

*patient information you can trust from our partners at* **MAYFIELD**

## **Coping with Parkinson's Disease**

### **basic level**

#### **Overview**

Parkinson's Disease (PD) is a degenerative, progressive neurologic disorder that affects the way you move. Treatment focuses on reducing the symptoms to enable a normal, active lifestyle. While medication is necessary, you can do your part to maintain a healthy lifestyle by eating a balanced diet and staying physically active in order to contribute to your overall health and well-being.

#### **Caregivers**

Coping with a chronic (ongoing) medical condition is challenging for all persons: patient, spouse, children, extended family, and friends. Everyone involved has their own emotions, finances, stresses, worries, and frustrations.

Support groups and respite care centers offer the primary caregiver a resource for help and a shared support network with others dealing with similar life challenges. The caregiver's health is just as important as the person with Parkinson's.

#### **Medications**

The goals of treatment are to manage symptoms, delay disease progression, and minimize the beginning of new symptoms. There is growing evidence that early treatment is beneficial in the long term, whether the symptoms interfere or not with daily activities. Medication for PD restores the concentration of dopamine in the brain to near-normal levels. Sinemet® (carbidopa-levodopa) is the "gold standard" of therapy. Brain cells use levodopa to produce more dopamine, which is the neurotransmitter lacking in PD. More dopamine helps relieve the symptoms of PD such as stiffness (rigidity), shaking (tremor), slow movements (bradykinesia), difficulty walking, smaller handwriting (micrographia), and a lack of facial expression.

#### **Maximize medication treatment**

- Because protein interferes with the absorption of carbidopa-levodopa, take the medication either 30 minutes before or one to two hours after a meal. If nausea is a problem, eat a low-protein snack, such as soda crackers or juice with your medication. If the nausea does not resolve, call your doctor. You may need supplemental carbidopa to help resolve this side

effect. Carbidopa minimizes some of the side effects (nausea, loss of appetite, vomiting, low blood pressure) of levodopa.

- Take all medication with a full glass of water. This allows the drug to fully dissolve and move through the digestive tract.
- Immediate-release carbidopa-levodopa tablets may be split, broken, or crushed and mixed in food, such as applesauce. However, the controlled-release (CR, SR, ER) or extended-release pills (blue, gray or speckled in color, depending on the dosage) should not be split, broken, or chewed as it can cause the medication to be absorbed in an ineffective manner.
- Dopamine agonists such as pramipexole (Mirapex) or ropinirole (Requip) may be prescribed. These medications require a low dosage at the beginning and a slow titration up to help avoid or minimize side effects. They should also be stopped slowly to avoid a sudden worsening of PD symptoms.
- If entacapone (Comtan) is prescribed, it should be taken with each dose of carbidopa-levodopa. This drug allows more levodopa to reach the brain by blocking enzymes that breakdown levodopa in the body before it reaches the brain.

#### **Exercise**

Research studies have shown that exercise and dance (e.g., Tango) are beneficial for symptom management and may slow down the progression of the disease.

- Regular exercise increases the power of neurotransmitters in the brain to enhance mood and positive thinking.
- Regular exercise can help relieve the muscle tension that builds up in the body.
- Regular exercise can improve self-image and thus help deal with life's daily stresses.
- Regular exercise helps patients with PD experience a milder and less-progressive disease process. It also helps keep bones strong, maintain balance and prevent falls.
- Stretching exercises enhance flexibility.
- Strengthening programs can improve the muscles for maintaining balance and good posture.
- The American Parkinson Disease Association (APDA) has free exercise booklets. Call 1-800-223-2732 or online at [www.apdaparkinson.org](http://www.apdaparkinson.org).

- The Parkinson's Disease Foundation (PDF) has two programs available in video or DVD format. Call 1-800-457-6676 or online at [www.pdf.org](http://www.pdf.org).

## Diet and nutrition

According to the National Institute of Aging, the element most absent from the diets of Americans is *nutrition*, foods that provide the proteins, carbohydrates, vitamins, minerals, hydration, fiber, and fats that allow the body to operate at it's best. PD medications and symptoms can sometimes reduce the pleasure of eating, so it is important to make the best food and nutrition choices to maintain optimal health as the disease progresses.

- See a nutritionist or dietician to help adapt your needs to your lifestyle. They can build a food plan that fits your likes and dislikes.
- Review the food pyramid recommended by the U.S. Department of Agriculture at [www.mypyramid.gov](http://www.mypyramid.gov).
- Water is the most important fluid to drink, flavor it with lemon or fruit juice if you don't like it straight. Drink six to eight glasses a day.
- Fiber (whole grain breads, brown rice, green leafy vegetables, nuts) is critical to help with prevention of constipation problems and provide natural sources of vitamin E, which may have a protective effect against PD.
- Calcium, magnesium, and vitamins D and K are bone-strengthening nutrients found in dairy products.

## Activities of daily living

There are many things a person does every day without even thinking about it such as bathing, brushing teeth, walking, turning in bed, signing checks, cutting food. When a person is diagnosed with Parkinson's, it can eventually make all of these things more difficult. The following tips are meant to be helpful and raise awareness of adjusting to some of the difficulties with PD.

### Falling

- Remove throw rugs and low-lying obstacles from pathways inside and outside your home.
- Use a cane when necessary.
- Avoid using stepladders or stools to reach high objects.
- Stop walking or sit down if you feel dizzy.
- Install handrails, especially along stairways.
- Slow down when you feel yourself in a hurry.
- Before rising from your bed or bath, pause for a moment in a sitting position.

### Sensory complaints

- Stretch every day, especially before exercising.
- Exercise daily to build stamina.
- Warm baths and regular massage will help relax tired muscles.
- When your hands or feet get cold, wear gloves or warm socks.
- Don't overdo physical activities; know your limits and stay within them.

## Turning in bed

- Install nightlights.
- Install light switches where you can reach them easily while in bed.
- When turning to one side, first turn your head, then push off with the opposite foot and rotate your hips. As soon as your hips start to move, reach with your uppermost arm in the same direction.
- When you want to sit up, lie on your side facing out, near the edge of the bed. Place both hands flat on the bed in front of your chest. Push down with your hands, and swing your legs over the edge.
- To get out of bed, first sit up on the edge of the bed, put both feet on the floor, place your hands next to your hips, and push off slowly.
- Satin bed sheets or satin pajamas reduce friction and make movement easier.

## Sleep problems

- Depression can cause insomnia. Tell your doctor about sleep problems and feelings of sadness.
- Watch for breathing difficulty during sleep. Sleep apnea can be associated with PD.
- Restless leg syndrome is a common off symptom in PD that can cause sleep problems.
- Excessive daytime sleepiness can be caused by dopamine agonists or other PD medications. Avoid alcohol, caffeine and fluid intake at night. Avoid daytime naps and try to re-establish a normal sleep-wake cycle.
- Tell your doctor about motor activity during dreams (striking out, yelling). This can be seen in PD, can disrupt sleep, and can be easily treated.

## Dressing

- Replace clothes that have complicated fasteners with ones you can slip on easily, such as sweatpants, sweatshirts, or pants with elastic waistbands.
- Avoid clothes that fasten in the back.
- Look for clothes and shoes with Velcro fasteners, or have the buttons and zippers on your clothes replaced with Velcro.
- Consult your medical supply store or a catalog for dressing aids, such as dressing sticks and long-handled shoehorns.
- Make your dressing area "user friendly." Install clothes rods and drawers that make your clothing easy to reach.
- Dress sitting down on a bed or a chair. Place the clothes you plan to wear next to you on the bed or on a table within easy reach.
- Always wear shoes or slippers.
- Put clothes on and take clothes off from your stiffer side first.

## Hygiene

- "Accident-proof" your bathroom. Replace glass partitions and slippery bath mats, and use paper cups.
- Tile flooring in the bathroom can become slippery and dangerous when wet. Consider replacing it with wall-to-wall carpeting.
- Install sturdy grab bars next to the bath, toilet, and wherever else you need balance and support. Never use towel racks for support.
- Avoid standing up in the bathtub. If you like to take showers, consider sitting down in the shower or place rubber mats on the floor of the tub.
- Instead of drying with a towel after you bathe, put on a terry-cloth robe.
- Use an electric toothbrush. Ask your dentist for recommendations.

## Walking

- If you notice yourself shuffling, slow down or stop walking and check your posture.
- Keep your feet a comfortable distance apart, eight to ten inches.
- Stand up straight with your head over your hips.
- Buy a good pair of walking shoes with a low heel and good arch support. Avoid running shoes or shoes with crepe soles.
- Exaggerate lifting your feet and swinging your arms. With each step, pretend you are stepping over a log.
- Practice taking long steps.
- When you need to turn around, don't pivot on one foot. Instead, walk around in a circle until you're facing the direction you want to go.

## Swallowing

- Take extra-small bites of food, chew thoroughly, and swallow carefully.
- Chop up your food in a food processor, so that it's easier to chew and swallow.
- Always swallow your food completely before taking more food into your mouth.
- Use an electric warming tray to keep your food hot so that you won't feel the need to rush.
- Family members and caregivers should consider receiving training in the Heimlich maneuver.
- Swallow excess saliva before you put food into your mouth.
- Keep a beverage at hand during meals and take frequent sips.

## Freezing

- When you freeze, stop trying to walk; instead, press your heels to the floor.
- Look straight ahead, not down.
- Pick a target and walk toward it, especially when walking through doorways.
- If you're walking with someone, have the person hold your arm or elbow.
- Develop a regular stretching and exercise program. Regular movement can help you maintain your sense of balance and posture.

- Stand up straight, with your head over your hips, but don't lean backwards.

## Tremor

- Perform difficult tasks when you feel well and when your medication is working effectively.
- Relax. Sit down from time to time, relax your arms and shoulders, and take deep breaths.
- Get a regular massage.
- Ask your physical therapist or doctor to recommend a stretching and exercise program.
- Avoid caffeine and alcohol.
- Get plenty of rest.

## Salivation

- To control saliva accumulation, you must swallow. Swallowing may no longer be an automatic reflex. You may have to force yourself to remember to swallow.
- Chew gum or suck on a piece of hard candy.
- Try sleeping on your side, so that you won't wake up choking during the night.
- Swallow excess saliva before you put food into your mouth.
- Keep a beverage near you during the day. Get in the habit of frequently taking small sips.

## Cutting food

- Use "non-skid" or rubber place mats that will help you keep your plates and serving dishes from sliding.
- Eat foods that do not require cutting with a knife.
- Use a food processor to chop or shred your food after it is cooked.
- Ask someone to cut your food for you.
- Use large-handled utensils that are easy to grip.
- If you own specially adapted utensils, carry them with you whenever you plan to eat out.
- Use flexible straws to prevent spills.

## Speech

- Take a breath before you start to speak, and pause between every few words or even between each word.
- Exaggerate your pronunciation. Pretend that your listener is hard of hearing and needs to read your lips.
- Face your listener directly when speaking.
- Finish saying the final consonant of a word before starting to say the next word.
- Express your ideas in short, concise phrases or sentences.
- Exaggerate facial motions as you practice reciting the alphabet, counting numbers, or reading a magazine or newspaper out loud.
- Encourage your family and friends to ask you to speak louder or repeat yourself if they can't understand what you're saying.
- Speak for yourself, and speak often. Don't get in the habit of letting others speak for you.

## Handwriting

- Try using a large-body pen or pencil or one with a build-up handle.
- Experiment with different types of pens. Felt-tip pens, for example, have a "slippery" feel that offers less resistance.
- Lift your arm up from time to time, straighten your elbow, and move your fingers.
- Instead of writing by hand, use a typewriter or word processor. If you don't have keyboard skills, practice a little every day. The exercise will help improve your dexterity.
- If someone is available to type for you, use a Dictaphone.
- Consider corresponding by recording your messages on tape.

## Taking care of business

The National Parkinson Foundation has developed a thorough guide to getting your household and personal documents organized at [www.parkinson.org](http://www.parkinson.org)

- Organize your medical histories
- Keep a journal of medications and dosages
- Organize your personal financial documents
- Insurance and long-term care plans
- Livings wills, durable power of attorney, advanced medical directives

## Sources & links

If you have any questions, please call the Mayfield Clinic at 800-325-7787 or contact the Gardner Center for Parkinson's Disease & Movement Disorders at the University of Cincinnati (UC) Neuroscience Institute at 513-475-8730.

## Support

Patients and their families can contact local support groups in Ohio, Kentucky, Indiana and Michigan through the Tristate Parkinson's Wellness Chapter at 513-948-1100 or 877-489-1110. A support group provides an opportunity for patients and their families to share experiences, receive support, and learn about advances in treatments, and medications.

## Links

Tristate Parkinson's Wellness Chapter  
[www.parkinsonswellness.org](http://www.parkinsonswellness.org)

Parkinson's Disease Foundation  
[www.pdf.org](http://www.pdf.org)

The National Parkinson Foundation  
[www.parkinson.org](http://www.parkinson.org)

American Parkinson Disease Association  
[www.apdaparkinson.com](http://www.apdaparkinson.com)

CARE: Caregivers Are Really Essential  
[www.pdcaregiver.org](http://www.pdcaregiver.org)

Parkinson's Training for Caregivers  
[www.parkinsonseducator.com](http://www.parkinsonseducator.com)

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## EDUCATIONAL RESOURCES

1. **AMERICAN PARKINSON DISEASE ASSOCIATION , INC**  
Conducts patient care and research activities related to this neurological disorder. Includes resources about the disease, events, and programs. Click on *Young Parkinson's* for The Arlette Johnson Young Parkinson Information and Referral Center; also click on *Local Information and Referral Center on the home page to locate a support group or chapter.*  
<http://www.parkinsonsdisease.com/> PH: 1-800-223-2732
2. **THE BACHMANN-STRAUSS DYSTONIA & PARKINSON FOUNDATION**  
This foundation focuses on research updates for dystonia and PD.  
[www.dystonia-parkinsons.org](http://www.dystonia-parkinsons.org) PH: 1-212-241-5614
3. **THE MICHAEL J. FOX FOUNDATION**  
Sign up for the e-mail on the home page to receive the newsletter and regular e-mail updates on research and other advances toward a cure.  
[www.michaeljfox.org](http://www.michaeljfox.org) PH: 1-800-708-7644
4. **THE MUHAMMAD ALI PARKINSON CENTER**  
Besides being an excellent resource of education, the site offers a PD Registry to help gather data on PD prevalence in the United States. Data collected from the registry will be used to facilitate the development of new therapies and healthcare services. The goal is to improve the quality of life for people with Parkinson's at MAPC and at PD centers worldwide.  
[www.maprc.com](http://www.maprc.com) PH: 1-602-406-4931
5. **NATIONAL PARKINSON FOUNDATION**  
Find the latest news and developments in Parkinson's disease research. Includes a list of publications, events, and support groups.  
<http://www.parkinson.org/> PH: 1-800-327-4545
6. **NUTRITION YOU CAN LIVE WITH**  
Registered dietician offers a book that focuses on the nutritional needs of people with Parkinson's disease. Includes ordering information.  
[www.nutritionucanlivewith.com](http://www.nutritionucanlivewith.com)
7. **PARKINSON'S ACTION NETWORK**  
The Parkinson's Action Network (PAN) is the unified voice of the Parkinson's disease community—advocating for more than one million Americans and their families. Click on *Become an Advocate* and join the fight for a cure.  
[www.parkinsonsaction.org](http://www.parkinsonsaction.org) PH: 1-800-850-4726
8. **PARKINSON'S DISEASE BOOK STORE**  
Books and resources specifically for individuals with Parkinson's disease and their caregivers.  
[www.wellnessbooks.com](http://www.wellnessbooks.com)

## RESOURCES FOR CAREGIVERS

9. **CARE: CAREGIVERS ARE REALLY ESSENTIAL**

A website which offers the CareGiver practical ideas to cope with all of the experiences of PD.  
[www.pdcaregiver.org](http://www.pdcaregiver.org)

10. **COUNCIL ON AGING OF SOUTHWEST OHIO**

A community resource guide to access local services  
[www.help4seniors.org](http://www.help4seniors.org)

11. **NATIONAL ALLIANCE FOR CAREGIVING**

The National Alliance for Caregiving is dedicated to providing support to family caregivers and the professionals who help them and to increasing public awareness of issues facing family caregivers.  
[www.caregiving.org](http://www.caregiving.org)

12. **NATIONAL FAMILY CAREGIVERS ASSOCIATION**

The National Family Caregivers Association educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.  
[www.nfcacares.org](http://www.nfcacares.org)

13. **NORTHERN KENTUCKY AGING SERVICES**

A community resource guide for northern Kentucky  
[www.nkadd.org](http://www.nkadd.org)

14. **PARKINSON'S TRAINING FOR CAREGIVERS**

A free online course developed to train caregivers in caring for those with Parkinson's Disease in long-term care settings.  
[www.parkinsonseducator.com](http://www.parkinsonseducator.com)

15. **PARKINSON FOUNDATION OF THE HEARTLAND**

The Parkinson Foundation of the Heartland is a non-profit organization dedicated to finding the cure for Parkinson's Disease and to providing services and educational programs for people with Parkinson's and their caregivers.  
[www.parkinsonheartland.org](http://www.parkinsonheartland.org)