

Parkinson's Disease: An Inside Look



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Parkinson's Disease: An Inside Look is a recently published series of articles created to help those living with Parkinson's understand the disease and how to manage it.

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Table of Contents

An Inside Look at Parkinson's Disease	1
<i>National Institutes of Health</i>	
Can You Be Too Young to Get Parkinson's Disease?	5
<i>American Parkinson's Disease Association</i>	
Building a Parkinson's Care Team.....	7
<i>Michael J. Fox Foundation</i>	
Parkinson's Foundation: Putting People with Parkinson's Disease First	10
<i>Parkinson's Foundation</i>	

An Inside Look at Parkinson's Disease

Editor's Note: The following information about Parkinson's Disease was originally published by the National Institutes of Health's (NIH) National Institute on Aging (NIA), which leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life. You can read the original information and access additional information about Parkinson's disease on the NIA web site by clicking [here](#).

Parkinson's disease is a brain disorder that leads to shaking, stiffness, and difficulty with walking, balance and coordination.

Parkinson's symptoms usually begin gradually and get worse over time. As the disease progresses, people may have difficulty walking and talking. They may also have mental and behavioral changes, sleep problems, depression, memory difficulties, and fatigue.

Both men and women can have Parkinson's disease. However, the disease affects about 50 percent more men than women.

One clear risk factor for Parkinson's is age. Although most people with Parkinson's first develop the disease at about age 60, about 5 to 10 percent of people with Parkinson's have "early-onset" disease, which begins before the age of 50. Early-onset forms of Parkinson's are often, but not always, inherited, and some forms have been linked to specific gene mutations.

What Causes Parkinson's Disease?

Parkinson's disease occurs when nerve cells in the basal ganglia, an area of the brain that controls movement, become impaired and/or die. Normally, these nerve cells, or neurons, produce an important brain chemical known as dopamine. When the neurons die or become impaired, they produce less dopamine, which causes the movement problems of Parkinson's. Scientists still do not know what causes cells that produce dopamine to die.

People with Parkinson's also lose the nerve endings that produce norepinephrine, the main chemical messenger of the sympathetic nervous system, which controls many functions of the body, such as heart rate and blood pressure. The loss of norepinephrine might help explain some of the non-movement features of Parkinson's, such as fatigue, irregular blood pressure, decreased movement of food through the digestive tract, and sudden drop in blood pressure when a person stands up from a sitting or lying-down position.

Many brain cells of people with Parkinson's contain Lewy bodies, unusual clumps of the protein alpha-synuclein. Scientists are trying to better understand the normal and abnormal functions of alpha-synuclein and its relationship to genetic mutations that impact Parkinson's disease and Lewy body dementia.

Although some cases of Parkinson's appear to be hereditary, and a few can be traced to specific genetic mutations, in most cases the disease occurs randomly and does not seem to run in families. Many researchers now believe that Parkinson's disease results from a combination of genetic factors and environmental factors such as exposure to toxins.

Symptoms of Parkinson's Disease

Parkinson's disease has four main symptoms:

- Tremor (trembling) in hands, arms, legs, jaw, or head
- Stiffness of the limbs and trunk
- Slowness of movement
- Impaired balance and coordination, sometimes leading to falls

Other symptoms may include depression and other emotional changes; difficulty swallowing, chewing, and speaking; urinary problems or constipation; skin problems; and sleep disruptions.

Symptoms of Parkinson's and the rate of progression differ among individuals. Sometimes people dismiss early symptoms of Parkinson's as the effects of normal aging. In most cases, there are no medical tests to definitively detect the disease, so it can be difficult to diagnose accurately.

Early symptoms of Parkinson's disease are subtle and occur gradually. For example, affected people may feel mild tremors or have difficulty getting out of a chair. They may notice that they speak too softly, or that their handwriting is slow and looks cramped or small. Friends or family members may be the first to notice changes in someone with early Parkinson's. They may see that the person's face lacks expression and animation, or that the person does not move an arm or leg normally.

People with Parkinson's often develop a parkinsonian gait that includes a tendency to lean forward, small quick steps as if hurrying forward, and reduced swinging of the arms. They also may have trouble initiating or continuing movement.

Symptoms often begin on one side of the body or even in one limb on one side of the body. As the disease progresses, it eventually affects both sides. However, the symptoms may still be more severe on one side than on the other.

Many people with Parkinson's note that prior to experiencing stiffness and tremor, they had sleep problems, constipation, decreased ability to smell, and restless legs.

Diagnosis of Parkinson's Disease

A number of disorders can cause symptoms similar to those of Parkinson's disease. People with Parkinson's-like symptoms that result from other causes are sometimes said to have parkinsonism. While these disorders initially may be misdiagnosed as Parkinson's, certain medical tests, as well as response to drug treatment, may help to distinguish them from Parkinson's. Since many other diseases have similar

features but require different treatments, it is important to make an exact diagnosis as soon as possible.

There are currently no blood or laboratory tests to diagnose nongenetic cases of Parkinson's disease. Diagnosis is based on a person's medical history and a neurological examination. Improvement after initiating medication is another important hallmark of Parkinson's disease.

Treatment of Parkinson's Disease

Although there is no cure for Parkinson's disease, medicines, surgical treatment and other therapies can often relieve symptoms.

Medicines for Parkinson's Disease

Medicines prescribed for Parkinson's include:

- Drugs that increase the level of dopamine in the brain
- Drugs that affect other brain chemicals in the body
- Drugs that help control nonmotor symptoms

The main therapy for Parkinson's is levodopa, also called L-dopa. Nerve cells use levodopa to make dopamine to replenish the brain's dwindling supply. Usually, people take levodopa along with another medication called carbidopa. Carbidopa prevents or reduces some of the side effects of levodopa therapy—such as nausea, vomiting, low blood pressure, and restlessness—and reduces the amount of levodopa needed to improve symptoms.

People with Parkinson's should never stop taking levodopa without telling their doctor. Suddenly stopping the drug may have serious side effects, such as being unable to move or having difficulty breathing.

Other medicines used to treat Parkinson's symptoms include:

- Dopamine agonists to mimic the role of dopamine in the brain
- MAO-B inhibitors to slow down an enzyme that breaks down dopamine in the brain
- COMT inhibitors to help break down dopamine
- Amantadine, an old antiviral drug, to reduce involuntary movements
- Anticholinergic drugs to reduce tremors and muscle rigidity

Deep Brain Stimulation

For people with Parkinson's who do not respond well to medications, deep brain stimulation, or DBS, may be appropriate. DBS is a surgical procedure that surgically implants electrodes into part of the brain and connects them to a small electrical device implanted in the chest. The device and electrodes painlessly stimulate the brain in a way that helps stop many of the movement-related symptoms of Parkinson's, such as tremor, slowness of movement, and rigidity.

Other Therapies

Other therapies may be used to help with Parkinson's disease symptoms. They include physical, occupational, and speech therapies, which help with gait and voice

disorders, tremors and rigidity, and decline in mental functions. Other supportive therapies include a healthy diet and exercises to strengthen muscles and improve balance.

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

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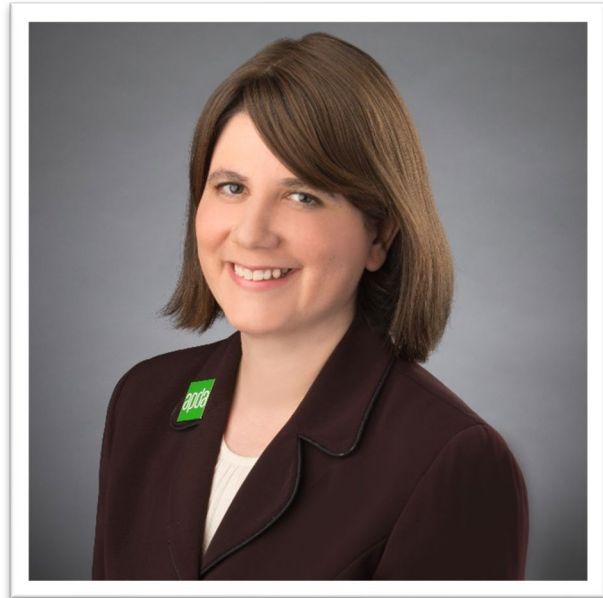
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Can You Be Too Young to Get Parkinson's Disease?

The majority of people who get Parkinson's Disease (PD) are over the age of 60. However, 10 to 20 percent of the 60,000 people diagnosed every year in the United States are under age 50 and about half of those are diagnosed before age 40.

Because PD is typically associated with older individuals, the disease is often overlooked in younger people, according to Rebecca Gilbert, MD, PhD, Chief Scientific Officer for the [American Parkinson Disease Association \(APDA\)](#). She said that that can lead to many being undiagnosed or misdiagnosed for extended periods of time.

"We don't yet have a prevention or cure for Parkinson's, so a later diagnosis does not mean missing out on any curative therapies," she said. "However, knowing you have the disease as early as possible gives you a leg up in terms of educating yourself, understanding how the disease progresses and learning the benefits of neuroprotective exercises that can also ease symptoms."



*Rebecca Gilbert
American Parkinson Disease Association*

What is Early Onset Parkinson's Disease?

Early onset PD (also called young onset PD) is diagnosed between the ages of 21-50. While symptoms of the disease are mostly the same at whatever age PD develops, younger people experience the disease differently due to their unique life circumstances. Disease progression is usually slower in younger than older people because younger people have fewer general health problems and are more capable during physical therapy treatment. Other problems associated with PD, such as memory loss, confusion, and balance difficulties also tend to be less frequent in young people with the disease.

Symptoms of young onset PD are similar to those of older-onset disease and include motor or movement symptoms such as:

- **Tremor** – a slow, rhythmic shaking that occurs at rest. It typically starts in one hand, foot or leg and often progresses to affect both sides of the body.
- **Rigidity** – a tightness or stiffness of the limbs or torso.
- **Bradykinesia** – slow movement, often demonstrated by problems with fine motor coordination, as well as decreased blinking with a mask-like expression of the face.

- **Balance problems** – inability to prevent a fall when thrown off balance.

"Younger people may only notice one or two of these motor symptoms, especially in the early stages of the disease," Dr. Gilbert said. "And these symptoms don't necessarily mean that you have Parkinson's. In most cases they don't. Tremor often raises concern, but many other conditions can cause tremor. A good rule is if you develop a new symptom, go see your doctor and get checked out."

People with early onset Parkinson's can also experience non-motor symptoms including depression and anxiety, loss of smell, eye and vision issues, fatigue, gastrointestinal issues, sleep problems, excess sweating and urinary issues.

Managing Early Onset Parkinson's Disease

According to Dr. Gilbert, while PD tends to progress more slowly in younger people, managing the disease can be particularly challenging from a psychological and social standpoint.

"Younger patients may be dating, or have young families, and are building their careers," she explained. "All of a sudden, they are grappling with something that nobody else at their stage of life is familiar with. It can be incredibly isolating. But it's important to realize that a PD diagnosis is not the end of their life. With the right perspective and support, they can continue to work, support their families and engage with friends and loved ones."

Dr. Gilbert recommends that once diagnosed, patients start building a care team headed by a neurologist – ideally a movement disorder specialist. Other key members of a PD care team include physical and occupational therapists to help maximize fine and gross motor skills; a speech pathologist to work on soft or garbled speech; and a dietician to address dietary changes, weight loss and constipation.

Finding a Supportive Community

Dr. Gilbert said it's also important for people with Parkinson's – especially those with early-onset disease – to find comfort and a sense of community from people like themselves. She recommends visiting the APDA website for information on [local chapters](#) and information and referral centers that can help people find local resources and support groups for those with early-onset PD.

[Share Your Story](#) is another APDA resource and is a good way to learn how others with early-onset PD – like, [Katja](#), diagnosed at age 46 – deal with their challenges. Additional insights for those with young-onset disease and their loved ones can be found in a recent APDA "[Dr. Gilbert Hosts](#)" online conversation in which she spoke with four inspiring individuals who are living with the disease.

"Their stories show the power of peer support, the importance of maintaining a positive attitude, and the promise of a path forward for a fruitful life as they live with PD," Dr. Gilbert said.

Building a Parkinson's Care Team

Editor's Note: The following has been excerpted, with permission, from The Parkinson's Journey: Building a Care Team, published by The Michael J. Fox Foundation for Parkinson's Research (MJFF). Real World Health Care invites our readers to visit MichaelJFox.org to help you and your loved ones navigate life with Parkinson's.

As a person living with Parkinson's, your needs for care can vary and evolve as the disease changes. Here are some of the people who can make valuable contributions to your care and well-being.

Movement Disorder Specialist

A movement disorder specialist is a neurologist with additional training in Parkinson's disease (PD) and other movement disorders. This type of doctor typically has extensive knowledge of Parkinson's therapies and ongoing research.

Because they have so much experience treating PD, movement disorder specialists are often best equipped to tailor a plan of care for you and your specific needs. Some people may wait to see a movement disorder specialist until later in their disease course. However, seeing this specialist early in your treatment could help you plan for your care in the future, prepare for potential changes in your Parkinson's and adapt to these changes as they happen. Movement disorder specialists also can connect you with clinical studies to help scientists learn more about Parkinson's and how to treat it.

Even if you have been treated for Parkinson's for some time, you may want to consult a movement disorder specialist to:

- Review your current medications and recommend adjustments if needed.
- Assemble a team of health care professionals who will work together to determine the most appropriate treatment for your changing condition.

If you live in a rural area or have difficulty traveling, it may be challenging to find or visit a movement disorder specialist. One option might be to travel to see a movement disorder specialist once or twice a year and follow up with a local general neurologist or primary care doctor more frequently. Technology, too, may help. Ask your doctor or support group about telemedicine opportunities. Any time spent with a specialist may be helpful.

Allied Care

Allied care professionals include physical therapists, occupational therapists, speech therapists, counselors and nutritionists. As members of your treatment team, they can help you manage many symptoms and other aspects of living with Parkinson's.

Involving these professionals early in your experience with PD can help you continue to do the things you want to do. Research shows that working with allied care professionals may help prevent or delay some difficulties as Parkinson's progresses. For example, these therapists can help you move better, manage your daily activities and prevent falls.

- A **physical therapist** (PT) can help you maintain or improve mobility and manage certain types of pain by working with you on exercises for walking and balance, strength, and range of motion. A PT can also design an exercise program for your specific symptoms and abilities.
- An **occupational therapist** (OT) helps people with activities of daily life, such as self-care skills, education, work and social interaction. An OT will help someone with PD prepare for, and adapt to, changes in their disease. An OT can teach you the best ways to move from sitting to standing, for example, or what to do if you find yourself freezing or losing balance.
- A **speech therapist** can help you maintain and improve communication skills. Many people with Parkinson's have difficulty communicating because they speak softly or in a monotone, or they slur words. A speech therapist can help you with this and with other issues. For example, as Parkinson's progresses, swallowing can become more troublesome and can pose a choking risk when eating. Speech therapists can teach you ways to chew and swallow to ease symptoms.
- A **therapist/counselor** can help people with Parkinson's disease manage depression, anxiety and other emotional changes that are common non-motor symptoms. They can also help you prepare for conversations or situations that may arise with a Parkinson's diagnosis, such as telling your employer or children about your disease.
- Eating well is important for overall good health. A **nutritionist/dietitian** can help you evaluate your diet and make changes, including helping you plan menus and make shopping lists. Many people with Parkinson's experience issues like unwanted weight loss or constipation, which can be managed with dietary changes. A nutritionist/dietitian can work with you to develop an individualized nutrition program.

Care Partners

When a person is diagnosed with Parkinson's disease (PD), someone who is close to them — whether their spouse, child, parent or friend — usually becomes their primary care partner.

Care partners take on many responsibilities, from accompanying a loved one to doctor appointments to managing more household responsibilities. For the most part, care partners do not need special medical training. What's important is establishing a partnership — a mutual understanding of what kind of help with daily tasks and emotional support the person with Parkinson's wants and needs as the disease impacts your routines and lives.

It's essential, too, for care partners to take care of themselves. Parkinson's progresses slowly, and the role of the care partner can last for decades. Care partners need to take time out to renew their energy and stay healthy.

In MJFF's free guide [You, Your Loved One and Parkinson's Disease](#), Lonnie Ali, wife of Muhammad Ali and member of The Michael J. Fox Foundation Founders Council, offers guidance for fellow Parkinson's disease caregivers.

You

You are an active member of your care team. Educate yourself about Parkinson's disease and talk with your doctor and loved ones to identify helpful health care professionals, decide on treatments and connect with research studies.

Establishing a comfortable, open and productive relationship with your health care providers is important for your overall care. In choosing any provider, your major considerations should be how much they know about Parkinson's and how well they listen.

Because Parkinson's involves a wide range of symptoms including movement- and non-movement-related issues, over the course of your life with Parkinson's you may wish to work with a variety of health care providers in addition to the doctor who primarily treats your Parkinson's.

Care teams are made not only of medical professionals. Care partners play an essential role in the health and well-being of people with Parkinson's. And you, the person with the disease, are in the driver's seat — gathering and guiding the players.

The Michael J. Fox Foundation for Parkinson's Research has an ambitious goal – find a cure and go out of business. Donations go directly to the Foundation's high-impact research programs to speed better treatments and a cure for the millions of families impacted by the disease. Together, we can end Parkinson's at MichaelJFox.org.

The medical information contained in this article is for general information purposes only. The Michael J. Fox Foundation for Parkinson's Research has a policy of refraining from advocating, endorsing or promoting any drug therapy, course of treatment, or specific company or institution. It is crucial that care and treatment decisions related to Parkinson's disease and any other medical condition be made in consultation with a physician or other qualified medical professional.

Parkinson's Foundation: Putting People with Parkinson's Disease First

People with Parkinson's disease (PD) can face numerous challenges. Some lack adequate access to high-quality, specialized health care and treatments. Others can't find local resources and community programs for support. And many cannot afford or take advantage of genetic testing to help them qualify for enrollment in clinical trials.

The Parkinson's Foundation understands these challenges and strives to make the lives of all those living with and affected by PD better today, while the search for a cure continues.

PD Education, Care and Research Programs

According to John Lehr, president & CEO, the Parkinson's Foundation puts people with PD first in its education, care and research programs.

"Through our educational programs, we provide people with PD the information and resources they need to manage their daily lives, including materials focused on mobility, mood disorders and mindfulness," he said. "Our care program is aimed at ensuring that people with PD receive the highest quality care possible and our research programs are designed to advance science so that we can ultimately cure this disease."

The Foundation's Global Care Network of Centers of Excellence and Comprehensive Care Centers provides care to hundreds of thousands of individuals with PD. Many of these Centers also serve as collaborators on research studies focusing on various issues such as hospitalization with PD and palliative care delivery.



John Lehr, Parkinson's Foundation

"We are working to increase access to care by expanding the network to areas where little or no comprehensive care currently exists, with a particular emphasis on hard-to-reach and underserved areas," Lehr explained, noting that the network is undergoing an expansion from 47 to 60 Centers of Excellence and has added a new level of designation for 15 Comprehensive Care Centers.

Expanding Research and Access to Genetic Testing

Lehr said that currently, genetic tests for PD are often unaffordable and not covered by health insurance. Moreover, many entities providing genetic tests do not offer genetic counseling, which is key to interpreting test results.

“Because of this, most people with PD and their clinicians do not know if they have a genetic component to their disease,” he said.

The Parkinson’s Foundation is working to address this unmet need through their work with PD GENERation: Mapping the Future of Parkinson’s Disease, an international initiative offering no-cost genetic testing and genetic counseling for people with PD. It is one of the world’s largest genetic testing studies to identify those with genetic mutations so they can participate in upcoming clinical trials.

In the research arena, the Parkinson’s Foundation funds investigator- and center-led basic research looking into the underlying causes and basic biology of PD. It also funds research on patient outcomes to see which investigations are having the greatest impact.

Lehr noted that the lack of new drugs to treat PD is due, in part, to the complexity of neurological diseases.

“Progress toward new medicines, better therapies and eventually a cure relies, almost exclusively, on innovative, high-quality research,” he said. “If we hope to improve the lives of those living with PD today, as well as those in the future, research efforts must be intensified.”

People with Parkinson’s Advisory Council

For the Parkinson’s Foundation, putting people with PD first also means engaging people with PD as collaborative partners. To that end, in 2006, the Foundation established its People with Parkinson’s Advisory Council. The Council is comprised of people with PD and care partners to ensure that the perspective of people living with PD is integrated into program development and priority setting.

Council members help to guide the Foundation’s research strategy; review and provide recommendations on programs, initiatives, policies and materials; serve as ambassadors for the Foundation in the PD community and public; identify and coordinate opportunities to share the Foundation’s resources; support local fundraising events and more.

“I am very proud to be a member of the People with Parkinson’s Advisory Council and to have a leadership role within the Parkinson’s community,” said Council Member Kelly Weinschreider. “I appreciate the opportunity to work alongside the Foundation’s CEO, COO and the most talented and dedicated group of people

working to help make life better for people with Parkinson's disease. I am also thankful for the opportunity to work on a national, regional and local scale to raise awareness for PD. All of us on the Council truly have a seat at the table."

Diagnosed with young onset PD at age 29, Weinschreider initially got involved with the Foundation after seeing a [Facebook](#) post recruiting women with Parkinson's to work on a women with PD initiative. At the time, she had stopped working due to Parkinson's and was looking for something to fill her time and get involved.



Kelly Weinschreider

"I wanted to find something meaningful in my diagnosis," she said. "I volunteered to be a member of the group and never looked back. Through the Council, I've had the opportunity to work on issues like improving mental health, educating the newly diagnosed and reaching people that don't have access to care."

Now living with PD for over 20 years, Weinschreider said the gravity of her diagnosis didn't hit her until much later.

"I've overcome many challenges and continue to fight new issues every day," she said, adding that the biggest challenges for her have been non-motor symptoms like constipation, bladder control and mental health, along with motor issues like balance and rigidity that she has helped to manage thanks to the Foundation's exercise guidelines.

According to Lehr, the Foundation welcomes applications to the Council from anyone who is living with PD, is a PD care partner, or who was previously a PD care partner. The Foundation places an emphasis on recruiting people with PD and PD care partners from diverse backgrounds.

"You're Not Alone"

When asked what advice she would offer to someone who is diagnosed with Young-Onset Parkinson's disease (YOPD), Weinschreider said: "You're not alone! There are many of us, diagnosed at a young age, who are living independent and happy lives. Find your place, through support groups or volunteer activities in the Parkinson's community. It's all about finding the right care and staying positive. Yes, there will be rough patches, but always look for the rainbow after the storm."