. Don't gulp or take multiple sips
- ◆ Don't throw your head back when swallowing. Keep your chin tucked
- ◆ Don't talk with food in your mouth
- ◆ Keep your lips closed when you are not talking or taking in food/liquid

Note:

Some speech and language pathologists are trained in the Lee Silverman Voice Treatment technique, an intensive method that focuses on vocal loudness. It has been found to be effective for persons with Parkinson's Disease. For more information go to the website www.lsvt.org.

Resources: Emergency

Lifeline Systems, Inc. 1-800-543-3546; <http://www.lifelinesys.com> — Security alert device for the home

Medical ID bracelets and necklaces 1-800-363-5985; <http://www.americanmedical-id.com/products/>

Are You Getting a Good Night's Sleep?

We all look forward to a good night's sleep because we want to stay as healthy as possible and have energy during the day for routine activities and recreation. Our needs for a good 7-8 hours a night don't change with age although we may experience lighter sleep and wake more often in the night. Even those of us without Parkinson's disease (PD), have changes in sleeping habits that cause us to be unable to

sleep. Several causes of age-related sleep problems are a decrease in the deep stages of sleep and medical problems such as heart disease, breathing difficulties, medications that cause wakefulness, and the frequent use of sleeping aids. Insomnia may also be temporary and related to depression, anxiety, sleeping in a strange place, or a restless bed partner.

Patients with PD commonly

experience sleep problems that might be related to the location of the sleep center in the substantia nigra--the part of the brain most affected by PD.

It is important to report sleep changes early on so the doctor or nurse can suggest remedies before problems worsen. Some PD medications can cause drowsiness, vivid dreams, or excessive daytime sleepiness.

Suggestions for Better Sleep

- ◆ Establish a regular time to go to bed and get up
- ◆ Use your bedroom primarily for sleeping
- ◆ Develop a bedtime ritual—have a glass of warm milk, watch a favorite TV program, say goodnight to family, read, take a warm bath
- ◆ Keep bedroom at comfortable temperature
- ◆ Keep the room quiete—no radios or ticking clocks
- ◆ Don't go to bed hungry or after drinking alcohol
- ◆ Drink less liquid after 6 or 7 pm
- ◆ Take naps early in the day and keep them short
- ◆ Reduce caffeine intake after noontime
- ◆ Worry about *not* sleeping makes matters worse
- ◆ Try mental games—subtract 7's, count sheep
- ◆ Try relaxation exercises—tapes and CDs are available
- ◆ Do your pets help or are they a distraction?

Ideas for Easier Living

- ◆ Avoid doing two things at once—for example, don't walk and talk; try not to carry too many things
- ◆ Take a driver safety course—some are free and you might receive a discount on your auto insurance
- ◆ Don't run out of medications at home or away from home
- ◆ When traveling, plan for delays—bad weather, flight cancellations
- ◆ Pack enough medications in your carry-on bag to last your entire trip
- ◆ When changing time zones, arrange your meds so you don't miss doses that could cause problems like freezing
- ◆ When in doubt, consult your pharmacist, physician, or nurse before leaving on your trip.

Resources: Driving

Contact the **Association of Driver Rehabilitation Specialists** (1-800-290-2344; www.driver-ed.org/) if you are concerned about your driving. They can refer you to a specialist in your area for evaluation and teach you ways to deal with driving problems related to PD and/or aging. The **Department of Motor Vehicles** (512-424-2600; www.dmv.org) also offers driving courses. The **Michael E. DeBakey VA Medical Center** has a driving safety specialist. If you are a veteran with driving concerns, you might ask your physician for a referral.

Get up and Go

by Betty MacNeill, PT, MEd, Physical Therapist

Over time, patients with Parkinson's disease (PD) experience difficulty with walking, posture, and balance resulting in problems with daily activities such as getting in and out of bed and moving from a seated to a standing position along with an increased risk of falling. The inability to move (freezing) and slowness of movement (bradykinesia) also contribute to mobility problems. Fortunately, recent research suggests that exercise is very beneficial for patients with PD, so don't hesitate to "get up and go" to help maintain your overall good health! The National Parkinson's Foundation's website (www.parkinson.org; 1-800-327-4545) has free exercise and activities booklets (*Fitness Counts* and *Practical Pointers for Parkinson Diseases*) and offers links to other resources such as exercise tapes, articles, and pamphlets. See "Sit and Be Fit" (www.sitandbefit.com; 1-509-448-9438) for TV exercise program times and/or exercise tapes. For an exercise program specifically suited to your needs, consult a physical therapist. In the meantime, increase your activity levels using the following **TIPS** as guidelines:

T – Take frequent walks

- ◆ Around the block in your neighborhood as long as the sidewalks are in good repair
- ◆ Around a shopping mall, possibly with a group of like-minded individuals
- ◆ In a local park using well-lit and well-maintained trails

I – Involve yourself in organized classes

- ◆ Attend community exercise and support groups for guided exercise sessions
- ◆ Experience the benefits of Tai Chi for individuals with PD
- ◆ Exercise in a swimming pool environment
- ◆ Exercise during the "Sit and Be Fit" video program

P – Problem solve your way out of movement challenges

- ◆ Roll over to one side in bed before sitting up on the edge of your bed
- ◆ Think about taking bigger steps when walking by bringing your heels down first
- ◆ Visualize stepping over lines on the floor or over a small obstacle
- ◆ Should *freezing* start to occur when you want to take a step, say to yourself, *STOP!* Shift weight to *one foot (e.g., right)* Take a step with the other foot (e.g., left) and do those actions as you think them

S – Safety is first and foremost

- ◆ Lean your trunk forward to balance over your feet when standing up and sitting down
- ◆ Avoid doing too many things at once (distractions can interfere with movement)
- ◆ Don't carry large objects that can block your view of the floor when walking
- ◆ Walk around in a circle rather than pivoting to turn around

Physical activity promotes good health in general, but movement is particularly important for patients with chronic conditions. Staying active in regular daily activities associated with personal care, housework, gardening, grocery shopping, hobbies, and in the community will allow your muscles and joints to work smoother and will encourage a more positive outlook on life.

Additional Resources

American Parkinson Disease Association —APDA
1-800-223-2732 www.apda.parkinson.org

Information and resources on Parkinson's disease

National Parkinson Foundation—NPF

1-800-327-4545 www.parkinson.org

Information and resources on Parkinson's disease

Houston Area Parkinson Society—HAPS

713-626-7114 www.hapsonline.org

Information and resources on PD, exercise groups, educational workshops and lectures

Parkinson's Foundation of Harris County—PFHC
713-552-0858

Information and resources on PD, exercise groups, educational programs

American Association of Retired Persons—AARP
1-800-424-3410; www.aarp.org/families/driversafety

Driver's online safety course and test, information on driving safety, and other resources

American Automobile Association Foundation for Driver Safety 202-638-5944; www.seniordrivers.org

Tools and resources plus a computer program to help older drivers

E-Pill Medication Reminders 1-800-0095
epill.com

Company that carries automatic pill organizers, wrist watches with alarms, pill boxes with automatic alarms

Sammons Preston Roylan 1-800-323-5547
www.sammonspreston.com

Aids for daily living such as equipment to help with bathing (shower seats), toileting (raised toilet seats), eating (scoop plates, utensil with big handles), dressing (button hook), seating (lift cushions/chairs, back supports), and other tasks (reachers)

Sears Health and Wellness Products/Catalogue
1-800-349-4358 www.sears.com

Aids for daily living, bathroom safety products, exercise equipment, etc.

Poison Center Helpline 1-800-222-1222

American Society of Health System Pharmacists
<http://www.safemedication.com>

Information on medication, dosing, how to administer, medication safety

Harris County Area Agency on Aging Nutrition Program—713-794-9001

www.houstontx.gov/health/Aging

Serves seniors a balanced meal Monday through Friday at different sites / places in the community plus information on the Meals on Wheels program, home-delivered hot meals for adults over 60 who have an impairment that prevents them from going to one of the area nutrition centers for lunch.

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