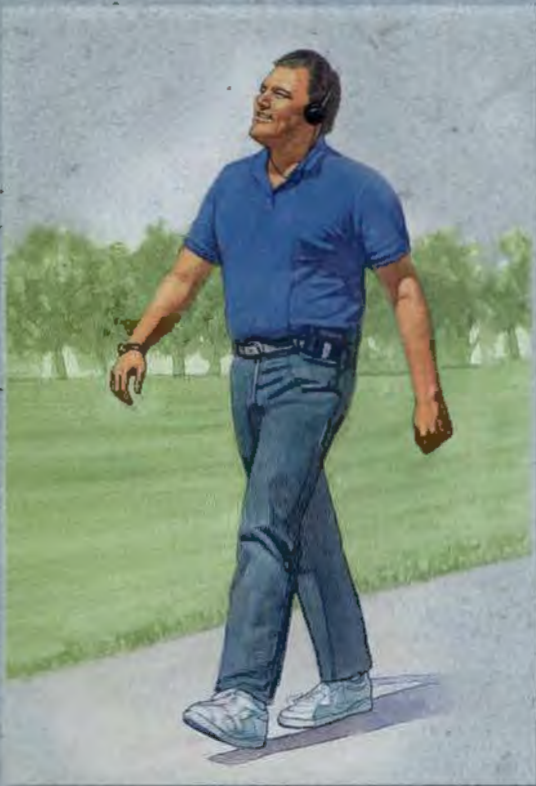


# Parkinson's Disease



Living with a Chronic Illness

# Living with Parkinson's Disease

Your doctor may have told you that you have Parkinson's disease, an illness that affects your control over your muscles. It's never easy to hear a diagnosis of a chronic illness. But having Parkinson's disease doesn't mean you can't live a full life. Your doctor and other members of your health care team can help. They can offer treatments and suggestions that can help you keep active and make your daily life easier. Family, friends, and community resources can also offer you support and encouragement.

*"It takes me a little longer to do things now. I start getting dressed earlier so I can be ready when everyone else is. My friends and family know they may need to wait for me sometimes. But that doesn't stop me from going out, or them from asking me along."*



*"I was worried that my shaking would keep me from my work and my hobbies. But if I take my medication, I can still do most of what I like."*

This booklet is not intended as a substitute for professional medical care. Only your doctor can diagnose and treat a medical problem.

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## Your Diagnosis

You may already have had an exam and one or more tests to help rule out other problems. No lab test can detect Parkinson's disease. It can only be diagnosed by looking at your medical history and symptoms. Because of this, your doctor tries to rule out other causes of your symptoms first.



## Your Treatment

Parkinson's disease affects everyone in different ways. As a result, treatment can vary greatly from person to person. Your treatment plan depends on which symptoms you have, how the symptoms affect your daily life, and how your body reacts to certain medications. Your health care team—which may include your doctor, nurse, a neurologist (doctor specializing in the nervous system), physical therapist, and others—will help determine the best treatment plan for you.

## What's Ahead

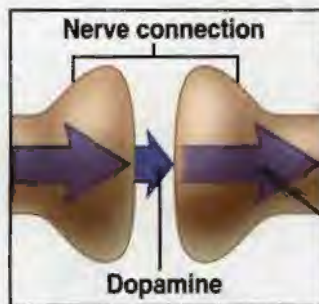
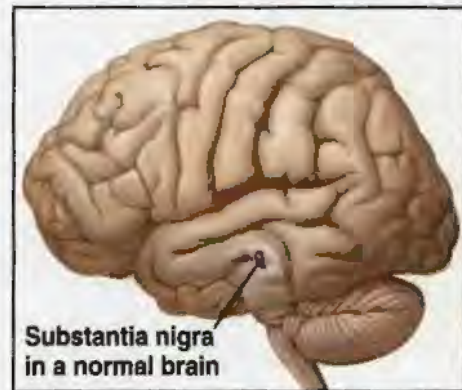
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# Understanding Parkinson's Disease

Parkinson's disease is caused by a problem with a small area of your brain. This part of the brain helps control your movement and balance. For reasons that are not yet clear, cells in this part of the brain stop working. This leads to the symptoms of Parkinson's disease.

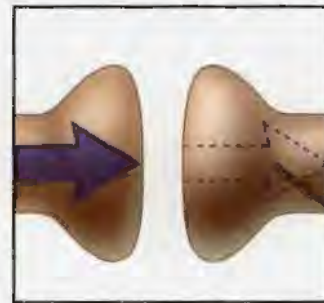
## A Problem in the Brain

A small area of the brain called the **substantia nigra** contains cells that produce the chemical **dopamine**. Your brain uses dopamine to help send messages to the part of your brain that controls your muscles. If cells in the substantia nigra stop working, less dopamine is produced. As a result, messages that help your body move smoothly have trouble traveling through your brain. This leads to symptoms such as shaking, stiffness, and slow movement.



**Dopamine helps** messages travel across nerve connections in the brain.

**Message travels**



**When dopamine is missing,** messages can't travel across the nerve connections in the brain.

**Message doesn't travel**

## Parkinson's Disease or Parkinsonism?

Symptoms such as shaking, stiffness, and slow movement can sometimes be traced to a particular cause. These causes include exposure to certain chemicals or medications, head injury, and some kinds of infection. In these cases, the condition is called **parkinsonism**. When the cause of the symptoms is not known, the condition is called Parkinson's disease.

## Common Parkinson's Disease Symptoms

Parkinson's disease symptoms vary from person to person. Some people may have many severe symptoms, while others have only a few mild ones. Parkinson's disease symptoms may involve only one side of the body at first. Later on, both sides are often involved. In general, symptoms change over time—different symptoms may occur at different stages, and symptoms may get worse as the disease progresses. Memory and reasoning generally are not affected. The most common symptoms of Parkinson's disease are listed below.

- **Tremor (shaking)** is a common symptom of Parkinson's disease. Most often, a hand or arm shakes on one or both sides of the body. Tremor may also affect other areas of the body, such as a leg, a foot, or the chin. Shaking usually lessens when the affected part is used. It usually stops completely during sleep.
- **Rigidity (stiffness)**, or muscle tightness, happens because the muscles don't get the signal to relax. Rigidity may cause muscle aches and a stooped posture.
- **Bradykinesia** means "slow movement." Starting to move takes extra effort, causing problems with actions such as getting out of chairs and beds. Walking may be limited to short, shuffling steps. People with Parkinson's disease sometimes feel "frozen," unable to move. Blinking, facial expressions, swinging of arms when walking, and other "unconscious movements" are also slowed down.
- **Problems with balance** can lead to falls, often forward or backward.
- **Other symptoms** may include speaking too softly and in a monotone, writing that gets shaky and smaller across the page, and sometimes trouble swallowing. Constipation is a common problem for people with Parkinson's disease. Oily skin, sweating, and changes in blood pressure may also be present.



# Treatment with Medication

Medication can help ease symptoms of Parkinson's disease and make daily life easier. Your doctor may prescribe one or more medications for you, depending on many factors. These include your age, the stage of the disease, and the severity of your symptoms. The chart\* below shows some types of medication you may be given and how they help.

\*This chart is not a complete list of available medications and does not imply endorsement of any type or brand of medication. This list does not contain every possible side effect, adverse reaction, interaction, or precaution for these drugs. Only your doctor can recommend or prescribe these medications.

Types of Medications	Examples of Medications	How They Help
Levodopa and Carbidopa	Sinemet Sinemet CR	<ul style="list-style-type: none"> <li>Levodopa relieves symptoms by replacing missing dopamine in the brain. Carbidopa helps levodopa reach the brain with fewer side effects.</li> </ul>
Dopamine agonists	Mirapex Requip Parlodel Permax	<ul style="list-style-type: none"> <li>Agonists improve some Parkinson's symptoms by acting on dopamine receptors in the brain.</li> </ul>
COMT inhibitors	Comtan Tasmar	<ul style="list-style-type: none"> <li>COMT inhibitors work by making more levodopa available to enter the brain and relieve symptoms. These medications are only used along with levodopa.</li> </ul>
MAO-B inhibitors	Eldepryl	<ul style="list-style-type: none"> <li>MAO-B inhibitors help levodopa work, and might slow the progression of Parkinson's disease.</li> </ul>
Amantadine	Symmetrel	<ul style="list-style-type: none"> <li>Amantadine may relieve symptoms by increasing the amount of dopamine in the brain.</li> </ul>
Anticholinergics	Akineton Artane Cogentin Kemadrin	<ul style="list-style-type: none"> <li>Anticholinergics may relieve shaking and stiffness and improve muscle control.</li> </ul>



### Some Possible Side Effects

- May cause constipation, nausea, vomiting, hallucinations, confusion, dizziness, or involuntary movements.
- May cause nausea, vomiting, dizziness, fainting, confusion, hallucinations, sleepiness, insomnia, or involuntary movements.
- May cause vivid dreams or other sleep disturbances, hallucinations, nausea, diarrhea, involuntary movements, urine discoloration, or changes in liver enzymes.
- May cause dizziness, headache, nausea, confusion, mood changes, or trouble sleeping.
- May cause skin rash, ankle swelling, leg discoloration, confusion, depression, dizziness, or hallucinations.
- May cause dry mouth, blurred vision, confusion, constipation, trouble urinating, hallucinations, or trouble sleeping.

### Using Your Medication

- Ask your pharmacist or doctor which of your medications can be taken with food.
- Ask whether any of the medications you're prescribed can cause trouble sleeping. These medications should be taken several hours before bedtime to help prevent sleep problems.
- Some medications for Parkinson's disease don't work as well as the disease progresses. Let your doctor know if you notice changes in how your medication is working.
- If you have any side effects from your medication, let your doctor or nurse know right away.

# Taking Your Medication

When taking your medication, follow your doctor's instructions carefully. **Never** stop taking a medication or change your dosage unless your doctor tells you to. To help make taking your medication and keeping track of it easier, try some of the tips below.

## Tips for Taking Medication

- Get a pillbox with sections for each day of the week. Fill the pillbox at the start of each week. Each day, simply open the section for that day and take your pills.
- Try to take your pills about the same time each day.
- If you tend to forget your pills, set a timer or alarm clock to help remind you. If you take them when you regularly do something else—like brushing your teeth or eating a meal—it will help you remember.



## Keeping Track of Your Medication

- Don't run out of medication. Order more medication when you still have a 2-week supply left.
- Bring your medication and copies of your prescriptions when you travel.
- Carry a list of the medications you take. Show the list to any doctor you visit for treatment. Also show it to your pharmacist before buying any prescription or non-prescription medication. Your pharmacist can tell you which medications can cause problems when taken together.





# If Surgery Is for You

If your symptoms of Parkinson's disease are severe and medications don't help, surgery may be suggested. Surgery is not a cure. It may help relieve some of the symptoms of Parkinson's disease, mainly tremor and rigidity. If surgery is an option for you, your doctor and other members of your health care team can explain its risks and benefits.



## Types of Surgery for Parkinson's Disease

There are three basic kinds of surgery to treat Parkinson's disease:

- **Lesioning:** This includes **pallidotomy** and **thalamotomy**. The goal of these surgeries is to block the pathways of messages that can lead to symptoms. During the surgery, a very small lesion is made in a specific area of the brain. Pallidotomy may help lessen tremor, stiffness, and slowness of movement. Thalamotomy is generally chosen if tremor is the main symptom.
- **Deep Brain Stimulation (DBS):** This is a method in which an electrode is implanted in the brain. The specific area of the brain depends on symptoms. The electrode is connected to an external control that allows stimulation of that part of the brain when needed.
- **Restorative surgery:** During this surgery, new brain tissue is transplanted into the brain. There, the new tissue takes over the function of damaged cells. This treatment is considered experimental.

# Keeping Active

With Parkinson's disease, your movements slow down and are less automatic. Because activity is harder, you may feel like doing less. But keep moving. Regular activity makes muscles stronger and more flexible. It also helps your body work better. Exercise every day. Talk to your doctor about working exercise into your daily routine. He or she may also suggest working with a physical therapist.

## Choosing Activities

Your health care provider can help you choose an activity you enjoy that meets your needs. Walking is one of the best exercises. Schedule daily walks if you can. Dancing is another good activity. Just doing daily chores or errands can help keep you moving. Don't push yourself, though. If you get tired, exercise for short periods, then rest. Keep your mind active by doing puzzles and playing games.



## Getting Physical Therapy

To help you design an exercise program, your doctor may refer you to a **physical therapist** (a person trained in the function and movement of the body) or other health care provider. He or she can teach you the best ways to exercise and help you while you learn.



## Exercises You Can Do

These exercises can help strengthen your muscles and keep them loose and flexible. Ask your doctor whether they're right for you. Your doctor or physical therapist may also suggest other exercises. Do the exercises once a day at first, then build up to several times a day. Exercise slowly, and rest if you feel pain. Other activities that may help include therapeutic aquatics, yoga, and tai chi.

### Body Twist

- Sit in a chair, facing forward. Place your hands on your shoulders.
- Turn your head and body to the side as far as possible, as if you were trying to look behind you.
- Return to starting position, then turn to the other side.
- Repeat 10 times.



### Back Stretch

- Stand or sit with your back straight.
- Hold your arms in front of you. Put your hands and elbows together, hands pointing toward the ceiling.
- Move your arms apart as far as possible, pushing your shoulder blades together.
- Slowly move your hands back together.
- Repeat 10 times.



### Seated March

- Sit in a chair, facing forward.
- Slowly lift one knee as high as you can, then lower your foot to the floor.
- Do the same with your other leg.
- Repeat 10 times with each leg.



# Your Daily Life

Parkinson's disease can make daily life harder. But certain adjustments and devices can help you stay independent and active. The tips below suggest ways to handle problems with some daily activities. If you need more suggestions, an occupational therapist, speech therapist, sex therapist, or other health care professional may be recommended.

## Dressing

Getting dressed in the morning may be slow and difficult. To help make dressing easier, try the following tips:

- Leave yourself plenty of time so you don't feel rushed.
- Lay out your clothes nearby.
- Do one thing at a time.
- Replace buttons with Velcro patches. Or try zippers. Adding a large paper clip to a zipper pull may make it easier to grasp.
- Choose shoes that slip on or that close with Velcro. They're easiest to get on and off.



**Velcro patches** can be added to clothes if buttons are a problem.

## Eating and Drinking

Try some of these tips at mealtimes:

- Use forks, knives, and spoons with large handles if you have trouble holding utensils when you eat. You can also buy rubber handle grips in medical supply stores.
- Use a warming tray under the plate if food gets cold before you're done eating.



**Try easy-to-hold utensils,** plate guards, and carton grips.

## Managing Constipation

- Drink plenty of water. Check with your doctor for a specific amount.
- Eat foods that are high in fiber, such as fruits, vegetables, and whole grains.
- Exercise, such as walking, often helps.
- If you need to, use over-the-counter laxatives.
- If these methods don't help, your doctor may recommend prescription laxatives.

## Bathing

These tips may help in the bathroom:

- Install bars in the shower or tub to make getting in and out easier. A shower chair may also be useful.
- Put no-slip decals on the bottom of the tub.
- Remove bathroom rugs, or make sure they have a no-slip rubber bottom.
- Try liquid soap with a pump, which is easier to hold and use than bar soap.
- Wear an absorbent robe for a few minutes if towel drying is difficult.



## Talking

Parkinson's disease can make the voice softer and less distinct. Try the following tips to help make your speech clearer and easier to understand:

- Read aloud, especially poetry. Singing is also a good exercise. These help strengthen the voice.
- Breathe deeply at the beginning of each sentence.
- Add a voice amplifier to the phone to help you be heard.



## Writing

To help make your writing clearer, try these tips:

- Write slowly and deliberately.
- Lift your pen from the paper every few lines.
- Try a wide pen or a pen with a foam grip added—it may be easier to hold.
- You may find it easier to use a computer than to write by hand. If using the keyboard becomes difficult, voice recognition programs may help.



## What About Sex?

Muscle problems and changes in your self-image may affect your sexuality. But Parkinson's disease doesn't have to stop you from having a satisfying sex life. Plan sex for the times that you feel your best. Kissing and cuddling are nice almost anytime. Talk to your partner about how you're feeling. Your health care team can address your problems and concerns and help you find ways to cope.

# Getting Around

Parkinson's disease affects muscle control, coordination, and balance, making it harder to get around. It may cause people to take small, shuffling steps or to fall backward or forward. Starting or stopping movement may also be difficult. Follow the tips below to help make certain types of movement easier for you.

## Walking and Turning

- Keep your feet apart.
- Raise your leg from the knee and take high, long steps. Swing your arms as you walk.
- Let your heel fall first with each step.
- Imagine that you're stepping over a series of lines on the floor. This can be especially helpful if you feel frozen.
- To turn, walk in an arc instead of trying to turn in place.



## Getting Up and Sitting Down

### To get up, use these tips:

- Slide to the edge of the chair.
- Put your hands on the armrests and lean forward. Move your feet under your body.
- Rock forward and back and say "one-two-three-go."
- Push upward on the armrests to boost yourself up.

### To sit down, use these tips:

- Back up to the chair as close as possible.
- Lean forward and bend your knees.
- Use the armrests to lower yourself into the chair.



**Choose chairs with armrests and firm seats.** Avoid chairs that are low or have wheels.

## Getting Out of Bed

- Turn onto your side. Bend your knees.
- Move your feet off the bed.
- Using your arms, push yourself up.



## Coping with Emotions

Living with a chronic illness can be frustrating. You may feel anxious, angry, or frightened—common and normal feelings. Parkinson's disease itself can cause changes that make you feel tired, cranky, or depressed. Your health care team may be able to help you or refer you to someone who can. Friends, family, and community groups can also offer support.



### When You Feel Down

You'll probably have days when you feel discouraged. The loss of control over your body can be frustrating. Also, chemical changes in your brain may make you feel depressed. If you're feeling down, tell your health care team. Certain medications and other measures may help you feel better.

### Don't Withdraw from Others

You may not always feel like being with others. But don't make your illness an excuse to pull away from those around you. They can keep you company, offer assistance, and help you keep your sense of humor. A support group for people with Parkinson's disease allows you to share experiences and learn how others cope. Your local hospital or the organizations listed on the back of this booklet can help you find a group near you.



### Notes for Family and Friends

- Encourage independence. You may feel tempted to do tasks for your loved one, but let him or her do them, even if it takes extra time. Be understanding and encouraging. Allow extra time, and try not to be impatient.
- Understand that the abilities of people with Parkinson's disease change all the time. Your loved one may not be able to do things that he or she could do just moments before. This is not stubbornness—it's the disease.
- Ask your loved one regularly how he or she is feeling. Parkinson's disease affects facial muscles, making it harder for a person to show emotion.

# Moving On with Your Life

Parkinson's disease has no cure yet, but its symptoms can be managed. This means that you can stay active and live a full life. Also, many new treatments for Parkinson's disease are being researched. Newsletters and other information sources are available to help you keep track of these developments. For more information on any aspect of Parkinson's disease, contact the organizations below.

**American Parkinson's  
Disease Association**

800-223-2732

**National Parkinson Foundation**

800-327-4545

[www.parkinson.org](http://www.parkinson.org)

**Parkinson's Disease Foundation**

800-457-6676

[www.pdf.org](http://www.pdf.org)

**The Parkinson Alliance**

800-688-0870

**The Michael J. Fox Foundation  
for Parkinson's Research**

800-708-7644

[www.michaeljfox.org](http://www.michaeljfox.org)

**National Institute of Neurological  
Diseases and Stroke**

800-352-9424

[www.ninds.nih.gov](http://www.ninds.nih.gov)



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