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Signs and symptoms

Some common and some lesser-known Parkinson's symptoms are:

- tremors
- slowness and stiffness
- impaired balance
- rigid muscles
- fatigue
- soft speech
- problems with handwriting
- stooped posture
- constipation
- sleep disturbances

Taking charge of your disease:

- Find a doctor you like and trust, ideally a neurologist.
- Do your research.
- Make decisions based on correct information.
- Make a list of what does and doesn't work for you.
- Remember that your progress, symptoms, and treatment will most likely be different from those of other people with Parkinson's.
- As your symptoms evolve, your treatment will need to be adjusted.
- See a physiotherapist who can recommend exercises and stretches to suit you.

Source: <http://parkinson.ca>

Living with Parkinson's

You or someone you know has just been told "You have Parkinson's." What is it? What do you or your family and friends need to know about how it will affect your life?

The first thing people hear about Parkinson's is complicated medical language. It's often confusing and a little frightening.

Simply put

Parkinson's is a neurodegenerative disease, meaning that the cells in the brain and spinal cord deteriorate. Movement is normally controlled by dopamine, a chemical that carries signals between the nerves in the brain. When the cells that normally produce dopamine die, the symptoms of Parkinson's appear. As the



disease progresses, non-motor signs may also appear, such as depression, difficulty swallowing, sexual problems, or cognitive changes. Parkinson's develops at a different rate for each individual person.

Just the facts

With nearly 100,000 Canadians suffering from the disease, Parkinson's does not discrimi-

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Parkinson's: a step-by-step understanding

No one knows exactly what causes Parkinson's, and there are both environmental and genetic theories. Most researchers believe that it is triggered by a combination of both, and determining the source of the disease remains the focus of most of the research.

Diagnosis

It is not always easy to diagnose Parkinson's. Diagnosis is determined by the symptoms described by the patient and the resulting neurological examination. Sometimes the diagnosis is more obvious because the patient exhibits the classic signs of trembling at rest, slowed movements, and stiffness on one side of the body. However, there are other diseases that bring about similar signs, so pinpointing Parkinson's can be difficult.

Other people will have what is called "akinetic-rigid Parkinson's," and will never display the usual symptoms. The most worrisome part of diagnosis is that, by the time Parkinson's has been diagnosed, about 80% of the dopamine-producing cells will have already stopped functioning.

Medication

The symptoms of Parkinson's are treated with medication, but some people also benefit from surgery. Medication is still the most effective treatment to assist with maintaining normal life activities, as symptoms differ for each individual and often change during the progression of the condition.

Generally, treatment should commence once quality of life has been disrupted and the symptoms begin to present themselves as obstacles to day-to-day functioning. The decision to begin using medication is dependant on many variables. Factors such as age, weight, and the nature of the symptoms are all relevant when deciding which medication to choose. Selecting a medication is not always easy, and it is important for signs and symptoms to be accurately described so that the physician can find the right medication for the individual.

A team approach

By working with a health care team to develop a treatment plan and receiving home care support services on an as-needed basis, most people with Parkinson's are able to remain active. There are a number of recommended therapies that can also help to manage the symptoms:

- Physical therapy helps to increase mobility, flexibility, and balance.
- Occupational therapy helps with daily activities.
- Speech therapy helps with voice control.
- Exercise helps muscles and joints, and improves overall health and well-being.

Understanding symptoms

As Parkinson's progresses, the brain loses its ability to store and use its reserves of levodopa (the precursor to dopamine) and motor fluctuations may appear.



Motor fluctuations can be broadly divided into two states: on and off. "On" describes a condition when a person with Parkinson's is responding well to his/her medication and can perform daily activities with relative ease. An "off" episode is usually when medication is losing its effect, and the person is having difficulty with movement and develops painful cramps.

"Dyskinesia" refers to involuntary movements that generally appear on the side of the body most severely affected by the disease. The movements are often sudden, jerky contractions that affect the face, tongue, respiratory muscles, upper body, arms, and legs. Dyskinesia usually occurs in between doses of medication.

"Freezing" also can occur when medication has worn off. Freezing is the short-term arrest of an ongoing movement or difficulty starting movement. It can occur in various situations, such as when beginning to walk, crossing a threshold, or using an escalator. People describe freezing as feeling like their feet are glued to the floor.

Beyond tremors and stiffness

Other, secondary symptoms can also affect a person's quality of life. Some medications can alleviate a few of these issues, but there are other things that can help.

A greasy scalp and skin (seborrheic dermatitis) are best confronted with tar-based shampoos and Parkinson's medicated lotions.

Parkinson's in the workplace

While the diagnosis of Parkinson's doesn't necessarily call for early retirement, it does require you to look at how you can do your job and minimize work-related stress. It is estimated that 25–30% of people with Parkinson's are still in the workforce. Some continue full or part-time work for many years and enjoy active lives.

Ankle swelling can be serious and should be checked by a physician in case of complications with the kidneys, heart, or blood vessels.

Excess saliva and drooling are usually counteracted by medications, because most are drying. If excess saliva persists, it may help to consciously think about swallowing more, particularly before speaking or opening the mouth.

Small, illegible handwriting (micrographia) often develops at the beginning of Parkinson's disease. It's often associated with akinesia (the inability to start a movement) and rigidity. Sometimes an occupational therapist can help; for other people, simply using lined paper can make writing easier.

Swallowing and chewing problems are also common in people with Parkinson's. It's important to address these symptoms because they can lead to weight loss or malnutrition, and therefore result in other health complications. A speech therapist or dietician can be consulted. They may suggest a few changes to natural habits, such as eating smaller meals several times a day or improving posture while eating and drinking.

Family issues

A diagnosis of Parkinson's disease affects both the person with the disease and his/her family members. It is important for couples and families to keep an open dialogue about the feelings and experiences of the person living with Parkinson's. Eventually, the healthier spouse or other family members may need to assume more tasks and roles within the family. Research shows that communication is key. Couples who manage best in the face of a chronic illness talk from day one about how the disease is affecting their daily life and what can be done to make things easier.

Care partners who manage best are those who learn early to be flexible and state their own changing needs, and who protect regular blocks of private time to meet those needs over the years.

How to manage

As Parkinson's progresses, one of the toughest hurdles families face is coping with emotions and finding new ways to relieve stress, provide physical assistance, and meet special needs. A person with Parkinson's will have good and bad days. It's best for families to listen, be patient



Get some rest

Fatigue or lack of sleep can be a part of Parkinson's, but there are a few ways to help:

- Keep a record of sleeping habits.
- Commit to a regular routine.
- Keep the room at a comfortable temperature.
- Avoid watching TV and reading in bed.
- Do some physical exercise early in the day.
- Get fresh air daily.
- Avoid strenuous exercise at least two hours prior to sleep.
- Avoid liquids after seven o'clock at night.

and understanding, and seek support if needed. Parkinson Society Canada offers a variety of resources, programs, and services on a complimentary basis. Visit <http://parkinson.ca> or call 1-800-565-3000 to find one of many support groups and for a free copy of "A Manual For People Living With Parkinson's Disease."

Living with Parkinson's continued from cover
nate between gender, race, or religion. However, age does play a defining role, with the incidence of Parkinson's increasing after middle-age. That said, 20% of persons with Parkinson's are under the age of 50 years, and 5–10% are not even 40 years old. In some rare instances, Parkinson's can affect those as young as 30 years.

Finding out if a person has Parkinson's can take time. A family doctor might first notice the symptoms. You may be referred to a neurologist—a

specialist who deals with Parkinson's. There are no blood tests or specific exams to confirm its presence. So, the neurologist will check your medical history, do a careful physical examination and certain tests, and rule out other conditions that may resemble Parkinson's.

While there is currently no cure for Parkinson's disease, many promising research projects are underway and, thankfully, with current medications and therapies, most people can live with Parkinson's for years with good quality of life.

Attention caregivers

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magazine, courtesy of your local We Care Home Health Services location.

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Staying active

People with Parkinson's need regular exercise to prevent the negative effects of inactivity. Moving, stretching, and walking as much as possible can help to counteract secondary effects that can develop. These include:

- poor posture
- loss of flexibility
- decreased strength of muscles
- decreased endurance
- poor balance

How to take care of yourself: a guide for caregivers

1. Know your limitations. Parkinson's is a progressive disease, so it may become increasingly difficult for you to provide care. Look into home care or daytime help.
2. Every caregiver needs a regular time-out. Take a break and visit some friends. Ask for and accept support, and make a list of tasks that others can do for you.
3. Find someone you trust to talk to when you're feeling low or just need a shoulder to lean on. Getting help when you're stressed and remembering that you're not alone are crucial to looking after yourself.

Ask our experts

Forward your questions or comments, and we'll ask our experienced nursing team to provide you with the latest advice and information.

My Father is 76 and has been diagnosed with Parkinson's. Is it safe for him to drive?

The determination of whether or not your father can drive is dependant on many things. Since Parkinson's affects reaction time, vision, and judgment, it is best to have your father speak with his physician about his abilities. If his medication is controlling his symptoms well, he may be able to drive. If you are driving with him, and feel uncomfortable with his ability, you should discuss this with him. Every person's body is different in how they respond to Parkinson's so there is no set time that a person living with Parkinson's should stop driving.

How quickly will Parkinson's progress and when should I make plans for additional care?

As each person reacts differently to the progression of Parkinson's symptoms, it is difficult to give an exact period. It is important to be prepared, so gaining as much knowledge as possible should help you in making plans. There are some things you can do that may slow the progression. Maintaining a positive attitude as much as possible and regular exercise (body and mind) are very important in keeping you as active as possible for as long as possible.

I am anxious and having trouble coping. How can I get my confidence back?

Stress can make your symptoms worse, so it is important to seek assistance wherever you can. Are you connected

with a Parkinson's support group? Talking to someone who knows what you are going through can help tremendously. Have you spoken with your doctor about your concerns? He/she may be able to refer you to support groups in your area. You can go online to www.parkinson.ca for additional information.

I often freeze and have trouble moving. What should I do?

Freezing is a common problem among people living with Parkinson's. It is very important for you and those around you to learn which visual or sensory cue will work to get you moving again. One cue is to have someone place a foot or object on the floor in front of you and have you step over it. Sometimes playing music or counting with a steady beat can help encourage movement. It is also important to wear proper walking shoes in order to prevent falls from occurring.

My 35-year-old sister has young onset Parkinson's disease and has recently had to stop working. I am worried that she won't be able to live for much longer?

Each person's journey is different in how they will progress, and in how they will be able to manage their symptoms. By assisting your sister in keeping active, going for walks with her and keeping her mind active, you can help her tremendously. Increase your knowledge about Parkinson's so you can help her get the support that she needs. In that way, she will be living a full life for as long as possible.

Send your questions to Julia Sommers at julia_sommers@wecare.ca



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