

# WHAT YOU NEED TO KNOW ABOUT PARKINSON'S DISEASE

## Definition

Parkinson's Disease develops gradually, often starting with a barely noticeable tremor in just one hand. But while the tremor may be the most well know sign of Parkinson's Disease, the disorder also commonly causes a slowing or freezing of movement.

Friends and family may notice that your face shows little or no expression and your arms don't swing when you walk. Speech often becomes soft and mumbling. Parkinson's symptoms tend to worsen as the disease progresses.

While there is no cure for Parkinson's Disease, many different types of medicines can treat it's symptoms. In some cases your doctor may suggest surgery.

## Symptoms:

The symptoms of Parkinson's Disease vary from person to person. Early signs may be subtle and can go unnoticed for months or years. Symptoms typically begin on one side of the body and usually remain worse on that side.

Parkinson's signs and symptoms may include:

- **Tremor**- The characteristic shaking associated with Parkinson's Disease often begins in a hand. A back-and-forth rubbing of your thumb and forefinger, known as pie-rolling, is common. However, many people with Parkinson's Disease do not experience substantial tremor.
- **Slow motion (bradykinesia)**- Over time, Parkinson's Disease may reduce your ability to initiate voluntary movement. This may make even the simplest tasks difficult and time-consuming. When you walk, your steps may become short and shuffling. Or your feet may freeze to the floor, making it hard to take the first step.
- **Rigid muscles**- Muscle stiffness often occurs in your limbs and neck. Sometimes the stiffness can be so severe that it limits the range of your movements and causes pain.
- **Impaired posture and balance**- Your posture may become stooped as a result of Parkinson's Disease. Imbalance is also common, although this is usually mild until the later stages of the disease.
- **Loss of automatic movements**- Blinking, smiling, and swinging your arms when you walk are all unconscious acts that are a normal part of being human. In Parkinson's Disease, these acts tend to be diminished and even lost. Some people may develop a fixed staring expression and unblinking eyes. Others may no longer gesture or seem animated when they speak.
- **Speech changes**- Many people with Parkinson's Disease have problems with speech. You may speak more softly, rapidly, or in a monotone, sometimes slurring or repeating words, or hesitating before speaking.
- **Dementia**- In the later stages of Parkinson's Disease, some people develop problems with memory and mental clarity. Alzheimer's drugs appear to alleviate some of these symptoms to a mild degree.

## Causes

Many symptoms of Parkinson's Disease result from the lack of a chemical messenger, called dopamine, in the brain. This occurs when the specific brain cells that produce dopamine die or become impaired. But researchers still aren't certain about what sets this chain of events in motion. Some theorize that genetic mutations or environmental toxins may play a role in Parkinson's Disease.

## Risk Factors

Risk factors for Parkinson's Disease include:

- **Age**- Young adults very rarely experience Parkinson's Disease. It ordinarily begins in middle or late life, and the risk continues to increase with age.
- **Heredity**- Having one or more close relatives with Parkinson's increases the chances that you'll also develop the disease, although your risk is still less than 5%. Recent evidence suggests a crucial role for small contributions from many different genes that program brain architecture.
- **Sex**- Men are more likely to develop Parkinson's Disease than women are.
- **Exposure to toxins**- Ongoing exposure to herbicides and pesticides puts you at slightly increased risk of Parkinson's.

## **Complications**

Parkinson's Disease is often accompanied by these additional problems:

- **Depression**- This can occur even before other Parkinson's symptoms. Receiving treatment for depression can make it easier to handle the other challenges of Parkinson's Disease.
- **Sleep problems**- People with Parkinson's Disease often have trouble falling asleep and may wake up frequently throughout the night. They may also experience sudden sleep onset, called sleep attacks, during the day.
- **Difficulty chewing and swallowing**- The muscles you use to swallow may be affected in the later stages of the disease, making eating more difficult.
- **Urinary problems**- Parkinson's Disease may cause either urinary incontinence or urine retention. Certain medications used to treat Parkinson's also can make it difficult to urinate.
- **Constipation**- Many people with Parkinson's Disease develop constipation because the digestive tract works more slowly. Constipation may also be a side effect of medications used to treat the disease.
- **Sexual dysfunction**- Some people with Parkinson's Disease may notice a decrease in sexual desire. This may stem from a combination of psychological and physical factors, or it may be the result of physical factors alone.

Medications for Parkinson's Disease also may cause a number of complications, including involuntary twitching or jerking movements of the arms or legs, hallucinations, sleepiness, and a drop in blood pressure when standing up.

## **Healthy Eating**

Eat a nutritionally balanced diet that contains plenty of fluids, vegetables, and whole grains. These foods are high in fiber, which is important for helping prevent the constipation that is common in Parkinson's Disease.

If you take a fiber supplement, such as psyllium powder, Metamucil, or Citrucel, be sure to introduce it gradually and drink plenty of fluids daily. Otherwise, your constipation may become worse. If you find that fiber helps your symptoms, use it on a regular basis for the best results.

## **Walking With Care**

Parkinson's Disease can disturb your sense of balance, making it difficult to walk with a normal gait. These suggestions may help:

- Try not to move too quickly.
- Aim for your heel to strike the floor first when you're walking.
- If you notice yourself shuffling, stop and check your posture. It's best to stand up straight with your head over your hips and your feet eight to ten inches apart.

## **Avoiding Falls**

In the later stages of the disease, you may fall more easily. That's because Parkinson's Disease affects the balance and coordination centers in the brain. In fact, you may be thrown off balance by just a small push or bump. The following suggestions may help:

- Don't pivot your body over your feet while turning. Instead, make a U-turn.
- Don't lean or reach. Keep your center of gravity over your feet.
- Don't carry things while walking.
- Avoid walking backward.

## **Dressing**

Dressing can be the most frustrating of all activities for someone with Parkinson's Disease. The loss of fine-motor control makes it hard to button and zip clothes, and even to step into a pair of pants. A physical therapist can point out techniques that make daily activities easier. These suggestions also may help:

- Allow plenty of time so that you don't feel rushed.

- Lay clothes nearby.
- Choose clothes that you can slip on easily, such as sweat pants, simple dresses, or pants with elastic waistbands.
- Use fabric fasteners, such as Velcro, instead of buttons.

## **PROVIDING CARE FOR PARKINSON'S DISEASE**

“Constant reassurance that my loved ones are supportive, patient, caring, understanding, and loving is, I believe, my greatest asset and most secure source of happiness.” Dwight C. McGoon, M.D., a Mayo Clinic surgeon with Parkinson's Disease.

High-fashion thermos coffee mugs, electric toothbrushes, hand-held shower heads, and yes, satin sheets- these are just a few of the items that make life easier for a person with Parkinson's Disease. Read on to learn more about providing care for a person with Parkinson's Disease.

### **Take Charge of Parkinson's**

A cure hasn't yet been found, but that doesn't mean there are no effective treatments for the symptoms of Parkinson's. If one approach to treatment doesn't work, insist that others be considered. Take charge.

Learn the course Parkinson's may take in the future and be prepared for changes in the level of care you will have to provide.

Parkinson's is life altering, not life threatening. This means life with PD will change. All the same pleasures are out there to be enjoyed; they just need a bit of modification. If your care recipient enjoyed running, some of the same enjoyment of the outdoors comes with walking. Look for versions of the same kinds of activities to keep your care recipient active, independent and interested in life.

### **Stress and Anxiety**

The symptoms of tremor, rigidity and bradykinesia (abnormal slowness of movement) are made worse by anxiety, stress, and pressure. Be a calming influence. Don't pressure your care recipient to speed up. The anxiety you create will make movement slower.

### **Depression**

Up to 50% of people with Parkinson's suffer from depression. Watch for signs of depression and get treatment for your care recipient right away. Depression can affect short-term memory and concentration that will aggravate Parkinson's Disease. There is a risk of suicide.

The signs of depression include:

- sadness
- suicidal ideas
- sleep disturbance
- fatigue
- problems concentrating
- weight loss or gain
- appetite change (usually loss)
- feelings of worthlessness
- anxiety
- irritability
- apathy
- unwillingness to socialize
- loss of interest in sex and reduced performance

Depression and Parkinson's Disease share the symptoms of fatigue and anxiety. The trick is to sense an unexplained increase in these symptoms that may be caused by depression.

### **Constipation**

Parkinson's and its medications combine to make constipation a problem. Take preventative action to avoid a crisis that will need medical attention.

Increase fluid intake, especially in hot weather. Your care recipient should drink eight cups of fluid every day.

High-fiber foods are traditionally recommended to prevent constipation but these may cause intestinal gas and cramping that are not tolerated by an older person with Parkinson's. Instead of raw fruits and vegetables, nutritionists recommend dried fruits, hot prune juice, canned fruits and soft cooked vegetables. If you introduce bran or high fiber cereal into the diet, start slowly with small amounts and increase fluid intake.

### **Fatigue**

Persons with Parkinson's have to pace their activities and take lots of rest breaks. It isn't lazy; it's smart.

When your care recipient is having a really good day, feeling well and full of energy, there will be a tendency to do too much. Gently remind him or her that overdoing it will mean exhaustion and inactivity for the next couple of days. Better to ration that new-found energy.

### **Irritability and Frustration**

Everyday tasks take longer with Parkinson's. They may take even longer on bad days. Allow time for this. Don't rush. Respond with tact and humor, not irritability and frustration. Place yourself in the mind and body of your care recipient and imagine how irritated and frustrated he or she must feel.

If it's a bad day, set some activities aside for another day and do just what is possible and necessary. If you don't make these allowances, you create a stressful situation that aggravates the Parkinson's symptoms and may actually slow your care recipient even further. There's always tomorrow.

### **Pets**

They are wonderful companions but be careful that they aren't surprise obstacles that cause tripping or falling.

### **Drugs**

Some medications may cause nightmares and vivid dreams. Taking medications a few hours ahead of bedtime may help. Reactions to the dreams may make the sleeper noisy and violent. The person with Parkinson's will sleep on while the rest of the household thinks war has broken out.

Hallucinations may be another side effect. Your care recipient may see small animals or children. Usually the patient knows it isn't real but if he or she insists it's real, maybe you should pay attention. One family got a bit of a surprise. Their family member with Parkinson's insisted that there was a mouse in their home. No one believed her until she presented them with a dead mouse in a trap.

If your care recipient sees a number of physicians, make sure all physicians know the complete list of medications your care recipient is taking. This will help prevent unpleasant or dangerous drug interactions. It's a good idea to consult your pharmacist.

Be careful about botanical or natural remedies. Ask your physician for advice. These remedies may interact with the medications your care recipient is already taking.

Never change dosages without guidance from your physician.

### **Exercise**

A well-designed exercise program can increase the benefits of Parkinson's medication, fight depression, and promote an overall sense of well being.

Your care recipient will benefit from three types of exercise:

- Stretching and range-of-motion exercises to maintain joint and soft tissue flexibility.
- Strengthening exercises to improve and maintain strength of abdominal and back muscles.
- Aerobic exercises to aid cardio-respiratory fitness.

Prevent fatigue by pacing short exercise sessions throughout the day. Join in with your care recipient. It's good for you too.

Don't stick to a rigid schedule. Instead, help your care recipient exercise when medications are working well and movement is easier.

Urge your care recipient to be patient. The gains of regular exercise are not immediately obvious but they will come with time.

Exercise should be fun. Look for organized programs at local community or commercial centers. If there is a Parkinson's support group in your community, they may offer programs specially designed for your care recipient. It may be possible to combine exercise with some social activities that are so important in fighting depression and maintaining a sense of independence.

### **Walking**

It's great exercise for you and your care recipient. Here are some tips that make it easier and safer for someone with Parkinson's.

Help your care recipient by encouraging him or her to stand up as straight as possible. Heads up- avoid looking at the ground. At home, remove unnecessary furniture and anything on the floor like loose rugs that could cause a fall. Avoid shoes with rubber or crepe soles. They can stick to the floor and cause a tumble. See a physiotherapist for tips on helping your care recipient if there are problems with starting, stopping, or maintaining momentum when walking. Offer your arm as support but try to avoid hanging on to your care recipient. It's easier for a person with Parkinson's to maintain balance if he or she isn't pinned to your side.

To prevent falls, encourage your care recipient to consciously lift each foot. This strategy combats the foot drag that may come with Parkinson's. When turning, a person with Parkinson's should avoid pivoting on one foot to change direction. Balance problems make this a dangerous maneuver that leads to falls. It works better to take several steps in a U-turn.

If your care recipient appears to freeze, feet glued to the floor or sidewalk, you can be sure that is exactly how it feels. Remain calm and quiet while he or she concentrates on getting going again. You can work together to find ways to overcome this temporary problem. Try rocking from side to side to get the feeling of moving again, or tell him or her to imagine stepping over a crack in the sidewalk or a small object immediately in front of one foot. You might try '1-2-3-go' or bending the arms and swinging them to set the rhythm for walking.

### **Make it Easier in the Kitchen**

Here are some hints to encourage your care recipient to help out in the kitchen:

1. Be patient. People with Parkinson's move slowly and take longer to get things done. Allow extra time.
2. Use a microwave to shorten cooking times. This leaves more time for your care recipient to get food ready for cooking. It means less pressure to hurry.
3. Encourage your care recipient to sit rather than stand. It's less tiring and safer if balance is a concern.
4. Provide a cart with wheels- like a tea trolley- for moving things. It takes less energy and has the added advantage of providing support for maintaining balance.
5. Keep frequently used items like the kettle, teapot, and tea at countertop level. A lazy susan is ideal for making items accessible.

### **Safety in the Bathroom**

The greatest danger is falling. The bathroom floor, bathtub, and shower are slick and slippery when wet. There isn't anything in the house more punishing in a fall than the unyielding sides of the bathtub.

Install a grab bar by the tub or in the shower. Test it to be sure you feel confident it will hold your care recipient's weight. Don't use a wall-mounted soap dish or a towel rack as a substitute.

If your care recipient is unsteady in the shower, get a shower bench. It's like a waterproof chair for the shower. If you don't have a hand-held shower head, install one on the existing shower head outlet. It makes a 'sitting-down shower' much easier.

Non-skid strips or rubber mats in the tub or shower are a good idea but you have to be careful. If they accumulate soap residue, they are just as slippery as the tub or shower.

Use soap on a rope. It's always within reach and stays out from under your feet!

Getting on and off the toilet can be a real challenge for someone with Parkinson's when the toilet is quite low relative to the floor. Use a raised toilet seat with armrests to help maintain balance and prevent falls.

Consider getting your care recipient an electric toothbrush. It isn't a safety issue; it just does a better job cleaning teeth because it mimics the quick wrist movements that can be difficult for someone with Parkinson's.

### **Comfort in the Bedroom**

Getting in and out of bed and turning in bed can be a real problem for your care recipient. These tips will make it easier:

Adjust the height of the bed so it is neither too high nor too low.

If you thought satin sheets were only for the rich and famous, you're in for a surprise. These slinky bed linens are great for Parkinson's because they make it much easier to turn and move in bed.

There are different approaches to help your care recipient get into bed. You might suggest sitting on the edge of the bed, lowering sideways onto an elbow, and then bringing the legs up onto the bed. Try having your care recipient kneel on the bed and crawl further onto the bed and then lower his or her body sideways. Another choice is to have your care recipient sit on the edge of the bed and fall back onto a pillow. Then you can help raise his or her legs onto the bed.

Turning in bed can be difficult if your care recipient has trouble initiating movement or is rigid. Suggest that he or she bend the knees and place the feet flat on the bed. Then he or she can turn the head in the direction of the turn. By reaching across the body toward the edge of the bed, the trunk and hip will follow- like rolling a log. It helps if they can grab the edge of the bed or a grab bar on an adjacent wall. This is where satin sheets make sliding and turning much easier.

Getting out of bed is much like getting in. With your care recipient on his or her side, bend the knees toward the chest so the feet are near the edge of the bed. By supporting him or her with a forearm, the care recipient can push up using an elbow and hands and at the same time swing the feet over the edge of the bed onto the floor.

An occupational therapist will have further suggestions that apply to your specific situation.

### **Falls**

As Parkinson's progresses, gait (the kind of step used in walking) and balance problems are more pronounced. Hard as you try to prevent it, a fall may happen. Keep these points in mind, just in case:

When a fall happens at home, encourage your care recipient to stay still and rest in a comfortable position for a few moments before getting up. Remain calm. If your care recipient becomes anxious, it will be more difficult to get up. If there appears to be injuries that would be aggravated by trying to get up, call for medical help.

Don't attempt to lift the person from the floor unless you have been trained to do it in a way that won't cause you to injure yourself.

If there are no apparent injuries, bring a chair to your care recipient and ask him or her to roll onto hands and knees. Have him or her bend one leg and put a foot firmly on the floor. With the opposite arm on the chair, your care recipient can use arms and legs to push up to a standing position. Provide support in case of dizziness or lightheadedness.

Have a hug, a laugh, and a cup of tea.